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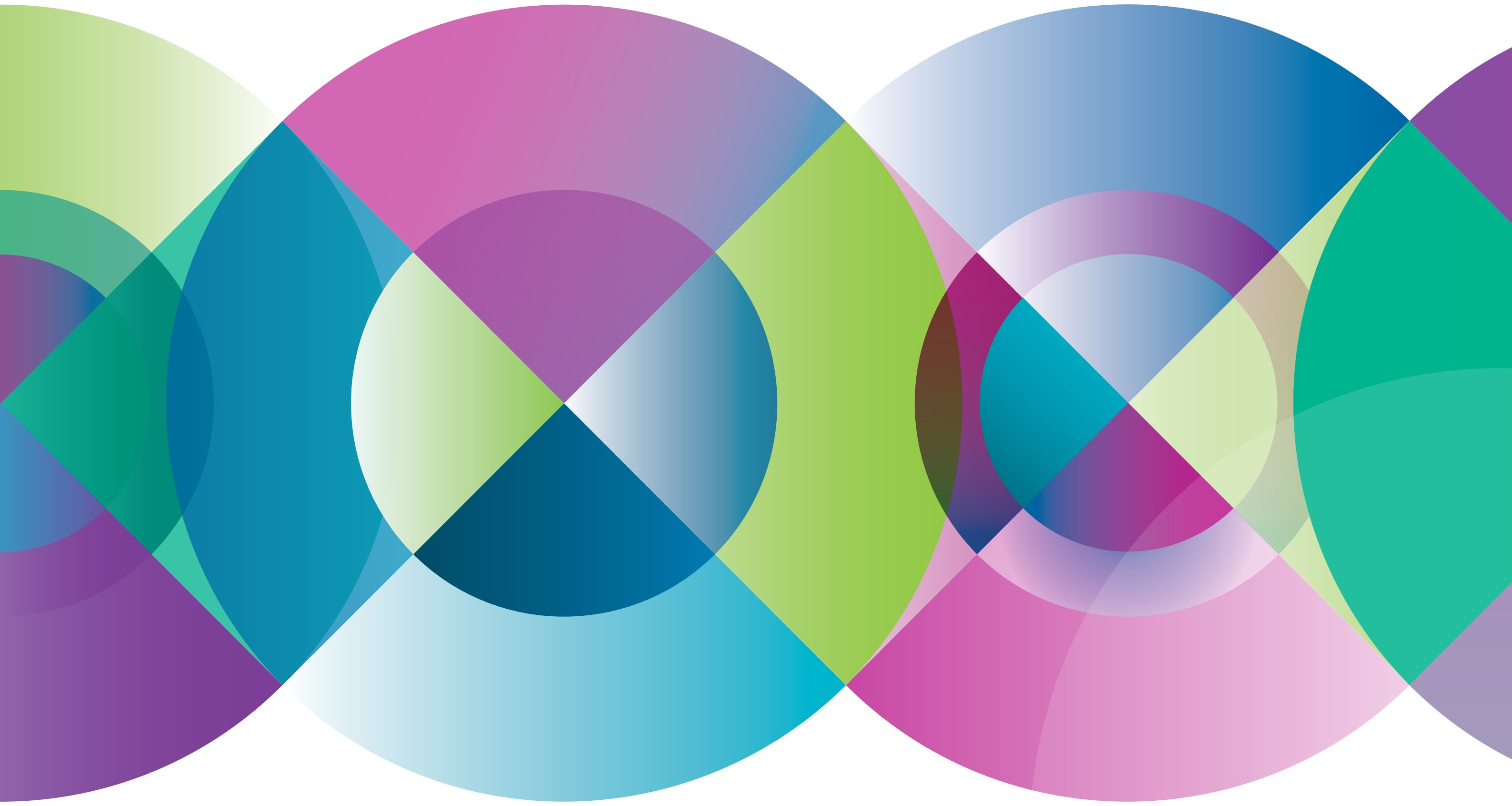
ON SAFETY AND QUALITY IN HEALTH CARE

NSQHS
STANDARDS



National Safety and Quality Health Service Standards

User Guide for the Health Care of People with Intellectual Disability

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Contents

Introduction

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, and people who use health services and their families 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. They provide a quality assurance mechanism that assesses whether relevant systems are in place to ensure that expected standards of safety and quality are met. Importantly, the NSQHS Standards have provided a nationally consistent statement about the standard of care that people can expect from health service organisations. Implementation is mandated in all hospitals, day procedure services and public dental services across Australia.

The Commission developed the NSQHS Standards User guide for the health care of people with intellectual disability (the User Guide) in response to significant evidence of poor health outcomes for people with intellectual disability in Australia's health system.[1,2,3]

The User Guide is consistent with the recommendations of the ***Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*** (DRC) Final Report. The Commission has contributed to the Australian Government's response to the DRC final report and will continue efforts to improve the health care of people with cognitive disability.

The User Guide complements other Commission resources for people with cognitive disability or impairment, including the:

- **Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard**
- **Four Steps to Inclusive Health Care: With Me and About Me**
- **NSQHS Standards User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium**
- **Delirium Clinical Care Standard**.

Although the User Guide focuses on intellectual disability, the recommended strategies for improvement are relevant to people with any form of cognitive disability receiving health care.

Definition of intellectual disability

Intellectual disability is a neurodevelopmental disorder that begins in childhood and is ‘characterised by intellectual difficulties as well as difficulties in conceptual, social and practical areas of living’.[4]

People with intellectual disability may also have communication difficulties and physical disabilities related to their neurodevelopmental disorder. Depending on the cause of the disorder, they may have associated health conditions and different healthcare needs.[5] Intellectual disability affects all stages of a person’s life. However, with early intervention, support and adjustments throughout their life stages, people with intellectual disability learn, achieve social and emotional growth, and participate actively in society.[5]

Diagnosis of intellectual disability

The diagnosis of intellectual disability is based on a combination of psychometric assessment, clinical judgement and the person’s adaptive functioning.[5]

Level of disability

The World Health Organization (WHO) ***International Classification of Functioning for Disability and Health (ICF)*** defines disability as the result of the interaction between a person’s impairment and their environment.[6] This is a biopsychosocial model of health and disability, combining both the medical and social models of disability. The ranges of disability encompass mild, moderate, severe and complete impairment. To measure health and disability, the ICF uses the domains of:[6,7]

- Body function
- Activities and participation
- Environment (physical, political, social and attitudinal)
- Body structure
- Healthcare needs of people with intellectual disability.

Common co-occurring conditions for people with intellectual disability

When compared with the general population, people with intellectual disability have significantly higher physical and psychiatric morbidities.[8,9,10,11,12] These co-occurring conditions are related to either a genetic condition, lifestyle risks or social determinants. They include:

- Sensory impairments
- Epilepsy
- Eating (feeding) difficulties and related nutritional complications
- Dysphagia
- Osteoporosis
- Respiratory illness
- Gastrointestinal illness
- Frailty and premature ageing

- Mental illness
- Diabetes
- Cardiovascular disease
- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder.

Social determinants of health

People with intellectual disability, in particular children and young people, are also at increased risk of poor health and reduced health outcomes as a result of poverty, social isolation, domestic violence, becoming victims of crime, homelessness, child abuse and neglect, living in out-of-home care, or over-representation in juvenile and adult criminal justice systems.[3,10,13]

These risks are amplified for people with intellectual disability who are also members of marginalised groups within the community. These groups include women, First Nations peoples, culturally and linguistically diverse people, and LGBTQI+ people.[14,15,16]

Safety and quality issues in health care for people with intellectual disability

International and national research identifies a number of safety and quality issues in health care for people with intellectual disability, including:[17,18,19,20]

- Higher mortality rate and comparatively lower life expectancy than people without intellectual disability[3,10,20,21]
- Preventable hospitalisations
- High morbidity, including from chronic disease
- Unmet healthcare needs such as delayed diagnosis and/or treatment
- Risks from polypharmacy
- Greater likelihood of being subject to restrictive practices
- High burden of potentially preventable health conditions
- Lower rates of access to preventive health and screening programs.

Contributors to poor safety and quality in health care

The combination of complex healthcare needs, communication difficulties and reliance on others for support has significant implications for the delivery of health care to people with intellectual disability.[2,10,22,23,24]

The WHO describes the health inequity experienced by people with disability using three indicators: mortality, morbidity and functioning.[10] It states that the 'persistent and pervasive differences' across these indicators in health outcomes for people with disability when compared with the general population are not solely explained by a 'person's disability or associated health conditions'. People with intellectual disability have poorer health outcomes when compared to people with other disabilities or the general population.[2,25,26]

National and international academic literature and government reports, including the DRC final report, describe the underlying contributors to poor safety and quality in health care as:[2,10,13,24,25,27,28,29,30]

- Limited training in the healthcare needs of people with intellectual disability
- Poor awareness of the barriers to accessing health care
- Direct and indirect discrimination through the failure to provide reasonable adjustments
- Limited data collection at individual, program and systemic levels.

A reasonable adjustment is an action a service provider takes to ensure that the person can fully participate in a service or activity and receive the full benefit of that service or activity.

The ***Disability Discrimination Act 1992*** **(Cth)** (DDA) defines reasonable adjustment as 'actions taken to eliminate or reduce direct or indirect discrimination'. The DDA requires services to make reasonable adjustments so as not to discriminate against a person on the grounds of disability.

Lack of access to health care

Direct and indirect discrimination against people with intellectual disability, through physical, attitudinal, social, structural and financial barriers, occurs at all levels of society.[10,25,28] Negative attitudes towards intellectual disability may lead to misdiagnosis or delayed diagnosis if a person's physical symptoms or behaviours are attributed to their intellectual disability. As a result, people with intellectual disability may not receive the same level of health care as the general population,[31] leading to preventable hospitalisations, chronic disease and early mortality.[22,32,33,34,35]

Common cognitive biases toward people with intellectual disability include assumptions about a person's quality of life, their ability to gain new skills and their capacity to participate in healthcare planning. Cognitive bias may influence decisions about providing proactive treatment, rehabilitation, preventive health care and end-of-life care.[36,37,38,39,40]

Scope

The Commission has developed the User Guide to support health service organisations and clinicians in providing safe and high-quality health care to people with intellectual disability.

Language

The person with intellectual disability

The User Guide uses the terms 'person', 'person with intellectual disability' and 'people with intellectual disability' to refer to the person or people receiving the healthcare service(s). The person may be a child, young person or adult with intellectual disability.

Family

Family refers to those who are related to the person receiving healthcare services by blood, marriage (including de facto), fostering or adoption. Family members may also act as unpaid carers or legally appointed guardians of adults with intellectual disability.

Supporters

People with intellectual disability may often have a wide range of people involved in their life beyond paid or unpaid carers. The term 'supporter' can encompass the titles and roles described below, as well as other professionals involved in a person's life.

Where relevant, the User Guide may highlight a specific role such as a National Disability Insurance Scheme (NDIS) disability support worker or NDIS health liaison officer.

- **Direct support**

  NDIS disability support worker: A paid carer who may often attend the hospital or day surgery with the person.

- **Indirect support**

  Disability advocate: An independent social or citizen advocate.

  NDIS accommodation support manager: A manager of NDIS accommodation services, responsible for delivering accommodation services. The manager may function as a liaison for admission and discharge planning on behalf of the NDIS accommodation service.

  NDIS behaviour support specialist and allied health therapist: Professionals who provide behavioural and therapeutic intervention to the person. These professionals may supply important information to assist in comprehensive care planning.

- **NDIS support coordination**

  NDIS support coordinator: Support coordinators assist the person with the management of their individual funding packages through referral and coordination of NDIS services. A support coordinator has an overview of all the NDIS services used by the person. Support coordinators may be involved in discharge planning.

- **NDIS planning**

  NDIS planner: NDIS planners are from the National Disability Insurance Agency (NDIA) and are responsible for the development of the person's NDIS funding plan. The NDIA planner may be involved in discharge planning when changes to the person's funding are required.

  Health liaison officer: Health liaison officers work directly with hospitals to streamline discharge for NDIS participants when they are medically ready. NDIS plans include funding that meets reasonable and necessary criteria and directly relates to the person's disability. The NDIS website has information for NDIS participants in hospital.

Guardian

A guardian is a person permitted under law to make healthcare decisions on behalf of another person.

Health service organisation

Refers to hospitals, day procedure services and public dental services.

Inclusion

Inclusion focuses on removing barriers, making adjustments, and recognising and adjusting for diverse needs across the population to ensure equity.

Reasonable adjustments

Reasonable adjustments in health care include policies, processes, systems and communication aids that cater to the needs of the person with disability. The User Guide identifies when and how reasonable adjustments may assist people with intellectual disability in accessing health care.

What is included in the User Guide?

The User Guide covers specific NSQHS Standards and Actions that ensure systems for clinical governance and person-centred approaches are in place.

The User Guide is arranged by each relevant NSQHS Standard. Each chapter contains:

- A brief description of the Standard
- Information on how the Standard is relevant to health care for people with intellectual disability
- Important Actions under the Standard for delivering health care for people with intellectual disability
- Strategies for improvement under these Actions
- Resources for health service organisations and clinicians.

The strategies for improvement are evidence-based. They encompass delivering person-centred care, planning for reasonable adjustments, communicating, working collaboratively, building workforce capacity and collecting data.[22,24,25,28,29]

Spotlight issues

Where relevant, the User Guide includes boxes containing spotlight issues. These highlight important aspects of healthcare delivery for people with intellectual disability, their family's and guardians.

The NSQHS Standards are designed to be implemented in an integrated way. The spotlight issues provide disability-specific information and links to important NSQHS Actions to show how these can contribute to the delivery of safe and high-quality health care for people with intellectual disability.

Spotlight issues

Supported decision-making: This spotlight provides strategies on how to integrate the process of supported decision-making with person-centred care and informed consent.

Co-design and consultation with people with intellectual disability: This spotlight provides information to help ensure that the perspectives, experiences and expertise of people with disability are considered in planning healthcare services.

Polypharmacy: People with intellectual disability and complex healthcare needs are more likely to experience polypharmacy with high-risk medications. The spotlight defines polypharmacy and the important NSQHS Actions to prevent adverse health outcomes for people with intellectual disability.

Supporting people with intellectual disability from admission to discharge: Admission and discharge from acute care are high-risk transitions of care for people with intellectual disability. This spotlight provides information on a range of considerations to support people with intellectual disability throughout an admission and through to discharge.

Comprehensive care at the end of a person's life: People with intellectual disability often experience barriers when accessing end-of-life care, or they may be referred for palliative care services without consideration of active treatment. Health service organisations can address this by implementing the Comprehensive Care Standard Actions that address end of life. This spotlight provides resources specific to people with intellectual disability.

Intellectual disability, communication and positive behaviour support: People with intellectual disability require reasonable adjustments focused on communication and behaviour. Health services and clinicians can provide these reasonable adjustments as part of their healthcare delivery, using knowledge and understanding of intellectual disability, communication and behaviour support.

Working collaboratively with the disability sector: The disability sector has a significant role in supporting people with intellectual disability to access health care by sharing information that supports reasonable adjustments, involvement with comprehensive care planning and transitions of care.

Transitions of care: Transitions of care are points at which valuable information for safety, quality and continuity of care can be lost. For people with intellectual disability all transitions of care can be high risk, as information about reasonable adjustments may not be considered as essential clinical information.

Table 1: Standards and Actions covered in the User Guide

Standard	Criterion	Item	Action
Clinical Governance	Governance, leadership and culture	Governance, leadership and culture	1.01 1.02
		Organisational leadership	1.05
		Clinical leadership	1.06
	Patient safety and quality systems	Policies and procedures	1.07
		Measurement and quality improvement	1.08
		Diversity and high-risk groups	1.15
	Clinical performance and effectiveness	Safety and quality training	1.20
		Evidence-based care	1.27
Partnering with Consumers	Partnering with patients in their own care	Healthcare rights and informed consent	2.03
		Sharing decisions and planning care	2.07
	Health literacy	Communication that supports effective partnerships	2.08 2.10
Medication Safety	Continuity of medication management	Medication review	4.10
		Information for patients	4.11
Comprehensive Care	Clinical governance and quality improvement to support comprehensive care	Designing systems to deliver comprehensive care	5.04
	Developing the comprehensive care plan	Screening of risk	5.10
		Clinical assessment	5.11
	Minimising patient harm	Preventing delirium and managing cognitive impairment	5.29
Communicating for Safety	Clinical governance and quality improvement to support effective communication	Organisational processes to support effective communication	6.04
	Communication at clinical handover	Clinical handover	6.08
Recognising and Responding to Acute Deterioration	Detecting and recognising acute deterioration, and escalating care	Recognising acute deterioration	8.04 8.05

Clinical Governance Standard

Intellectual disability and the Clinical Governance Standard

The **Clinical Governance Standard** can facilitate equity in health care for people with intellectual disability.

Leadership and planning are required to establish and maintain safety and quality systems that:

- Identify intellectual disability
- Support reasonable adjustments
- Review and monitor outcomes for people with intellectual disability
- Allow for flexibility of service delivery
- Maintain a focus on building workforce knowledge, intellectual disability awareness, and confidence in communication and caring for people with intellectual disability.

Governance, leadership and culture

Action 1.01

The governing body:

a. Provides leadership to develop a culture of safety and quality improvement, and satisfies itself that this culture exists within the organisation
b. Provides leadership to ensure partnering with patients, carers and consumers
c. Sets priorities and strategic directions for safe and high-quality clinical care, and ensures that these are communicated effectively to the workforce and the community
d. Endorses the organisation's clinical governance framework
e. Ensures that roles and responsibilities are clearly defined for the governing body, management, clinicians and the workforce
f. Monitors the action taken as a result of analyses of clinical incidents
g. Reviews reports and monitors the organisation's progress on safety and quality performance.

Intent

The governing body must assure itself that a culture of safety and quality improvement operates in the organisation.

Strategies for improvement

Provide leadership on reasonable adjustments as a part of the safety culture

Leadership and culture development that supports positive attitudes towards people with intellectual disability requires clear leadership. Reasonable adjustments are essential components of safety and quality.[41,42] This can include encouraging the commitment to accessibility by producing Easy Read versions of key organisational documents that support access to important information about health care.

The health service organisation's leadership should increase the visibility of healthcare strategies to improve outcomes for people with intellectual disability, by developing a disability service plan, providing training and collecting demographic data to identify people with intellectual disability. The **Metro South Health Disability Service Plan 2023–26** is an example of a disability service plan.

Involve people with intellectual disability, and their family, supporters or guardians in describing their experience of health care and respond to the issues identified

It is important to consult people with intellectual disability as part of organisational planning, monitoring and review, and to have systems in place for identifying safety and quality issues for people with intellectual disability.

It is also important to involve people with intellectual disability and their supporters in reviewing and assessing their experience of care. The Commission's **Australian Hospital Patient Experience Question Set – Easy English** for people with low English literacy is a survey hospitals and healthcare services use to ask recent patients about their experiences of treatment and care. It is based on the aspects of treatment and care that patients in Australian hospitals and healthcare services have told the Commission are most important to them.

A person with intellectual disability, and/or their family supporter or guardian, could describe to members of the governing body their experience of the following aspects of care:

Before going to hospital	During hospital stay	After leaving hospital
• Parking • Signage • Reception • Filling out forms • Waiting times and areas • Pre-admission processes and information • Communication needs, gaps and accessibility of information (e.g. Easy Read versions or video animations)	• Support during all aspects of admission • Understanding of multi-disciplinary approaches • Meeting disability support needs during admission • Communication between clinicians for transitions of care	• Discharge planning • Transition of care

Action 1.02

The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander peoples.

Intent

The health needs of Aboriginal and Torres Strait Islander peoples are identified in partnership with local communities, and improvement actions are supported by the governing body.

Strategies for improvement

Incorporate the identification of Aboriginal and Torres Strait Islander people with intellectual disability into the organisation's demographic profile

Aboriginal and Torres Strait Islander people with disability, including people with intellectual disability, should be identified as a priority group within relevant First Nations health service plans. People with disability are an identified priority group within the **National Aboriginal and Torres Strait Islander Health Plan 2021–2031**.

Partner with local Aboriginal and Torres Strait Islander communities to develop an understanding of how many local Aboriginal and Torres Strait Islander people have intellectual disability, and their experience of health care. This information can inform the co-design of strategies to address their specific access barriers and health needs.

Data from the **2018 Survey of Disability, Ageing and Carers** found that 10.1% of Aboriginal and Torres Strait Islander males had an intellectual disability and 5.9% of females had an intellectual disability. The combined rate for men and women is 15.9%.[43]

Consult with Aboriginal and Torres Strait Islander health service providers and communities on safety and quality issues for people with intellectual disability

The **2023 Commonwealth Closing the Gap Implementation Plan** has incorporated disability into the reform agenda and priority targets. Consult with local communities on culturally inclusive concepts of disability to assist with identifying specific approaches required for Aboriginal and Torres Strait Islander people with intellectual disability.

For more information see:

- The **First Peoples Disability Network** website, which provides background reading and information on effective health care
- Data from the **2018 Survey of Disability, Ageing and Carers** on Aboriginal and Torres Strait Islander people with disability
- The 2023 Commonwealth Closing the Gap Implementation Plan **Disability Sector Strengthening Plan**.

Organisational leadership

Action 1.05

The health service organisation considers the safety and quality of health care for patients in its business decision-making.

Intent

Decisions relating to equipment, plant, building works, consumables, staffing and other resources consider the safety and quality implications for patients.

Strategies for improvement

Business decision-making considers access, inclusion and universal design

Equity and good health outcomes can be achieved through business decision-making that is based on the concepts of inclusion and universal design.[25,44] This will also support the health service organisation's compliance with the ***Disability Discrimination Act 1992* (Cth)**.

The **Australian Disability Network** defines inclusion as the 'consideration and incorporation of the needs of people with disability in all areas of an organisation's operations.' The Australian Disability Network provides information on inclusive organisations and the **Quick 10 Assessment tool** to help organisations understand their level of access and inclusion.

Universal design is an inclusive method or way of thinking when planning and making decisions. It can prevent the need for specialised technology or arrangements as it requires 'products, environments, programmes and services to be usable by all people, to the greatest extent possible'.[44] Co-design and consultation are strategies that support inclusion and universal design methods.

The Victorian Health Building Authority incorporated a **Universal Design Policy** into its infrastructure planning in 2021.

The Centre for Universal Design Australia **Introduction to Universal Design** course covers the classic definition and the eight goals of universal design.

Figure 1: Eight Goals of Universal Design[45]

Body fit	**Comfort**	**Awareness**	**Understanding**
Wellness	**Social integration**	**Personalisation**	**Cultural appropriateness**

Clinical leadership

Action 1.06

Clinical leaders support clinicians to:

a. Understand and perform their delegated safety and quality roles and responsibilities

b. Operate within the clinical governance framework to improve the safety and quality of health care for patients.

Intent

Clinical leaders and leaders of clinical services work with other clinicians to optimise the safety and quality of care.

Strategies for improvement

Develop disability awareness and capacity to address safety and quality risks for people with intellectual disability

Ensure that clinical leaders, clinicians and safety and quality managers are knowledgeable about people with intellectual disability and:

- Their complex care needs
- Safety and quality risks in health care
- The importance of reasonable adjustments.

Awareness activities could include:

- Presenting cases at clinical review meetings regarding the clinical care of people with intellectual disability
- Including subject matter experts in clinical reviews to ensure barriers are considered and to guide the development of recommendations for quality improvements for people with intellectual disability
- Providing clinical supervision to assist clinicians to critically review their clinical practice, how they plan for reasonable adjustments and how they screen for unmet healthcare needs
- Involving people with intellectual disability in workforce training to provide insight into their personal experience of health care
- Delivering training focused on reasonable adjustments.

Resources

The Council for Intellectual Disability has developed the **Reasonable Adjustments Checklist for Health Professionals** as a guide for health professionals to use before, during and after a person with intellectual disability presents for a health appointment. This resource has ideas for reasonable adjustments when providing health care to people with intellectual disability.

Policies and procedures

Action 1.07

The health service organisation uses a risk management approach to:

a. Set out, review, and maintain the currency and effectiveness of policies, procedures and protocols
b. Monitor and take action to improve adherence to policies, procedures and protocols
c. Review compliance with legislation, regulation and jurisdictional requirements.

Intent

The health service organisation has current, comprehensive and effective policies, procedures and protocols that address safety and quality risks.

Strategies for improvement

Review and amend policies, procedures and protocols to act on safety and quality risks for people with intellectual disability

Review policies, procedures and protocols to incorporate reasonable adjustments, disability inclusion and access strategies. Appropriate policies include clinical governance, data collection, priority consumer groups, complaint processes and communication systems. This should be standard practice in all policy and procedure development efforts.[2,3,30,31,46,47,48,49]

Review compliance with disability legislation, regulation and jurisdictional requirements, and act on findings

The legal and policy framework for disability and health in Australia includes legislation and regulations at the national, state and territory levels.

National:

- *Disability Discrimination Act 1992* (Cth)
- *National Disability Insurance Scheme Act 2013* (Cth)
- National Health Reform Agreement – Schedule F: Interfaces between Health, Disability and Aged Care Systems
- The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other Service Systems
- Health Policy Priorities under Australia's Disability Strategy 2021–2031.

States and territories:

- NSW Health Disability Inclusion Action Plans
- Inclusive Victoria: state disability plan (2022–2026)
- Queensland Health Department of Health Disability Service Plan 2022–2024
- Western Australian Department of Health Disability Access and Inclusion Plan
- Accessible Island: Tasmania's Disability Framework for Action 2018–2021
- Northern Territory Disability strategy and action plan
- South Australian Department for Health and Wellbeing's Disability Access and Inclusion Plan 2020–2024
- ACT Disability Health Strategy 2024–2033
- Canberra Health Services Disability Action and Inclusion Plan 2022–2025.

Measurement and quality improvement

Action 1.08

The health service organisation uses organisation-wide quality improvement systems that:

a. Identify safety and quality measures, and monitor and report performance and outcomes
b. Identify areas for improvement in safety and quality
c. Implement and monitor safety and quality improvement strategies
d. Involve consumers and the workforce in the review of safety and quality performance and system.

Intent

An effective quality improvement system is operating across the organisation.

Strategies for improvement

Incorporate consideration of intellectual disability into the health service organisation's safety and quality systems

Involving people with intellectual disability, their families and supporters in the development, implementation, monitoring and evaluation of healthcare delivery can increase the visibility of people with intellectual disability at all levels of the health service organisation.[2,3]

Strategies to increase the visibility of people with intellectual disability include:

- Adjusting consumer feedback systems and patient satisfaction surveys to accommodate people with intellectual disability
- Exploring models of care that support flexible approaches, for example a clinical pathway for access to examination or investigation under anaesthesia, or the Victorian Department of Health **Disability Liaison Officer program**. Disability Liaison Officers create a link between the person and the health system to facilitate reasonable adjustments
- Developing and making public the clinical care pathways available for people with intellectual disability in core elements of the health services system
- Identifying the risks of psychological and emotional trauma in the healthcare setting and how reasonable adjustments may address these risks
- Increasing workforce awareness of how to provide health care to people who use non-verbal communication
- Including consumer representatives and/or specialist clinicians as part of the organisation's safety and quality systems – for example, in the review of a critical incident in a health service involving a person with intellectual disability.

Audit systems and processes to identify where there may be risks for people with intellectual disability

Conduct a review of existing systems, staff knowledge and skills to identify risks and gaps in safety and quality systems for people with intellectual disability. This can lead into developing and implementing an action plan to improve healthcare outcomes for people with intellectual disability.

This review could include an audit of staff knowledge, confidence and attitudes in the provision of health care to people with intellectual disability. For example, the review could ask how safe and high-quality health care is provided to a person who cannot communicate verbally or who needs support to understand information?

Resources

- **National Roadmap for Improving the Health of People with Intellectual Disability** – A Primary Care Enhancement Program is being piloted in four Primary Health Networks (PHNs) over four years, with a view to national rollout across all PHNs.
- Queensland's **Metro South Health** Equity and Access Team is working to improve health services for people with disability, and has developed initiatives and tools for use in an acute care setting.

Diversity and high-risk groups

Action 1.15

The health service organisation:

a. Identifies the diversity of the consumers using its services
b. Identifies groups of patients using its services who are at higher risk of harm
c. Incorporates information on the diversity of its consumers and higher-risk groups into the planning and delivery of care.

Intent

The diversity of consumers and high-risk groups are considered in the planning and delivery of care and services.

Strategies for improvement

Include intellectual disability in the collection of demographic data to ensure visibility of people with intellectual disability in the health service organisation

Review the process for collecting demographic information on intellectual disability to ensure relevant data is systematically captured to inform service planning and evaluation. Collecting this information can assist in the delivery of clinical care, to support local systems improvement and to monitor outcomes.

Under Action 1.15c, include intellectual disability in the collection of demographic information about Aboriginal and Torres Strait Islander, culturally and linguistically diverse and LGBTQI+ communities.

Encourage clinicians, if they suspect a person has intellectual disability, to ask the person if they have intellectual disability, and to record the response. People with intellectual disability have told the Commission that they are not often asked if they have intellectual disability, but that they would appreciate being asked. In addition, people with intellectual disability have told the Commission that they are not likely to proactively identify their intellectual disability. Even when known, intellectual disability may not be recorded on an individual's health record or included in data collection systems.[29,47,50]

Incorporate diversity into the organisation's safety and quality risk assessment processes

Ensure the health service organisation's risk assessment processes address the safety and quality risks people with intellectual disability face. Capture diversity as part of this process.

Identify safety and quality risks for people with intellectual disability and incorporate these into safety and quality monitoring

Ensure that the health service organisation's safety and quality mechanisms can quantify and address the safety and quality risks for people with intellectual disability. This can include staff training, recording episodes of restrictive practice, recording reasonable adjustments made and monitoring outcomes.

Resources

- The **National Disability Data Asset**, which provides linked data to understand the life experiences of people with intellectual disability
- Australian Bureau of Statistics data on **Disability, Ageing and Carers, Australia**
- The Commission's 2023 report on **Health outcomes for adults with cognitive impairment** admitted to public hospitals in Australia
- The Australian Institute of Health and Welfare **Australia's Disability Strategy 2021–2031 Outcomes Framework: Second annual report**.
- The NSW Agency for Clinical Innovation guide **Building capability in health services for people with intellectual disability: the Essentials** provides a safety and quality self-assessment tool, and links to a range of resources for health service organisations to better meet the needs of people with intellectual disability.
- The **Clinical Care Standards** address specific clinical conditions and defined clinical pathways. Health services or clinicians can use these to measure improvements in safety and quality.

Safety and quality training

Action 1.20

The health service organisation uses its training systems to:

a. Assess the competency and training needs of its workforce
b. Implement a mandatory training program to meet its requirements arising from these standards
c. Provide access to training to meet its safety and quality training needs
d. Monitor the workforce's participation in training.

Intent

The workforce is appropriately trained to meet the need of the organisation to provide safe and high-quality care.

Strategies for improvement

The governing body ensures that disability awareness and knowledge is part of the health service organisation's regular training and cultural environment

Engage the workforce in intellectual disability awareness training and the application of reasonable adjustments. Training from people with intellectual disability, their families and supporters is also an effective way to build understanding of disability and confidence supporting those with disability.[28,51]

In addition, provide awareness-raising activities and access to resources to promote the confidence and skills of clinicians to partner with people with intellectual disability, their families and supporters in their care.

Ensure clinicians and the healthcare workforce know how to identify whether a person with intellectual disability is a National Disability Insurance Scheme (NDIS) participant and if so how to contact their NDIS service provider.

The governing body prioritises and monitors the capacity of the workforce to provide inclusive health care to people with intellectual disability, their families and supporters

Develop corporate knowledge on inclusive health care and monitor its progress towards competency. A Disability Inclusion Action Plan may assist this process. This approach ensures disability awareness is part of the organisation's safety culture.[25,28] See Action 1.07 of this User Guide for more information about disability inclusion action plans.

Resources

- **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) is an international human rights convention setting out the fundamental human rights of people with disability. The purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
- **Australia's Disability Strategy 2021–2031** is Australia's national disability policy framework. It is driving action at all levels of government to improve the lives of people with disability.
- **Every Nurse's Business** is an online learning site for Australian Registered Nurses to help build nursing capacity to address the healthcare needs of people with intellectual disability and/or autism spectrum disorder in mainstream health settings.
- **National Roadmap for Improving the Health of People with Intellectual Disability** is part of a 10-year plan aimed at improving serious health inequalities faced by people with intellectual disability. The overall goal of the roadmap is to develop a healthcare system in which people with intellectual disability are valued and respected, and have access to high-quality, timely and comprehensive health care.
- **Intellectual Disability Health Capability Framework** aims to equip future health professionals with the required core capabilities to provide quality health care to people with intellectual disability.
- The Department of Health and Aged Care **intellectual disability health contact** provides updates and information on disability inclusion and improving the health of people with intellectual disability.
- **National Disability Insurance Agency** (NDIA) is a statutory agency that implements the National Disability Insurance Scheme (NDIS). Its purpose is to increase the ability of individuals with a significant and permanent disability (participants) to be more independent and engage more socially and economically.
- **NDIS offices and contacts** in each state or territory.
- **NDIS Quality and Safeguards Commission** is an independent agency established to improve the quality and safety of NDIS supports and services.
- **Disability Gateway** has information and services to help people with disability, their family, friends and carers, to find the support they need in Australia.
- **My Lived iD CALD Information and Support** has resources and information for people with intellectual disability, their families, carers and healthcare professionals.
- **Council for Intellectual Disability Just Include Me: Inclusive Health Care eLearning** is an online self-paced training for health professionals which aims to shine a light on person-centred care and support health professionals to learn more about resources, tools, and actions to promote inclusion in health care for people with intellectual disability.

Evidence-based care

Action 1.27

The health service organisation has processes that:

a. Provide clinicians with ready access to best-practice guidelines, integrated care pathways, clinical pathways and decision support tools relevant to their clinical practice

b. Support clinicians to use the best available evidence, including relevant **clinical care standards** developed by the Australian Commission on Safety and Quality in Health Care.

Intent

The clinical workforce is supported to use the best available evidence.

Strategies for improvement

Educate the workforce on a range of evidence-based guidelines relevant to people with intellectual disability.

The following guidelines are relevant to people with intellectual disability:

- **NSQHS Standards User guide for health service organisations providing care for patients with cognitive impairment or at risk of delirium** – This guideline supports the implementation of Actions 5.29 and 5.30 for people with cognitive impairment (including intellectual disability) at risk of developing delirium. See Action 5.29 in the 'Comprehensive Care Standard' section of this User Guide for further information.
- **Delirium Clinical Care Standard** – People with intellectual disability have an elevated risk of developing delirium, particularly when they are acutely unwell or in an unfamiliar environment.
- **Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard** – The Standard provides eight Quality Statements to guide safe health care for people with intellectual disability who have behaviours of concern. Individuals may be prescribed psychotropic medications when they present for care, or the question of prescribing these medications may emerge during their admission.

Partnering with Consumers Standard

Intellectual disability and the Partnering with Consumers Standard

The aim of the **Partnering with Consumers Standard** is to create an organisation in which those receiving health care are involved in service planning, design, delivery, measurement and evaluation, and are partners in their own care. The organisation's systems and processes are designed to support the workforce to deliver person-centred care.[52] Person-centred care is fundamental to safe and high-quality health care. It is care that is respectful of, and responsive to, the person's preferences, needs and values.[53]

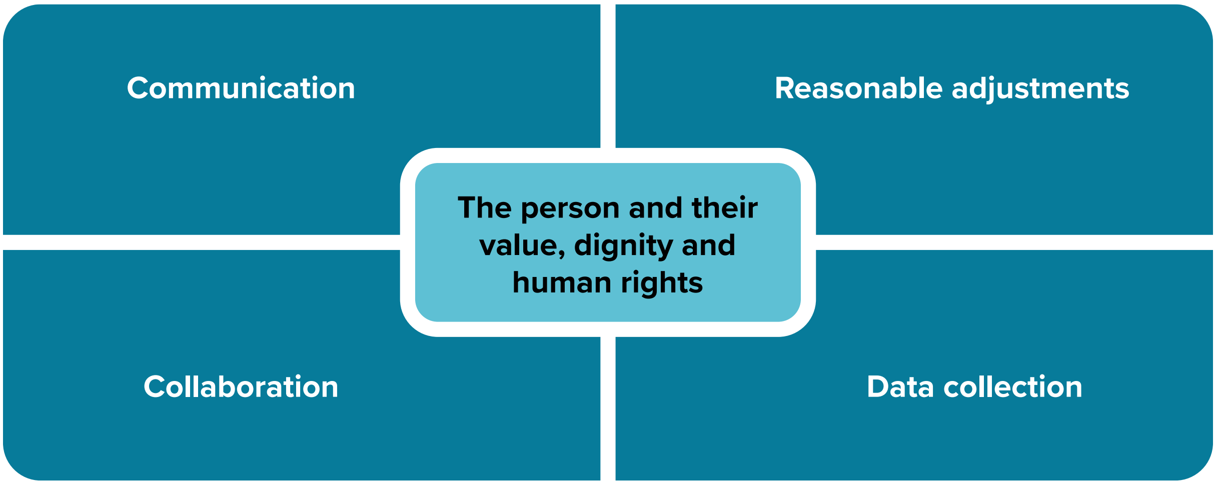
For people with intellectual disability, the lack of targeted adaptations, policies, knowledge and confidence within health services is often a barrier to genuine partnership.[22,25,46,47,54,55,56,57]

People with intellectual disability and their families are more likely to have poor experiences in healthcare settings that include:[2,14,15,34,35,54,56,58]

- Healthcare providers failing to ask if the person has an intellectual disability
- Healthcare providers not effectively communicating with the person with intellectual disability
- A lack of understanding of the role of National Disability Insurance Scheme (NDIS) service providers
- Little or no consideration of critical information provided by the family, supporters or guardian
- A lack of follow-up and communication with family, supporters or guardians after physical examinations, tests and treatments
- Medication errors and polypharmacy
- Trauma, neglect and untreated pain.

The Commission has developed a model with four domains of action to develop effective organisational and individual partnerships with people with intellectual disability.[2,10,24,34,50,54,57]

Figure 2: Components needed for inclusive health care



Healthcare rights and informed consent

Action 2.03

The health service organisation has a charter of rights that is:

a. Consistent with the **Australian Charter of Healthcare Rights**
b. Easily accessible for patients, carers, families and consumers.

Intent

Consumers are provided with information about their healthcare rights.

Strategies for improvement

Incorporate the United Nations Convention on the Rights of Persons with Disabilities and the Australian Charter of Healthcare Rights into health service information for people with intellectual disability

The **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) sets out the human rights of people with disability, as ratified by 186 countries including Australia. Three articles relevant to health service organisations are:

- **Article 12**, which recognises that people with disability have legal capacity on an equal basis with all others. This means the right to make decisions such as consenting to healthcare treatment. The person has a right to access the support required to make decisions. The person's legal capacity is inviolable and cannot be removed. Safeguards such as guardianship should be used to support equal recognition and must be legal, proportional and for the shortest period necessary[44]
- **Article 25**, about health and the right to the enjoyment of the highest attainable standard of health, without discrimination
- **Article 26**, about habilitation and rehabilitation. Countries must take effective and appropriate measures to enable people with disability to develop, attain and maintain maximum ability, independence and participation.

The **Australian Charter of Healthcare Rights** was developed by the Commission and approved by all health ministers in 2008. These rights are essential to ensure that safe and high-quality care is provided to all people, including people with intellectual disability, in all health settings in Australia, including public and private hospitals.

Provide information about healthcare rights that is easy to understand

Provide information on the Australian Charter of Healthcare Rights in a format that is accessible for people with intellectual disability, such as an Easy Read version.

The Easy Read format describes everyday concepts and ideas with words and pictures and is designed specifically for people with intellectual disability.

Easy English resources are designed for broader audiences but may exclude people with intellectual disability if everyday concepts are not explained or illustrated.

People with intellectual disability may still require assistance with Easy Read and Easy English resources. These resources assist the clinician, family, supporters or guardian to discuss health care with the person.

Monitor whether the rights in the CRPD have been respected for people with intellectual disability. This monitoring can include, for example, conducting surveys involving the person, their family and/or their supporters.

Resources

- Department of Health and Aged Care **Easy Read resources for people with intellectual disability**
- The **Australian Government Style Manual** has information on developing Easy Read communications
- The **NSW Council for Intellectual Disability** provides guidance and training to help organisations develop Easy Read resources
- Australian Commission on Safety and Quality in Health Care:
  - **About Me – Questions to ask about Reasonable Adjustments Fact Sheet**
  - **Australian Charter of Healthcare Rights (second edition) – Easy English version**
  - **About healthcare rights for people with cognitive impairment – Easy English Guide** is a guide to help people living with cognitive impairment to get good health care
  - **Goals of Care – Easy English** provides tips to help make sure everyone in the healthcare team knows what is important to the person with intellectual disability.

Sharing decisions and planning care

Action 2.07

The health service organisation supports the workforce to form partnerships with patients and carers so that patients can be actively involved in their own care.

Intent

Clinicians work with patients to enable them to be partners in their own care.

Strategies for improvement

Build a disability confident workforce

A disability confident workforce understands and acts on the concepts of inclusion and accessibility. The Australian Council of Learned Academies (ACOLA) report ***Ensuring Occupations are Responsive to People with Disability*** includes a good practice guide for professions, and useful tools and definitions to raise disability awareness.[28]

ACOLA has identified six key principles associated with positive interactions between people with disability and professionals. The six principles are outlined below.

- **Nothing about us without us:**
  Education and training about disability must be developed and delivered with, or by, people with disability.
- **Capability areas:**
  Training must develop skills, knowledge and attitudes.
- **Experiential learning:**
  Training must include 'on the job' learning.
- **Addressing bias:**
  Training should enhance a learner's ability to critically reflect on their attitudes and behaviours towards people with disability.
- **Fit for purpose:**
  Training must enhance a learner's ability to critically reflect on their personal attitudes towards and perceptions of people with disability.
- **Quantum:**
  Disability responsiveness will not be achieved through a single training event or course. Outcomes will require an ongoing commitment.

Facilitate the involvement of families, supporters or guardians of people with intellectual disability in a person's health care

Families and supporters of people with intellectual disability can provide valuable information about the person and how they will respond in a healthcare setting. Strategies to facilitate this involvement may include:

- Providing accessible information about the relevant health condition or treatment – such as symptoms, who participates in the person's care, length of stay in hospital, what to expect or prognosis – to the person and their family, supporters or guardian
- Keeping family, supporters or guardians regularly updated. Planning clinical assessments or reviews when the family or NDIS disability support workers can be present, or having regular discussions scheduled, especially if the person is non-verbal
- Completing organisational planning to meet the needs of families or paid disability support workers when they are supporting a person in acute care, such as quiet rooms or a cot to sleep on
- Keeping NDIS disability service providers or NDIS health liaison officers up to date on changes in the person's clinical information (with the proper consent and where relevant)
- Building the organisation's knowledge and understanding of the disability sector (see the Spotlight issue 'Working collaboratively with the disability sector').

Practise shared decision-making

Shared decision-making is a critical part of making sure people with intellectual disability are partners in their own health care.

To facilitate shared decision-making, a clinician should adjust their methods of communication with the person to maximise the person's participation in decision-making and informed consent to treatment.

Reasonable adjustments may include taking more time to explain the benefits and risks of a treatment and using Easy Read information or assistive communication technologies.

A person's skill and ability to participate in decision-making can fluctuate over time and depend on their underlying health condition, acute condition and the type of decision being made.

If a person's physical, emotional or behavioural state affects their ability to participate in shared decision-making and to consent to treatment, the clinician should engage substitute decision-makers or nominated persons, in line with legislation.

Resources

- Queensland Health **See Me. Hear Me. Respect Me. Campaign Resources**
- Metro South Health **Working with people with intellectual disability fact sheet**, part of the See Me. Hear Me. Respect Me. Campaign resources. Metro South Health has co-designed health worker fact sheets about supporting and communicating with people with disability. These have been adopted across Queensland.

Spotlight issue: Supported decision-making

A supported decision-making process is undertaken in collaboration with the person and their family, supporters or guardian, to provide the person with information in a way they can understand and the means of communicating their will and preferences in response.

A person with intellectual disability can meaningfully contribute to decision-making, even if a substitute decision-maker is required. Under the CRPD:

- Every person has the right and legal capacity to express their will and preference
- A person with disability has the right to make decisions
- A person with disability can expect to have access to appropriate support to make decisions.

A supported decision-making process may facilitate shared decision-making and informed consent in health care.

Important NSQHS actions

Action 2.04: The health service organisation ensures that its informed consent processes comply with legislation and best practice.

Action 2.06: The health service organisation has processes for clinicians to partner with patients and/or their substitute decision-maker to plan, communicate, set goals and make decisions about their current and future care.

Action 2.07: The health service organisation supports the workforce to form partnerships with patients and carers so that patients can be actively involved in their own care.

Strategies for improvement

Strategies to support Actions 2.04, 2.06 and 2.07 include:

- Incorporating supported decision-making principles and practices into clinical practices to enable shared decision-making and informed consent
- Including supported decision-making in disability awareness training, with a focus on how it can be incorporated into shared decision-making and informed consent procedures
- Encouraging clinicians to ask if a supported decision-making process can be used, particularly where there are family members, guardians or disability advocates to support the person's own decision-making process
- Supporting clinicians with the resources to facilitate reasonable adjustments, such as extra time and accessible information.

Resources

- NSW Council for Intellectual Disability **Supported Decision Making Framework**
- NSW Council for Intellectual Disability **My Rights Matter Hub – Supported Decision Making**
- **The La Trobe Support for Decision Making Practice Framework Learning Resource**
- NDIS **Supported decision making policy**
- Australian Law Reform Commission **National Decision-Making Principles**.

Communication that supports effective partnerships

Action 2.08

The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community.

Intent

Consumers receive the information they need in a way that is appropriate for them.

Strategies for improvement

Review communication mechanisms

Develop a framework for inclusive communication that takes into consideration the diversity of people with intellectual disability who access health care in the organisation.

Determine whether the organisation's current communication mechanisms meet the needs of people with intellectual disability by reviewing:

- Information developed by the organisation, such as patient brochures, posters and consent forms, to see whether they are available:
  - In a variety of community languages
  - In a variety of accessible formats, such as audio or Easy Read
- The cultural competency and confidence of the workforce in communicating with diverse patient populations.

Use augmentative and alternative communication

Two methods that can assist communication are augmentative and alternative communication (AAC).[59] See the **Speech Pathology Australia AAC fact sheet** for further information.

Augmentative communication is when something is added to speech to make it clearer for the audience. This can include using signs or pictures to clarify what is being said, for example, in the form of a supplemental Easy Read document.[2]

Alternative communication is when a different communication method is provided for someone who is unable to speak, or if the listeners do not understand speech. AAC encompasses a wide range of methods, from sign language and picture boards to mobile device apps and dedicated speech-generating devices. These methods, systems, tools and strategies can be used when a person uses something other than speech to communicate.[59]

Organisational policies should aim for early identification of communication difficulties and the use of AAC during a hospital admission to ensure safe health care. See the 'Comprehensive Care Standard' section in this User Guide for more on including communication needs in a person's comprehensive care plan.

Use existing networks to support communication with people with intellectual disability

Provide access to key contacts who can support the clinician's use of accessible communication strategies, including speech pathologists, the National Relay Service (NRS) and the Translating and Interpreting Service.

Network with other organisations or individuals in the community to share knowledge about communication preferences and needs. Networks may include culturally and linguistically diverse community groups; NDIS behaviour support clinicians; Primary Health Networks; Local Hospital Networks; local, state and territory government organisations; and professional associations.

Training for effective communication between clinicians and people with intellectual disability

People with intellectual disability are often not included directly in the discussions about their health.[41,54,60] It is important for clinician training to incorporate the requirement to include people with an intellectual disability in discussions about their health care.

Education and training for clinicians should include the appropriate use of Easy Read and AAC, and other reasonable adjustments for communication.

Resources

- Speech Pathology Australia **Communications Hub**
- Mater **EASY-Health – Easy Access for Everyone**
- NDIS Quality and Safeguards Commission **NDIS practice standards**
- Agency for Clinical Innovation **Guiding principles of quality health services for people with intellectual disability** (an Easy Read version is available: **10 things we believe about good health services for people with intellectual disability**)
- **Teach-back** – a simple yet effective communication tool used to check understanding, developed by South Eastern Sydney Local Health District and the Institute for Health Transformation at Deakin University
- World Health Organization information and fact sheets on **Disability**
- NSW Health **Responding to Needs of People with Disability during Hospitalisation Policy Directive** requiring the development of a pre-admission plan for people with disability[61]
- The **Australian Network on Disability** – a national not-for-profit that helps organisations engage with people with disability
- University of NSW Department of Developmental Disability Neuropsychiatry **Easy Read resources on mental health services** – information for people with intellectual disability and for health professionals
- NSW Council for Intellectual Disability **Just Include Me** online training, which supports health professionals to learn more about resources and tools, and to promote inclusion in health care for people with intellectual disability.

Action 2.10

The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that:

a. Information is provided in a way that meets the needs of patients, carers, families and consumers
b. Information provided is easy to understand and use
c. The clinical needs of patients are addressed while they are in the health service organisation
d. Information needs for ongoing care are provided on discharge.

Intent

Consumers receive the information they need to get the best health outcomes, and this information is easy to understand and act on.

Strategies for improvement

Provide access to appropriate information resources and tools to support communication with people who have intellectual disability

Provide clinicians with resources for effective communication, including Easy Read documents when needed.

Include accessible information on the organisation's website, such as information about coming to hospital; resources and visual aids; and information to support people with intellectual disability to seek help and assistance.

Resources

- **Say less show more** – a NSW Agency for Clinical Innovation communication initiative that provides information through a series of simple photo stories
- NSW Council for Intellectual Disability **Easy Read Resources**
- NSW Council for Intellectual Disability **My Health Cards** health conversation cards
- **My Health My Communication**
- Eastern Health **Cue Cards in Community Languages** – cue cards and symbols to support communication with people who do not understand English
- Inclusion Australia **Easy Read Resources**
- National Health Service England **Easy read information**
- Australian Commission on Safety and Quality in Health Care **About healthcare rights for people with cognitive impairment – Easy English Guide**
- Australian Commission on Safety and Quality in Health Care **Health Literacy: Taking action to improve safety and quality**
- Inclusion Melbourne **Your Dental Health**.

Set up an environment that supports open, clear and effective communication with people with intellectual disability, their families and supporters

This may involve:

- Engaging leadership and governing bodies to integrate the importance of health literacy and clear communication into the organisation's operations
- Aligning communication with other organisational priorities, such as reducing preventable hospitalisations, hospital-acquired complications and early mortality[62]
- Providing clinicians with training that highlights the importance of health literacy for the person with intellectual disability, and the use of tools such as Easy Read to provide information
- Implementing a plain-language policy that makes written information easier to understand
- Providing information on the organisation's website for families and supporters, for instance details about visiting hours, exemptions for essential carers, complaints processes and healthcare rights.

Resources

A range of communication resources are available for health services collaborating with people with intellectual disability:

Communication

- Speech Pathology Australia **fact sheets** (with Easy Read)
- The **National Relay Service** allows communication with another person via a third-party hearing person, even if the person accessing the NRS cannot hear or use their voice.

Informing care in hospital

- **Julian's Key Health Passport** is a consumer-controlled communication tool to assist people with disability to communicate their disability support and healthcare needs to Queensland Health staff. It is available in a fillable PDF or paper-based format.
- **My Health Matters** is an Easy Read folder that people with intellectual disability can create to improve communication with their healthcare providers.
- The **Admission 2 Discharge (A2D) Together Folder**, created in a partnership between the South Eastern Sydney Local Health District Carer Program and the Metro-Regional Intellectual Disability Network. The folder facilitates timely transfer of relevant and current information to enable hospital staff to meet the needs of people with intellectual disability in hospital.
- SA Health **My Health Information** is a resource to support people with intellectual disability to communicate their needs and preferences to healthcare staff while in hospital.
- Western Australian Department of Health **Hospital Stay Guidelines**, which aim to inform people with disability and their support networks, disability service providers and hospital staff of their respective roles.
- Central Coast Local Health District **TOP 5**, which invites carers to share up to five essential strategies or care tips that would assist staff in supporting the patient or client during their everyday life or during hospital admission. This information is written on a TOP 5 form to guide the person's care.

Providing healthcare information

- NSW Agency for Clinical Innovation **Circle of Support videos** show how health outcomes for people with intellectual disability can be improved if fear, anxiety or mental health concerns are preventing them from getting the medical help they need. Captioned versions of the videos are also available.
- NSW Council for Intellectual Disability **Health guides** in Easy Read support people with intellectual disability.
- North Metropolitan Health Service – Mental Health, Public Health and Dental Services **'Maggie goes to the dentist' social story** helps prepare people for the experience of going to the dentist.
- NSW Health **COVID-19 Easy Read resources** are a range of accessible resources about COVID-19 for people with disability. The videos and Easy Read fact sheets were developed in collaboration with the NSW Council for Intellectual Disability.
- **Books Beyond Words** creates award-winning wordless picture stories covering topics including physical and mental health. Each story is co-created with and for people who find pictures easier to understand than words.

Spotlight issue: Co-design and consultation with people with intellectual disability

Engaging people with intellectual disability through co-design or consultation in the planning and development of health services can provide benefits to the organisation and the community.

Co-design is the process in which all stakeholders participate and have a decision-making role in the planning, design, production and delivery of a policy, procedure or resource.

The consultation process involves gaining the relevant stakeholders' views to inform decisions made by the health service organisation.

Using a co-design or consultation process widens the range of perspectives, experiences and expertise involved, which benefits all consumers, including those who do not have intellectual disability.

The process also creates engagement between the health service organisation and the local community. People with intellectual disability are able to make a valuable contribution through the co-design or consultation process.

Important NSQHS Actions

Action 2.09: Where information for patients, carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review.

Spotlight issue: Co-design and consultation with people with intellectual disability

Action 2.11: The health service organisation:

a. Involves consumers in partnerships in the governance of, and to design, measure and evaluate, health care
b. Has processes so that the consumers involved in these partnerships reflect the diversity of consumers who use the service or, where relevant, the diversity of the local community.

Action 2.12: The health service organisation provides orientation, support and education to consumers who are partnering in the governance, design, measurement and evaluation of the organisation.

Action 2.13: The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs.

Action 2.14: The health service organisation works in partnership with consumers to incorporate their views and experiences into training and education for the workforce.

Strategies for improvement

Strategies to support Actions 2.09, 2.11, 2.12. 2.13 and 2.14 include:

- Engaging with local disability advocacy agencies to support the development of co-design or consultation processes
- Translating key documents and presentations into Easy Read versions
- Providing training for committees and boards on disability awareness and inclusive meetings
- Involving someone with intellectual disability in training and educating the workforce to provide a greater awareness of the reasonable adjustments required.

Resources

- The Agency for Clinical Innovation **Co-design toolkit: Working together with Aboriginal communities**
- The **NSW Council for Intellectual Disability**
- **Inclusion Melbourne**
- **Developmental Disability Western Australia**
- **People with Disabilities ACT**
- Down Syndrome Australia **Health Ambassadors program**
- Side by Side Advocacy **Inclusive Governance Project**
- **Voice at the Table** governance training, includes guidance and training from people with intellectual disability and acquired brain injury
- NSW Council for Intellectual Disability **Inclusive governance framework** and training sessions.

Medication Safety Standard

Intellectual disability and the Medication Safety Standard

The **Medication Safety Standard** is about the safe prescribing, dispensing, administration and monitoring of medicines. Medication safety includes continuity of management, ensuring regular medication reviews, accurate recording of current prescriptions and dispensing, and transfer of information at key transition points.[22,53]

The provision of person-centred care, as described in the Partnering with Consumers Standard, is central to medication safety.

People with intellectual disability are often at a higher risk of adverse effects from medications and the use of psychotropic medications for behaviour.[63,64,65] In addition to issues of safe prescribing, monitoring and review of medications, people with intellectual disability may not have access to information about their medicine, including:

- The reason for taking the medicine
- The name of the medicine, including the generic substitution
- How and when to take the medicine
- Potential side effects.

To promote the person's understanding of their medicines, provide information in the most appropriate way for the person, which may include pictures or diagrams, Easy Read, audio, video or braille. The required level of resources should be available for clinicians to use when engaging with a person with intellectual disability. See the sections below for resources to assist health service organisations and clinicians in this area.

Medication review

Action 4.10

The health service organisation has processes:

a. To perform medication reviews for patients, in line with evidence and best practice
b. To prioritise medication reviews, based on a patient's clinical needs and minimising the risk of medication-related problems
c. That specify the requirements for documentation of medication reviews, including actions taken as a result.

Intent

Medicine use is optimised, and medicine-related problems are minimised by conducting medication reviews and documenting the outcomes in partnership with patients.

Strategies for improvement

Set up processes to conduct and document medication reviews

Ensure medication reviews are prioritised for people with intellectual disability, given the higher risk of adverse medication events.

Require high-priority treatment when a person at substantial risk is identified in the risk assessment for a medication review. In these cases, the medication review should be documented and the prioritisation policy monitored for quality improvement purposes.[66] The NSQHS Standards include further information on **conducting structured medication reviews**.

Make reasonable adjustment to medication reviews

Reasonable adjustments to support the person's involvement in a medication review include making adjustments to communication approaches and gaining knowledge of the person's decision-making capacity. The person's family, supporters or guardian may be able to provide history and other relevant details to support the medication review.

Assess individual risks

Put processes in place to identify and prevent potential medication-related harm, and to make sure these processes consider additional risks such as:

- Age over 65 years
- Use of high-risk medicines
- Obesity
- Multiple prescribers
- Multiple comorbidities

- Impaired hepatic or renal function
- Taking more than five regular medicines (including over-the-counter and complementary medicines).

For people with intellectual disability the above risks may be amplified as a result of:

- The person's communication abilities
- The health literacy or understanding of the person supporting them
- The capacity of the person and the level of support and assistance the person needs to understand and manage their medications safely.

Promote best practice prescribing

Promote best practice in prescribing and reviewing inappropriate prescribing. This includes using an evidence-based deprescribing process in which the prescribing review identifies medicines that are no longer required or are inappropriate, or where the harms outweigh the benefits.[63,64,67]

People with intellectual disability have been shown to be at higher risk of being inappropriately prescribed antipsychotics, particularly when the medication is used to control their behaviour. It is critical that if medicines are deprescribed (or prescribed), the rationale and protocol for deprescribing is documented in the discharge summary. Deprescribing can often involve prolonged weaning or tapering regimens, which should be communicated at transition of care.

Any change to a person's medicine regimen should first be discussed with the person and their family, supporters or guardian, to explain why the change may be necessary, including the risks and benefits. Informed consent is required. The person may have a formal or informal support network for assistance in their home, so it is important to ensure these supporters are aware of the change and why it was made.

If a new medicine is prescribed, ensure the patient receives relevant information about the new medicine in an accessible format, including information about potential side effects and when to seek support if required.

Resources

- Therapeutic Guidelines **Prescribing psychotropic drugs to adults with an intellectual disability** provide relevant guidance on prescribing.[23]
- University of NSW Department of Developmental Disability Neuropsychiatry (3DN) **Responsible Psychotropic Prescribing to People with an Intellectual Disability Podcasts** aim to educate health professionals on safe and effective prescribing practices for the treatment of mental health disorders in people with an intellectual disability.

Information for patients

Action 4.11

The health service organisation has processes to support clinicians to provide patients with information about their individual medicines needs and risks.

Intent

Clinicians are supported to provide information to their patients about medicines options, benefits and risks.

Strategies for improvement

Provide the person, their family, disability support workers or guardian with targeted information

People with intellectual disability need accessible and tailored information to ensure they and/or their family, disability support worker or guardian understand their medicine, its potential risks and the reason for any changes. This includes providing the information to the appropriate support people and using communication methods appropriate for the person. The method of 'teach-back' – asking the person to repeat what has been said to them, to check their understanding – may also assist.[68]

Support clinicians to provide an Easy Read medication list on discharge. Clinicians should explain any medication changes and the reason for the change to the person and their family, disability support workers or guardian.

Review policies, procedures and guidelines

Evaluate the medicine-related information available to people with intellectual disability to ensure it is suitable. This may include providing Easy Read information, pictures, diagrams or videos to demonstrate device techniques.

Resources

- NSW Council for Intellectual Disability **Resources for health Practitioners**
- National Disability Services **Get Ready to Assist Clients with Medication**
- SPECTROM **Easy read medication leaflets (Medicine (Psychotropics)** for people with intellectual disability
- National Health System England **Stopping over medication of people with a learning disability and autistic people (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP)**
- **Choice and Medication** provides printable leaflets used by health services to provide information on medications used in mental health conditions

- The Very Easy Read Leaflets (VERAs format) is for people with learning disabilities and low health literacy:
  - NSW: **South Eastern Sydney Local Health District** and **Sydney Local Health District**
  - South Australia: **SA Health**
  - Western Australia: **Child and Adolescent Health Service**
  - Queensland: **Queensland Health**
  - Victoria: **Alfred Health**
- Lung Foundation Australia educational videos on **videos on inhaler device techniques**
- The NDIS Quality and Safeguards Commission **Medicines for health, not control** brings together many resources that are available to help reduce or eliminate the inappropriate use of psychotropic medicines people with disabilities.

Spotlight issue: Polypharmacy

Polypharmacy is the use of five or more medicines at the same time, including prescription, over-the-counter and complementary medicines.[63] Polypharmacy may be necessary and appropriate in certain circumstances, such as in patients with complex medical needs. Monitoring through regular medication reviews will identify potentially inappropriate polypharmacy and its associated risks.

People with intellectual disability with complex health care needs are often at risk of polypharmacy that may result in adverse events, drug interactions and medication-related complications.[64,65,69]

Polypharmacy and the inappropriate use of psychotropics for behaviours of concern are also prevalent among people with intellectual disability.[63,64,67]

Important NSQHS Actions

Action 4.01: Clinicians use the safety and quality systems from the **Clinical Governance Standard** when:

a. Implementing policies and procedures for medication management
b. Managing risks associated with medication management
c. Identifying training requirements for medication management.

Action 4.03: Clinicians use organisational processes from the **Partnering with Consumers Standard** in medication management to:

a. Actively involve patients in their own care
b. Meet the patient’s information needs
c. Share decision-making.

Action 4.06: Clinicians review a patient’s current medication orders against their best possible medication history and the documented treatment plan and reconcile any discrepancies on presentation and at transitions of care.

Spotlight issue: Polypharmacy

Strategies for Improvement

Strategies to support Actions 4.01, 4.03 and 4.06 include:

- Strengthening medication reviews using the **best possible medication history**. This involves reconciling and confirming medicines with at least two sources and includes a discussion with the person and their family, NDIS service providers and guardian. Medication reviews provide an opportunity to confirm that all currently prescribed medications are still clinically appropriate and effective
- Discharge planning, which should commence early into the admission, particularly in relation to medicine management
- Handing over medicines information to the GP and to the community pharmacist if required, to facilitate continuity in medication management. For example, blister packs may need to be changed. Early engagement with the hospital or community pharmacy will support continuity of care with medicines upon discharge.

Resources

- National Institute for Health and Care Excellence **Learning disability: behaviour that challenges** quality standard, which includes the following statement:

  "People with a learning disability and behaviour that challenges have a multidisciplinary review of their antipsychotic medication 12 weeks after starting treatment and then at least every 6 months." (Statement 12)
- The NHS England **STOMP campaign**, which attempts to prevent inappropriate polypharmacy with psychotropic medications among patients with a learning disability and autistic people
- The **Frith Prescribing Guidelines for People with Intellectual Disability**, focused on the appropriate prescription and review of medicine for people with intellectual disability
- The UNSW 3DN **Responsible Prescribing course for health professionals**
- The World Health Organization report on **Medication Safety in Polypharmacy**.

Comprehensive Care Standard

Intellectual disability and the Comprehensive Care Standard

An inclusive approach to implementing the **Comprehensive Care Standard** will build the capacity of the health service organisation and its clinicians to address the needs of people with intellectual disability.[2,19,27,28,29,58]

The Commission's **Implementing the Comprehensive Care Standard – A conceptual model for supporting comprehensive care delivery**[70] emphasises the importance of involving the person in the planning and the processes of 'risk screening, goal identification, care coordination and care'.

Comprehensive planning for people with intellectual disability should include identifying reasonable adjustments and alternative or augmentative communication needs.

Designing systems to deliver comprehensive care

Action 5.04

The health service organisation has systems for comprehensive care that:

a. Support clinicians to develop, document and communicate comprehensive plans for patients' care and treatment
b. Provide care to patients in the setting that best meets their clinical needs
c. Ensure timely referral of patients with specialist healthcare needs to relevant services
d. Identify, at all times, the clinician with overall accountability for a patient's care.

Intent

The health service organisation provides systems to enable and support the delivery of comprehensive care to patients.

Strategies for improvement

Include reasonable adjustments in all systems that enable and support the delivery of comprehensive care

Organisations should develop processes to ensure that the person receives care in the setting that best meets their needs. Clinicians have an important role in proactively explaining a person's communication or accessibility needs as part of a referral, to reduce the burden on the person, families and supporters to re-explain their needs to each subsequent clinician.

People with intellectual disability often need assistance to manage the unfamiliar environment when entering a healthcare organisation, as they may not realise what is expected of them. For example, they may not know that there is a call button, understand the purpose of a ward round, know that different clinicians may be coming to see them at their bedside, or understand that they may be transferred to another part of the hospital for different procedures and processes.

With information and guidance, a person with intellectual disability can be assisted to understand their environment and manage independently or with minimal aid. Where possible, maximise staff continuity to provide people with familiarity, safety and reasonable adjustments, and to ensure clinicians retain knowledge of the person's reasonable adjustments.

When considering patient flow and placing a person in the right bed, it is important to ensure that the workforce is aware of the person's disability support needs so they can provide a person-centred approach.

Multidisciplinary teams should work collaboratively to identify strategies that support appropriate risk screening, goal identification and any additional needs for care coordination.

Screening of risk

Action 5.10

Clinicians use relevant screening processes:

a. On presentation, during clinical examination and history taking, and when required during care
b. To identify cognitive, behavioural, mental and physical conditions, issues and risks of harm
c. To identify social and other circumstances that may compound these risks.

Intent

Patients receive initial and, if necessary, repeated screening for cognitive, behavioural, mental and physical conditions, issues or risks of harm.

Strategies for improvement

Understand the person's baseline

Assessment of risks needs to be tailored to the person. This includes understanding how the person is when they are well, in particular their behaviour, so that any changes can be investigated.

Understanding how someone communicates or usually behaves forms the basis for accurate clinical assessment. The person with intellectual disability may have individual information in personalised resources – such as a **My Health Matters** folder or **Admission 2 Discharge Together (A2D)** folder – that clinicians can use during an assessment.

The involvement of the family, NDIS disability support worker or guardian during screening, with the person's permission, assists in gaining relevant information – for example, if the person is uncharacteristically subdued, agitated, distressed, or experiencing appetite changes or sleep disturbance. Feedback and concerns from family, supporters or guardians should be treated as clinically important information.

Take a person-centred approach to screening

Training clinicians in person-centred approaches for people with intellectual disability builds their capacity to adapt their approach and use reasonable adjustments in conducting assessments. A person-centred approach includes allowing more time and checking that the person understands the information they have been given. The clinician needs to be aware of the person's non-verbal cues so they can adjust their behaviour as a clinician accordingly. The reasonable adjustments required for each person may be different.

The NSW Statewide Intellectual Disability Health Service provides consultative healthcare services for children and adults with intellectual disability and complex health needs. It also works to build capacity among mainstream health staff and general practice teams, to better meet the health needs of people with intellectual disability.

Spotlight issue: Supporting people with intellectual disability from admission to discharge

People with intellectual disability may be at risk of poor health outcomes when admitted to an acute care setting, whether through an emergency admission or planned admission.[2,20,27] The lack of reasonable adjustments to effectively communicate with people is a safety and quality risk.

Women, children and young people, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people and LGBTQI+ people with intellectual disability are at higher risk of poor health outcomes.

Many people with intellectual disability have experienced or are at risk of abuse, neglect, domestic violence, homelessness, contact with the criminal justice system and stressful encounters with health services.[71] Understanding and preventing these experiences is part of improving health outcomes.[72]

Important NSQHS Actions

Action 5.12: Clinicians document the findings of the screening and clinical assessment processes, including any relevant alerts, in the healthcare record.

Action 5.13: Clinicians use processes for shared decision-making to develop and document a comprehensive and individualised plan that: …

d. Commences discharge planning at the beginning of the episode of care.

Action 5.27: The health service organisation that admits patients overnight has systems for the preparation and distribution of food and fluids that include nutrition care plans based on current evidence and best practice.

Spotlight issue: Supporting people with intellectual disability from admission to discharge

Strategies for improvement

Strategies to support Actions 5.12, 5.13d and 5.27 include:

- Understanding that people with intellectual disability may have unmet healthcare needs, specific disability support needs or clinical risks relating to their condition or intellectual disability. Identifying and recording these will facilitate a safer admission
- Collecting information from the person and their family, supporters or guardian ahead of time for planned admissions. If the person with intellectual disability cannot communicate their needs, a family member or NDIS disability support worker will be able to provide this information. Information to collect includes:
  - How much assistance with daily activities does the person require?
  - What support is needed for the person to understand what is happening to them and how to navigate an unfamiliar environment?
  - Does the person require referral to a dietician, speech therapist or occupational therapist to assist with safety and quality during the period of admission?
  - What are the person's communication needs?
  - What is the best emotional and behavioural support? This may include familiar phrases, music, photos, daily routines, and visits from significant others that can assist the person to manage the stress of a hospital admission.
  - Does the person have any cultural safety needs?
  - What is the person's living situation? For adults, what is the role of the family or NDIS service providers in the person's life, especially in health care including managing medication?
  - How will the person be supported to make informed decisions and consent to their health care?
  - For children or young people, how is key health information being shared with the parents or guardians?
  - What is the best way to communicate with family, supporters or guardians throughout the admission?
- Collaborating with the person, their family, supporters or guardians to plan the person's transition from hospital to home. This includes ensuring:
  - Clear details about the environment or setting the person is being discharged to. Is it a disability residential accommodation, their own home or home with family?
  - The person and their family, supporters or guardian have a sound understanding of the person's healthcare needs, medication and follow-up requirements after discharge
- Determining whether clinical support can be provided by the hospital as part of recovery at home. This can include allied health or nursing supports as part of rehabilitation, or hospital in the home programs.

Spotlight issue: Supporting people with intellectual disability from admission to discharge

Resources

- Metro South Health **Disability Nurse Navigators** support people with intellectual disability during hospital admission and work closely with the person's general practitioner and NDIS provider to ensure that supports are in place on discharge.
- National Disability Services **Ready to Go Home Resources**
- NDIS Quality and Safeguards Commission **Practice Alert: Transitions of care between disability services and hospitals**
- The NSW Health **Responding to Needs of People with Disability during Hospitalisation Policy Directive** sets out guiding principles for responding to the needs of people with disability including reasonable adjustments, person-centred services, accessibility and communication.
- The Western Australia Department of Health **Disability Health Framework 2015–2025** provides direction for the Department and its partners on policy development and service delivery, to achieve improved health outcomes for people with disability.
- The NSW Agency for Clinical Innovation **NSW Intellectual Disability Network** works to improve the experience and delivery of health care for people with intellectual disability through clinical leadership, research and education.
- The **Centre for Developmental Disability Health** supports mainstream health service organisations in building their capacity to address the health needs of adults with intellectual and associated developmental disabilities.
- The **Mater Intellectual Disability and Autism Service** is a Queensland state-wide service that supports health practitioners and service providers to improve the health and wellbeing of adults with intellectual and neurodevelopmental disability.
- The **Specialist Mental Health Intellectual Disability Service** is a Queensland state-wide service providing consultation and liaison service to help people with intellectual disability and those who may have or are diagnosed with mental health disorders to achieve better health outcomes.

Clinical assessment

Action 5.11

Clinicians comprehensively assess the conditions and risks identified through the screening process.

Intent

Patients receive comprehensive assessment to determine their healthcare needs and appropriate treatment options.

Strategies for improvement

Build capacity to identify and respond appropriately to people with intellectual disability

Even when the intellectual disability is known, it may not be documented in a person's medical record. The notation of intellectual disability does not always guarantee that the person's disability support needs, in particular communication, have been identified, assessed and included in care planning.

Clinicians can use existing processes and alerts within medical records to document:

- Intellectual disability and other disability alerts
- Clinical risks (such as difficulty swallowing, aspiration and falls)
- If the person is a NDIS participant
- Communication or interpreter requirements
- Communication with family, supporters or guardians.

Assessment of risks includes:

- Identifying if the person's intellectual disability is related to a particular syndrome and if there are there any clinical considerations as a result
- Ensuring that physical symptoms of ill health are not immediately attributed to a mental or behavioural problem, leaving other co-existing conditions undiagnosed
- Identifying what the person is like when they are well, so any changes can be noted and explored
- Establishing accurate medical and health history, including previous episodes of delirium
- Reviewing lifestyle risks and strengths
- Identifying the person's social and community situation
- Reviewing the level of disability support that is needed in the healthcare setting and on discharge to the community.

Preventing delirium and managing cognitive impairment

Action 5.29

The health service organisation providing services to patients who have cognitive impairment or are at risk of developing delirium has a system for caring for patients with cognitive impairment to:

a. Incorporate best-practice strategies for early recognition, prevention, treatment and management of cognitive impairment in the care plan, including the **Delirium Clinical Care Standard**, where relevant
b. Manage the use of antipsychotics and other psychoactive medicines, in accordance with best practice and legislation.

Intent

A system for caring for cognitive impairment is implemented that minimises the risk of harm for people with cognitive impairment or at risk of developing delirium. The use of antipsychotics and other psychoactive medicines is in line with best practice and legislation.

Suggested strategies

Incorporate reasonable adjustment for people with intellectual disability

Ensure that clinicians are aware people with intellectual disability are at risk of developing early onset dementia and delirium.

People with intellectual disability in Australia are at a higher risk of developing dementia than the general Australian population. People with Downs Syndrome are at risk of Alzheimer's disease from about the age of 40, while people with intellectual disability generally are at risk of dementia onset at least 10 years earlier than the general population.[73]

To address these risks, it is important to incorporate reasonable adjustments when implementing the **Delirium Clinical Care Standard**. For instance:

- Include intellectual disability as a risk factor for delirium
- Support clinicians to consider whether dementia or cognitive impairment may have gone undiagnosed for a person with intellectual disability
- Where a diagnosis of either dementia or delirium is suspected, make sure clinicians consider:
  - Using appropriate cognitive impairment screening and carer report interview tools
  - Referring patients for comprehensive cognitive assessments during the admission if any risk is suspected.[73]

Resources

- University of NSW Department of Developmental Disability Neuropsychiatry (3DN) **Dementia in people with Intellectual Disability: Guidelines for Australian GPs**
- Intellectual Disability Health Education by 3DN **e-Learning for carers, health professionals and disability professionals**
- **Dementia and people with learning disabilities: making reasonable adjustments - guidance - GOV.UK (www.gov.uk)**
- Dementia Australia **Intellectual disability and dementia** training tools
- National Task Group on Intellectual Disabilities and Dementia Practices **NTG Early Detection Screen for Dementia**
- The British Psychological Society **Dementia and People with Intellectual Disabilities**.

Spotlight issue: Comprehensive care at the end of a person's life

People with intellectual disability experience barriers in access to health care, including access to end-of-life care.[37,38] Referral to end-of-life care should be based on sound clinical evidence, as often people with intellectual disability are referred for palliative care when active treatment should have been pursued.[2]

A recent cross-sectional study found a low level of awareness among people with intellectual disability and clinicians about approaching death and involvement in end-of-life care.[38] These barriers are the same as those that impact general health care, for instance, communication barriers, cognitive bias, and lack of involvement of the person, their family, supporters or guardians in decision-making.

Another barrier in health care is the difficulty in identifying when long-term management of chronic comorbidities becomes end-of-life care. A person's different ways of expressing pain can also mean that illness is missed until it is too late and end of life can be unexpected.[74]

Important NSQHS Actions

Action 5.15: The health service organisation has processes to identify patients who are at the end of life that are consistent with the **National Consensus Statement: Essential elements for safe and high-quality end-of-life care**.

Action 5.19: The health service organisation has processes for routinely reviewing the safety and quality of end-of-life care that is provided against the planned goals of care.

Action 5.20: Clinicians support patients, carers and families to make shared decisions about end-of-life care in accordance with the **National Consensus Statement: Essential elements for safe and high-quality end-of-life care**.

Spotlight issue: Comprehensive care at the end of a person’s life

Strategies for improvement

Strategies to support Actions 5.15, 5.19 and 5.20 include:

- Building expertise within the health service by including end-of-life care in the health service’s training on intellectual disability
- Using **Delivering and Supporting Comprehensive End-of-Life Care: a user guide** for practical strategies health service organisations and clinicians can use to deliver comprehensive care that aligns with the person’s expressed wishes and goals at the end of their life. The guide addresses the essential elements of the **Essential elements for safe and high-quality end-of-life-care: National Consensus Statement**.

Resources

- Palliative Care New South Wales **Palliative care for people with intellectual disability**
- **Talking End of Life** toolkit and training modules
- University of Hertfordshire **Palliative Care and Intellectual Disabilities**
- Council for Intellectual Disability **End of life care**
- **Palliative Care Education & Training Collaborative** – supports, education and resources to assist services for people with intellectual disability
- 3DN **How can we improve palliative care for people with intellectual disability?**
- 3DN **New e-Learning module on end-of-life discussions is now available for disability professionals**.

Spotlight issue: Intellectual disability, communication and positive behaviour support

For people with intellectual disability, communication issues are a significant barrier to safe health care. This is because:

- The person's intellectual disability can affect their ability to communicate verbally and to understand what others are saying
- The person's communication may be a combination of verbal, non-verbal and behavioural communications[75]
- Behavioural communication, under stress or from past traumas, may include behaviours of concern.

A behaviour of concern is defined as a behavioural response that creates a risk to the safety or wellbeing of the person or those around them.[76] It is important to recognise that a behaviour may indicate an unmet healthcare need, including pain or discomfort.

Not all people with intellectual disability and communication difficulties display behaviours of concern. Some people may only display behaviours of concern in response to specific triggers such as new or distressing environments.

However, some people with intellectual disability and communication difficulties may display behaviours of concern in all settings. For these individuals, healthcare barriers and stressors are compounded, and they are at high risk of poor health outcomes and use of restrictive practices.

The safety and quality risk of misdiagnosis is relevant in this situation. Life-threatening conditions can be missed if the person has a behavioural response to pain or physical symptoms that are, in turn, attributed to the person's intellectual disability.

The type and extent of a person's behaviour of concern depends on the immediate context, how unwell they are, their existing communication modes and their psychosocial history.

Important NSQHS Actions

See the discussion of **Action 1.27** in this User Guide, as well as the following Actions.

Action 1.29: The health service organisation maximises safety and quality of care:

a. Through the design of the environment
b. By maintaining buildings, plant, equipment, utilities, devices and other infrastructure that are fit for purpose.

Action 5.14: The workforce, patients, carers and families work in partnership.

Action 5.33: The health service organisation has processes to identify and mitigate situations that may precipitate aggression.

Action 5.34: The health service organisation has processes to support collaboration with patients, carers and families to:

a. Identify patients at risk of becoming aggressive or violent
b. Implement de-escalation strategies
c. Safely manage aggression, and minimise harm to patients, carers, families and the workforce.

Spotlight issue: Intellectual disability, communication and positive behaviour support

Action 5.35: Where restraint is clinically necessary to prevent harm, the health service organisation has systems that:

a. Minimise and, where possible, eliminate the use of restraint
b. Govern the use of restraint in accordance with legislation
c. Report use of restraint to the governing body.

Action 5.36: Where seclusion is clinically necessary to prevent harm and is permitted under legislation, the health service organisation has systems that:

a. Minimise and, where possible, eliminate the use of seclusion
b. Govern the use of seclusion in accordance with legislation
c. Report use of seclusion to the governing body.

Strategies for improvement

Strategies to support Actions 1.29, 5.14, 5.33, 5.34, 5.35 and 5.36 include:

- Designing the environment to include Easy Read posters, quiet rooms and facilities that allow families or supporters to be with the person
- Developing policies about reasonable adjustments for communication and behaviour. These policies can support clinicians and hospital staff to provide positive behaviour support. Positive behaviour support plans include guidance on:
  - Effective communication, identification of risks, and prevention of escalation or de-escalation of a situation
  - Environmental strategies that are needed to support the person, such as speaking slowly, providing quiet spaces, adjusting communication and physical contact styles, adjusting medical procedures and managing a fear of needles
- Ensuring procedures support the involvement of families or disability support workers in assessing risk and developing strategies
- Considering clinical, communication, psychosocial and environmental factors. Could the person’s behaviours be the result of pain, other symptoms or emotional distress? Ask family, supporters or guardians whether these behaviours have occurred before and in what circumstances
- Ensuring that clinicians and hospital staff who interact or coordinate care for people with intellectual disability understand how they as care providers can respond to individuals and manage the environment
- Identifying alternate models of care or patient pathways to facilitate care. Examples include those provided by:
  - South Australian Intellectual Disability Service
  - Austin Health Disability Service
  - GeneEQUAL toolkit
  - Better Health Channel Disability Liaison Officer program
  - Western Australian Department of Health Disability Health Network

Spotlight issue: Intellectual disability, communication and positive behaviour support

- Establishing organisational relationships with the National Disability Insurance Agency and NDIS service providers to develop guidelines for people with behaviours of concern when they are admitted to hospital. For people with significant behaviours of concern, developing a joint plan (pre-admission or at admission) between the person, family, NDIS service providers and/or guardians to identify potential risks and mitigation strategies in a hospital environment
- In line with the **Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard**, if the person presents with behaviours of concern or these emerge during the admission, assessing the potential reasons for the behaviours in consultation with the person and their family, supporters or guardian.

Resources

- Blue Knot has developed the first **Guidelines for Trauma Informed Practice: Supporting People with Disability who have experienced Complex Trauma**. A plain English version is also available: **Plain English Guide: Supporting People with Disability who have experienced Complex Trauma**.
- The Berry Street Take Two program has developed the **Taking Time Framework** to guide service providers who support people with intellectual disability. The framework can be downloaded for free from the Berry Street resources and bookstore.
- National Institute for Health and Care Excellence **Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges** – guidelines for health professionals.
- **Autism and developmental disability: Management of distress/agitation** is guidance from the Royal Children's Hospital Melbourne on inpatient management of anxiety and agitation in young people with developmental disabilities (including autism) who may require medical or surgical care.
- **Caring for people displaying acute behavioural disturbance**[77] from Safer Care Victoria notes the importance of pain in people with intellectual disability as a possible underlying cause of acute behavioural disturbance.
- **Challenging behaviour in a person with developmental disability** covers the use of restrictive practices for challenging behaviour in a person with developmental disability. Any form of restrictive practice (for example, physical, chemical or mechanical restraint, or seclusion or containment) has legal implications. Use of restraint during an emergency should be a 'last resort' and only in response to a behaviour that might cause harm to the person or others.
- **POSSUM Restraint-free Sedation for Kids** is a model of care implemented at the Sunshine Coast Hospital and health service organisation aimed at reducing anxiety and distress experienced by children because of previous medical procedures.
- The **A better way to care user guide** (specifically Actions 5.29 and 5.30) provides strategies and resources to assist in establishing a system that has capacity to respond to the needs of people with cognitive impairment. These strategies are all relevant to people with intellectual disability.
- The NDIS Quality and Safeguards Commission has produced a suite of resources on **Understanding behaviour support and restrictive practices – for providers**.

Communicating for Safety Standard

Intellectual disability and the Communicating for Safety Standard

The **Communicating for Safety Standard** recognises the importance of effective communication in health care and the essential role that communication plays in ensuring safe, coordinated and continuous care.[53]

For people with intellectual disability and their families and supporters, there are a number of barriers to communicating for safety. These barriers include:

- The person's own receptive, expressive or linguistic difficulties
- The number and variety of professionals and services involved in their support.

These situations may increase the risk of communication failures and subsequent inadequate or poor documentation of clinical information that can result in errors, misdiagnosis, inappropriate treatment and poor healthcare outcomes.

Spotlight issue: Working collaboratively with the disability sector

Working collaboratively with the disability sector is critical for safety and high-quality health care of people with intellectual disability in acute care. Within a healthcare setting, people with intellectual disability often rely on others to access health care and make reasonable adjustments for their safety, particularly with communication. This means safe and high-quality health care depends on the quality of communication with the disability sector.

The disability sector includes the National Disability Insurance Scheme (NDIS), NDIS service providers and disability advocacy agencies.

The level of NDIS service involvement in a person's life will often relate to the level of disability support they require in their daily activities and to participate in the community.

Many people with intellectual disability may also have other complex circumstances such as being disconnected from family and NDIS services; in contact with the criminal justice system; or at risk of homelessness. A person may receive NDIS supports in the person's family home, supported independent living, or disability specialist accommodation with 24-hour staff support.

NDIS service providers may be integrally involved in a planned or unplanned admission to hospital. Disability support workers may accompany the person to hospital, bringing the person's health file and guardianship orders.

NDIS service providers have a role in providing critical information to clinicians in the safe transition of care into hospital and the transition back to the community.

National Disability Insurance Agency (NDIA) staff, such as NDIS planners or NDIS health liaison officers, may also be involved if the person requires a new NDIS plan or funding for post-admission disability support services.

The NDIS does not typically fund support workers for NDIS participants while they are in hospital. However, reasonable and necessary supports may be funded to provide guidance and training for hospital staff if the NDIS participant has behaviours of concern and/or complex communication needs. The NDIS has further information on **Services if you're in hospital**.

Disability advocacy services are available for people facing complex challenges. Depending on the individual's circumstances, a disability advocate may be involved in their health care and may provide representation to the health service on the person's behalf or support the person in decision-making and informed consent processes. The Department of Social services has more information about **Disability advocacy for individuals**.

Spotlight issue: Working collaboratively with the disability sector

Important NSQHS Actions

Action 6.03: Clinicians use organisational processes from the **Partnering with Consumers Standard** to effectively communicate with patients, carers and families during high-risk situations to:

a. Actively involve patients in their own care
b. Meet the patient's information needs
c. Share decision-making.

Strategies for improvement

Involve the person with intellectual disability in decision-making about their health care. This includes, with appropriate consent:

- Discussing and planning clear roles and responsibilities during the person's admission, factoring in the roles of NDIS service providers and hospital staff. This includes who is responsible for making regular updates, contributing to reasonable adjustments and determining how best to support the person
- Working collaboratively with NDIS service providers and disability advocates to understand and recognise the supports provided to the person in the community on discharge. For instance, disability support workers have a role in administering and reviewing medication, whereas a disability advocate may support the person to understand information they need to make a decision
- Providing NDIS service providers and disability advocates with relevant information about healthcare rights, how the system works, and a consistent liaison point for reviewing and contributing to the person's comprehensive care plan.

Organisational processes to support effective communication

Action 6.04

The health service organisation has clinical communications processes to support effective communication when:

a. Identification and procedure matching should occur
b. All or part of a patient's care is transferred within the organisation, between multidisciplinary teams, between clinicians or between organisations, and on discharge
c. Critical information about a patient's care, including information on risks, emerges or changes.

Intent

Processes to support effective clinical communication are in place for key high-risk situations, where effective communication with patients, carers and families, and between clinicians and multidisciplinary teams, is critical to ensure safe patient care.

Strategies for improvement

Apply the principles of communicating for safety to most if not all situations

Consideration and action to ensure safe communication in the health care of people with intellectual disability will be required in most if not all situations throughout a hospital or day clinic admission.

The Commission's **Communicating for Safety Resource Portal** provides guidance, tools and resources to support the core skills for structured clinical communication; that is, 'the exchange of information about a person's care that occurs between treating clinicians, members of a multidisciplinary team, and between clinicians and patients, families and carers'.

Consider using tools and resources such as **ISBAR** (Introduction, Situation, Background, Assessment and Recommendation) to promote a structured process. ISBAR is a clinical handover process that helps ensure completeness of information and can be used in a wide range of clinical contexts. ISBAR allows for inclusion of a range of factors that may affect the care of a person with intellectual disability.

The touchpoints at which clinical communication occurs are described in the **Framework for Communicating for Safety**.

Figure 3: Framework for Communicating for Safety touchpoints for clinical communication

All those involved in any aspect of a person's hospital admission need to know that the person has intellectual disability, as well as the person's required level of support and any specific risks while they are in an acute care setting.

Communicating this information will facilitate any reasonable adjustments that may be needed for the person and ensure that those reasonable adjustments are made consistently throughout the person's stay in hospital or a day clinic.

Strategies to assist include:

- Using the appropriate communication methods or systems when talking to the person with intellectual disability
- Liaising with the person's family, supporters or guardians to ensure communication for safety is a priority. This includes having regular discussions and sharing updates to address concerns or seek additional information about an emerging risk
- Facilitating a transition of care plan with those supporting the person in the community, including their family, NDIS service providers, GP and other healthcare providers.

Clinical handover

Action 6.08

Clinicians use structured clinical handover processes that include:

a. Preparing and scheduling clinical handover
b. Having the relevant information at clinical handover
c. Organising relevant clinicians and others to participate in clinical handover
d. Being aware of the patient's goals and preferences
e. Supporting patients, carers and families to be involved in clinical handover, in accordance with the wishes of the patient
f. Ensuring that clinical handover results in the transfer of responsibility and accountability for care.

Intent

Clinicians use structured clinical handover processes that are consistent with the key principles of clinical handover, to effectively communicate relevant, accurate and up-to-date information about a patient's care to ensure patient safety.

Strategies for improvement

Collaboration in clinical handovers

Recognising the role and the importance of family, supporters or guardians is critical to safe clinical handovers.

Effective communication within clinical handover processes requires the clinician to:

- Place the person at the centre of the clinical handover process
- Include accurate and relevant information about the person
- Maximise the person's choice and control
- Understand the varying roles of the person's family or supporters
- Collaborate with those family or supporters in clinical handover.

Supporting people with intellectual disability to be involved in clinical handover

Providing accessible information about the handover – including what is important and recommendations for treatment or lifestyle interventions – assists the person and their family and supporters to understand what they need to do before, during and after an admission.

Involve family NDIS support services and primary and community healthcare services in a clinical handover

People with intellectual disability often rely on effective communication between their services to maintain their health and wellbeing in the community. A person may have a mix of supports in the community, including:

- Family support
- Advocacy services
- Substitute decision-makers
- NDIS support coordinators
- NDIS service providers
- Primary and community healthcare services
- General practitioners (GPs).

NDIS services can include accommodation support or other community access supports. These disability services have responsibilities to support the health and wellbeing of the person with disability.

Ensure effective clinical handover to these services to assist those supporting the person to meet the person's healthcare needs, update the person's support needs and coordinate any follow-up that may be required.

Identify if there are primary and community healthcare services involved with the person and, with the consent of the person, provide a clinical handover or discharge summary.

Provide a discharge summary and/or outpatient correspondence for the person's GP. This information will be important for the person's follow-up and regular **comprehensive health assessment**. If the person has not had a comprehensive health assessment, the discharge summary may alert the GP that further assessment is required.

For people with no family, supporters or guardian

Many people with intellectual disability may not have family, NDIS service providers or a GP. In these cases, it is important to consult with the NDIS Health Liaison Officer or Local Area Coordinator early in the person's admission to arrange referrals for support on discharge.

Spotlight issue: Transitions of care

Transitions of care are points at which valuable information for safety, quality and continuity of care can be lost. For people with intellectual disability, all transitions of care can be high risk, as information about reasonable adjustments may not be considered as essential clinical information. This includes information about disability support needs, psychosocial needs, communication needs, behavioural supports and comorbidities.[17,20,27]

Important NSQHS Actions

Action 2.10: The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care.

Action 6.10: The health service organisation ensures that there are communication processes for patients, carers and families to directly communicate critical information and risks about care to clinicians.

Strategies for improvement

Strategies to support Actions 2.10 and 6.10 include:

- Ensuring that the person's intellectual disability, communication needs and other reasonable adjustments are recorded. Use a peer review process to maintain continuity of knowledge about the person or check that all important information about the person is included in any transition
- Coordinating with the person's family, supporters or guardian so they are able to attend transitions of care meetings or are informed shortly afterward. This is especially important for people who are non-verbal
- Allocating a consistent point of contact to provide regular updates to the family, supporters or guardian.

The Commission has developed **Principles to guide safe and high-quality transitions of care**. These principles and their enablers apply to transitions of care wherever health care is received, including primary, community, acute, subacute, aged and disability care. It is important to apply these principles consistently within practice, standards, policy and guidance, to ensure safe transitions of care. The principles state that:

- Transitions of care are person-centred
- There is multidisciplinary collaboration to support the transition of care
- There is an enduring, comprehensive and secure record system to document and access information about the person's current and ongoing care
- There is ongoing continuity of care.

Recognising and Responding to Acute Deterioration Standard

Intellectual disability and the Recognising and Responding to Acute Deterioration Standard

The **Recognising and Responding to Acute Deterioration Standard** outlines Actions to ensure early identification of changes in a person's mental state or physical condition.

When caring for a person with intellectual disability, it can be difficult to identify the relevant physical signs of change, particularly if the clinician does not know the person well and the person is not able to communicate their pain or distress.[20] Deteriorations are more likely because of complex health problems, further complicated by the fact that health problems may be present but undocumented. A deterioration can occur without the clinician being aware of the risks.[8,12]

Build workforce capacity – and working with family, supporters or guardians – to meet the complex healthcare needs of people with intellectual disability. This can reduce risk and improve health outcomes.[24,50,54]

Promote a culture of reasonable adjustments for people with intellectual disability, which can improve recognition of and the response to acute deterioration. Providing reasonable adjustments facilitates communication and improves knowledge about the person's presentation, so that if it differs from when they are well, the clinician can recognise and respond to acute deterioration.[20,24,49,50,54]

The Commission has developed National Consensus Statements to support health service organisations to embed a systematic approach to recognising and responding to acute deterioration:

- **National Consensus Statement: Essential elements for recognising and responding to clinical deterioration**
- **National Consensus Statement: Essential elements for recognising and responding to deterioration in a person's mental state**

The Commission has also developed the online **Escalation Mapping Template**, which supports health services to assess the effectiveness of their systems in recognising and responding to deterioration in a person's mental state.

Recognising acute deterioration

Action 8.04

The health service organisation has processes for clinicians to detect acute physiological deterioration that require clinicians to:

a. Document individualised vital sign monitoring plans
b. Monitor patients as required by their individualised monitoring plan
c. Graphically document and track changes in agreed observations to detect acute deterioration over time, as appropriate for the patient.

Intent

Patients with acute physiological deterioration are identified early.

Strategies for improvement

Coordinated and reasonably adjusted care for best health outcomes

To assist with early identification of physiological deterioration, update vital sign monitoring plans to include accurate documentation of any complex health conditions and reasonable adjustments. Ensure the flow of this information across the person's health care. The coordination of care is important to decrease delays in the treatment of an illness.[20,49,54] For instance, people who are non-verbal or have genetic syndromes may need a specific plan.

Develop individually tailored monitoring plans

Consider monitoring a person's vital signs using 'soft signs' – changes in their normal behaviour – to identify initial stages of acute physiological deterioration. Monitoring methods such as early warning scores – which measure and record physiological data including pulse rate, blood pressure, respiratory rate, oxygen saturation and conscious level – have been shown to be effective for people with intellectual disability, when combined with observed changes in a person's normal behaviour, such as new confusion, sleep, appetite and mood.[78,79] A person's family, supporters or guardian may be able to provide information about the person's 'soft signs'.

Maintain patient safety using reasonable adjustment

Implement systems for identifying people who require reasonable adjustments and put those reasonable adjustments in place to assist with monitoring and observations that may detect physical and psychological changes.[41,49]

With the person's permission, include their family, NDIS disability support worker, behaviour support specialist or guardian, to gain advice about the person's care, communication requirements and what reassurance they might need. This enables early recognition of a change in the person's condition.

Resources

- The NSW Clinical Excellence Commission **REACH program** actively promotes partnership between patients, carers, family members and the treating team, in recognising and escalating deterioration. It encourages patients, carers and family members to initially engage with the nurse or medical team, to escalate concerns about worrying changes in a patient's condition.
- The NSW Clinical Excellence Commission **Between the Flags system** is designed to assist clinicians to recognise when patients are deteriorating and respond appropriately.
- **Ryan's Rule** is a three-step escalation process to support patients of any age, and their families and carers, to raise concerns if a patient's health condition is getting worse or not improving as well as expected. Ryan's Rule applies to all patients admitted to any Queensland public hospital, including the emergency department, and in some 'hospital in the home' services.
- Queensland Health has tailored Ryan's Rule resources for consumers with disability in an **Easy Read social script and video**.

Action 8.05

The health service organisation has processes for clinicians to recognise acute deterioration in mental state that require clinicians to:

a. Monitor patients at risk of acute deterioration in mental state, including patients at risk of developing delirium
b. Include the person's known early warning signs of deterioration in mental state in their individualised monitoring plan
c. Assess potential causes of acute deterioration in mental state, including delirium, when changes in behaviour, cognitive function, perception, physical function or emotional state are observed or reported
d. Determine the required level of observation
e. Document and communicate observed or reported changes in mental state.

Intent

Adverse outcomes relating to acute deterioration in a person's mental state are prevented through early recognition and effective response.

Strategies for improvement

Understand what is usual for the person with intellectual disability and maintain two-way communication

As mentioned in Action 5.10 (Screening of risk), it is important to know what is normal for the person, and their baseline indicators of wellbeing. Baseline information can assist in recognising deterioration or signs of new confusion in a person's mental state.

Strategies to identify a person's baseline and subsequent deterioration in mental state include:

- Educating staff that a change or escalation in behaviour may indicate a change in underlying health and wellbeing, particularly for people who do not communicate verbally. These changes should trigger clinical assessments to establish underlying drivers of behaviour (such as pain, infections, constipation, ulcers or hunger)
- Asking the person's family, NDIS disability support worker or behaviour support specialist about what is usual for the person. They may be able to assist with information about the person's:
  - Usual skills and capacity when well
  - Ways of expressing pain and distress
  - Usual mental state.
- Using alternative or augmentative communication (described under Action 2.08) to provide the clinician with a means of directly assessing the person. An acute deterioration in the person's mental state may impact their ability to communicate. Knowing how the person usually communicates will assist in identifying deterioration
- Providing the person and their family, supporters or guardian with accessible information.

The University of NSW Department of Developmental Disability Neuropsychiatry has developed the **MySigns** app to support mental health assessment for people with intellectual disability and significant communication difficulties.

Glossary

Term	**Definition**
Augmentative and alternative communication (AAC)	When a person uses something other than speech to communicate. They might use body movements, gestures, sign language, a computer or device, communication books or other printed material.
Australian Charter of Health Care Rights	The Charter describes what consumers, or someone they care for, can expect when receiving health care. These rights apply to all people receiving health care in Australia, including in public and private hospitals, day procedure services, general practice, and other community health services.
Australia's Disability Strategy 2021–2031	This Strategy is a national framework to improve the lives of people with disability in Australia. It is signed by the Australian, state, territory and local governments. The first National Disability Strategy was released in 2010; this Strategy builds on the outcomes of the first.
Behaviour of concern	Behaviours that indicate a risk to the safety or wellbeing of the person who exhibits them or those around them, and that suggest a need for support.[80]Behaviours may challenge individuals, their supporters and the services they are in, but may serve a purpose for the person, such as communicating their needs and responses to their environment.[80]
Cognitive bias	The unconscious assumptions made about a person that can directly impact the way in which health care is provided.
Disability Action or Service Plan	A Disability Action or Service Plan sets out an organisation's strategy for identifying and addressing practices that might result in discrimination against people with disability and promoting the recognition of the rights of people with disability. They detail how an organisation is making its workplace, products and services accessible and inclusive to people with disability, and inform the public how the organisation is approaching diversity and inclusion.[81]
Disability Discrimination Act 1992 (Cth)	The DDA provides protection from discrimination on the basis of disability. It defines disability as including physical, intellectual, psychiatric, sensory, neurological and learning disability, physical disfigurement, and the presence of disease-causing organisms.
Easy Read	**Easy Read** documents use clear, everyday language matched with images to make sure everyone understands. They help to reach people with disability, including people with intellectual disability, people with English as a second language and people with lower literacy levels.
Informed consent	A person's voluntary decision about their health care that is made with knowledge and understanding of the benefits and risks involved.
Medication review	A systematic assessment of medication management for an individual patient that aims to optimise the patient's medicines and outcomes of therapy by providing a recommendation or making a change. The review includes the objective of reaching an agreement with the person about their treatment, optimising the impact of medicines, minimising the number of medicine-related problems and reducing waste. Medication review may be part of medication reconciliation.

Term	**Definition**
National Disability Insurance Scheme Act 2013 (Cth)	The NDIS Act established the National Disability Insurance Scheme (NDIS). It is based on the rights of people with a disability to participate equally in society, to receive reasonable and necessary supports for this participation, and to have choice and control over decisions in their life.
National Disability Insurance Agency	An independent statutory agency that administers the National Disability Insurance Scheme under the auspices of the *National Disability Insurance Scheme Act 2013*.
National Disability Insurance Scheme Quality and Safeguards Commission	The independent agency established to improve the quality and safety of NDIS supports and services under the auspices of the *National Disability Insurance Scheme Act 2013*.
The National Roadmap for Improving the Health of People with Intellectual Disability	Part of the Department of Health and Aged Care 10-year Primary Health Action Plan, released in September 2021. The roadmap is a collaborative, cross-agency action plan to implement the systemic reforms needed to improve health outcomes for people with intellectual disability.
Polypharmacy	The use of multiple medicines to prevent or treat medical conditions. It is commonly defined as the concurrent use of five of more medicines by the same person. Medicines include prescription, complementary and non prescription, over-the-counter medicines.
Positive behaviour support	Individualised strategies that address the needs of the person and the underlying causes of behaviours of concern, while safeguarding the dignity and quality of life of people who require behaviour support.[82]
Reasonable adjustment	Defined under the *Commonwealth Disability Discrimination Act 1992* as actions taken to prevent indirect or direct discrimination on the basis of disability.
Supported decision-making	The process of enabling a person who requires decision-making support to make and/or communicate decisions about their own life. The decision-making is supported, but the person makes their own decision.[83]
United Nations Convention on the Rights of Persons with Disabilities	Sets out the universal human rights of persons with disability. Australia is a signatory, along with 185 other countries.

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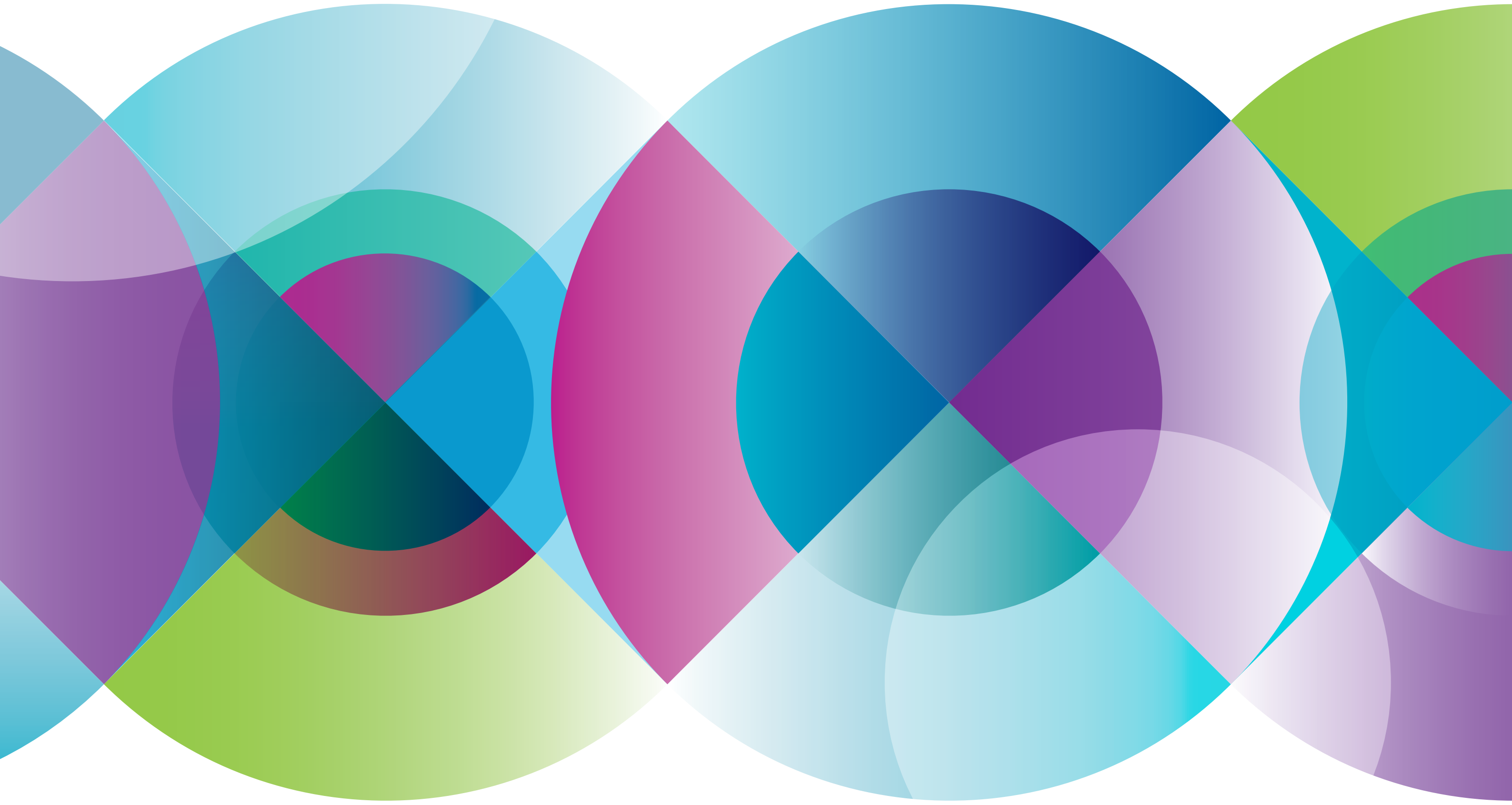

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