

FACT SHEET
for health service
organisations

Intellectual disability

Person-centred care

Intellectual disability

Intellectual disability is a lifelong condition that originates in the developmental period. It affects a person's ability to learn, communicate, retain information and undertake everyday activities.¹ People with intellectual disability have a wide range of capabilities and needs² and their neurological, developmental and co-existing health conditions, circumstances and experiences vary considerably.

Safety and quality issues in health care

People with intellectual disability can have high healthcare needs, often multiple health conditions, with frequent hospital admissions. A person with intellectual disability is at high risk of poor health, chronic disease and premature death from preventable illness.³

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

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

Fact sheet 2

This fact sheet provides information to support clinicians to provide better health care for people with intellectual disability. It focuses on person-centred care strategies.

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

Safety and quality issues related to person-centred care

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

- Not being supported to be involved in decisions about their health care⁴
- Not being provided information in accessible formats, particularly information on medicines
- Experiencing distress from the clinical environment and treatments
- Encountering clinicians who assume they lack capacity, not directly communicating with them and automatically talking to family members or support staff⁴
- Encountering clinicians not knowing how to effectively communicate with nor understanding their specific communication or care needs.

Person-centred care

Person-centred care is fundamental to safe, high-quality healthcare. It is care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.⁵

Person-centred care involves clinicians seeking out and understanding what is important to the person, fostering trust, establishing mutual respect and working together to share decisions and plan care.⁶ These fundamentals apply to everyone but may require additional considerations when caring for a person with intellectual disability.

A person with intellectual disability may need extra time and support to make decisions. This requires clinicians to talk directly to the person, provide clear explanations, present information that is easy to understand and to use augmented and alternative communication methods.

Supported decision-making is a key principle of the UN Convention on the Rights of Persons with Disabilities. Substitute decision-making should be a last resort. It should not be a substitute to providing support to the person with intellectual disability. The use of substitute decision-maker should be for the shortest time possible, and be regularly reviewed.⁷

For people with complex healthcare needs and difficulty with communication, the involvement of people who know the person can be enormously beneficial. This includes people such as carers, family members, the person's general practice, primary care provider, support person or disability support worker. These people can:

- Provide important information on a person's needs, preferences, communication methods, health history
- Interpret non-verbal cues, current changes or deterioration, including pain
- Suggest strategies to reduce a person's distress
- Support clinicians to obtain valid informed consent.

Documenting and communicating this information in a patient's health record can lead to better diagnoses and tailored care plans.⁴

By understanding a person's specific needs, clinicians can prepare the person for an episode of care and clinicians can make reasonable adjustments to the way they provide care and communicate.

How to support person-centred care for people with intellectual disability

To be responsive to the preferences, needs and values of the person with intellectual disability clinicians may need support to:

- 1 **Plan for and make reasonable adjustments** to treatment and procedures
- 2 **Communicate effectively** with people with intellectual disability
- 3 **Understand** and focus on an individual's needs and wants
- 4 **Partner with the person** so they can be involved in their own care.

Determining how well a service is performing needs feedback from people with intellectual disability, carers, family and support people as well as the workforce. Feedback provides information on the gaps in comprehensive care and allows strategies to be developed to improve person-centred care.

Strategies for better care:

1 Planning

- Undertake pre-admission planning to determine a person's preparation needs and who will undertake this. Collect information on the person's healthcare during an episode of care such as mobility, physical support, communication, hygiene assistance or nutrition requirements. Identify the substitute decision-maker and any advance care plans
- Review and revise existing investigation and treatment procedures to enable clinicians to respond to the specific, individual needs of people with intellectual disability. This may involve extra appointment time, reduced waiting times, access to communication equipment, or anaesthetics and sedation for investigations.⁸

2 Communication

- Review the availability and appropriateness of health information. Is it easy to understand and use⁴ and does it reflect the diversity of people with intellectual disability who access the care in the organisation?
- Include access to training and education for clinicians to develop communication skills in delivering accessible health information, using visual aids, augmentative and alternative communication aids and appropriate engagement with family, carers, and support people

- Review the admission processes to ask the person if they have specific communication requirements.⁹ Check if the person requires an interpreter
- Provide access to key contacts who can support clinician to use accessible communication strategies, such as Speech Pathologists and the National Relay Service⁹
- Make Australian Charter of Healthcare Rights available in accessible formats.

3 Understanding

- Adopt a structured communication tool to communicate important information about the person to clinicians when a person cannot communicate their needs and preferences.

4 Partnering with the person

- With the consent of the person, identify the person's advocate and relevant members of the person's support network that need to be involved in their health care. Accurately identify the person's substitute decision-maker when required
- Provide the workforce with training on capacity assessments and techniques to support decision making by people with intellectual disability
- Review current informed consent processes to ensure they are inclusive of people with intellectual disability.

NSQHS Standards

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

- Partnering with Consumers Standard
- Communicating for Safety Standard.

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

Figure 1: Relevant NSQHS Standards



Table 1: Relevant actions in the NSQHS Standards

| NSQHS Standard | Action | Item |
|-------------------------------|------------------|---|
| Partnering with Consumers | 2.03, 2.04, 2.05 | Healthcare rights and informed consent |
| | 2.06, 2.07 | Sharing decisions and planning care |
| | 2.08, 2.09, 2.10 | Communication that supports effective partnerships |
| Communicating for Safety | 6.03 | Partnering with consumers |
| | 6.04 | Organisational processes to support effective communication |
| | 6.07, 6.08 | Clinical handover |
| | 6.09, 6.10 | Communicating critical information |
| | 6.11 | Documentation of information |

Learning from others

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

1 Planning

Pre-admission plan for a person with disability

- **NSW Health policy on Responding to Needs of People with Disability during Hospitalisation 2017** requires the development of a pre-admission plan for people with disability¹⁰ at Appendix 1.

Preparing for healthcare

- The Western Australia North Metropolitan Health Service – Dental Health Services has created a **social story** of going to the dentist to prepare people for the experience of going to the dentist
- Circle of support **videos** are available on the Agency for Clinical Innovation website that show how health outcomes for people with intellectual disability can be improved when fear, anxiety or mental health concerns prevent them from getting the medical help they need. Captioned versions of the videos are also available
- **Say less, Show more** is a NSW Agency for Clinical Innovation (ACI) communication initiative that provides a series of simple photo stories for children, young people and adults with a disability, illustrating what happens during health procedures, such as a physical examination
- Rady's Children's Hospital (San Diego) Autism Discovery Institute has hospital visit tips including a **Hospital Visit Toolkit**.

2 Communication

Easy Read Health Guides

- The Council for Intellectual Disability has **Health Guide** resources in Easy Read for people with intellectual disability.

Communication changes after an acquired brain injury (ABI)

- Queensland **Acquired Brain Injury Outreach Service (ABIOS)** outlines common communication changes after an acquired brain injury (ABI) and provides a range of practical resources to assist in understanding and managing communication difficulties.

Communication aids

- Speech Pathology Australia has a range of **fact sheets** (with easy read) including one on augmentative and alternative communication.

Healthcare rights

- Australian Commission on Safety and Quality in Health Care (ACSQHC) has developed an Easy Read Guide **About healthcare rights for people with cognitive impairment**.

3 Understanding

Information about the person

- **Julian's Key Health Passport** is a Queensland Health communication tool to assist people with disability to communicate their specific disability support and health care needs to staff in hospitals. It is available via mobile application (phone or tablet), fillable PDF or paper-based format. Queensland Health is undertaking a trial to address system level barriers to patient experience, service access and coordination at Ipswich and Logan Hospitals
- **SA Health** is implementing a **My Health Information** resource to support people with intellectual disability to communicate their needs and preferences to healthcare staff while in hospital
- In NSW **an admission to discharge folder (A2D)** was created by a partnership between Family and Community Services (Disability) at South East Sydney District, South Eastern Sydney Local Health District, Carer Program, and Metro-Regional Intellectual Disability Network (MRID). 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.

4 Partnering with the person

- Principles to follow whenever a person's capacity is being considered are outlined on page 39 of the **User Guide for health service organisations providing care for patients with cognitive Impairment or at risk of delirium**
- ACSQHC has developed resources for **informed consent** to assist health service organisations meet the requirement of the NSQHS Standards regarding consent.

Fact sheet series

Other fact sheets in this series include:

- Fact sheet 1: [Intellectual disability – safety and quality issues](#)
- Fact sheet 2: [Intellectual disability – comprehensive care](#)
- Fact sheet 4: [Intellectual disability – governance](#)
- [Safe and high quality care for people with intellectual disability: Actions for clinicians.](#)

References

1. SA Health. SA Intellectual Disability Health Service Model of Care. SA Health; 2020.
2. NSW ACI. Building Capability in NSW health services for people with intellectual disability: the Essentials. NSW Agency for Clinical Innovation; 2017.
3. NDIS Quality and Safeguards Commission and ACSQHC. Comprehensive health assessment Provider Practice Alert pending; 2021.
4. Royal Commission into Violence Abuse Neglect and Exploitation of People with Disability. Report of Public hearing 4: Health Care and Services for People with Cognitive Disability. Sydney 2020.
5. Australian Commission on Safety and Quality in Health Care. Fact sheet 9 – Attributes – Supporting person-centred attributes in your healthcare organisation. Sydney: ACSQHC; 2018.
6. Australian Commission on Safety and Quality in Health Care. Person-centred care [Internet] [cited 19 April 2021] Available from: <https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>.
7. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards User Guide for health services providing care for patients with cognitive impairment or at risk of delirium ACSQHC; 2019.
8. Royal Commission into Violence A, Neglect and Exploitation of People with Disability. Statement of Dr Jacqueline Small 12 February 2020. 2020.
9. Australian Human Rights Commission. Guidelines on the rights of people with disability in health and disability care during COVID-19. Sydney 2020.
10. NSW Ministry of Health. Policy Directive Responding to Needs of People with Disability during Hospitalisation. [Internet] Sydney: NSW Ministry of Health 2017 [cited 14 January 2019] Available from: https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2017_001.

Appendix 1: Pre-admission plan

Adapted extract from *NSW Health Responding to Needs of People with Disability during Hospitalisation 2017*.

The following issues may need to be addressed in order to complete a pre-admission plan for a person with disability:

- Disclosure of information and the inclusion of others from the person's support networks in the pre-admission and discharge planning process in line with the *NSW Health Privacy Manual for Health Information*
 - Identification of whether the person is a participant of the NDIS or in the process of making an application to the Scheme
 - Procedures for determining informed consent
 - Accurate identification of the substitute decision-maker and any advance care plans
 - Information regarding medical history, social and functional skills
 - Clarification of the role of parties involved in care of a person with disability during the hospital stay, including the role of hospital staff, carer/family and disability support staff
 - Key community resource contacts, where community or disability service agencies are involved or may be available
 - Transportation and mobility requirements
 - Physical support needs including appropriate lifting and positioning
 - Nutrition and diet requirements; eating and drinking techniques
 - Hygiene assistance needs
 - The person's specific communication requirements
 - Hospital staff responsible for planning the admission should ensure that if required a person with disability can bring to hospital their communication resources or equipment such as augmentative communication devices, mobility or functional aids
 - Management strategies for newly changed or long standing behaviours that impedes the provision of care or daily activities and may create a risk of harm to the person or others.
 - Consideration of usual care and activity routines to ensure that any medical intervention causes the minimal amount of disruption, confusion and stress to them
 - Specific information on equipment that patients must bring to the hospital, e.g. for pressure care, respiratory support, should also be discussed.
 - Consider involving occupational therapy and physiotherapy in discussions regarding required equipment
 - Hospital staff should ensure that space is provided for comfortable operation and safe storage of equipment, and that the equipment is readily available for use
 - Patients who use an assistance animal, such as a guide dog, should not be separated unnecessarily from the animal, and space and care for the animal should be planned and made available
 - Conflict resolution mechanisms
 - Hospital complaints mechanisms and processes.
- Planning for an extended hospital stay may need to include strategies to assist the person to maintain their skills and capacities such as:
- Hospital day passes to access day program and community services can assist in sustaining pre-hospital functional capacity
 - Patients, their carer and family, where the patient is an NDIS participant, should be consulted to acquire details of any education, home or day programs that they receive funding for and how those may be accessed
 - Where the patient is not an NDIS participant, they should be consulted to determine whether they are involved in any Information Linkages and Capacity Building (ILC), state-/territory-/Commonwealth-provided education, respite or day supports and how these are accessed
 - Where the patient is a long stay resident, the NDIA will need to be informed that the hospital will temporarily assume the status as the clients' place of residence and that all correspondence should be sent there
 - Patients with intellectual disability who underutilise their skills will risk losing those skills. In extended admissions, where possible, hospitals should seek input from their current disability supports and education services for their day-to-day care.
 - Where practicable, enable children to continue their school education activities and have access to play therapy.