

Submission: National Safety and Quality Health Service Standards (NSQHSS) - third edition review

Ensuring a strong voice for all people with Down syndrome, their families and carers

September 2026



DOWN SYNDROME
NEW SOUTH WALES





About Down Syndrome NSW

The Down Syndrome Association of NSW was established in 1980 by parents of young people with Down syndrome. As the children of the founding members grew to adolescence and adulthood, so too our services extended to all life stages. We now provide information and support, advocacy, capacity building workshops, training in schools, community participation programs, pre-natal expert advice, new parent resources and support and specialist employment preparation and connection.

We are an enthusiastic team of professionals with expertise in our relevant fields of service provision, support and advocacy. Some of us have lived experience with a family member with Down syndrome, some bring a range of expertise and industry experience. We are here to support you – all working together to help our members with Down syndrome achieve their full potential.





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Introduction

Down Syndrome NSW welcomes the opportunity to provide a submission to the Australian Commission on Safety and Quality in Health Care on the proposed third edition of the National Safety and Quality Health Service (NSQHS) Standards.

Down Syndrome NSW is the peak organisation representing people with Down syndrome, their families and supporters across New South Wales. Our work is grounded in the fact that people with Down syndrome have the same rights as everyone else to safe, accessible, high-quality healthcare and to be treated with dignity, respect and equality.

We strongly support the intention of the third edition to place greater emphasis **on person-centred care, patient experience, outcomes, integration and continuous improvement.**

However, Down Syndrome NSW considers that the proposed Standards must go considerably further in making the healthcare system safe and accessible for people with intellectual disability.

For people with Down syndrome, safety and quality cannot be separated from **communication, reasonable adjustments, supported decision-making, health literacy, recognition of individual baselines, family and supporter involvement, and the capacity of health professionals to understand disability without making assumptions about the person.**

A health service can technically comply with a standard while a person with Down syndrome can still experience poor, unsafe or discriminatory healthcare.

The third edition provides an important opportunity to change this.

People with Down syndrome must not have to be unusually articulate, unusually assertive or unusually well supported to receive safe and effective healthcare.

The health system must be designed so that people with intellectual disability can understand what is happening, communicate their needs, participate in decisions, receive appropriate adjustments and have their concerns taken seriously.

Down Syndrome NSW therefore recommends that disability inclusion, accessibility and supported decision-making are embedded as explicit and measurable requirements throughout all three proposed Standards, rather than being treated as matters that health services may address through general person-centred care.

Recommendations and Priority Actions

In addition to completely supporting the Recommendations made to this review by the National Centre of Excellence in Intellectual Disability Health (see point 3 below), Down





Syndrome NSW has provided a set of priority actions (refer Point 27) that would improve the safety and quality of health services to people with Down syndrome.

Real Life Experiences

Down Syndrome NSW regularly hears stories from people with Down syndrome, families and supporters about inadequate, misguided or judgmental treatment in health facilities including situations of inadequate care in hospitals. We have provided only a few stories of the experiences of people with Down syndrome in hospitals, but there are others that resulted in fatalities. The following examples have been de-identified but are the true experience of people with Down syndrome and families:

Story 1: Prejudiced assumptions

A person with Down syndrome in their 40s presented at the Emergency Department of a metropolitan hospital with a serious condition that is routinely successfully treated in other people. The family was immediately asked if there was, or do they want, a Do Not Resuscitate order. This question would not have been asked of another presenting patient.

Story 2: Discriminatory treatment

A woman in her 20s with Down syndrome was in hospital after suffering a catastrophic stroke. The treating doctor told the mother to put the young woman in an aged care nursing home as soon as possible. The mother asked about the treatment plan for stroke in any other 25 year old woman and was told about the then 9 month stroke recovery and rehab plan. When asked why this young woman was not offered the same recovery plan, the doctor said “Look, she has Down syndrome, how hard are you going to try?” The mother insisted on the usual recovery plan, but in hospital rehab, the only regular treatment the young woman received was Speech Therapy. Both Physiotherapy and Occupational Therapy had the young woman on their treatment lists but did not schedule session times to treat her. No ongoing treatments were offered to the young woman after discharge...so much for the 9 month recovery plan.

Story 3: Inattention causing harm

A young adult with Down syndrome had an unexpected seizure and was taken by ambulance to the Emergency Department of a metropolitan hospital. The person with Down syndrome has coeliac disease and this was written on every document and mentioned by the accompanying mother at every opportunity. Doctors decided that the person would stay overnight and be discharged in the morning, and then sent the mother home. When the mother arrived early the next morning, it was very clear that the person was suffering a severe gluten reaction. The person with Down syndrome was unable to speak at that time so the breakfast orderly gave the person a gluten breakfast because there were few other





choices. When approached about discharge, the mother insisted on remaining at the hospital until the gluten reaction was treated by doctors.

Story 4: Person requiring critical support is left unattended

A man in his 30s has Down syndrome as well as dementia with very high support needs. The man is unable to attend to his most basic needs, and is unable to initiate, request assistance or drink or eat without assistance. The man was admitted to hospital. Under recent changes to NDIS support rules, it is expected that the NDIS will not provide a support worker in hospital under the man's NDIS Plan. The man's meals were delivered to his bedside, but he was unable to recognise the tray as food as a lid covered the plate or to open the sealed packaging. The man may be left without critical care while in hospital.

Story 5: Inadequate time and unnecessary use of force causing trauma

One family reports that, during an emergency admission of their adult with Down syndrome, two burly uniformed security guards were automatically called to hold the person down to insert a canula. There had been no attempt to adjust communication about what was needed and how it would be done nor to seek input from the parent who was on her way to the hospital, before acting. Although the person with Down Syndrome was very unwell there was no immediate emergency necessitating the action before the parent arrived. The person with Down syndrome was left unnecessarily highly traumatised for the rest of the hospital stay and for all subsequent hospital admissions. The person with Down syndrome now finds every hospital attendance highly triggering and terrifying.

National Centre of Excellence in Intellectual Disability Health

Down Syndrome NSW strongly urges the review to act on the key points made by the National Centre of Excellence in Intellectual Disability Health. These are listed below.

The current review of the National Safety and Quality Health Service Standards is a vital opportunity to address the stark health inequalities facing Australians with intellectual disability.

Action on those key points is required to meet the commitments of Australian Governments in response to the Disability Royal Commission that the revised Standards will "ensure equal access to health care services for all people with disability throughout life".





Key points

1. There are approximately 560,000 people with intellectual disability in Australia.
2. A very strong research base shows that people with intellectual disability experience extreme disadvantage in the Australian health care system. This includes twice the usual rate of potentially avoidable deaths, four times the rate of potentially preventable hospitalisations and dying 27 years earlier.
3. Most hospital clinicians have minimal undergraduate or continuing education in the needs of people with intellectual disability. They commonly show inadequate understanding of their needs and often show unconscious bias concerning their needs and quality of life.
4. Hospital clinicians do not routinely think about people with intellectual disability when faced with broader expressions like “equity”, “disability”, “cognitive disability” or “cognitive impairment”.
5. The Standards therefore need to include a specific focus on people with intellectual disability.
6. We welcome the inclusion of a section on “Equity” in the Introduction to the draft Standards. However, for that section to have impact, it requires at least a succinct subsection focused on each equity population, including specifically people with intellectual disability. The section on people with intellectual disability should reflect paras 2-4 above and other key aspects of disadvantage experienced by people with intellectual disability in the health system.
7. The Standards should require hospitals to give ongoing and specific consideration to the needs of people with intellectual disability and each other equity population in implementing relevant Standards. This should include:
 - a. A requirement to focus on intersectional needs, for example needs of a First Nations person with intellectual disability.
 - b. A requirement to identify and avoid disadvantage related to stigma.
 - c. A need to act on relevant ACSQHC user guides, including the Standards User Guide for the Health Care of People with Intellectual Disability, and the Standards User guide for Aboriginal and Torres Strait Islander health.





8. We welcome draft Standard 1.10 c. which requires hospitals to have organisational systems to “provide equitable access to health care for people with a disability and identify and action the need for reasonable adjustments”. However, this requirement is too general so that there will be tendency to focus on physical and sensory disability and not intellectual disability. The Standard should be reworded to read:

Provide equitable access to health care for people with intellectual, physical, sensory and other disabilities and action the need for:

9. Reasonable adjustments
- Steps to counter conscious and unconscious bias
 - Avoiding diagnostic overshadowing, specifically the assumption that symptoms relate to a person’s disability rather than to a health condition.

“Reasonable adjustments” are fundamental to providing equitable care to people with disability but hospital personnel commonly have very limited understanding of them. An additional Standard should be created along the following lines:

Reasonable adjustments

Hospitals should ensure reasonable adjustments to meet the needs of people with disability by having systems to:

- Identify consumers with disabilities including their types of disability and intersectional needs.
 - In conjunction with the person and their families, carers and disability support providers, identify reasonable adjustments the consumer needs in relation to matters including communication, time needed for interactions, support for decision making, comfortable environments, waiting times, behaviour support, and support and sedation for intrusive treatments.
 - Provide identified reasonable adjustments.
 - Train clinicians in identifying and providing reasonable adjustments.
 - Monitor and audit to assess whether reasonable adjustments have been made.
10. The need to identify and act on reasonable adjustments should also be restated in draft Standards 2.04 and 2.05 (clinical assessments and plans of care).
11. The draft Standards do not but should include requirements for trauma informed care including in relation to trauma resulting from medical treatment.



12. Behaviours of concern (2.11 and 2.12) – There should be specific requirements in relation to:
 - a. Use of positive behaviour support.
 - b. The need to comply with legal requirements for consent or authorisation of restrictive practices.
13. Recognising and responding to acute deterioration (2.16-2.18) – A consumer’s “usual baseline” should be documented on admission to avoid diagnostic overshadowing. All too often, deterioration is not adequately recognised because hospital staff assume a person’s presentation relates to their disability.
14. Coordinated and connected care (2.19- 2.22) –
 - a. There should be specific inclusion of any “disability support services” in the list of those to be involved in coordination of care. All too often, this does not occur to the detriment of a person with disability
 - b. There should be a specific requirement for hospitals to liaise with disability support services and families to
 - a. clarify the disability support needs of a consumer and whether these have significantly altered as a result of a health condition, and
 - b. resolve arrangements to meet those needs both in hospital and on discharge.
15. Safe environments – Standard 3.01 should be extended by:
 - a. Amending the Purpose statement to encompass accessibility. The Purpose statement should read, “Care environments are safe, accessible, culturally welcoming and therapeutic.
 - b. Including requirements to:
 - a. Provide hospital environments that will minimise anxiety and maximise psychological comfort for individuals.
 - b. Where appropriate, offer ambulatory and outreach models of care.
16. Health care record systems (3.04) – These should record any disability and related needs for reasonable adjustments. (The Single Digital Patient Record currently being piloted by NSW Health incorporates this feature.)
17. Medicines safety and quality (3.10-3.12)- There should be a requirement to comply with relevant authoritative guidelines such as the ACSQHC Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard.
18. The glossary should be amended to include definitions of the following expressions which will not routinely be understood in hospitals:



- a. Reasonable adjustments
 - b. “Disability” and different kinds of disability including “intellectual disability”
 - c. Positive behaviour support
 - d. Diagnostic overshadowing
19. “Substitute decision maker” is defined in the Glossary as a person authorised to make decisions for a person “who has lost decision-making capacity”. This incorrectly indicates that capacity is an all or nothing concept. The words “who has lost decision-making capacity” should be replaced by “who lacks capacity to make a particular decision”.
20. The definition of “bias” should be elaborated on to explain both conscious and unconscious bias.
21. Like the existing Standards, the new Standards should be accompanied by a Guide for Hospitals which has to be considered by hospitals implementing the Standards and by accreditation agencies. The existing intellectual disability User Guide is a valuable document but does not carry sufficient authority to be routinely considered by hospitals and assessors. Considerable material related to people with intellectual disability should be incorporated into the new Guide for Hospitals.

Government Commitments to the Disability Royal Commission

We argue that action on our recommendations is required to meet the commitments of Australian Governments that the revised Standards will “ensure equal access to health care services for all people with disability throughout life”.

Disability Royal Commission Recommendation 6.31(a) was to embed the right of people with disability to good health care in key policies and in legislation – the Australian Charter of Healthcare Rights, the National Quality and Safety Health Service Standards and Community Healthcare Standards.

In the 2024 joint response of all Australian Governments, they said “Accept” to this recommendation and stated:

Governments are committed to ensuring key policy instruments and plans support an inclusive Australian society that ensures people with disability have access to health care services that address their needs. The Australian Government, through the Australian Commission on Safety and Quality in Health Care and in





consultation with Commonwealth and State and Territory health governments, will develop a plan to update key policy instruments to ensure they articulate the requirements for safe and equitable access to health services for people with disability.

In their 2025 update on action, the governments said:

The ACSQHC will continue to undertake wide consultation with key stakeholder groups and the public when developing the third edition of the Standards and supporting resources to ensure equal access to health care services for all people with disability throughout life.

Equal healthcare does not mean identical healthcare

Down Syndrome NSW strongly supports equality in healthcare. However, equality does not mean that every patient should receive exactly the same process.

A person with Down syndrome may require additional time, simpler explanations, visual information, repetition, a quieter environment, communication support, assistance from a trusted person, or adjustments to the way consent and clinical information are provided.

These adjustments do not represent preferential treatment. They are the practical measures required to provide **equitable healthcare**.

The third edition should therefore make clear that person-centred care requires health services to identify and respond to individual accessibility requirements.

A person should not have to repeatedly explain their disability and communication needs to every new health professional.

Nor should the quality of care depend upon whether the person's family happens to know how to advocate effectively within the health system.

People with Down syndrome must be visible within the Standards

One of our strongest concerns is that people with intellectual disability can become invisible when standards use broad terms such as “vulnerable patients”, “people with additional needs” or “patients requiring additional support”.

People with Down syndrome are not simply a generic vulnerable population. They have particular experiences within healthcare that require specific understanding.

For example, changes in behaviour, communication, appetite, mobility, sleep, functioning or mood may be clinically significant.



A person who communicates differently may not be able to describe pain or symptoms in conventional ways.

A person may understand considerably more than they are able to express verbally.

A person may require support to communicate a decision without lacking the ability to make that decision.

These distinctions are fundamental to safe clinical care.

The third edition should explicitly refer to people with intellectual disability wherever requirements concerning accessibility, communication, supported decision-making, reasonable adjustments, patient safety and equity are addressed.

Supported decision-making must be embedded throughout the Standards

Down Syndrome NSW strongly recommends that supported decision-making become an explicit requirement throughout the third edition.

People with Down syndrome have the right to make decisions about their own healthcare.

Health professionals should be required to:

- presume that the person can make decisions unless there is clear evidence otherwise;
- provide information in a form the person can understand;
- explain any procedure or treatment prior to starting;
- allow sufficient time for processing and responding;
- offer communication supports;
- ask the person how they want to be supported;
- involve a trusted supporter where the person wants this;
- distinguish between difficulty communicating a decision and inability to make a decision;
- avoid making assumptions based on diagnosis;
- record the person's preferences about communication and decision-making;
- respect the person's right to refuse treatment; and
- use substitute decision-making only where legally required and after appropriate efforts have been made to support the person's own decision-making.
- Person-centred care must include supported decision-making as essential and not optional. It is fundamental to safe and lawful healthcare.

The third edition should include an explicit requirement that health services have systems to enable and document supported decision-making for people with disability, including appropriate communication supports and involvement of chosen supporters



Communication is a patient safety issue

Communication should be treated as a core clinical safety issue.

For many people with Down syndrome, communication can be affected by speech, hearing, processing speed, anxiety, unfamiliar environments and the complexity of medical language.

The solution is not simply to “speak more slowly”. Health services need to provide practical communication adjustments.

These may include:

- plain English;
- Easy Read information;
- pictures and visual information;
- demonstrations;
- written summaries;
- additional time;
- repetition;
- checking understanding;
- allowing the person to communicate in their preferred way;
- communication aids;
- access to familiar supporters;
- appropriate interpreters or communication professionals where required; and
- ensuring that the person is addressed directly.

A health professional should never assume that a person who speaks little or differently has little understanding.

Health services should be required to identify, document and provide each person's reasonable communication adjustments throughout their episode of care.

Individual health baselines must be part of clinical safety

This is particularly important for people with Down syndrome. People who know a person well may be able to identify subtle changes in their usual behaviour, communication, mobility, appetite, sleep, mood or functioning. Those changes can sometimes be early indicators that a person is unwell.

A health service must not assume that behaviour is simply “part of the disability”.

For example, withdrawal, agitation, reduced communication, changes in eating or drinking, altered mobility or increased sleepiness may require clinical assessment.





Down Syndrome NSW recommends that health services develop mechanisms for documenting relevant individual baseline information and ensuring that it is available to staff involved in the person's care.

This information should include, where relevant:

- preferred communication;
- usual communication style;
- hearing or vision needs;
- mobility;
- usual level of independence;
- known signs of pain or distress;
- usual behaviour and presentation;
- relevant health conditions;
- medication;
- allergies;
- sensory requirements;
- support needs;
- decision-making preferences; and
- people the patient wants involved in their care.

This information should follow the patient through the health system where appropriate and lawful.

Diagnostic overshadowing must be explicitly addressed

Diagnostic overshadowing is a serious patient safety issue.

It occurs when symptoms or changes in health are incorrectly attributed to a person's disability rather than being properly investigated.

For people with Down syndrome, there is a particular risk that behaviour, communication differences or intellectual disability may influence how symptoms are interpreted.

The Standards should make clear that:

A diagnosis of Down syndrome or intellectual disability must never be used as a substitute for clinical assessment.

Health professionals should be required to consider the person's individual presentation and investigate unexplained changes. This is particularly important when the person is unable to communicate symptoms in conventional ways.

The third edition should include an explicit requirement for health services to have systems, education and clinical processes designed to identify and prevent diagnostic overshadowing.



Disability competence must be a workforce requirement

Good intentions are not enough. Health professionals need practical skills.

Down Syndrome NSW recommends mandatory disability competency education for relevant health workers, developed in partnership with people with intellectual disability and representative organisations.

Training should include:

- understanding intellectual disability;
- Down syndrome;
- communication;
- supported decision-making;
- reasonable adjustments;
- diagnostic overshadowing;
- recognising pain and deterioration;
- working with families and supporters;
- consent;
- disability rights;
- restrictive practices;
- accessible information;
- trauma-informed approaches;
- health inequities;
- discharge planning; and
- respectful language and attitudes.

Importantly, training should not be based solely on clinical descriptions of disability.

People with Down syndrome and other people with intellectual disability should be directly involved in developing and delivering training.

The third edition should require health services to demonstrate workforce competency in providing accessible and equitable healthcare to people with intellectual disability.

Family members and supporters should be recognised as partners, but not substitutes

Families and supporters can play an important role in helping a person with Down syndrome communicate, understand information and navigate healthcare. They may also have valuable knowledge about the person's usual health and presentation.

However, the person with Down syndrome must remain at the centre.



Family involvement must not become a reason for clinicians to speak about the person rather than to them.

The correct approach is:

talk to the person, support the person, and involve their chosen supporters.

Health services should establish systems to identify:

- who the person wants involved;
- what assistance the person wants;
- what information can be shared;
- how supporters should be involved; and
- what happens if the person's wishes differ from those of their family.

Supporters should also not be expected to fill gaps created by inadequate health service systems.

Accessibility must include more than physical access

Accessibility is often understood primarily as ramps, lifts, toilets and physical access.

These are important, but they are only part of accessibility.

For people with Down syndrome, healthcare accessibility also includes:

- accessible information;
- accessible communication;
- accessible consent processes;
- accessible appointment systems;
- accessible websites;
- accessible signage;
- appropriate waiting environments;
- sensory considerations;
- adequate appointment time;
- accessible discharge instructions;
- accessible complaints processes; and
- staff who understand disability.

The third edition should explicitly adopt this broader understanding of accessibility.

Person-Centred Practice Standard

Down Syndrome NSW strongly supports the proposed Person-Centred Practice Standard. However, the concept of person-centred care should be strengthened by requiring health



services to demonstrate that people with disability actually experience care as person-centred.

It is not sufficient for a policy to state that care is person-centred.

Health services should be able to demonstrate:

- that the person was involved in decisions;
- that communication adjustments were provided;
- that reasonable adjustments were made;
- that the person's preferences were recorded;
- that their chosen supporters were involved where appropriate;
- that information was understandable;
- that the person was treated with dignity;
- that their concerns were taken seriously; and
- that their healthcare outcomes were not compromised because of disability.

Health and hospitals must regularly and publicly report on the consumer experience outcomes of Person-Centered Practice in order to identify whether people with disability are experiencing poorer access, communication, participation or outcomes.

Clinical Governance Standard

The Clinical Governance Standard provides an important opportunity to make disability inclusion a leadership responsibility. Boards and executives should be accountable for ensuring that people with disability receive equitable care.

Disability inclusion should not be delegated solely to individual clinicians.

Health service leaders should be required to know:

- whether people with disability experience poorer outcomes;
- whether complaints involving disability are increasing;
- whether reasonable adjustments are being provided;
- whether staff have disability competency;
- whether accessible information is available;
- whether people with intellectual disability are represented in consumer engagement;
- whether disability-related incidents are identified and reviewed; and
- whether improvements are being made.

Disability equity should be incorporated into clinical governance, quality improvement and risk-management systems.



Health services should regularly and publicly report on disability-related safety and quality measures as part of their governance responsibilities.

Safe Clinical Systems Standard

The Safe Clinical Systems Standard should recognise that systems designed for the average patient can create risks for people with disability.

For example, medication instructions may be technically correct but inaccessible.

Discharge information may be provided in writing but not understood.

A patient identification process may work well for most people but create confusion for someone who communicates differently.

A consent process may be legally documented without ensuring that the patient actually understood the information.

Safety systems need to account for these issues.

Down Syndrome NSW recommends that each relevant safety system be tested against the question:

“Will this system work safely for a person with intellectual disability?”

Medication Safety

Medication errors can occur when people do not understand:

- what a medicine is for;
- when to take it;
- how much to take;
- what side effects to look for;
- what to do if a dose is missed; or
- when to seek help.

Medication information should therefore be provided in an accessible form.

Where a supporter assists with medication, the person should be included in discussions to the greatest extent possible. Medication reconciliation should also involve checking whether the person and their support network understand changes to medication.

Recognition of Deterioration

The third edition should require health services to have systems that support recognition of deterioration in people who may communicate differently.

This should include consideration of:



- individual baseline;
- communication style;
- behaviour changes;
- pain presentation;
- mobility;
- eating and drinking;
- sleep;
- cognition;
- usual functioning; and
- information from people who know the patient well.

A person should not have to become critically unwell before their concerns are believed.

Emergency Departments and Acute Care

Emergency departments can be particularly challenging environments for people with Down syndrome.

They may involve:

- long waiting periods;
- noise;
- bright lighting;
- unfamiliar people;
- rapid changes in staff;
- complex communication;
- pain;
- anxiety; and
- limited opportunity for supporters to explain the person's usual presentation.

The Standards should require reasonable adjustments in emergency care.

Where clinically appropriate, these should include:

- communication supports;
- involvement of a chosen supporter;
- access to individual baseline information;
- consideration of sensory needs;
- clear explanations;
- minimisation of unnecessary distress; and
- timely assessment.





Restrictive Practices

Down Syndrome NSW supports a strong presumption against restrictive practices in healthcare.

People with intellectual disability must not be restrained simply because they communicate differently, become distressed in unfamiliar environments, or require additional support.

Where restrictive practices are considered, health services must demonstrate:

- that all reasonable alternatives were considered;
- that communication and environmental adjustments were attempted;
- that the person's distress was understood;
- that the practice was lawful;
- that it was proportionate;
- that it was the least restrictive option;
- that appropriate safeguards were in place; and
- that the incident was reviewed.

The Standards should require health services to monitor the use of restrictive practices involving people with disability.

Discharge Planning

Poor discharge planning can create significant safety risks.

A person with Down syndrome may leave hospital with:

- new medication;
- follow-up appointments;
- changed treatment;
- new equipment;
- altered support requirements;
- restrictions on activity; or
- warning signs that need monitoring.

The discharge process must ensure that the person understands what they need to do.

Where the person wants support, their chosen supporter should be involved.

Discharge information should be provided in an accessible format.

Health services should also ensure appropriate communication with GPs, specialists, disability services and other relevant providers.



Integration Across the Health System

Down Syndrome NSW strongly supports the third edition's focus on integration.

People with Down syndrome frequently interact with multiple parts of the health system.

The system should not require the person or their family to repeatedly reconstruct their health history.

Health services should have processes for appropriate transfer of relevant information between:

- hospitals;
- emergency departments;
- GPs;
- specialists;
- allied health;
- community health;
- mental health services;
- disability services; and
- other relevant providers.

Integration must include the information necessary to support safe and accessible care.

Consumer engagement must include people with intellectual disability

It is not enough for health services to consult families, carers or general consumer representatives.

People with intellectual disability must be directly involved.

Health services should actively seek participation from people with intellectual disability in:
service design;

- quality improvement;
- policy development;
- complaints review;
- patient information development;
- staff training;
- consumer committees; and
- evaluation of patient experience.



Participation must be genuine. People with Down syndrome should not simply be invited to endorse decisions that have already been made. They should be involved from the beginning.

Complaints and Feedback

An inaccessible complaints system is not a meaningful complaints system. People with Down syndrome should be able to raise concerns without needing a family member or advocate to do so.

Health services should provide:

- Easy Read complaints information;
- accessible online processes;
- options for verbal complaints;
- assistance to make a complaint;
- communication support;
- protection from retaliation;
- clear explanations of outcomes; and
- opportunities for independent advocacy.

Complaints involving disability should be analysed to identify systemic issues rather than treated only as individual incidents.

Measuring Outcomes

One of the strengths of the proposed third edition is its emphasis on outcomes. Down Syndrome NSW strongly supports this direction. However, outcomes must be measurable for people with disability.

Health services should collect and report appropriate information about:

- access;
- waiting times;
- communication adjustments;
- patient experience;
- adverse events;
- complaints;
- readmissions;
- discharge outcomes;
- preventable hospitalisations where measurable;
- use of restrictive practices; and
- other relevant safety and quality outcomes.



Where the data on outcomes demonstrates inequity, health services should be required to identify and address the causes.

Co-design and Implementation

The success of the third edition will depend heavily on implementation.

Down Syndrome NSW recommends that the Commission work with:

- people with Down syndrome;
- people with intellectual disability;
- families;
- disability representative organisations;
- clinicians with expertise in intellectual disability;
- researchers; and
- disability advocates.

Implementation resources should include practical examples showing health services what good practice looks like.

This should include examples of:

- supported decision-making;
- accessible communication;
- reasonable adjustments;
- accessible consent;
- disability-inclusive clinical governance;
- discharge planning;
- recognising deterioration;
- avoiding diagnostic overshadowing;
- engaging supporters; and
- accessible complaints.

Measurable Indicators

Down Syndrome NSW recommends that the third edition be accompanied by measurable indicators. Possible indicators include:

1. Percentage of staff who have completed disability competency training.
2. Percentage of patients with intellectual disability who have documented communication requirements.
3. Percentage of patients with intellectual disability whose preferred decision-making supports are documented.
4. Consumer experience results for people with intellectual disability.





5. Number and nature of complaints relating to disability accessibility.
6. Use of restrictive practices involving people with intellectual disability.
7. Evidence that reasonable adjustments were provided.
8. Evidence that discharge information was provided in an accessible format.
9. Evidence of involvement of people with intellectual disability in service design and quality improvement.
10. Evidence that disability-related incidents and adverse outcomes are reviewed at governance level.

These measures would move disability inclusion from an aspirational principle to an accountable component of healthcare quality.

Down Syndrome NSW's Priority Actions

Down Syndrome NSW asks the Commission to adopt the following actions in the final third edition.

1. Explicitly recognise people with intellectual disability as a population requiring specific consideration within the NSQHS Standards.
2. Embed supported decision-making across all three Standards.
3. Require health services to identify and provide reasonable adjustments.
4. Require accessible communication and health information.
5. Require documentation of individual communication requirements and relevant baseline information.
6. Explicitly address diagnostic overshadowing as a patient safety risk.
7. Require disability-specific competency for relevant health workers.
8. Recognise the role of chosen supporters and families while maintaining the person with disability as the decision-maker wherever possible.
9. Require accessible consent processes.
10. Ensure disability-inclusive emergency and acute care.
11. Strengthen safeguards concerning restrictive practices.
12. Require disability-inclusive discharge planning.
13. Require accessible complaints and feedback mechanisms.
14. Measure healthcare experiences and outcomes for people with disability.
15. Require meaningful participation of people with intellectual disability in health service design, governance and quality improvement.
16. Develop specific implementation guidance and indicators for disability-inclusive healthcare.





Conclusion

Down Syndrome NSW welcomes the opportunity to contribute to the development of the third edition of the NSQHS Standards. We support the Commission's ambition to create standards that focus on high-quality care, patient experience, integration, learning and outcomes.

People with Down syndrome should not receive a lower standard of healthcare because they communicate differently, need more time, require support to make decisions, or have an intellectual disability.

They should not have to be exceptionally confident advocates to have their symptoms investigated.

They should not have to fight to obtain reasonable adjustments.

And they should never be excluded from decisions about their own bodies and their own healthcare simply because they have Down syndrome.

The third edition should make it clear that **safe healthcare is accessible healthcare, and person-centred healthcare is healthcare in which people with intellectual disability are genuinely heard, understood, respected and included.**

Down Syndrome NSW therefore urges the Australian Commission on Safety and Quality in Health Care to strengthen the third edition so that disability inclusion, accessibility, supported decision-making and equitable healthcare are explicit, measurable and accountable requirements across the national health system.

Down Syndrome NSW recognises that implementing any of the recommendations and actions in this submission will have benefits for many other patients and people outside the sphere of intellectual disability. These improvements will have far-reaching benefits for other specific populations as well as patients in general.

People with Down syndrome have the same right as every other Australian to safe, high-quality healthcare.

Down Syndrome NSW looks to the third edition to ensure this right is respected and exercised.

Should you have any questions or require further information, Down Syndrome NSW will be happy to respond.





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