National Centre of Excellence in Intellectual Disability Health

Conjoint Professor Anne Duggan
Chief Executive Officer
Australia Commission on Safety and Quality in Health Care

Sent via email: nsqhssthirdedition@safetyandquality.gov.au

24 September 2025

Dear Professor Duggan,

Submission on the National Safety and Quality Health Service (NSQHS) Standards (third edition)

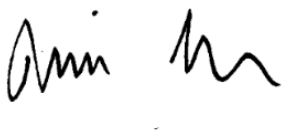
We write on behalf of the National Centre of Excellence in Intellectual Disability Health to provide input on this review. Our submission on this consultation is below.

In our submission, we provide key recommendations to ensure that the Standards address the stark health inequalities faced by people with intellectual disability.

We trust you will find this information useful in the development of the NSQHS Standards (third edition).

We would welcome the opportunity to discuss our comments further, and should you require further information about this submission, please do not hesitate to contact Jim Simpson on 0418 635 630 or at jim@cid.org.au.

Sincerely,



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Down Syndrome Australia

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Scope Australia

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About us

The National Centre of Excellence in Intellectual Disability Health ('the Centre') is an important initiative supported by the Australian Government Department of Health and Aged Care. The Centre is a consortium of nine organisations, including:

1. UNSW Sydney,
2. Centre for Disability Studies (University of Sydney),
3. Council for Intellectual Disability,
4. Down Syndrome Australia,
5. First Peoples Disability Network,
6. Queensland Centre of Excellence in Autism and Intellectual Disability Health
7. Queenslanders with Disability Network,
8. The Kids Institute and,
9. University of Melbourne.

It also includes another 56 health and disability organisations as partners and collaborators. The vision of the Centre is to ensure that the 500,000 people with intellectual disability in Australia receive the highest attainable level of healthcare.

EXECUTIVE SUMMARY

Why the Standards need a specific focus on people with intellectual disability

The third edition of the NSQHS needs a strong focus on the approximately 550,000 people with intellectual disability in Australia.

This is needed for the following reasons:

1. The strong Australian research evidence shows stark health inequalities facing people with intellectual disability, including twice the rate of potentially avoidable deaths as other people and up to 4.5 times the rate of potentially preventable hospitalisations. Acute presentations are over-represented, costly and inefficient.

2. The cost of these inequalities is profound in terms of the suffering of people with intellectual disability, elevated hospital costs, increased disability support

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needs and therefore cost to the NDIS, and diversion of family carers from the workforce.

3. The present Australian Commission on Safety and Quality in Health Care (ACSQHC) User Guide for the Health Care of People with Intellectual Disability has reinforced the inequalities faced by people with intellectual disability, including highlighting:

    a. People with intellectual disability experienced poorer health outcomes than the general population and people with other disabilities.

    b. People with intellectual disability experience direct and indirect discrimination and cognitive bias in the health care system, leading to misdiagnosis or delayed diagnosis and then preventable hospitalisations, chronic disease and early mortality.

4. The Disability Royal Commission found people with intellectual and other cognitive disabilities experience ongoing "systemic neglect" in the Australian healthcare system.

5. In response to the Disability Royal Commission Report, all Australian governments have 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 ACSQHC 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. Enacting this recommendation will … set clear expectations on health services and clinicians." Joint government response to the Disability Royal Commission | Australian Government Department of Health, Disability and Ageing

A specific focus on people with intellectual disability should occur within the context of the diversity of people who use hospitals.

The Standards should not subsume intellectual disability within the broader expressions of disability or "cognitive impairment". Clinicians often do not think of intellectual disability when cognitive impairment is spoken of. People with intellectual

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disability have their own specific needs and experience profound health disadvantages.

Our recommendations for content in the 3rd edition of the Standards

1. **There should be a specific standard focused on Diversity. This standard should:**

    a. Be the first standard so that other standards are considered with diversity squarely in mind.

    b. Set out specifically:

        i. the various kinds of diversity that are often associated with poorer hospital care, for example, being an Aboriginal or Torres Strait Islander person, a person with intellectual disability, or a person with a mental illness.
        ii. that intersectionality between two or more kinds of diversity and disadvantage are associated with poorest health outcomes.

    c. Spell out the highest priority actions required to meet diverse needs in hospital. There may be an overarching set of actions focused on issues such as:

        i. Treating all patients with respect and kindness – Disrespect is a commonly reported hospital experience for people with diverse backgrounds.
        ii. Communicating with people in a way that they can understand, for example, providing information in accessible formats.
        iii. Intersectionality – identifying and responding to intersecting diverse needs, for example, the needs of an Aboriginal person with intellectual disability.

    d. To avoid diversity being seen homogenously, there should also be specific key actions required in relation to each disadvantaged group.

    e. For people with intellectual disability, key actions should cover:

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i. Identification of intellectual disability.
ii. Meeting communication needs both through general hospital information being available in Easy Read and meeting individual needs in clinician/patient interactions.
iii. Identifying and providing reasonable adjustments in the delivery of health care.
iv. Recognising and countering unconscious bias and diagnostic overshadowing.
v. Supported decision-making complemented by respect for the roles of families and disability support providers as informants of health needs and partners in care.
vi. Trauma-informed practice.
vii. Demonstrated non-discrimination in access to hospital services.

2. **Other standards should regularly refer to the Diversity standard and spell out specific actions within the province of each standard. This should include specific highlighting of key actions needed in relation to people with intellectual disability.**

   In this submission, we have not sought to provide a comprehensive list of actions related to people with intellectual disability that should be included in the Standards, but we have provided examples. We would be very happy to work with the Commission on the details and wording.

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SUBMISSION

A stark safety and quality risk – the health of people with intellectual disability

In Australia, approximately 550,000 people with intellectual disability face stark health inequalities and multiple barriers to accessing health care that meets their needs. With their close families, over two million people are affected.

The NSW data linkage work of the Department of Developmental Disability Neuropsychiatry, UNSW (now incorporated into the National Centre), explores the health outcomes for people with intellectual disability. These linkage studies were based on approximately 1.1% of the NSW population who were identified as having intellectual disability.[1] In the absence of any available source of population health data at a national level, NSW findings can be taken as nationally representative. Below is a summary of some of the findings.

In comparison to the general population, health outcomes for people with intellectual disability are characterised by:

- Premature mortality occurring 27 years earlier.[2]
- More than double the proportion of potentially avoidable deaths at 38%.[2]
- Four times the rate of potentially preventable hospitalisations (PPHs).[3]
- PPHs up to 4.5 times higher than for the general population, with PPHs for acute conditions being up to 8 times higher and PPHs for vaccine-preventable conditions up to 3 times higher.[4]

Compared to people in the general population, health service interactions for people with intellectual disability are:

- Over-represented, with hospitalisations and emergency presentation rates being twice as high.[4]
- Costly, with:
  - Admissions being on average twice as long and twice as expensive.[4]
- Inefficient:
  - With higher rates of representation to emergency departments and inpatient units following discharge from mental health facilities, even for first-ever admission.[5]

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- Even with a clear clinical pathway for epilepsy and seizure admissions, there are significant disparities. Age-standardised admission rates per 100,000 people are 21 times higher, with longer admissions and higher readmission rates within 30 days.[6]

Australians with intellectual disability are also less likely to have their preventative health care needs met through primary care compared to the general population.[8,9] This contributes to high acute care service use.[10]

People with intellectual disability are over-represented in every compartment of the acute health care system, experiencing very high rates of emergency department presentation and admissions, with substantially higher associated costs. Despite only representing 1.1% of the NSW population, identified people with intellectual disability comprise 4% of people using ED services, 4% of people using inpatient non-mental health services, and over 6% of inpatient mental health services (Figure 1).

Furthermore, despite this over-representation, **people with intellectual disability receive ineffective care characterised by repeated presentation to acute care after mental health inpatient stays.**[5]

Figure 1. Percentage of NSW Health Service Users with INTELLECTUAL DISABILITY per compartment, FY 2014/15

Mental health

Mental health conditions account for 24% of the non-fatal burden of disease in Australia[11], and are leading causes of disability and morbidity. Intellectual disability is associated with substantial over-representation of mental illness.

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In NSW, 76% of people with intellectual disability experience mental health disorders (as against 38% in the general population), including serious mental illnesses 16% (as against 5% in the general population).[12]

Available data suggests overrepresentation for most mental health disorders, including schizophrenia, affective disorders, anxiety disorders and dementia, of 2-3 times that of the general population.[13,14,15]

The research of the Department of Developmental Disability Neuropsychiatry demonstrates the lack of capacity of professionals and systems to respond to this issue. The research shows that people with intellectual disability are very high users of acute mental health services at greatly inflated cost [4,5,16]; experience multiple barriers to mental health services[17]; receive ineffective care characterised by repeat presentation to acute care after a mental health inpatient stay[5]; encounter professionals and services that are ill-equipped to meet their basic rights to access mental health care[18,19,20]; and are usually excluded from mental health policy.[21,22]

Findings and recommendations of the Disability Royal Commission

Based mainly on lived experience testimonies and research, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) made this finding: "***people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system.***"[23]

The Royal Commission made wide ranging recommendations including that the Australian Commission on Safety and Quality in Health Care (ACSQHC) review and revise the National Safety and Quality Health Service Standards and the National Safety and Quality Primary and Community Health Care Standards to provide for the delivery of safe and high quality health care for people with disability and align with the scope of the Commission's proposed right to equitable access to health services (Recommendation 6.31a).

The response to this recommendation by the Australian and State and Territory Governments says

> *The Australian Government and state and territory 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*

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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. Enacting this recommendation will enable a more person-centred approach to health care planning and delivery, reduce health disparities, provide guidance to patients, and set clear expectations on health services and clinicians.
australian-government-response-to-the-disability-royal-commission.docx

The 2021 Standards and 2024 Intellectual Disability User Guide

The 2021 National Standards introduction says that the standards "set requirements for providing comprehensive care for all patients and include actions relating to…. care for people with lived experience of… cognitive impairment". Intellectual disability is one form of cognitive impairment, though practitioners tend to think of cognitive impairment predominantly in terms of dementia and delirium.

However, there is very little specific reference in the standards to issues for people with cognitive impairment. Specific issues for people with cognitive impairment are only stated in one out of eight standards, namely the comprehensive care standard. The issues there relate only to risks of falls and screening of risk in the development of comprehensive care plans.

In 2024, the Commission released the National Safety and Quality Health Standards User Guide for the Health Care of People with Intellectual Disability.

The introduction to the User Guide explains the safety and quality issues experienced by people with intellectual disability:

- People with intellectual disability experience a range of disadvantage, including elevated and early mortality rates, preventable hospitalisations, risks from polypharmacy and a high burden of preventable health conditions.
- While people with disability generally experience health inequities, people with intellectual disability have poorer health outcomes compared to people with other disabilities or the general population.

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- The combination of complex healthcare needs, communication difficulties and reliance on others for support has significant implications for the delivery of healthcare to people with intellectual disability.

- Barriers to appropriate healthcare for people with intellectual disability include direct and indirect discrimination and negative attitudes leading to misdiagnosis or delayed diagnosis, with the person's symptoms being attributed to their intellectual disability, and in turn leading to preventable hospitalisations, chronic disease and early mortality.

- Cognitive biases towards 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 health care planning. Cognitive bias may influence decisions about providing proactive treatment, rehabilitation, preventative health care and end-of-life care.

Through the body of the User Guide, these barriers are further elaborated on, including:

- The lack of targeted adaptations, policies, knowledge and confidence within health services is often a barrier to genuine partnership with consumers with intellectual disability (page 28).

- Elevated likelihood of poor experiences in healthcare, including:

    - providers not effectively communicating with the person with intellectual disability,
    - little or no consideration of critical information provided by family members,
    - medication error and polypharmacy
    - trauma, neglect and untreated pain (page 28).

- Heightened risk of adverse effects from medication and the use of psychotropic medications for behaviour (page 41).

- Transitions of care points being potentially high risk for people with intellectual disability due to essential information not being passed on, including

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information about disability support nodes, communication needs, behavioural supports and comorbidities (page 67).

- It can be difficult to identify the relevant signs of acute deterioration in a patient with intellectual disability, particularly if the clinician does not know the person well and the person is not able to communicate their pain or distress (page 68).

The User Guide goes through each standard, explaining its relevance to health care for people with intellectual disability and setting out actions and evidence-based strategies for delivering appropriate healthcare to people with intellectual disability. The strategies focus on issues including person-centred care, planning for reasonable adjustments, communication with people with intellectual disability, working collaboratively, building workforce capacity and collecting data.

"Spotlight issues" are also highlighted, focusing on supported decision-making, co-design with people with intellectual disability, polypharmacy, support from admission to discharge, end of life care, positive behaviour support, working collaboratively with the disability sector and transition of care.

The Commission's User Guide is very good; however, because it has no mandatory status, it is unlikely to have a major impact.

The recommendations below on matters that should be included in the 3rd standards draw very heavily on the User Guide.

Unconscious bias

As the Commission has highlighted in its Intellectual Disability User Guide, cognitive or unconscious bias towards people with intellectual disability includes assumptions about a person's quality of life, their ability to gain new skills and their capacity to participate in health care planning. Health care professionals' biases may influence decisions about providing proactive treatment, rehabilitation, preventative health care and end-of-life care.

Specific examples of unconscious or cognitive bias can be found in evidence to the Disability Royal Commission and in a recent coronial inquest.

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Finlay Browne – findings in coronial inquest
Inquest into the death of Finlay Browne | Coroners Court of New South Wales

Finlay Browne arrived at Bathurst Hospital Emergency Department on 30 September 2016. He had acute abdominal pain. He was 16 years old and had Down Syndrome. A series of failures by Emergency Department staff denied Finlay the chance of early surgery and possible recovery. He did not recover and died in December 2016.

The coroner found that hospital staff showed unconscious bias that affected Finlay's care.

The coroner was particularly impressed by the evidence of Finlay's mother, Rachel, who was herself an experienced nurse. In finding unconscious bias, the coroner relied on the evidence of Rachel, not just her observations of the crucial night at the Emergency Department, but also her experiences over many years with Finlay and contrasting experiences of health care for her other children.

Unconscious bias led to assumptions about Finley being nonverbal and impacted where he was placed in the emergency department, the attention he was given, observations which were not taken regularly, assumptions about his pain levels and his overall supervision and assessment. This may have contributed to missed opportunities to recognise the significance of his condition and his deterioration.

Evidence of AAJ, Senior Staff Specialist in Palliative Medicine to the Disability Royal Commission
February 2020 STAT.0051.0001.0001.pdf

AAJ's evidence was based on her 20 years of service as a palliative care specialist.

AAJ recounted several instances in which people with intellectual disability had been referred to palliative care rather than being provided with usual active treatment for cancers and other conditions. AAJ commented:

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"Doctors and other clinicians can find it hard to understand that a person with a severe disability can still have a good quality of life.... All too frequently, doctors and nurses seem unable to think outside their own life experiences when presented with a patient who has a disability."

Evidence of Christine Regan

Public hearing 4: Health care and services for people with cognitive disability | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Christine's daughter Erin has Down syndrome. She loves karaoke and her favourite band is ABBA.

When Erin was born, the hospital's advice was, *"We think you should send this baby to a place where it can be looked after because you can't."* Hospital staff took her husband aside every time he visited before he got to Christine's bed to convince him to give Erin up.

When Erin was 25, she had a stroke, and Christine took her to the emergency department. Erin was not offered the usual rehabilitation. When Christine pressed clinicians about recovery, the response was *"Oh, look, she has Down syndrome. How hard are you going to try?"*

Christine felt like she had been punched in the gut. *"There was no medical reason for her not to do rehabilitation. ... this man was ... going to send her home to a life of paralysis ... and possibly an early departure from this world ... because he had decided how important it was for her to be alive... it wasn't a medical decision."*

Many years on, Erin was now living a full life and working in a coffee shop. Christine emphasised that doctors should not be providing their social opinions. They should stick to medical opinions.

The third edition of the national standards needs a strong focus on people with intellectual disability

This is needed for the following reasons:

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1. The strong Australian research evidence shows stark health inequalities for people with intellectual disability, including twice the rate of potentially avoidable deaths as other people and up to 4.5 times the rate of potentially preventable hospitalisations.

2. The cost of these inequalities is profound in terms of the suffering of people with intellectual disability, elevated hospital costs, increased disability support needs and therefore cost to the NDIS and diversion of family carers from the workforce.

3. The present ACSQHC User Guide for the Health Care of People with Intellectual Disability has reinforced the inequalities faced by people with intellectual disability, including highlighting:

    a. People with intellectual disability experienced poorer health outcomes than the general population and people with other disabilities.

    b. People with intellectual disability experience direct and indirect discrimination and cognitive bias in the health care system, leading to misdiagnosis or delayed diagnosis and then preventable hospitalisations, chronic disease and early mortality.

4. The Disability Royal Commission found people with intellectual and other cognitive disabilities experience ongoing “systemic neglect” in the Australian healthcare system.

5. In response to the Disability Royal Commission Report, all Australian governments have 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 ACSQHC 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. Enacting this recommendation will …. set clear expectations on health services and clinicians.” Joint government response to the Disability Royal Commission | Australian Government Department of Health, Disability and Ageing

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A specific focus on people with intellectual disability would be a logical extension of the explicit focus in some of the existing standards on First Nations people, whose marked health disadvantage bears similarities to those faced by people with intellectual disability.

A specific focus on people with intellectual disability should occur within a context of the diversity of people who use hospitals.

The Standards should not subsume intellectual disability within the broader expression "cognitive impairment". Clinicians often do not think of intellectual disability when cognitive impairment is spoken of. People with intellectual disability have their own specific needs and experience profound health disadvantages.

Our recommendations for content in the 3rd edition of the Standards

1. **There should be a specific standard focused on Diversity. This standard should:**

    a. Be the first standard so that other standards are considered with diversity squarely in mind.

    b. Set out specifically:

        i. the various kinds of diversity that are often associated with poorer hospital care, for example, being an Aboriginal or Torres Strait Islander person, a person with intellectual disability, or a person with mental illness.
        ii. that intersectionality between two or more kinds of diversity and disadvantage are associated with poorest health outcomes.

    c. Spell out the highest priority actions required to meet diverse needs in hospital. There may be an overarching set of actions focused on issues such as:

        i. Treating all patients with respect and kindness – Disrespect is a commonly reported hospital experience for people with diverse

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backgrounds. Compliance could be monitored through measures such as patient satisfaction surveys.

ii. Communicating with people in a way that they can understand, for example, providing information in accessible formats.

iii. Intersectionality – identifying and responding to intersecting diverse needs, for example, the needs of an Aboriginal person with intellectual disability.

d. To avoid diversity being seen homogenously, there should also be specific key actions required in relation to each disadvantaged group.

e. For people with intellectual disability, key actions should cover:

i. Identification of intellectual disability

ii. Meeting communication needs both through general hospital information being available in Easy Read and meeting individual needs in clinician/patient interactions. (This specific requirement spells out a logical application of the existing Actions 2.08 – 2.10 and should inform other actions that relate to provision of information to patients.)

iii. Identifying and providing reasonable adjustments in the delivery of health care

iv. Recognising and countering unconscious bias and diagnostic overshadowing

v. Supported decision-making complemented by respect for the roles of families and disability support providers as informants of health needs and partners in care.

vi. Trauma-informed practice. See Taking Time Literature Review and Framework | Berry Street

vii. Demonstrated non-discrimination in access to hospital services.

A Council for Intellectual Disability project worker contrasted her experiences at two large public hospitals. At one, the staff were rude and did not communicate well with her. They talked to her mother, and not her. At the other hospital, the staff were kind and respectful. They were easy to understand and used simple language. They checked in regularly with her.

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Members of our Learn and Lead Group of people with intellectual disability emphasise similar themes in relation to hospital care:

- *Treat us with empathy and respect.*
- *Don't make assumptions.*
- *Walk in our shoes.*
- *Speak in a way that we can understand.*
- *Don't talk down to us like we are children.*
- *Be respectful of our wishes and listen to us.*
- *Keep reassuring the patient. Some people can be terrified.*

2. **Other standards should regularly refer back to the Diversity standard and spell out specific actions within the province of each standard. This should include specific highlighting of key actions needed in relation to people with intellectual disability.**

   We do not seek here to provide a comprehensive list of actions related to people with intellectual disability that we recommend be included in the standards. We would be very happy to work with the Commission on this. However, some standout examples of actions that could be included in the standards are as follows (linked to existing standards):

   a. **Clinical governance** – It should be a specific requirement for the governing body to ensure that the health service addresses the specific health needs of people with intellectual disability (as there appropriately already is in relation to Aboriginal and Torres Strait Islander peoples – Actions 1.02, 1.04, 1.211.33). Key relevant needs here include:

      i. ensuring a welcoming environment for people with intellectual disability,

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ii. building of workforce skills in identification, communication and working with people with intellectual disability,

iii. provision of reasonable adjustments,

iv. incorporation of intellectual disability into the service's planning, safety and quality systems.

b. **Partnering with consumers** – Actions in the standard should reflect key and often neglected strategies to ensure partnering with consumers with intellectual disability, including focus on:

i. supported decision making and personalised communication,

ii. respecting the role and knowledge of families to complement the input that people with intellectual disability can directly provide. Families often become key coordinators of health care for their family member and need ready access to all health information that enables them to perform this role.

iii. including people with intellectual disability and their families in service organisational design and governance mechanisms. Just as the existing Actions 2.11 – 2.14 include a general focus on diversity and a specific focus on First Nations communities. Those actions need a specific focus on people with intellectual disability and their families, who are often not included in consultative mechanisms (sometimes on the false assumption that people with physical or sensory disabilities can represent all people with disability). It is particularly important to specifically focus on people with intellectual disability here, as later actions in the existing standards refer to 2.11 – 2.14 as requirements to be followed.

[Public hearing 4: Health care and services for people with cognitive disability | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability]

At the Disability Royal Commission, parent Rebecca Kelly talked about the barriers she had faced in getting access to health records that she needs to coordinate the complex care of her young son, Ryan. Rebecca described the amount of time that she has spent

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following up on Ryan's test results, reports, and other medical records as *"absolutely enormous"*, and *"almost like a job in its own right"*. She was told, *"No, you're just a parent. We don't give those to parents. That's policy."*

Rebecca has had to do freedom of information requests to get some of Ryan's health information. *"You know, the idea that I wouldn't … understand … that detailed information … When I got it was … fundamental. There were things … in those notes that I needed to know because no one else had been told them and they were vital in terms of his ongoing care."*

c. **Medication safety standard** –

i. Adopt best practice for psychotropic medication use in line with the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard | Australian Commission on Safety and Quality in Health Care This includes documentation regarding obtaining informed consent, ensuring the individual has had a comprehensive assessment of their health and mental health in the context of behaviour change, that non-medication strategies have been considered as first-line in conjunction with behaviour support practitioners.

ii. If psychotropic medication is prescribed, the indication and target symptom(s) should be documented, the person should have access to regular medication reviews for side effects and consideration for the ongoing need, and medications ceased if no longer indicated, ineffective or causing problematic side effects.

iii. Information for patients – Beyond just providing information about medications (existing action 4.11), the requirement should be for information to be provided in a form that meets patients' communication support needs, for example, Easy Read is appropriate for a high proportion of people with intellectual disability.

Greg (not his real name) has intellectual disability and no speech. He was in hospital with pneumonia. He was very restless, and doctors mistakenly assumed that this was because of his disability. Seven different psychoactive medications were tried to address Greg's restlessness, two with massive

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> *negative reactions. His mother then pointed out a growth on his tailbone. This was a pilonidal sinus on his buttock, causing great pain and restlessness. With Greg unable to explain his restlessness, he should have had a very thorough physical examination, which would have shown the sinus.*

d. **Comprehensive care standard** – This should include specific focuses on:

i. optimising communication with the patient and their informal supports,

ii. supported decision making,

iii. provision of reasonable adjustments,

iv. ensuring clinicians have appropriate skills in issues for people with intellectual disability,

v. collaborating with disability support providers to: understand a patient's disability support needs; ensure those needs are met in hospital; agree on respective roles while the person is in hospital; and ensure safe transition when the person leaves hospital.

vi. use of positive behaviour support in collaboration with the patient's behaviour support practitioner and thereby minimising any restrictive practices and ensuring that the hospital environment and staff interactions do not promote challenging behaviour.

Actions i. – iii. would modernise the focus in existing Action 2.05 on capacity as a static quality to be identified rather than a dynamic quality to be maximised.

Actions v. – vi. build on existing actions, in particular 5.30 – 5.36.

e. **Communicating for safety standard** – This should include:

i. Communication not just between health providers but also with disability support services, who are part of a person's support in hospital and on discharge. (The existing 6.09 covers this issue to some degree, but the

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word “carers” is often interpreted as people who provide informal rather than paid support.)

ii. Ensuring the appropriate sharing of information that a patient will have difficulty sharing with a new clinician.
As the User Guide says, “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”.

f. **Responding to acute deterioration** – There is a risk of diagnostic overshadowing here, with deterioration being falsely ascribed to a patient’s disability. A patient’s individualised monitoring plan (current action 8.04) should include a baseline documenting the patient’s normal functioning and behaviour, and individualised consideration of how to detect signs of deterioration both through physiological data and observed changes in a person's normal behaviour. The plan should address challenges of recognising deterioration if a patient has a communication impairment or a history of atypical reaction to pain. Families and disability support workers often bring vital skills in identifying normal presentation and warning signs of deterioration.

g. **Terminology** – If the newer standards continue to use the expression “higher risk (patients at higher risk of harm)”, people with intellectual disability should be specifically included in the definition (page 78).

We strongly urge the adoption of these recommendations in the review of the NSQHS Standards. We welcome the opportunity to engage further on these recommendations with the view to helping to incorporate these recommendations into the NSQHS Standards (third edition).

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