Roundtable Report

Models of support and sedation for health care interventions for people with intellectual disability

July 2026

National Centre of Excellence in Intellectual Disability Health

Executive summary

The Roundtable

This Roundtable aimed to identify practical strategies to address a major cause of health inequalities for people with intellectual disability. Many people with intellectual disability need support and/or sedation to assist them to accept vaccinations, blood tests and other physically intrusive medical and dental treatments. Appropriate support and sedation are commonly not available, and so many necessary treatments do not occur.

The National Centre of Excellence in Intellectual Disability Health (The Centre) led this Roundtable in collaboration with the Department of Health, Disability and Ageing (DHDA). The Roundtable brought together some key community experts – people with intellectual disability, family members, clinicians, researchers and advocates – along with representatives from key branches of DHDA.

Speakers outlined the experiences and challenges facing people with intellectual disability in accessing support and sedation. They described successful but limited service models that are in place in some locations around Australia. Barriers to those services being widely available were identified.

Good practice requires a tiered approach starting with providing supportive environments to minimise the need for sedation, through medication, to general anaesthetic as a last resort where less intrusive options are inadequate.

Action required

Action is needed across a range of parts of the health system including general practice and state and territory health agencies.

There was a strong consensus that the highest priority focus should be on the roles of state/territory health agencies. They are the most key players and the

ones where some models of excellent practice have been demonstrated. They should build on those models towards comprehensive statewide services.

Ingredients of a strong case to take to the state/territory agencies would be:

1. A nationally endorsed model of care based on the kinds of tiered options that were discussed at the Roundtable.
2. The best evidence that can be gathered on the extent of the need for a support and sedation pathway.
3. Guidance on how to cost appropriate services.
4. A recommended approach to evaluation.
5. Guidance for services on development of business cases for funding bids.
6. Case examples that emphasise the risks to individuals of not having support and sedation pathways and the human and financial gains of having pathways. This includes financial savings to health systems from enhanced preventive health care and early intervention on health problems.
7. People with disability and family members willing to share their personal stories.

Next steps and recommendations

1. The Centre will work with DHDA to carry forward action from the Roundtable, including ongoing input from people with intellectual disability, families, clinicians and researchers.
2. The Centre will bring together a small working group to develop a tiered model of care proposal for state/territory health agencies to meet the support and sedation needs of people with intellectual disability who find it difficult to understand and accept health care interventions. The proposal will extend to population cohorts beyond people with intellectual disability who have similar support and sedation needs.

3. In liaison with the Centre, DHDA should pursue actions to make appropriate support and sedation available in general practice, focusing firstly on:
    a. Actions that could be taken by Primary Health Networks in collaboration with state/territory Local Health Districts, particularly the four PHNs that are piloting the Primary Care Enhancement Program.
    b. Encouraging primary health care professionals to take advantage of continuing professional development modules that will enhance their skills in communicating with and providing reasonable adjustments to people with intellectual disability.
4. In collaboration with the Centre, the DHDA should raise the importance of action with the states and territories through the Health Chief Executives Forum (HCEF), the Disability Deputy Department Heads (DDH) and the Roadmap Implementation Governance Group for the National Roadmap for Improving the Health of People with Intellectual Disability.
5. In ongoing work towards enhancing the data related to the health of people with intellectual disability, the Centre and relevant government agencies should work together towards identifying data relating to the extent of need for support and sedation pathways, potential costs and cost savings from meeting that need, and the potential enhancement in the health and quality of life of people with disability.

Introduction

The National Centre of Excellence in Intellectual Disability Health (The Centre) led this Roundtable in collaboration with the Department of Health, Disability and Ageing (DHDA).

The Roundtable brought together some key community experts – people with intellectual disability, family members, clinicians, researchers and advocates –

along with representatives from key branches of DHDA. Roundtable participants are listed in the **Appendix**.

Roundtable facilitator Jim Simpson AO outlined the focus of the meeting on the support and sedation needed by many people with intellectual disability to assist them to accept health interventions that they find hard to understand. The Roundtable aimed to clearly identify the barriers and challenges to availability of support and sedation, and identify practical solutions and next steps to drive action across health services around Australia.

Expert speakers would give a baseline of the issues and some practical solutions that have been implemented in some parts of Australia.

Setting the scene

Nisette Anderson, Assistant Secretary, DHDA, gave an opening address. Ms Anderson acknowledged that current pathways for accessing supports and sedation are limited, and that this has a major impact on access to healthcare for many people with intellectual disability.

The Commonwealth, states and territories need to work together to address the barriers and enable implementation of solutions, including flexible, evidence-based models of support and sedation. This will be vital in addressing the serious health inequities experienced by people with intellectual disability.

A previous Roundtable on procedural support and sedation, chaired in July 2023 by the then Assistant Minister for Health and Aged Care, The Hon Ged Kearney MP, was an important start in identifying ways to address some of these issues. Ms Anderson acknowledged that there has been limited progress in response to the recommendations from that Roundtable. It was important to build on the previous discussions, and focus on enabling and implementing tangible

solutions. The Commonwealth and states and territories will need to provide leadership in this, and work together to support and drive action at the national, state and local levels.

Lived experience perspective

Ms Michelle Templeton, Acting Head of the Centre for Developmental Disability Health (CDDH) at Monash Health welcomed Ms Natasha Bazil and her son, Max Marley, who has intellectual disability. Ms Bazil spoke about being a mother to 3 autistic children, with Max being the eldest at 23 years. Ms Bazil highlighted that her children are her greatest achievements.

Ms Bazil discussed the barriers that she and her children experienced before the CDDH Disability Healthcare Access Service became available in 2021. Ms Bazil noted that finding safe healthcare was like walking into a maze and not knowing where to go. She described having to be a strong advocate for her children, and the many difficulties that she faced in navigating the health system with her sons.

Engaging with the Disability Healthcare Access Service at CCDH has been of great benefit to her and her children’s lives. Access to supports and sedation through the Disability Healthcare Access Service has enabled them to have multiple procedures done, giving her a sense of relief in being able to get insight into their health and healthcare needs, including more timely identification and treatment of health issues.

The spectrum of need from reasonable adjustments to general anaesthetics

Dr Jessica Smith, GP and Rehabilitation Physician at Adelaide Disability Medical Services, outlined the spectrum of need for supports and sedation among people with intellectual disability. It is important to consider options, not just medicines. We need to provide options ranging from avoiding sedation wherever possible, to providing it when needed.

Dr Smith outlined the model of care in the Inclusive Care Clinic project. This project began in 2023 as a research pilot project that focused on supporting delivery of blood tests and immunisations. The pilot included 16 adult participants with intellectual or developmental disability who had not been able to have any needle-based procedures.

The model started with 3 tiers:

- Tier 1 involved an occupational therapist providing a sensory assessment and adjusting the approach to suit the patient's needs.
- Tier 2 was a nurse-led sedation tier, with anaesthetic nurses involved to provide nitrous oxide in an outpatient setting.
- If tier 1 and tier 2 supports were unsuccessful, the patient was moved up to tier 3, which required an anaesthetist to provide deep sedation either in an outpatient setting or theatre.

Through the pilot project, Dr Smith and her team tried to build the least restrictive approach possible by using a multi-disciplinary team and looking at what sensory interventions and adjustments could be done before they escalated to using sedation. The objective was to develop a person centred and trauma informed model that balanced patient safety.

Since the project has moved from pilot to clinical implementation, the model has been updated to a 4-tier model with a dual governance approach; one for the procedure and care coordination by a disability physician, and one for the sedation by an anaesthetist. The Clinic is now advocating for specialist support due to the specialist conditions of some patients.

Disability Healthcare Access Service

Michelle Templeton is Senior Disability Nurse Consultant and Acting Head, Centre for Developmental Disability Health, Monash Health. Michelle told participants about the Disability Healthcare Access Service (DHAS) in Melbourne. DHAS is a nurse led service model. Referrals are assessed and triaged by nursing staff. DHAS commenced in 2019 with a 3-tier sedation support model aimed at providing the least restrictive method. The nurses involved in the initial assessment remain involved throughout the process, promoting continuity of care. This service facilitates blood tests, immunisations and health checks, and has expanded to include diagnostic imaging, dental care and specialised procedures. DHAS has its sedation clinic in a community health building with doctors on site.

There is a general assumption by both referring doctors and parents that a general anaesthetic will be needed. This often has a long wait list and is higher risk than less restrictive methods. Using a standardised screening tool, which can be done over the phone, has shown that usually a less restrictive method could work.

DHAS Support Levels

There are **4 levels of support** depending on what the person needs:

- **Tier 1** – Quiet space, calming techniques, mild medicine.
- **Tier 2 (Community)** – Moderate medicine and calming gas.
- **Tier 2 (Tertiary)** – Stronger medicine and calming gas.
- **Tier 3** – Full general anaesthetic.

Interventions range from immunisations, taking blood and physical health checks through to diagnostic imaging, electrocardiogram (ECG), dental care, ear check and clean, and cervical screening.

In the period since January 2023, 264 people with disability were supported in community settings with adaptations such as quiet spaces and a mild anxiolytic, 113 people in hospitals with sedation such as midazolam and 180 with general anaesthetics.

Despite not advertising this service, current waitlists are very long, indicating the high level of need for this service.

Hospital Avoidance for Blood Tests in Intellectual Disability Care

Bridget Farrell is Manager in the Specialist Intellectual Disability Health Team at the South Western Sydney Local Health District. Her team's project has developed community partnerships for blood collection in familiar settings such as schools and homes for children and young adults with severe disability and challenging behaviours. The model is a systematic, tiered pathway that has been co-designed with carers and providers. This project is a first of its kind, using community pathways recommended by the carers.

Efforts go into preparing a patient for blood collection such as the use of social stories, sensory tools and videos, with the carers very involved from planning to delivery.

Data to date indicates a high success rate for each of the non-hospital locations. Blood collection has been successful in 37 out of 44 attempts. No sedation has been required in 31.2% of cases.

This project now operates as business as usual in South Western Sydney and has recently been awarded the 2025 NSW Government Health Equity Award.

Discussion of barriers

Participants discussed a list of barriers to availability of appropriate support and sedation:

A) Broad systemic barriers

1. Lack of high-level mandate in state/territory health departments
2. Broad lack of awareness of best practice models of care
3. Federal/state division of responsibility
4. Health professional general skills/commitment regarding people with intellectual disability
5. Inadequate supply of specialist services/advice – Intellectual disability health services, disability liaison officers, special needs dentists
6. Barriers lower for children due to specialist paediatric services

B) Minimising the need for sedation

1. Inadequate positive behaviour intervention and support

2. Desensitisation availability

3. Requirements to attend unfamiliar and stressful environments

C) Primary health care barriers

1. General practice skills and time

2. Barriers to use of midazolam – College of Anaesthetists guidelines and potentially undue focus on risk of sedation versus risk of tests and procedures not being done

3. Funding models – disincentive to take the time needed

D) Public hospitals and general anaesthetics

1. Lack of dedicated general anaesthetics lists

2. Inadequate supply of dental lists

3. Cancellation of beds for elective anaesthetic lists

4. Availability of willing and skilled anaesthetists and anaesthetic nurses

5. Challenges in coordination of multiple procedures at one time

E) Private Hospitals

1. Cost

2. Willingness to accept people with intellectual disability

3. List culling for higher cost work

4. Inappropriate facilities

Roundtable participants reconfirmed that significant and persistent barriers are preventing equitable access to sedation and healthcare for people with intellectual disability. Participants highlighted widespread fragmentation across the health system, with poor coordination of services in both public and

private hospitals for complex patients. There is also a lack of referral pathways, or limited awareness of referral pathways where they exist. Services available were noted to be heavily metro-concentrated within tertiary facilities, leaving considerable gaps in access for those in regional and rural areas.

Systemic issues emerged as a major obstacle, including a lack of high-level mandates for local health districts to provide a tiered sedation pathway, and under-resourcing within hospitals. Participants cited uncertainty and inconsistency regarding responsibility for funding, particularly the intersecting roles of the Commonwealth, states and territories, local health districts, and the NDIS. Hospitals prioritise meeting KPIs, with theatres and outpatient clinics prioritised to bring down elective surgery waitlists. Procedural sedation bookings are therefore viewed as low value by hospitals.

The discussion covered the difficulty in meeting referral criteria, and insufficient clinical expertise in intellectual disability. A lack of specialist hubs further impedes access to sedation pathways. These challenges reinforce inequities in both primary and hospital-based care, limiting timely and appropriate interventions for people with intellectual disability.

Collectively, the barriers identified demonstrate a need for coordinated, system wide reform supported by strong leadership, clear accountability, and consistent models of care across jurisdictions.

Discussion on overcoming barriers

Participants discussed a range of potential solutions:

A) Broad systemic solutions

1. An authoritative national (or at least state) model of care including:

a. Individual needs assessment based on a screening tool

b. A tiered response

c. Recognising differences between children and adults

2. Top level leadership in state/territory health departments and districts

3. Clarify and resolve federal/state coordination of responsibilities

4. Training for health professionals in intellectual disability health, including regarding adjustments and sedation

5. Enhance supply of intellectual disability health services, disability liaison officers, special needs dentists

6. Health navigators

7. Electronic health records – Incorporation of adjustment needs and what has worked

8. Accessible information for people with intellectual disability and families, social stories

9. Discrimination complaints

10. Advocate for change.

B) Minimising the need for sedation

1. Better positive behaviour intervention and support

2. Increase availability of desensitisation

3. Reduce requirements to attend unfamiliar and stressful environments

C) Primary health care solutions

1. General practice skills and time

2. Address barriers to use of sedation – Enhance College of Anaesthetists guidelines, plus other potential steps

3. Enhance primary health funding models – long consultations, an intellectual disability incentive payment

4. A role for PHNs including the Primary Care Enhancement Program

Participants made a number of important points including:

- Population data is important to identifying need, estimating demand, and supporting strengthened advocacy.
- Continued data collection is critical to building an evidence base demonstrating the cost of inaction and the impact on quality of life outcomes.
- Improved models for people with intellectual disability would benefit wider populations including some autistic individuals. This broader population focus may help to demonstrate higher demand for services and strengthen collaborative advocacy efforts.
- Strong, experienced advocates are needed when engaging with the hospital system.
- Allowance is needed for variations across jurisdictions in clinical leadership and clinical pathways.
- We need person-centred, trauma-informed, person-driven models, with permanent resourcing and skilled, multidisciplinary staff.
- The need for a nationally endorsed model of care that is based on tiered sedation pathways (like those outlined above), includes workforce requirements and considers both metropolitan models and solutions for rural and regional areas.

- A dedicated team to coordinate sedation opportunities both within and across services is needed to enable multiple procedures to be bundled into one sedation episode.
- Coordination between physical and oral health services was also identified as critical to delivering holistic care.
- Better integration across primary and tertiary care is needed. Suggestions for improvement included providing GP incentive payments as well as appropriate resources, strengthening multidisciplinary teams, and exploring technologies such as virtual reality to support desensitisation. Increasing access through primary care settings was seen as essential.

Top priority action

Following the Roundtable, the facilitator liaised with clinicians who had attended the meeting, in relation to top priority action.

There was a strong consensus that the key priority focus should be on the roles of state/territory health agencies. They are the most key players and the ones where some models of excellent practice have been demonstrated. They should build on those models towards comprehensive statewide services providing graduated responses, from medication-free support through to general anaesthetics as a last resort.

Ingredients of a strong case to take to the state/territory agencies would be:

1. A nationally endorsed model of care based on the kinds of tiered options that were outlined in the presentations at the Roundtable. There was a high level of consistency in models that are currently working.
2. The best evidence that can be gathered on the extent of the need for a support and sedation pathway.

3. Guidance on how to cost appropriate services.
4. A recommended approach to evaluation.
5. Guidance for services on development of business cases for funding bids.
6. Case examples that emphasise the risks to individuals of not having support and sedation pathways and the human and financial gains of having pathways. This includes financial savings to health systems from enhanced preventive health care and early intervention on health problems.
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Next steps and recommendations

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4. In collaboration with the Centre, the DHDA should raise the importance of action with the states and territories through the Health Chief Executives Forum (HCEF), the Disability Deputy Department Heads (DDH) and the Roadmap Implementation Governance Group for the National Roadmap for Improving the Health of People with Intellectual Disability.

5. In ongoing work towards enhancing the data related to the health of people with intellectual disability, the Centre and relevant government agencies should work together towards identifying data relating to the extent of need for support and sedation pathways, potential costs and cost savings from meeting that need, and the potential enhancement in the health and quality of life of people with disability.

Appendix

Roundtable Meeting: Models of support and sedation for health care interventions for people with intellectual disability

Attendee List - Wednesday 4 February 2026

Agency/Organisation/Department	Name and Role
People with intellectual disability and family members	
Max Marley	Person with intellectual disability
Natasha Bazil	Parent Advocate
Dr Rebecca Kelly	Parent Advocate Chair, Down Syndrome Australia
National Centre of Excellence in Intellectual Disability Health (the Centre)	
Council for Intellectual Disability (CID)	Jim Simpson AO **(Meeting Facilitator)** Senior Advocate, Driving Change Team, Centre
CID	Simon Cotterell, Senior Advocate Driving Change Team
UNSW	Scientia Professor Julian Trollor AM Director, Centre (Consultant Psychiatrist)
Disability Representative Organisations	
South Australian Council on Intellectual Disability (SACID)	Jill Metcalfe Developmental Educator
Developmental Disability Western Australia	Trish Sullivan Chairperson and parent (Nurse and former senior health services manager)

Disability Health Services, Professional Colleges and Associations	
Adelaide Disability Medical Services	Dr Jessica Smith **(Presenter)** GP and Rehabilitation Physician Adelaide Disability Medical Services
Flinders University	Dr Flynn Slattery PhD, Respiratory Health
Australian and New Zealand Academy of Special Needs Dentistry	Dr Zanab Malik President (Specialist in Special Needs Dentistry)
Queensland Centre of Excellence, Intellectual Disability and Autism Health	Dr Cathy Franklin Director (Consultant psychiatrist)
Australian Association of Developmental Disability Medicine	Dr Alexis Berry President (Rehabilitation physician, Specialist Intellectual Disability Health Teams, Sydney and Northern Sydney Local Health Districts)
State and Territory Governments	
Monash Health	Michelle Templeton **(Presenter)** Senior Disability Nurse Consultant and A/Head Centre for Developmental Disability Health, Monash Health
South Western Sydney Local Health District	Bridget Farrell **(Presenter)** Manager Specialist Intellectual Disability Health Team South Western Sydney Local Health District
Department of Health, Disability and Ageing (DHDA)	
Access and Integration Branch (AIB), Primary Care Division	Nisette Anderson, Assistant Secretary
AIB, Primary Care Division	Professor Nick Lennox Senior Medical Advisor, Disability and Health
Priority Populations Section, AIB	Kat Davies, Director

Priority Populations Section, AIB	Judith Baker, Assistant Director
Priority Populations Section, AIB	Genevieve Johnsson, Assistant Director
Priority Populations Section, AIB	Rebecca Donnelly, Project Officer
Oral Health Section, AIB	Bec Sykes, Director

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