



Procedural support and sedation to facilitate access to health care for people with intellectual disability: Roundtable discussion with the Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP

Meeting Summary – Tuesday 25 July 2023

Background

The [National Roadmap for Improving the Health of People with Intellectual Disability](#) (the Roadmap) is overseen by the Roadmap Implementation Governance Group (RIGG). The RIGG has highlighted the need for better pathways to procedural sedation for people with intellectual disability so they can access the health care they need.

Some people with disability become so distressed when undergoing medical procedures (such as a blood test, vaccination, dental procedure or x-ray) that it is not safe for the procedure to be performed. In these situations, adjustments are required to accommodate the person's sensory, social and communication needs. These adjustments may include procedural sedation.

Current pathways to access procedural sedation are inconsistent and often only available at the discretion of individual health professionals. This issue is pervasive across all stages of life, with limited pathways in paediatric hospitals, and fewer services available for adults. The inability of people with intellectual disability to access the health care they need contributes to health care inequity within this population.

The Department of Health and Aged Care convened a roundtable on 25 July 2023, led by the Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP.

The roundtable provided opportunity to identify short- to medium-term actions to improve access to procedural support and sedation for people with disability.

The roundtable was attended by:

- people with disability
- families and carers of people with intellectual disability
- disability advocacy organisations
- disability support services
- professional colleges and associations

- specialist intellectual disability health services and medical practitioners, and
- government officials from the states, territories and Commonwealth.

This paper provides a summary of the roundtable and outlines recommendations from the group for further action.

Meeting Summary

The Assistant Minister for Health and Aged Care, the Hon Ged Kearney MP, opened the meeting and thanked the group for raising the issue of access to procedural sedation for people with intellectual disability. The Assistant Minister emphasised the serious health inequities people with intellectual disability face and noted her own experience as the sister of a person with intellectual disability. The Assistant Minister highlighted the investment by the Australian Government of \$43.3 million for actions under the Roadmap, including for a National Centre of Excellence in Intellectual Disability Health.

The Assistant Minister invited people with lived experience to speak to their health care experiences, including the importance of procedural support and sedation. Two participants with lived experience spoke to the importance of recognising patients as individuals with their own set of requirements. They spoke to reasonable adjustments such as:

- providing information in ways the patient can understand, by speaking in plain English, using Easy Read texts, or audio-visual resources, and
- planning for transport to and from the hospital (if required), admission practices, and pre-operative and post-operative practices.

People with intellectual disability have the right to be involved in and make decisions about their own health and care. These adjustments help them to access these rights.

A representative from the South Australian Intellectual Disability Health Service spoke about:

- people who may require procedural sedation
- pathways to access sedation in primary care and hospital settings, and
- the current challenges accessing procedural support and sedation.

Participants emphasised the importance of flexible service delivery models. While hospitals are better resourced for some forms of sedation, they do not commonly offer primary care services that may be required by the patient. There may also be difficulty in hospitals ensuring multiple health professionals can be involved to make best use of a single sedation. Some professions, such as dentistry, may struggle to receive visiting rights in a hospital setting. The group also highlighted the need for specialised training for healthcare workers to ensure people with intellectual disability get high-quality care.

A representative from the Australian and New Zealand College of Anaesthetists spoke about:

- the current procedural sedation safety guidelines, developed by the College¹,
- procedural sedation outside of hospital settings, and
- risk and safety considerations involved in decision-making.

Participants discussed the need to:

¹ ANZCA, 2022, [PG09\(G\)BP Guideline on procedural sedation background paper 2022](#)

- educate people with disability and their supporters of the risks associated with sedation, and
- raise health professionals' awareness of people with disability and their right to receive high-quality healthcare.

The Department of Health and Aged Care led a discussion on how to improve access to procedural support and sedation, and short and medium-term actions to achieve this for people that need it.

The Department committed to developing this summary and circulating it to participants. The Assistant Minister thanked participants for their contributions and closed the meeting.

Recommendations

Participants of the roundtable made the following recommendations:

1. Expand hospital-based Disability Liaison Officer (DLO) programs

Participants recommended DLO programs be established in states and territories where they are not currently operating.

Where DLO programs are already operational, participants recommended they should be expanded, including:

- their role in discussing the individual's needs for:
 - health services when being admitted to hospital (including primary care, preventive, dental and diagnostic services)
 - admission and discharge from hospital (including transport to and from the hospital)
 - pre-procedural and post-operative care, and
 - organising and communicating the patient's support needs with proceduralists and other health professionals.
- building strong relationships with health professionals, including surgeons and anaesthetists,
- ensuring clear communication of outcomes and discharge plans are provided to the patient's family and GP.

2. Improve awareness of pathways and services to access procedural support and sedation

Participants recommended that:

- GP awareness of DLO programs, where they exist, should be improved.
- dedicated Clinical Pathways (i.e. HealthPathways) should be established in each Primary Health Network region that cover local procedural sedation and support pathways for people with disability. This would assist with referrals and to communicate local solutions that can help people with disability access services in both primary care and hospital settings.
- each local health network should publicise a clinical pathway to access services (e.g. investigations) under sedation, including contact points. This would ensure people with disability, their families and supporters, as well as GPs can access information in order to activate the pathway when required.

3. Improve referral pathways to procedural support and sedation

Participants recommended that work be done to ensure people with intellectual disability their families and carers are aware that they are entitled to reasonable adjustments.

Awareness of pathways to access reasonable adjustments, including procedural sedation, should also be improved.

4. Establish more specialised and flexible service delivery models

Participants recommended that more flexible service delivery models are set up. There was discussion on the importance on delivering healthcare with low to moderate levels of sedation wherever possible, including in purpose-built clinics that can administer these forms of sedation.

There was a focus on service delivery outside of hospitals, including:

- specialised community/outpatient clinics, similar to the Centre for Developmental Disability Health in Victoria, and
- services in the home (including Hospital in the Home services run by hospitals).

5. Develop and promote widespread use of a screening tool to assess the procedural support and sedation needs of a patient

Participants recommended that a screening tool be developed for, and adopted by, those involved in administering sedation, including health professionals such as GPs. The tool should be used before every procedure to assess the person's needs, with outcomes to be documented and communicated back to the person's GP. Tools such as health passports should be used to ensure the person's needs can be communicated to other health professionals when required.

Using a screening tool before every procedure would provide an important opportunity for adjustments to be made. A person's requirements may change depending on the type of procedure and over the course of their life.

6. Improve training for health professionals

Participants emphasised the lack of training health professionals usually receive in working with people with intellectual disability. They recommended that health professionals have access to appropriate training to provide quality care for people with intellectual disability. Clinicians should be supported in GP practices and hospital settings through education programs and training to improve accessibility for people with intellectual disability, including through improved awareness of reasonable adjustments.

Training was also noted as important for health professionals working in outpatient clinics, community clinics and home services, as people with intellectual disability often find these settings more accessible than standard GP practices or hospital settings.

7. Improve access to operating theatre time

Operating theatres and hospitals are not set up to provide primary care services. This makes it difficult for people to get these types of services (e.g. immunisations and dental care) even if they are being admitted to theatre for surgery.

Participants recommended that access to operating theatres be made more flexible. It was noted that some hospitals cater to this better than others.

There was strong recognition that each jurisdiction has its own rules and resources available and that solutions should be localised and tailored to these capabilities. However, there was strong support for being opportunistic when people are already being admitted to hospital and put under sedation for more complex procedures. Centralised disability healthcare services, such as the SA Intellectual Disability Health Service, could assist services in their areas establish structures to facilitate this.

8. Improve awareness of, and access to, technology to support people with intellectual disability, their families and professionals to communicate

Participants noted how technology can be used to help people with intellectual disability, their families and carers to communicate.

Heath Passports hold key patient information in a format that can be shared efficiently with people with intellectual disability, their families, carers and health staff. This includes important medical information as well as reasonable adjustments needed for people.

Participants recommended that tools such as these should be utilised to:

- record patient outcomes to ensure that important data stays connected to the patient, and
- communicate any reasonable adjustments required for the person.

9. Ensure sufficient knowledge of low-level sedation safety requirements

Participants recommended ensuring there was increased GP awareness of guidelines for low-level sedation outside of hospital. These included the Australian and New Zealand College of Anaesthetists [PG09\(G\)BP Guideline on procedural sedation background paper 2022](#).