

Clinician Network & Oral Health Community of Practice
General Meeting Minutes
Advocacy - Systemic, service level, and family
Thursday 26th February 2026
1.00pm – 3.00pm AEDT

1. Welcome & Session Overview

- The meeting focused on advocacy from three perspectives and five presenters with The Network's Seeta Durvasula facilitating:
 1. Systemic advocacy: Sophie Howlett and Jim Simpson from The Centre's Driving Change team.
 2. Organisational/service advocacy: Alfred Health Disability Liaison Officer Alyce Jenkins.
 3. Family/parent advocacy: Dalal Baumgartner and Maria Heaton.

2. Advocacy at the System Level – Driving Change Team

Presenters: Sophie Howlett & Jim Simpson

2.1 About the Driving Change Team

- Lead advocacy for the National Centre of Excellence in Intellectual Disability Health.
- Team includes a Lead, 2 Senior Advocates, 2 Policy staff, and 2 people with lived experience.
- The team determines their advocacy priorities by using the following:
 - Driving Change Strategy
 - Driving Change Engagement plan
 - Prioritisation matrix (assesses priority, timeliness, feasibility, media interest, alignment with strategy, etc.).
- Priority review moving from 6-monthly to annual cycle for better continuity.

2.2 Current Advocacy Priorities (10 areas)

1. **Health professional education** – mandated training, capability framework rollout, CPD supports.
2. **Commitment to National Roadmap implementation** – short/medium/long-term- government commitment.
3. **Building systemic advocacy capacity across Australia** – currently funded around state/territory election cycles. This may change in the future.
4. **Improved data collection** – focus on a **disability identifier**.
5. **Health rights** – unconscious bias, discrimination, social determinants, NDIS–health interface.

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6. **Inclusion of people with ID in major health reforms** – e.g., National Health Reform Agreement, Oral Health Plan.
7. **Adaptations & supports** – e.g., sedation pathways (Jim to expand).
8. **Primary care & preventative health** – annual health assessments, CHAP, MyMedicare continuity of care.
9. **Oral health** – embedded across priorities.
10. **Health of people with Intellectual Disability in the justice system.**

2.3 Examples of Successful Advocacy (Jim Simpson)

Long-term systemic change in NSW

- 25+ years of work pushing for Intellectual Disability health specialists alongside mainstream services.
- Led to establishment of Intellectual Disability Health Teams from 2010 onward.
- Ongoing efforts for further expansion (budget bid; possible pre-election campaign for 2027).

National Roadmap

- Result of sustained advocacy culminating in engagement with federal ministers and advisors.
- Roadmap produced with strong bureaucratic leadership (e.g., Simon Cotterell, Senior Advocate in Driving Change team, former Fed Govt Assistant Secretary for Health).
- Concrete achievements:
 - Primary Care Enhancement Program
 - Capability framework for university health curriculum
 - National Centre of Excellence in Intellectual Disability Health funding

Effective strategies highlighted

- Combining research evidence + lived experience
- Building broad coalitions – professional colleges, DPOs, universities.
- Careful planning for ministerial meetings – clarity, brevity, strategic sequencing.
- Persistence; knowing when to pause and when to escalate.

2.4 Current Issues Under Active Advocacy

Reform of National Safety & Quality Health Service (NSQHS) Standards

- No existing reference to intellectual disability.
- Centre pushing for meaningful inclusion in revised standards.
- Expectation that draft standards may fall short → likely need for focused advocacy campaign.

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Sedation Pathways & Support for People with High Anxiety/Procedural Distress

- Significant unmet need nationally.
- Monash Health model recognised as exemplary (serving hundreds annually).
- Aim: secure development of similar models across all health districts.
- Planned engagement with paediatric and adult specialists.

2.5 Working with the Clinician Network

- Driving Change team to provide opportunities for clinicians to:
 - Input to advocacy priority reviews
 - Join working groups or expert lists
 - Share models, case examples, success stories
- Clinicians encouraged to be advocates within their own organisations.

3. Advocacy at the Service Level – Disability Liaison Officers (DLOs)

Presenter: Alyce Jenkins

3.1 Overview of the DLO Program (Victoria)

- Established during COVID; now permanent across ~20 metro/regional health services.
- Eligibility broad – no requirement for formal diagnosis, NDIS registration, or age limitations.
- Work includes both direct clinical coordination and systems-level improvement.

3.2 Key Functions

Clinical support

- Support during ED, ICU, OPD, surgery, rehab and inpatient care.
- Sensory/communication supports, disability care plans.
- Coordination with other services and DLOs (statewide network).
- Liaison to improve accessibility (equipment, scheduling, care coordination).

Non-clinical/systemic work

- Staff education & disability awareness.
- Representation on steering groups, committees.
- Quality improvement and co-designed resources.
- Development of social scripts, easy-English materials, accessible information.

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4. Advocacy from Parents

Dalal Baumgartner (SATB2 Connect) and Maria Heaton (Nurse, Carer, Advocate).

Both Dalal and Maria shared their emotional journey and challenges within the healthcare system being parent advocates for their children with intellectual disability.

5. Closing

- Summary notes, presentation slides, and shared resources will be circulated.
- Contact details for speakers to be distributed where permission is given.
- Feedback form to be sent.
- Strong interest expressed by clinicians in participating in future advocacy initiatives.

Recommended Actions

For the Driving Change / Clinician Network teams at The Centre

- Provide network members with opt-in options for advocacy working groups.
- Invite Steering Committees of the Clinician Network and Oral Health Community of Practice to contribute to the next annual advocacy priority review.
- Facilitate follow-up on sedation pathway project, including paediatric perspectives.

For Clinicians

- Engage with offered advocacy modules and training materials.
- Integrate lived experience stories into team education sessions.
- Review local sedation, accessibility, and communication support pathways.
- Promote culture of addressing patients with disability directly, not only through carers.

For Services / Organisations

- Consider local replication of DLO models and shared resources (social scripts, easy-English docs).
- Review organisational readiness to support disability adjustments and care plans.
- Engage families early in service design and quality improvement.

For the Clinician Network Team

- Collate and distribute:
 - Slides

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- Shared resources/links from chat
- Speaker contacts
- Summary notes (this document)

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