

Queensland Roundtable

Driving Change: Better Health for People with Intellectual Disability



Summary Report Queensland Roundtable Driving Change: Better Health for People with Intellectual Disability



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1. Executive Summary

People with intellectual disability experience significantly poorer health outcomes than the general population despite many of these outcomes being preventable. Around 560,000 Australians have intellectual disability. They die on average 27 years earlier than the general population, are more than twice as likely to die a potentially avoidable death and are admitted to hospital at twice the rate and at twice the cost.

The Queensland Roundtable *Driving Change: Better Health for People with Intellectual Disability* was convened on 12 June 2026 and brought together people with intellectual disability, families, clinicians, researchers, health services, advocacy organisations and government representatives to identify practical actions that can improve health outcomes and strengthen Queensland's health system.

Across the Roundtable there was strong consensus that while important reforms are underway, people with intellectual disability continue to experience significant barriers to equitable healthcare. These include fragmented services, inconsistent recognition of reasonable adjustments, limited workforce capability, poor visibility within health data systems, and insufficient specialist pathways for people with complex needs. The consequences were set out starkly in December 2025, when the Office of the Health Ombudsman reported on the death of Mr Stewart Kelly at Robina Hospital, made 18 recommendations to Gold Coast Hospital and Health Service, and noted that the learnings would be raised with Queensland Health.

The discussions identified five priority areas for reform:

1. People with intellectual disability must be visible and counted within the health system through consistent disability identifiers, communication support information and improved health data.
2. Reasonable adjustments should become standard practice throughout the healthcare journey and embedded within routine clinical care.
3. Consumer and workforce capability must be strengthened through mandatory education, lived experience leadership and ongoing professional development.
4. Specialist intellectual disability pathways should provide timely access to coordinated care, specialist expertise and improved transitions across health, disability and community services.

5. Strong partnerships, governance and accountability are needed to implement outstanding recommendations from the Disability Royal Commission and the National Roadmap for Improving the Health of People with Intellectual Disability.

Together these reforms provide an opportunity for Queensland Health to improve equity, safety and health outcomes while delivering a more coordinated, person-centred and accountable health system. The Roundtable identified immediate actions that could commence within 100 days alongside longer-term reforms to be achieved by 2028, set out in Section 5.

There are three actions that could commence immediately which includes: establish a statewide working group on disability identifiers; commence work to identify a pathway to mandatory disability awareness training across the public, primary and private health systems; and identify actions to require each Hospital and Health Service and Primary Health Network to publish a Disability Service Plan. Each builds on existing national and Queensland policy commitments and each can begin within existing structures.

Background:

Queenslanders with Disability Network (QDN), the National Centre of Excellence in Intellectual Disability Health and Queensland Centre of Excellence in Intellectual Disability and Autism Health worked together to deliver the Queensland Roundtable – Driving Change: Better Health for People with Intellectual Disability.

The Queensland Roundtable was held on 12 June 2026 and brought together 75 people with intellectual disability, families, and key decision makers including experts and professionals from health, disability, and advocacy organisations.

The Roundtable focused on what is happening now in Queensland across health and disability and about what has changed since the Disability Royal Commission and the National Roadmap for Improving the Health of People with Intellectual Disability. It included information about new research and ideas as well as what is working well and ideas for what needs to change and how.

This built upon the previous Queensland roundtable that was held on 22 March 2019, which was hosted by QDN, Office of the Public Advocate (OPA), Queensland Centre for Intellectual and Developmental Disability (QCIDD), ICAN! – Institute for the Clinical Advancement of Neuroplasticity, and was supported by Australian Society for Intellectual Disability, Queensland Division (ASID).

2. Why action is needed

The population

Over 560,000 people in Australia have intellectual disability. Including their families, that is over two million Australians.

Stark and costly health inequalities

People with intellectual disability (ID) comprise ~2% of the Australian population yet they experience profound, unmitigated health inequities. This inequity arises not from intellectual disability itself, but from entrenched structural barriers across policy, service design and access to care. Compared with the general population, people with intellectual disability experience:

- Premature death, on average 27 years earlier than the general population.
- Over twice the rate of avoidable deaths.
- Twice the rate of emergency department and hospital admissions.
- Hospital admissions costing twice as much.
- Higher rates of physical and mental health conditions.
- Lower rates of preventative healthcare.

A Queensland Case

In December 2025, the Office of the Health Ombudsman reported on the care of Mr Stewart Kelly, a Queensland man with intellectual disability and autism who died at Robina Hospital in August 2022. It found inadequate staff training, policies that did not account for his needs, failure to make reasonable adjustments, diagnostic overshadowing, and failure to act on his family's escalation under Ryan's Rule. Its 18 recommendations align closely with the priorities at Section 5, and the Ombudsman noted the learnings would be raised with Queensland Health.

The policy and system context

Addressing systemic barriers sits within commitments Queensland has already made and reform programs already underway. The Disability Royal Commission (DRC) found that “people with cognitive disability have been, and continue to be, subject to systemic neglect in the Australian health system”, resulting in people receiving poor care, the wrong care or no care and contributing to poor health outcomes, trauma and distress. Work around DRC recommendations related to health and intellectual disability are ongoing. The National Roadmap for Improving the Health of People with Intellectual Disability provides the agreed

national framework for that work and for Queensland's contribution to it with again progress made in some actions and areas whilst others still remain outstanding.

At the same time, the health and support needs of people with intellectual disability are becoming increasingly complex. Queensland's mental health reforms and digital health reforms, including the single digital patient record, each create an opportunity to embed disability identification, communication information and reasonable adjustments into routine practice while those systems are being designed, rather than retrofitting them later at greater cost. Taken together, the recommendations in this report align with, and would accelerate, the Queensland Health reform agenda.

3. What we heard

From the speakers

The Roundtable focused on three main themes:

1. Improving health care experiences including hospitals and healthcare people use in the community like GPs and local health services.
2. Better models of care.
3. Building a stronger workforce

Key Themes from the Speaker Presentations

The following summary sets out key themes from speaker presentations. A more detailed summary of speakers and key points is provided at Attachment 1, and the agenda for the day at Appendix 2.

1. People with intellectual disability must be at the centre of their healthcare, visible and counted

Across all presentations, speakers reinforced that people with intellectual disability must be recognised as active participants in their own healthcare. This includes listening directly to people with intellectual disability, recognising the rights of non-speaking people to be heard through appropriate communication supports, and involving people with lived experience in the design, delivery and evaluation of health services.

2. The health system must become more accessible, coordinated and responsive

Speakers consistently highlighted that people with intellectual disability continue to experience fragmented and difficult-to-navigate health systems. Better coordination between health and disability services, clearer clinical pathways, improved transitions between services and greater continuity of care are needed to reduce barriers and improve health outcomes. The challenges at the interface with other systems, particularly the NDIS, were highlighted.

3. Building a capable workforce and specialist supports is essential

Improving health outcomes requires both a more capable mainstream workforce and access to specialist intellectual disability expertise. Presentations highlighted the need for mandatory disability capability training, specialist clinical pathways, disability nurse navigators, improved access to oral health and mental health services, and better support for complex care needs.

4. Better data and system capability are critical to driving reform

Speakers highlighted the importance of being able to identify people with intellectual disability within health systems to enable reasonable adjustments, improve continuity of care and measure health outcomes. Better data, consistent disability identifiers and stronger evidence are essential to informing policy, monitoring inequities and supporting implementation of national and state reforms.

5. Sustained leadership, partnership and accountability are needed to deliver change

While significant work is underway through national initiatives, Queensland reforms and local service improvements, speakers agreed that meaningful change requires continued collaboration between governments, health services, people with intellectual disability, families, carers and advocacy organisations. Implementing outstanding recommendations from the Disability Royal Commission, the National Roadmap for Improving the Health of People with Intellectual Disability and other key reform initiatives will require clear leadership, shared accountability and ongoing partnership.

Key Steps Needed Going Forward

- Professor Julian Trollor FAHMS, AM

- Dr Cathy Franklin

Following the two rounds of table discussion, Professor Trollor and Dr Franklin reflected on what they had heard and on the opportunities that exist to improve outcomes for people with intellectual disability in Queensland.

Key points of reflection included:

- Queensland has made real progress and there is excellent work underway, but much more remains to be done
- Awareness of, and a formal voice for non-speaking people must be built across the health system, with communication partners formally recognised and documented.
- A major gap exists in specialist intellectual disability health services. Tiered sedation and procedural support pathways are needed so that people with intellectual disability can access diagnostics and treatment safely.
- Better data is needed, including a reliable means of identifying people with intellectual disability within the health information systems, so that inequities can be measured and reform monitored.
- Queensland Health's 'See Me, Hear Me, Respect Me' campaign should be extended and embedded in routine practice.
- Peer navigator roles should be introduced across all parts of the healthcare system, not only in acute care.
- Oral health services for people with intellectual disability should be expanded and actively promoted, as poor oral health remains a persistent and avoidable driver of ill health.

4. What we heard – from the Roundtable participants

Overall, the key message was that people with intellectual disability need to be seen, be heard and be counted.

The Roundtable facilitated two rounds of questions in response to the following:

- In round one, attendees were asked to discuss what are two or three things Queensland could do in the next 100 days that would make a real difference now.
- Round two focused what is one big change Queensland should aim to achieve by 2028 to create a health system that is more connected, more inclusive, easier to use and more accountable for people with intellectual disability?

Five key themes we heard from the people at the Roundtable:

1. Data is key - People with intellectual disability must be visible and counted in the health system.
2. Reasonable adjustments need to become standard practice across the patient's healthcare journey.
3. Building consumer and workforce capability to deliver inclusive healthcare.
4. Developing specialist intellectual disability health pathways.
5. Strengthening partnerships, leadership and accountability for system reform.

1. Data is key - people with intellectual disability must be visible and counted in the health system.

People with intellectual disability are often invisible within health data systems, making it difficult to identify health inequities, plan services and measure outcomes. The Roundtable identified the need for consistent disability identifiers, communication profiles and reasonable adjustment information to be embedded within patient records. Better data will support person-centred care, reduce the need for people to repeatedly explain their circumstances, and enable Queensland Health to monitor health outcomes, evaluate reforms and plan services based on evidence.

Participants at the Roundtable identified the importance of statewide disability identifiers noting the challenges of the multiple different reporting/recording data systems that are used across Queensland Health and primary health care. Participants identified the following as critical areas where people needed to be counted and/or identifiers put in place:

- Intellectual disability identifiers
- Communication support identifiers
- Reasonable adjustment flags
- Integrated patient profiles
- Identifier if person has Julian's Key or another person-centred patient information tool that requires clinicians/health professionals to review as part of their delivery of care.

In relation to how outcomes are reported and measured, participants identified the importance of patient-reported experience and outcome measures (PREMS and PROMS). People with intellectual disability need accessible ways to contribute to these data sets, and the resulting information needs to be provided back to patients in accessible formats such as Easy Read.

2. Reasonable adjustments need to become standard practice across the patient's healthcare journey.

Reasonable adjustments need to be recognised as a core component of safe, equitable healthcare rather than individual exceptions. Participants highlighted the need for consistent approaches across all stages of care—from accessing services and attending appointments through to assessment, treatment, discharge and follow-up. Embedding reasonable adjustments into clinical practice, supported by documented adjustment plans and clear pathways, will improve patient experience, safety and health outcomes.

Participants at the Roundtable identified key areas of reasonable adjustments that need to become a standard part of clinical care and be clearly documented on individual patient records. These include:

- Communication supports
- Sensory supports
- Information provided by Queensland Health, Primary Health Networks and Hospital and Health Services in formats that are accessible for people with intellectual disability, such as Easy Read.
- Outpatient appointments with accessibility and reasonable adjustment measures built in as business as usual
- Reasonable adjustment plans for pathology and sedation pathways.
- Resolving the issue of 'concurrent supports' across the NDIS/Queensland Health interface to enable people with intellectual disability to be able to have a support worker with them in hospital to support their disability needs.
- Access to additional supports in clinical settings that may include support person and/or disability liaison, nurse navigators, peer support or advocacy.

3. Building consumer and workforce capability to deliver inclusive healthcare.

A capable and confident workforce is fundamental to improving health outcomes for people with intellectual disability. Alongside this, a capable and confident health consumer with intellectual disability who has information, knowledge and skills in navigating the health system is equally important. Participants consistently identified the need for disability capability to be embedded across undergraduate education, professional development and ongoing workforce training. This includes strengthening communication skills, understanding reasonable adjustments, working in partnership with people with intellectual

disability and their supporters, and increasing opportunities for education to be co-designed and co-delivered by people with lived experience.

This aligns with the National Centre of Excellence in Intellectual Disability Health's Position Statement on health workforce education and training to support people with intellectual disability (February 2026) and the Intellectual Disability Health Capability Framework (2025), which set out the capabilities every health professional requires.

Participants identified the following key areas:

- Need for mandatory training in disability awareness for healthcare staff across acute, sub-acute, primary health settings across public and private health systems including the already developed resources such as Easy Health and “See Me, Hear Me Respect Me” training.
- Intellectual disability to be included in university and medical colleges content to build clinical capability.
- Opportunities to link specific requirements for procurement that build in demonstration by businesses including Private Health facilities procuring for Queensland Health contracts that they deliver disability awareness training to their staff and they have disability action plans in place.
- Co-design and delivery of learning and development and training by people with intellectual disability and their family/carers who are their communication partners.
- Build knowledge and skills of workforce in NDIS and housing pathways including for people who are clinically well and discharge delayed.
- Skills based training in reasonable adjustments and other key areas like restrictive practices.
- Participants identified that people with intellectual disability need to understand what their rights are across the health system including specifically around reasonable adjustments, how they can ask for reasonable adjustments and what they can expect in how this will be managed by the hospital and health service or primary care provider. People with intellectual disability also need information about health passport information like Julian’s Key so they are informed and can have their own health and disability support information available to share with healthcare staff.

4. Developing specialist intellectual disability health pathways.

Roundtable participants acknowledged that mainstream health services need to be equipped and delivering inclusive care for people with intellectual disability and this is an important focus. However, alongside this, it was also identified that patients with intellectual disability also require specialist expertise and specialist pathways for the right care in the right place at the right time.

The National Centre's scoping review, Australian models of health care for people with intellectual disability (2025), documents the models currently operating across Australia and the evidence supporting them, and provides a basis for identifying which models Queensland should adopt or expand.

The roundtable identified the need for

- Specialist pathways that improve access to diagnostics, oral health, mental health, sedation services and complex care, supported by disability liaison roles, peer navigators, nurse navigators and multidisciplinary models of care.
- Disability liaison, peer navigator, advocacy and nurse navigator roles, which are critical when people experience service gaps or difficulties with care delivered, to help them navigate their way to safe, accessible and inclusive care.
- Specialised intellectual disability health care teams.
- A sedation care model that provides tiered options, access to the right equipment and appropriate referral pathways for GPs and specialists.
- Clinical prioritisation pathways for people with intellectual disability with direct referral where the community or primary care pathway is not suitable.
- Staff with expertise in working with people with intellectual disability across a broad range of roles, including specialist roles such as anaesthetists.
- Outreach pathways alongside Hospital in the Home that deliver important options for safe and accessible care for some people with intellectual disability.
- Specialist pathways addressing the needs of people with intellectual disability in contact with the criminal justice system. These pathways should strengthen connections between primary care, hospitals and community services to provide more coordinated and timely support.

Two roundtable reports address this issue directly: the national Roundtable on procedural support and sedation for people with disability (Department of Health, 2023) and the Centre's Roundtable Report: Models of support and sedation for health care interventions for people with intellectual disability (July 2026).

5. Strengthening partnerships, leadership and accountability for system reform.

Sustainable improvement requires genuine partnership with people with intellectual disability, families, carers, advocacy organisations and the broader health sector. Participants highlighted the importance of embedding lived experience in governance, co-design, service planning and evaluation, while strengthening accountability through measurable outcomes, transparent reporting and implementation of outstanding recommendations from the Disability Royal Commission and the National Roadmap for Improving the Health of People with Intellectual Disability.

Strong partnerships and clear accountability mechanisms are essential to ensuring reform translates into improved experiences and health outcomes. Key areas highlighted in regard to governance included people with intellectual disability and their families/carers/communication partners to be part of Governance arrangements in Hospital and Health Services, Primary Health Networks and advisory mechanisms that ensure people including people who are non-speaking have a voice at the table.

Monitoring and evaluation of services from the perspective of people with intellectual disability was also identified as key issue including how and when people with intellectual disability are part of the monitoring and evaluation team. This could include key areas like looking at how Julian's Key, CHAP or Rare Voices Toolkit is implemented as well as reasonable adjustments and models of care and clinical pathways.

5. Key Recommendations

Participants were asked to identify key actions that could be implemented in 100 days as well as by 2028. A critical part of the planning, design, delivery and evaluation of these actions is to work WITH people with intellectual disability in co-design and engagement processes.

Based upon the discussions and key actions identified by participants at the Roundtable (see Appendix 3) the following key recommendations are provided across the five thematic areas:

1. Data

1.1 Develop consistent statewide identifier that enables key information for:

- Intellectual disability identifiers
- Communication support identifiers including who the communication support person is and how they assist/support the person in their healthcare journey.
- Reasonable adjustment flags, with capacity to upload adjustment information in varying formats.
- Integrated patient profiles
- Identifier if person has Julian's Key or another person-centred patient information tool that requires clinicians/health professionals to review as part of their delivery of care.

Example of Universal digital identifier

Level 1 – Disability

Level 2 – Intellectual disability

Level 3 – Communication disability

Level 4 – Rare disease (complexity)

- 1.2 Establish reporting that measures health outcomes, monitors health inequities and tracks service utilisation by people with intellectual disability
- 1.3 Develop accessible ways for people with intellectual disability to contribute to PREMS and PROMS data and for this to then be shared in accessible ways to close feedback loop.

2. Reasonable adjustments

- 2.1 Development of a Reasonable Adjustment Framework that delivers health services that identify, record, implement and review reasonable adjustments as standard part of care. The Reasonable Adjustment Framework to include:
 - 2.1.1 Patient Journey mapping to identify key steps of patient journey for touch points for identification/implementation of reasonable adjustments in acute and primary health care.
 - 2.1.2 The patient data schema across public and private primary, acute, sub-acute and community settings is developed to record and flag reasonable adjustments in a systematic way. The system needs to ensure at each point of the journey reasonable adjustments are asked about, delivered and checked with the patient (and their support person, carer or communication partner) for satisfaction after delivery.
- 2.2 Clinical care and documented plans for reasonable adjustments (plan on a page through individual health passports) are in place for individual patient records that includes communication supports, sensory supports, information formats, pathology and sedation pathways, appointment flexibility, longer consultations, accessible information, environmental adjustments, disability supports, disability liaison, navigation or advocacy.
- 2.3 Ensure resources and documents are in accessible and easy read formats.

3. Consumer and workforce capability

- 3.1 Deliver mandatory requirements for disability awareness training for all employees of Queensland Health, Primary Health Networks and private health providers, commencing with a staged rollout focused on frontline staff. Existing resources such as EASY Health can be utilised and building further on the See Me, Hear Me, Respect Me training modules.
- 3.2 Develop and deliver specific skills-based training for clinical and frontline staff using See Me, Hear Me, Respect Me framework that includes key areas like conscious and unconscious bias, reasonable adjustments and restrictive practices.
- 3.3 Review “Know your rights in healthcare” resource that was developed by QDN and Health Consumers Queensland in COVID-19 to deliver universal suite of resources

for patients with disability including specific resources for people with intellectual disability across key areas identified including reasonable adjustments and specialist intellectual disability pathways of care.

- 3.4 Develop state-wide mechanisms that ensures consistent implementation of reasonable adjustments to ensure that at each touch point on patient journey, healthcare staff and volunteers deliver patient care that asks, delivers and reviews reasonable adjustments where required.
- 3.5 Continue work through National Centre of Excellence in Intellectual Disability Health with universities, colleges and clinical peak bodies to include content about people with intellectual disability in courses and professional development, consistent with the Centre's Position Statement on health workforce education and training (2026) and the Intellectual Disability Health Capability Framework (2025).
- 3.6 Develop an awareness campaign for people with disability as health consumers as well as healthcare workforce in regard to non-speaking people to build capacity and ensure they have a formal identity and tailored specialist support within health system.
- 3.7 Identify key roles in health system workforce for workshops in working with people with intellectual disability around 'My Housing Options Toolkit' to support people in their development of housing plans to support effective transitions and discharge from hospital care.
- 3.8 Develop an intellectual disability workforce development strategy that can be integrated with Queensland Health Workforce Strategy, including building workforce knowledge of the NDIS, particularly for new staff, to meet the challenges of staff turnover.

4. Specialist intellectual disability pathways

- 4.1 Develop statewide clinical pathways for people with intellectual disability requiring:

- pathology and diagnostic procedures
- sedation and anaesthetic services
- complex investigations which may involve multiple appointments, specialist equipment, being required to remain still, invasive procedures, unfamiliar environments and communication barriers
- mental health assessment and treatment
- oral health care.

These pathways should include tiered models of care, desensitisation approaches where appropriate, appropriate equipment and clear referral pathways from both primary care and specialist services.

- 4.2 Establish and expand specialist intellectual disability support across Hospital and Health Services that includes intellectual disability liaison roles, peer workers and specialist nurse navigator functions.
- 4.3 Expand specialist intellectual disability health services across Queensland including Intellectual and Developmental Disability Mental Health (IDDMH) teams, outreach services, Hospital in the Home options and specialised primary healthcare teams to improve access and reduce avoidable hospital admissions.
- 4.4 Develop clinical prioritisation pathway that enables direct access to diagnostics, imaging and specialist services where community pathways are not appropriate for people with intellectual disability.
- 4.5 Establish peer navigator and advocacy pathways to support people with intellectual disability before, during and after episodes of care, particularly for people with complex needs or where barriers to accessing care exist, including people with intellectual disability in contact with the justice system.
- 4.6 Expand and promote access to oral health services for people with intellectual disability. This should include clear and accessible public information about how to access public oral health services, prioritised access for people who require sedation or desensitisation support, and appointment models that allow adequate time and reasonable adjustments.

5. Partnerships, monitoring and systems leadership

- 5.1 Each Hospital and Health Service and Primary Health Network in Queensland to have a Disability Service Plan which is published and publicly available and reported on progress each year as best practice.
- 5.2 Use procurement and contracting mechanisms to require private hospitals delivering services on behalf of Queensland Health to develop and implement a Disability Service Plan and provide relevant employees with training in intellectual disability health.
- 5.3 Development of a 'how to guide' for the development of disability service plans including templates etc for health context.
- 5.4 Inclusion of people with intellectual disability in roles within hospital and health services as co-designers, peer workers, educators, researchers, consumer engagement and Governance roles.
- 5.5 Work with Primary Health Networks (PHN) to include people with intellectual disability as a specific priority population within their needs assessments and commissioning strategies.
- 5.6 Identify accessibility audits and reviews as part of continuous improvement processes, informed by PREMS and PROMS data from the perspective of people with intellectual disability.
- 5.7 Develop a statewide Communication Support Framework to ensure people with intellectual disability who communicate non-verbally or use alternative and augmentative communication have their communication needs identified and

documented, and that trusted communication partners are recognised and appropriately involved in supporting communication, understanding and decision-making throughout clinical care.

- 5.8 Develop a System Interface Plan for disability, health and NDIS across those key Government agencies that includes priority actions including resolving concurrent supports across NDIS and Queensland Health, housing pathways using resources such as My Housing Options and coordinated support for people in contact with the justice system.
- 5.9 Explore the establishment of a Disability Clinical Network and integration with Queensland Health structures for clinical governance.
- 5.10 Identify options to use Queensland Health procurement and contracting mechanisms to incentivise and recognise progress against priority disability inclusion actions, including implementation of intellectual disability health training, Disability Service Plans and other agreed performance measures. This could include incorporating relevant KPIs, deliverables and reporting requirements into procurement evaluations, contracts and contract performance reviews.

Snapshot of key actions - implementation roadmap

Priority area	100 day actions	System reform priorities by 2028
1. People with intellectual disability must be visible and counted	Establish statewide working group on disability identifiers including working with Gold Coast HHS and the learnings from its response to the office of the Health Ombudsman's Robina Hospital investigation (December 2025). Identify minimum data set Establish working group around accessible PREMs and PROMs.	Implement statewide disability identifier across QH. Integrate communication profiles and reasonable adjustment flags into patient records. Use data to monitor outcomes, equity and service utilisation. Implement education awareness campaign about communication supporters.
2. Reasonable adjustments become standard practice	Scope work to develop a Queensland Reasonable Adjustment Framework Undertaken engagement and co-design with people with intellectual disability and their families to map the patient journey Review and identify priority resources for Easy Read accessibility.	Develop a Queensland Reasonable Adjustment Framework Embed framework as standard practice across services. Implement electronic reasonable adjustment plans linking with work occurring in Julian's Key. Undertake monitoring and review of implementation.
3. Build consumer and workforce capability	Explore options for mandatory training using existing resources at point of induction	Implement co-designed education delivered by

	as employees of public, primary and private health systems. Review and update “Know Your Rights In Healthcare” resources.	people with intellectual disability. Build peer workforce of people with intellectual disability Embed intellectual disability into undergraduate education and professional development.
4. Develop specialist intellectual disability pathways	Map existing specialist services Commence work on co-designing statewide pathways for sedation and complex diagnostics. Identify priority HHSs for pilot. Begin co-design of an accessible public resource on how to access public oral health services.	Implement statewide specialist pathways Expand MH-IDD teams and specialised intellectual disability primary care teams statewide. Establish tiered sedation and procedural support pathways in every Hospital and Health Service.
5. Partnerships, monitoring and systems leadership	Establish working group for Systems Interface Plan Identify resources required and commence development of suite to support development of Disability Service Plans for HHSs and PHNs.	Deliver Systems Interface Plan across disability, health and NDIS Disability Services Plans in place across all HHSs and PHNs Establish Statewide Clinical Network for Disability Embed people with intellectual disability into governance, co-design and evaluation. Annual reporting across KPIs using data identifiers and

		framework established as part of priority area 1.
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Proposed lead and supporting agencies (for confirmation by Queensland Health)

Priority 1 – Data: Lead – Queensland Health (Digital Health and Data). Support – Hospital and Health Services, Primary Health Networks, QCEIDAH, QDN.

Priority 2 – Reasonable adjustments: Lead – Clinical Excellence Queensland. Support – Hospital and Health Services, QDN, Health Consumers Queensland.

Priority 3 – Consumer and workforce capability: Lead – Queensland Health (Workforce Strategy). Support – National Centre of Excellence in Intellectual Disability Health, QCEIDAH, universities and clinical colleges, QDN.

Priority 4 – Specialist pathways: Lead – Clinical Excellence Queensland with QCEIDAH. Support – Hospital and Health Services, Oral Health Services, Primary Health Networks.

Priority 5 – Partnerships and accountability: Lead – Queensland Health (Strategy, Policy and Reform Division). Support – Department of Families, Seniors, Disability Services and Child Safety; NDIA; QDN; Hospital and Health Service boards.

Appendix 1 – Summary of panels and key note speaker presentation points

Roundtable Panels and Key Note Speakers

The format for the Roundtable included two panels – one panel of people with lived experience of intellectual disability, and one panel of health professionals across primary, acute and service system perspectives - as well as key note addresses from Professor Julian Trollor and Dr Cathy Franklin.

Panel 1: Personal Perspectives from People with Lived Experience

- Gillian Gerhke, lived experience advocate
- Darryl Steff, CEO Down Syndrome Australia
- Donna Best, lived experience advocate
- Aunty Semah Mokak-Wischki, carer and disability advocate

The attendees spoke about their experiences with the health system including the importance of how the voice of non-speaking people is seen, heard and included and the important role that communication partners (who are often family members or carers) have in supporting non-speaking people with intellectual disability. The panel also discussed the importance of having people with lived experience being involved in decision making and being part of the process of improving health care for people with intellectual disability in hospital settings. Oral and dental healthcare for people with intellectual disability was also highlighted as a key issue.

Key Notes:

National Perspectives on Driving Change – Professor Julian Trollor FAHMS, AM, Director, National Centre of Excellence in Intellectual Disability Health

Professor Trollor highlighted the work that was being undertaken by the National Centre of Excellence for Intellectual Disability Health, what has been improved and what needs to be done to improve intellectual disability health across Australia. This included the implementation of recommendations from the National Roadmap for Improving the Health of People with Intellectual Disability.

Professor Trollor also highlighted the gaps in health outcomes for people with intellectual disability compared to the rest of the population and the overall higher support needs required for people with intellectual disability and the key work needed around data, identifiers, training and workforce capability to deliver safe, person-centred health care.

Driving Change in Queensland - Dr Cathy Franklin, Director, Queensland Centre of Excellence in Intellectual Disability and Autism Health

Dr Franklin highlighted the work that was being undertaken by the Queensland Centre of Excellence Intellectual Disability and Autism Health (QCEIDAH), including its work with the establishment of 12 Intellectual and Developmental Disability Mental Health teams across Queensland. Dr Franklin also presented a number of case studies which illustrating the difficulties that people with disability face when trying to obtain health care, and the options currently available to them in Queensland.

Dr Franklin concluded her presentation by providing some ideas to improve services in Queensland. These included:

- Expand services to provide specialised support to help mainstream health services provide quality care to people with intellectual disability
- Require hospitals to provide a pathway for people with complex health needs who need additional support for blood tests and scans
- Establish intellectual disability nurse navigator positions and expand the role to interface with the community and provide clinical support to access services in hospitals efficiently.
- Support public dental services to provide care to people with intellectual disability
- Make EASY Health education mandatory in Queensland Health facilities.

Panel 2 Discussion: Better Health for People with Intellectual Disability

Speakers

- Fiona Lawton, Disability Advocacy Manager, Rare Voices Australia
- Professor Nick Lennox, Advisor, Department of Health, Disability and Ageing (Commonwealth)
- Tricia Matthias, Executive Director, System Policy Branch, Strategy, Policy and Reform Division, Queensland Health
- Sally Bidewell, Senior Audiologist, Gold Coast Hospital and Health Service

The panel highlighted that improving health outcomes for people with intellectual disability requires coordinated reform across health, disability and government systems. While important initiatives are underway nationally and within Queensland, participants identified significant gaps in translating policy into consistent practice and equitable health outcomes.

Key themes included:

- **Better integration between health and disability systems**, reducing fragmentation, improving coordination and ensuring people do not need to repeatedly explain their needs or navigate disconnected services.
- **Building workforce capability**, recognising that health professionals often lack knowledge and confidence in supporting people with intellectual disability and rare conditions.
- **Learning from existing reforms**, including the Comprehensive Health Assessment Program (CHAP), the *See Me, Hear Me, Respect Me* campaign, and current national reform initiatives, to strengthen future system improvements.
- **Embedding accountability and continuous improvement**, including implementing recommendations of the Office of the Health Ombudsman's Systemic investigation into health services provided by Robina Hospital to Mr Stewart Kelly (December 2025) to improve clinical practice, workforce capability and organisational culture.
- **Recognising the role of families and supporters**, who continue to support people with intellectual disability with coordination of care and advocating within complex health systems.

Appendix 2 – Agenda

AGENDA		
9.00am	Registrations	
9:30am	Opening and welcome	Alison Maclean (MC) Alycia Staples (MC)
9:35am	Acknowledgement to country	Willie Prince
9:40am	Overview and purpose of day	Alison Maclean (MC) Alycia Staples (MC) Michelle Moss – Queenslanders with Disability Network
9:50am	Personal Perspectives from people with lived experience	- Gillian Gerhke and Darryl Steff - Donna Best - Aunty Semah Mokak-Wischki
10:30am	National perspectives on driving change	Julian Trollor AM, FAHMS, Director, National Centre of Excellence in Intellectual Disability Health, UNSW Medicine and Health
11:00am	Morning Tea	
11:25am	Driving change in Queensland	Dr Cathy Franklin, Queensland Centre of Excellence in Intellectual Disability and Autism Health
11:55am	Better health for people with intellectual disability	- Fiona Lawton, Disability Advocacy Manager – Rare Voices Australia - Professor Nick Lennox, Advisor, Department of Health, Disability and Ageing (Commonwealth) - Tricia Matthias, Executive Director, System Policy Branch, Strategy, Policy and Reform Division, Queensland Health - Sally Bidewell, Gold Coast Hospital and Health Service Q&A
1:00pm	Lunch	
1:45pm	Roundtable discussions	All participants discussion
2:30pm	Feedback	Each table to provide feedback
2:45pm	Key steps needed going forward	Response from Professor Julian Trollor and Dr Cathy Franklin
3:00pm	Closing, thank you and finish	Michelle Moss

Appendix 3 - Summary data from Roundtable discussions

The following is a record of points raised by participants during the two rounds of table discussion. Points are presented as they were raised and have not been prioritised. The recommendations at Section 5 draw on this material.

Round One

In round one, attendees were asked to discuss what are two or three things Queensland could do in the next 100 days that would make a real difference now.

From these discussions, the following themes came from the discussions.

- Education and training of staff and of people with intellectual disability
- Health service systems that better integrate people with intellectual disability into decision-making.
- Oral health for people with intellectual disability
- Improve accessibility and co-design of resources, including documents that use simple language and Easy Read formats.

Education and Training of Staff and of People with Intellectual Disability

- Health Directive for all HHS's to mandate Easy Health & Disability Awareness Training to be completed within 12 months.
- Eligibility for funding via Queensland Government for private health sector is tied to mandatory completion of Easy Health & Disability Awareness Training by staff.
- Training and Awareness programs to include intersectionality including nonverbal/noncommunicative as a distinct cohort.
- Procurement and guidelines require services and contractors to have completed Disability Awareness Training.
- Training for all hospital staff in using HASTS and manual handling procedures for patients and increased availability of HAST equipment.
- Share available training, for example EASY Health for primary care, with dedicated funding for PHN's to support and promote access.
- Ensure disability support workers know how to identify potential health issues when required.
- Find an extra lecture spot about intellectual disability in medical, nursing, OT, dietitian, physio, speech, psychology, dental, pharmacy and social work.
- Co-deliver the education with a person with intellectual disability and a person who doesn't use words to communicate.

- Health professionals training on intellectual disability – liaise with DSIDQ as they're peak body – work closely with services to better understand issues and challenges in making improvements.

Health service systems that better integrate people with intellectual disability into decision making

- Patient centred care and direct communication to patient.
- Mobile outreach services for people who can't leave home to get to hospitals.
- Commit to disability liaison workers at all QH hospitals.
- Access to a disability advocate to help when hospitals refuse treatment to people with complex disability.
- Clinical care pathway
 - Accessible.
 - Public.
 - Interlinked.
 - Cross service.
- Hospitals to have a disability action plan.
- Baseline information in the health system to help people with disabilities and families from repeating medical stories.
- No wrong door approach to accessing health care.
- Disability peer navigator and ambassador roles in health care and make sure people have access to advocates/navigators in hospitals.
- Have a team of volunteers or a “buddy” member of staff who can help someone with intellectual disability to get around the hospital or facilities.
- Options when having blood tests, e.g. butterfly needles, sensory supports and fidget toys, and better coordination between GP and specialist services to support people with intellectual disability with blood tests or procedures.
- Could include or engage with RACGP around accreditation.
- Recording medical appointments.
- Help people to know where to access free or low-cost health care.
- Get all the people with disability to do their health passport.
- Sensory/Quiet rooms in hospitals.
- Have people with intellectual disability conduct accessibility audits in hospitals.
- In-the-home care for primary care services explored and trials for home bound patients.
- Better clarity and integration of health and NDIS services.
- Appoint people with disability on every HHS & PHN boards with a network for board members.

Oral health for people with intellectual disability

- Invest in better dental care, “caring for your teeth” – increase funding and services.
- Equally well -> disability specific program includes oral health.
- Waiting times for dental appointments, for example a two-hour wait, should trigger rescheduling.
- Make a resource to tell people about public oral health (QEII/Herston) and get it on their website. Ask HealthPathways to update Metro South + Metro North information so it can be found.

Improve accessibility and co-design of resources

- Ensure 'offender health' is included in all considerations
 - Justice system.
 - People denied access.
 - Communication disabilities.
- Australian Government requiring bulk billing for people with disability.
- Medicare line item for general appointments for people with disability to support bulk billing.
- PHN strategies to include disability as a vulnerable cohort.
- Include people with disabilities in design and development of systems from day 1 (inception of process)
- Start conversations about non-speaking people to have a formal identity.
- Performance management for funded services to ensure tools, e.g. Julian's key, CHAP, Rare Voices Toolkit.
- NDIS stops making people jump through 'concurrent support' hoops to have support in hospital.
- Presume communications partners are required for people with intellectual disability.
- Appropriate adjustments for consumer engagement.
- Ensure information is in simple language or easy to read format.
- Make sure disability services (frontline) have the latest information about health programs.
- Online resources need to be designed in an accessible way.

Key 100 Day Opportunities

- Work with Health Departments to integrate mandated training for all Employees, with a focus on frontline staff.
- Disability Action Plans (DAPs) in hospitals up-to-date or being updated.
- Update Health Department resources and documents to ensure all resources are in accessible and easy read formats.
- Begin to prepare resource to assist with understanding oral health. Draft and co-design process should have begun before the end of the 100 day cycle.

Round Two

Round two focused what is one big change Queensland should aim to achieve by 2028 to create a health system that is more connected, more inclusive, easier to use and more accountable for people with intellectual disability?

From these discussions, the following themes came from the discussions.

- Education and training to integrate programs to support people with intellectual disability when they need health care.
- Integration of support workers/peer workers, including those with intellectual disability into the health system to help people with intellectual disability.
- Improvements in Health Service delivery for people with intellectual disability

- Data collection improvements for people with intellectual disability
- Better integration of NDIS and health supports when interacting with the health system for people with intellectual disability.

Education and training to integrate programs to support people with intellectual disability when they need health care

- QAS training for Easy Health.
- All university healthcare education has intellectual disability embedded workforce supports for training.
- In QLD schools' education starts younger – awareness and attitudes starting young.
- Formal identity of non-speaking people with intellectual/complex disability, public awareness campaign in place.
- Employment for people with intellectual disabilities with hospital start with training.

Integration of support workers/peer workers, including those with intellectual disability into the health system to help people with intellectual disability

- Dedicated health hubs in the hospitals and services – seamless transitions, skilled staff, standardised pathways.
- Have lived experience person working on board.
- A person with disability should be able to choose who should be in the Doctor's room whether it is a family member or support worker.
- Embed disability and action plan in health services, including:
 - More jobs for people with disability at all levels (leadership and on the ground).
 - Disability – liaison officers at all sites.
 - Dedicated peer workers.
 - Nurse navigators – in patient and community.
 - A watchdog to ensure hospitals adhere to human rights.
 - Access to trained/funded advocates.
 - Disability-specific medical and nurse educators.
 - “Translators” – to aid those with different communication needs
 - Outreach disability services, HITH?
 - Dedicated anaesthetic staff for accessible investigations.
 - Incorporate KPIS, funding careers for compliance for the above.
 - Dedicated escalations pathways.
 - Funding incentives.
 - Have an annual audit of compliance – include people with lived experience on the audit team!
- All QLD hospital have a lived experience advisor board.
- Introduce hospital disability service standards.
- Better integration between health and disability.

Improvements in Health Service delivery for people with intellectual disability

- Roll out of specialised ID primary health care teams across the state.
- Expand and advertise oral health services for intellectual disabilities.

- Clinical prioritisation pathway for people with intellectual disabilities for direct referral for screening/scans/pathology when community pathway is not suitable.
- After hours crisis mental health service options.
- Single digital patient record – this supports data/data collection and outcomes
 - Flag.
 - Adjustments.
 - Julian's key.
- Set up a sedation model at care that all hospitals in QLD can implement
 - Need a clear model that offers tiered options.
 - Need buy in from hospitals, clear ways to bring in specialists from other hospitals when needed.
 - Hospitals need right equipment like dental equipment, clippers to do hair, etc.
 - Still need tools to support desensitisation.
 - Pathway for GPs to refer too, not just specialist.
- Broader the disability nurse navigator role to be a patient-facing navigator role
 - Doesn't have to be nurse, but need clear roles, frameworks and flexibility to do role.
 - Shouldn't necessarily sit within hospitals/be focused only on hospital-based care – needs to include primary care.
- Mobile preventative health and wellness vans that assess, immunise, screen at home -> change the healthcare delivery model.
- Improved reporting/data collection of disability identifiers across all health information systems -> creates evidence for system reforms, workforce capacity.
- Communication that ensures people are working together as a team and listening to the person/support person where required
 - Easier to understand information.
 - Focused on the person.
- Incentivise supporting people with intellectual disability (funding to support the complexity of care).

Data collection improvements for people with intellectual disability

- Universal digital identifier
 - Level 1 – Disability
 - Level 2 – Intellectual Disability
 - Level 3 – Communication Disability
 - Level 4 – Rare Disease (complexity)
- Formal identity of non-speaking people with intellectual/complex disability, public awareness campaign in place
- Tab that includes identifier and communication/RA plan that is developed with person and their supporters.

Better integration of NDIS and health supports when interacting with the health system for people with intellectual disability

- The interface between health and NDIS is smooth, especially in hospitals

- Allow NDIS supports when in hospital to support disability related needs.

Key 2028 Opportunities

- Tertiary education curriculums that have specialised training for students across health professions.
- Centralise data collection to assist people with intellectual disability and reduce the amount of time and work required for people with intellectual disability when they are accessing the health system.
- Initiate programs that will build support/peer networks in hospitals that will also include opportunities for people with intellectual disability.
- Clear campaign on oral health for people with intellectual disability that is ready for roll out to coincide with 2028 Federal Election and 2028 QLD State Election.