



Summary Document

Roundtable: Health and Intellectual Disability

Upholding the right to health and life

Queensland Roundtable

On Friday 22 March 2019, the Queensland Roundtable on health and intellectual disability brought together over 80 delegates from a diverse range of lived experiences of disability and health, disability, community, advocacy and rights and justice sectors. Please see attachment 1 for a summary of individuals or their representative organisations.

The Roundtable was a joint initiative of Queenslanders with Disability Network (QDN), Office of the Public Advocate (OPA), Queensland Centre for Intellectual and Developmental Disability (QCIDD), ICAN! – Institute for the Clinical Advancement of Neuroplasticity and is supported by Australasian Society for Intellectual Disability Queensland Division (ASID).

The Statistics:

Over 400,000 people in Australia have intellectual disability. Including their families, two million Australians are impacted. Compared with the general population, people with intellectual disability experience:

- 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.

This document provides a summary of the agenda and the roundtable discussions.



Speakers

The program included a diverse range of speakers:

Program	Speakers
Official welcome	Sharon Boyce – Chairperson Queensland Disability Advisory Council
My health matters in Queensland: Personal Perspectives from people with lived experience	Panel <ul style="list-style-type: none"> • Willie Prince • Michael Cherry • Kim and Jae Creevey
My health matters in Queensland: A systems perspective	Mary Burgess – Public Advocate Queensland
My health matters in Queensland: The current environment	Paige Armstrong – CEO, Queenslanders with Disability Network
Primary Health Matters	Professor Nick Lennox - Honorary Professor Queensland Centre for Intellectual Disability, Mater Research Institute, University of Queensland
Health Inequities: views from a clinical specialist	Professor Harry McConnell - Director Institute for the Clinical Advancement of Neuroplasticity - I CAN!, Clinical Sub Dean and Professor of Neuropsychiatry and Neurodisability, Griffith University School of Medicine, Gold Coast University Hospital
National Health Matters	Jim Simpson - Senior Advocate, New South Wales Council for Intellectual Disability

Roundtable discussions: Round 1

The first roundtable discussions were held in response to the individual speakers with lived experience of disability, and presentations by Mary Burgess Public Advocate Queensland, and Paige Armstrong, CEO, Queenslanders with Disability Network (QDN).

The question was **“What stands out from stories, presentations and experiences that we need to focus on for people with intellectual disability at the individual and systems levels?”**

The following information provides a summary of these table discussions. It has been themed at the individual level into five areas:

- Individual patient care
- Delivery of direct health services and care (primary, sub-acute, acute and community health services)
- Integration and collaboration across health and disability systems



- Education, training, and development
- Human rights within health system

Individual:

Individual Patient Care:

- Good care involves people in their care, helps people understand, kind care, involving family and listening
- Families have pride and strive to be independent
- What matters to the patient gets forgotten
- How do you empower individuals
- Having a health record for individual – outlining support needs
- Person centred approach
- Need for strength based approach
- Need to be known
- Access to own information
- Disillusion with health system: access to GP; access to own information; tired
- Person with two disabilities needed safety rail because of second disability but because it was secondary disability couldn't get rail.
- Whole person approach – AAC!!

Delivery of direct health services and care:

- Easy English and good communication is important for **all** processes (bookings, letters, assessments, reception staff)
- People with intellectual disability need accessible information
- Access to advocacy
- Support – appointed advocate/culturally appropriate
- Health professionals need to check in – have you understood what we talked about
- Better communication (listen first)
- Talking face to face with person with a disability
- Poor, premature diagnosis
- Clear discharge notes need to be completed and follow the patient
- Safeguard protocol allowing nursing staff to raise concerns
- Access to support workers, like access to interpreters should be easy
- On admission, patients to be provided with information about health treatment expectation
- Address all Accessibility barriers
- Queensland Government to renew CHAP licence
- Drugs and medication – right medicine with support around taking medication. Perhaps people don't understand writing on the bottle
- Medical staff don't look you in the eye – they look over you and don't really talk to you
- Doctors and other health professionals who don't listen – need to be willing to spend time
- Don't explain properly – need to improve communication



- Families often say that person with disability baseline behaviour has changed dramatically however health system discount what they say
- Address time pressures within appointments and consultations for people with disability
- Systems don't adapt to meet the needs of individuals – “flexible systems”

Integration and collaboration across health and disability systems

- Enormous reliance on family and informal supports needs to be considered in planning and delivery of health services
- NDIS needs to provide support to people to access health system particularly when having to go and do lots of different medical people
- Support workers need funding to assist people to access appointments
- Lack of co-ordination and understanding between health and disability systems. NDIS currently not supporting health. Hospitals don't think it is their role to provide support
- Health and disability Interface is being deconstructed via NDIS
- Lack of clear picture – fallout and consequences that will go unnoticed
- Tension brought forward NDIS needs diagnosis (while professionals reluctant to impose early/premature diagnosis) → NDIS promoting labelling of people with disability
- Individuals being resources (NDIS) to link health and well being

Education, training and development

For People with Intellectual Disability and families:

- Training and support for individuals, family and carers to navigate the system

For healthcare providers, doctors, health staff

- Values and attitudes – respect
- Challenging assumptions
- Culturally appropriate support for ATSI and CALD community
- Education course specifically designed for experience in disability for disability and Health Sector
- How do you empower staff?
- Cognitive bias

Human Rights within healthcare:

- A person's disability is **part** of who they are but not all of who they are. How do systems understand the individual
- There is lots that needs to be done to make sure people with disability get access to equal quality care
- Having a voice – people and families
- Having a fair go
- Reduce discrimination. People are feeling like they are being treated differently
- Bad experience for people with intellectual disability in the health system



- Lack of power
- Cognitive bias
- Attitudes
- Not being heard
- System acknowledge and support equal treatment of people with disability
Acknowledge difference
- Changing attitudes of health professionals and wider community towards disability
can the Human Rights Act impact this.

Systems:

The following information provides a summary of the recommendations for action by Roundtable delegates with regards to the systems and what actions can be taken to improve healthcare and health outcomes across the systems.

Systems – Recommendations for action by Roundtable Delegates:

1. Provide Health literacy support for people with disability and families
2. Deliver better communication with people AND systems through health records for individuals and on admission, provide people with accessible information about health treatment expectations
3. Ensure that good data systems exist to turn stories into evidence
4. Provide Disability Education for staff
5. Appoint individual advocates for people to negotiate system – culturally appropriate
6. Ensure that people with disability are advising the system
7. Specific strategies with regards to Advocacy:
 - 7.1. Provide dedicated resources for example liaison person for people with intellectual disability
 - 7.2. Independent Advocacy when carers are unsure and when presenting on their own to hospital
 - 7.3. Clinical advocate (independent) to review care
8. Provide Reasonable adjustments to healthcare via policy and procedures
9. Review procedures to implement Ryan’s Law/rule as Hari’s Law for people with intellectual disability
10. Education for GPs, doctors, and health professionals to address disability bias in health system, diagnostic overshadowing and cognitive bias and increase skills and knowledge in working with people with intellectual disability
11. Education for disability workers around what is needed
12. Quality and Safeguarding to incorporate Disability and Health interface
13. A strategy to address culture change – proactive; listening; collaboration with disability services
14. Integrated care design pathways that are holistic, multidisciplinary care forming linkages and support across primary health and tertiary health and community (eg service providers)
15. Prioritise early intervention ie; early childhood; birth; neo-natal. Prevention and early intervention to deliver better outcomes and increase capacity
16. Deaths in health system should be investigated



Roundtable discussions: Round 2

The second round of discussions used a systems map of all the different parts of the health, disability and other service systems, placing with person with intellectual disability at the centre. Delegates were invited to look at the different parts of the systems and respond to the question, '**What action can we take now and into the future?**'

The following provides a summary of discussions across the tables responding to what actions each parts of the systems can focus on right now and into the future.

Specialist Disability Support

- NDIS needs to make all messages clear and simpler to help people access the system
- Supports to increase understanding – formal and informal
- NDIS fund people as part of their plan for support to interact with health system
- Needs to be national approach - NSW ahead of other states
- Include aspects of health and well-being in training for support workers
- Greater focus on and responsibility for health and well-being and proactive preventative health communication and facilitation between the person and health professionals
- A person who helps or has responsibility to navigates the patient through various specialists
- Health App implemented properly
- Communication leads to anxiety – communication becomes a challenge
- Identify disabilities and address them
- Treat people as people first, not a disability
- Address advocacy gap that will result from NDIS
- Specialist Disability Support in group settings
- Health training for disability support staff – language, health support, dealing with health services, communication

Allied Health Professionals

- Queensland Health to take over responsibility for nursing care
- Training for all of the basic/foundation level across the entire spectrum (all professionals)
- Health Literacy for clinicians
- Education about ID for uni students in all professions

Community Services

- Improve services between primary and secondary health care - community services and secondary health care
- Communication between specialists, advocacy etc so that treatment can be complete and holistic – Central Liaison Officer
- Use the networks we've got. Have to make sure our channels are safe guarded



- Holding Queensland government accountable regardless of the existence of NDIS
- Better training in specialist disability healthcare for workers
- Finding workers with lived experience
- Make disability support a viable and recognised employment option
- Involve people with disability in policy and leadership

GP and Primary Health

- Awareness of specific medical issues for people with disability (epilepsy etc)
- Support NSWCID call for Intellectual Disability specialist services
- Multiple appointment and clinics – why is it so hard and why does it take so long
- electronic health records although incomplete
- Better integration, co-ordination and connected services
- Support annual health check
- Encourage GPs to utilise programs like CHAP and other initiatives
- Queensland Government to review CHAP licence for Health Plan
- Support for people to communicate with doctors.
- Support to doctors to understand and communicate with people with intellectual disability
- Implementation Health Checks/assessment
- Audit of process
- HHS and PHNs to co-ordinate services to people with disability
- Disability and Aged care death review panel/board in Coroners
- Promote opportunities to contribute to inquires eg; Audit Office report and Qld Productivity Commission
- Population approach
- Queensland Government to re-fund CHAP
- Promote CHAP tool – education; make CHAPS easier to access
- Improved preventative care for people with disability
- More training /experience in any health professional (radiologist, pharmacist, nurse etc)
- Cohesion and Integration – reduce silos
- Using systems and technology for better cohesion (eg; My Health Record)
- Tell GP about disability and be confident
- Support GPs about people with disabilities eg; NDIS guide for GPs – not written in useful language for GPs (Language NDIS)
- Structural changes to PHC MBS items
- Specialist nurses in GP Clinics
- Disability and health systems – all different languages – need to get some commonalities
- There is a need for co-ordination, connection, generalist roles in health services (who links specialists and see the whole patient journey)
- Structures in health services so people with disability have a voice in service planning and priorities



Specialists

- Provide expectation to individuals
- Holistic healthcare – what I want; what I don't want
- Need to be affordable for people with intellectual disability
- Support to people with Intellectual disability and Epilepsy to seek specialist support
- Build relationships with support system and health system
- Disability GPs be a specialist field
- Incentives for Specialist Disability GPs
- Identify what supports and services are being lost – gaps widening as a result of NDIS
- Specialist knowledge across all population cohorts
- Benefit everyone – not just those who can afford it
- Specialist training positions and people to support these
- Train nurses and allied health to work with specialists and their clients with disability
- Co-ordinated care/holistic care – specialist positions including medical specialist with these as a focus (eg; general paed and Physician)

Hospital and Emergency

- Co-ordination/communication: strengthen health promotion role, don't assume Primary Health Network only space where this should occur
- Adapt and respond to individuals
- Transport for those in need
- Advocacy for vulnerable people
- Better integration, co-ordination and connected services
- Across all systems, educate people to acknowledge and avoid disability bias
- Disability bias in psychiatric emergency against people with intellectual disability – where psychiatrists likely to attribute change in behaviour to disability and not mental health
- Across all systems reduce barriers
- Intellectual Disability Specialist team in each region
- Orientation and Induction - dedicated section on ID and on-going mandatory training
- Training and induction for doctors and nurses
- A Queensland person with an intellectual disability should be on the Round Table with Minister Hunt
- Cultural Competency embedded in training for medical and nursing students for Healthcare for people with intellectual disability
- All intellectual disability major in university nursing degrees
- Disability specialist nurses
- Emergency Department presentations – access to advocates
- Access to comprehensive clear discharge notes
- Avoid perception that all health has to go to NDIS
- Train nurses and doctors and specialists to work with people with disability
- Health professional using the systems that already exist. Write a discharge summary



Whole System

- Enhance Intellectual Disability training in Unit for Doctors, Nurses and Allied Health
- Incorporate lived experience in medical training
- Improved training of doctors and nurses and other medical professionals
- Hold Government accountable
- Training/understand in our training of health professional, expectations are communicated/know what to do; how long to wait
- All can improve efficiency – tell my story once not every time
- A Queensland person with an Intellectual Disability should be on the Round Table with Minister Hunt
- Royal Commission investigate neglect in Health as one of its areas - Raise these concerns with the Royal Commission into abuse, neglect and exploitation of people with disability.
- Advocating for Queensland Government to respond appropriately and effectively
- Strengthening advocacy voice and empowerment and education of people with disability, identifying areas and speaking up
- Address advocacy gap that will result from NDIS
- Recognising and work with political process and strategic action
- Queensland representative on Advisory Council – NDIA. Subgroup for intellectual disability
- Oversight and transparency for accountability and transparency
- Mainstream and integration
- Respecting and accepting disability
- Awareness and education
- Use your voice to advocate for others with disability
- Bring together the voice of all with disability
- How do we break into the room with our voices
- Quality safeguards Commission role include oversight of disability sector health support eg; in supported accommodation
- Lived experience informs education of health professionals
- Cultural change
- Politicians need to understand about this – PM and opposition
- Linked up and transportable records. Will My Health Record do this?
- We have to have health workers know what are person's care needs and preferences

Other Services

- Access to physical activity, nutrition and social connection for all
- Support for building advocacy skills of people with disability – adequate funding over time – succession plans – new young advocates
- Treatment should start with person when they are born
- Listen to the person with intellectual disability and understand
- Employment Training Resume writing, cover letter, interview techniques
- Disability Literacy
- Specialist advocacy to help interpret the health language and interactions



- People with disability have the right to give feedback and make complaints in a way that suits them

Key actions to take forward from each speaker for the health and disability systems:

Sharon Boyce	A key link that we have to develop is between health and disability. We need to educate across all areas of health, particularly within the hospital systems where the deaths are occurring. Health professionals are unsure of what they need to do. The education needs to be specific in creating those levels of knowledge so solutions can be put in place and real change can occur. If we do this, we will create solutions that will minimise the numbers of deaths in care and we will be able to showcase a system that understands both physical and intellectual impairment. We cannot separate health and disability. We have to deliver education, which links across both sectors. With adjustments and education, there will be a better system and we will create a solution to the high levels of deaths we are seeing at present.
Michael Cherry	Doctors need to listen more and try to understand what it is that each person needs. Doctors make assumptions. We need more understanding to help people with disability.
Kim Creevey/Jae Creevey	Changing fundamental intrinsic understanding permissions that medical health professionals have towards people with disability. One of the best ways is education, integration, and seeing the people as being people and not just their underlying diagnosis.
Mary Burgess	Annual health checks and proper health plans for people with disability with complex health conditions. In addition, some system of connecting the NDIS with health services or primary health networks to ensure people are getting proper health supports.
Paige Armstrong	Better health literacy for patients and families. We need clear information and we need the way that professionals speak with people about their conditions, treatment and options going forward put in a way that people can understand. We also want people to have supports that they need. If they can't get those supports, we need to train every health professional to write down, at the end of a consultation, a summary for the patient of the key things they have just told the patients in very simple ways that they can take away with them.
Nick Lennox	Fundamentally, we need to empower people with intellectual disability and people that support them. If we have a national

	enquiry into this area and we listen what they are doing and force the system to make sure the recommendations are actually applied.
Harry McConnell	Clear solution is integrated health and disability services. People need to talk to each other, health care providers and disability providers. The person needs to be treated as a whole person not as a disability. This is critical. We should take this all to the royal commission.
Jim Simpson	So much of this goes back to values and attitudes. People with disability themselves should be at the centre of all of the actions that are taken from here. For example, if we get more into university teaching content - people with intellectual disability being teachers in university. We get the kind of programs we are pushing with primary health networks. People with intellectual disability being trainers of GP's. With people with intellectual disability are part of the normal mainstream roles that health professionals are dealing with then we will see big changes in values and attitudes.

Appendix 1: Summary of delegate representatives

Queenslanders with Disability Network (QDN)	Queensland Centre for Intellectual and Development Disability (QCIDD)
Institute for the Clinical Advancement of Neuroplasticity (ICAN)	Office of the Public Advocate
Department of Communities	AEIOU
Mental Health Alcohol & Other Drugs Branch. QLD Health	NSW Council of Intellectual Disability
West Morton PHN	Children's Health QLD
Sunshine Coast HHS	Synapse
Community Resource Unit	Metro South HHS
Queensland Health, Strategic Policy & Legislation Branch	National Disability Insurance Agency (NDIA)
Speaking Up For You (SUFY)	Shadow Minister for Disability
National Disability Services (NDS)	WWILD

 ICAN The
Public
Advocate
influencing change to transform lives QCIDD
Queensland Centre for Intellectual
& Developmental Disability QDN
QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

Darling Downs HHS Representative	Parent to Parent
QDN Board of Directors	Centre of Excellence for Clinical Innovation & Behaviour Support
University of QLD	Department of the Premier & Cabinet
Royal Australian & New Zealand College of Psychiatrists – QLD Branch (RANZCP)	Queensland Advocacy Incorporated (QAI)
Griffith University	Loud and Clear Self Advocacy Group
Allied Health and Research	ADA Australia
Queensland Disability Advisory Council (QDAC)	Anti-Discrimination Commissioner
Metro South Health	Community Living Association
Carers Queensland	Metro North HHS
Metro North Health Alliance	Member for Caloundra and Queensland Parliament Committee - Health, Communities, Disability Services & Domestic & Family Violence Prevention Committee
QDN Members Brisbane and Gold Coast Hot Topics	Media