

**Submission: Royal Commission into Violence, Abuse,  
Neglect and Exploitation of People with Disability:  
*Health Care for People with Cognitive Disability Issues Paper***

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**QDN**

**QUEENSLANDERS WITH DISABILITY NETWORK**  
*NOTHING ABOUT US WITHOUT US*

Submitted to the Disability Royal Commission  
June 2020

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## About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a statewide network of over 2,000 members and supporters who provide information, feedback and views from a consumer perspective to inform systemic disability policy and disability advocacy. This submission is informed by the lived experience of our members and supporters.

### Introduction

Queenslanders with Disability Network (QDN) welcomes the opportunity to make a submission to the Disability Royal Commission's Health Care for People with Cognitive Disability Issues Paper.

In making our submission, QDN supports the human rights-based approach to this inquiry, in particular, Article 25 under the United Nations Convention on the Rights of Persons with Disability (UNCRPD), which recognises the right to the highest attainable standard of health, without discrimination on the basis of disability and Article 16 which provide obligations in respect to reintegration and rehabilitation. Access to health services for people with disability is a fundamental human right enshrined in the UNCRP and in Queensland's *Human Rights Act 2019* that every person has the right to access health services without discrimination.

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 health care

QDN acknowledges that people with disability often have more complex health needs and a higher mortality rate, and face many barriers accessing appropriate health care, and a narrower margin of health, than the general population. QDN members highlight the many challenges they experience in both accessing health care and being an informed, participating consumer of health services.

QDN members have informed us of issues relating to health, including unaffordable health care, complex health needs, a health workforce with perceived limited knowledge of disability and inadequate systems, inaccessible health services and limited personal knowledge of how to access and navigate the health system.

A health system that delivers integrated care across acute, sub-acute and primary health care, and greater integration and connected care across disability services is essential in delivering quality health care for people with disability. People with disability need to be actively included in the design, implementation and evaluation of integrated health services.

QDN supports the call for improved health outcomes and health care for people with intellectual disability.

It is critical that governments set clearer boundaries and ensure that there are continuity of care arrangements in place to ensure that people can access essential services.

QDN's response to the Health Care for People with Cognitive Disability Issues Paper is informed by Queenslanders with disability including QDN's 2,000 strong membership and support base and QDN's 20 Local Support Groups across the state.

Whilst this submission is being provided to the Disability Royal Commission during the COVID-19 pandemic and public health emergency, please note this does not seek to address the issues or impacts that people with disability, including people with intellectual disability have experienced with regards to health care during this time. QDN will provide a specific submission to the Emergency Planning and Response Issues paper that addresses these critical issues and experiences of people during this time.

## **Experiences of people with cognitive disability in the health care system**

People with intellectual disability, and their families and carers are recognised to experience poorer outcomes across the spectrum of health and wellbeing than the general population. People with intellectual disability experience a large range of potential risk factors for early death, including heart problems, high blood pressure and obesity, and experience challenges accessing health care, in part due to capacity and communication issues and active discrimination. People with mental health and psychosocial disability also experience poorer health outcomes and additional challenges with accessing the right care, at the right time in the right place.

For people with intellectual disability, recent evidence provided to the Disability Royal Commission highlighted:

- An estimated 400 adults die each year from potentially preventable causes
  - Poor participation rates in primary care
- Complexity of, and differing patterns of health care needs that contribute to high levels of undetected, unmanaged health issues and premature deaths<sup>1</sup>.

This is further supported by the Queensland Public Advocate 2016 report *'Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland'*, which examined premature deaths for people with disability in Queensland, noting 53% of those deaths were potentially avoidable with a range of health conditions prevalent that should have been identified and treated earlier - all fundamental to comprehensive access to primary health care.

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<sup>1</sup> Evidence to the Disability Royal Commission by Professor Julian Trollor reported via. <https://www1.racgp.org.au/newsgp/clinical/disability-royal-commission-told-of-hundreds-of-pr>

It is acknowledged that on average, people with intellectual disability have about 2.5 times the number of health conditions as people who do not have intellectual disability; and approximately 50% of the health conditions of people with intellectual disability are undiagnosed<sup>2</sup>.

In recent times, disability service provision has shifted away from the institutional medical model, which has historically dominated disability service provision. Instead moving to a person-centred approach, which focuses on the multi-dimensional needs of people, including their social wellbeing and inclusion. While this shift has resulted in many positive outcomes for the quality of life of people with disability, it has also resulted in less interactions between the health system and disability system. Consequently, this has seen a reduction in health literacy in the disability workforce, and a reduction in disability literacy within the health workforce.

People with intellectual and cognitive disability have a right to health care, as well as a right to freedom and decisions about their health and their body. For many people with disability, particularly women with disability, this right to sexual health and reproduction has been denied and compromised, historically and in the present time.

## **People experiencing violence abuse neglect and exploitation in health care settings**

QDN members acknowledge that people with intellectual disability experience violence, abuse, neglect and exploitation in a variety of health care settings across primary care, sub-acute and acute health settings as well as the impacts that people experience in their residential settings and where they live.

## **Systems and complexity**

People with intellectual disability are often engaged in multiple systems and have a range of complexity in their lives as a result of the intersection these systems at different stages of their life. This includes housing and homelessness, justice system, cultural and identity diversity, socio-economic disadvantage, early life and child protection system, and disperse geographical spread across Queensland.

QDN members have raised the impacts of this on their life and their health and wellbeing and have raised that this can be related to the trauma and experience people have had in their life. The prevalence of mental ill-health is at least two to three times higher in people with intellectual disability compared to the general population. People with intellectual disability are more vulnerable to mental ill-health due to complex interrelationships between disability and other medical, social and psychological factors.<sup>3</sup>

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<sup>2</sup> Professor Trollor, Roundtable on the Health of People with Intellectual Disability Summit, 2 August 2019  
[https://www1.health.gov.au/internet/main/publishing.nsf/Content/8D96BCAC9A5B553ACA2584880001A667/\\$File/Roundtable-on-the-Health-of-People-with-Intellectual-Disability-Summary-and-Recommendations.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/8D96BCAC9A5B553ACA2584880001A667/$File/Roundtable-on-the-Health-of-People-with-Intellectual-Disability-Summary-and-Recommendations.pdf)

<sup>3</sup> Professor Trollor, Roundtable on the Health of People with Intellectual Disability Summit, 2 August 2019  
[https://www1.health.gov.au/internet/main/publishing.nsf/Content/8D96BCAC9A5B553ACA2584880001A667/\\$File/Roundtable-on-the-Health-of-People-with-Intellectual-Disability-Summary-and-Recommendations.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/8D96BCAC9A5B553ACA2584880001A667/$File/Roundtable-on-the-Health-of-People-with-Intellectual-Disability-Summary-and-Recommendations.pdf)

## Access to health care and barriers

Queenslanders with intellectual disability experience barriers to accessing health across preventative, primary, sub-acute and acute health settings and QDN members have reported a range of experiences a spectrum of violence, abuse, neglect, exploitation and discrimination.

People with intellectual disability report an over reliance on family and informal and formal supports to ensure there is someone with them assist with communicating their needs, advocate alongside them and sometimes to speak on their behalf.

Access to health care is impacted by lack of accessible spaces and places that meet their physical, sensory and communication needs. QDN members have also reported that primary practices and general practitioners in regional, rural and remote areas are closing their books and not taking on new patients.

For people with intellectual disability, there are additional barriers because of the lack of provision of information that is accessible, Easy English and provided in user friendly ways.

It is very important that people with disability access quality health care across their lifespan, and throughout all stages of an individual's lives from childhood through to older periods of life.

Research has shown that annual health assessments have assisted in minimising the barriers to health care for people with intellectual disability by prompting health care and screening. The Comprehensive Health Assessment Program (CHAP) developed at the University of Queensland by Professor Nick Lennox has been validated through several Australian studies and its importance has been recognised by leading international researchers.<sup>4</sup> Having a tool that is designed to prompt annual comprehensive health assessments that helps doctors focus on critical areas of their diagnosis that are most commonly missed, poorly managed or syndrome specific health conditions and provide appropriate treatment and ultimately contribute to overall better health.

Access is also impacted by poor interface the disability support and health care systems. QDN members report experiences of both the NDIS and health system seeing the responsibility for coordination of their care sitting in respective systems, which results in people, falling through the gaps. This leads to increased vulnerability and risk of significant health problems, illness and ultimately potentially preventable and avoidable deaths.

### Data

Through QDN's work we are aware of the significant impacts of no nationally consistent approach to collecting data about disability and health, which has clear individual and systemic consequences. The lack of jurisdictional or nationally integrated and consistently collected data in primary and acute health care settings reduces the understanding of systemic health issues and their impacts and limits capacity to inform the development of good public policy based upon evidence and data.

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<sup>4</sup> Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *Int J Epidemiol.* 2007 Feb;36(1):139-46.

## **Individual health information and health care decision making**

QDN members have identified the challenges they experience in navigating the health system in a way that acknowledges them as individuals and takes into consideration their disability needs. People with disability often face issues communicating with health professionals and their health and disability support team in order to receive the right care and support in a way that meets their needs and upholds their rights.

Whilst it is acknowledged that ehealth records and a range of clinical mechanisms to record and keep information are important, people with intellectual disability have also identified that a patient controlled communication tool is important, reflective of person-centred and patient-centred care principles and empowering for individuals to be more involved, and directive of their care.

There are a range of tools and resources that have been developed in different jurisdictions and it will be important going forward to consider how this can be implemented in a consistent and informed way that directly involves people with intellectual disability.

QDN members have also raised challenges when they are not supported to be involved in the range of healthcare and health decisions, including decisions about reproductive and sexual health, as well as end of life decision making, including advanced health directives, statements of care and end of life palliative care. health care

## **Cognitive bias**

Some QDN members have reported experiences of cognitive bias in accessing health care that reflect underpinning values, assumptions and beliefs that do not place people with disability equally, meaning they don't receive equal access to a range of care and treatment options reflective of individual human rights.

QDN members have reported that this can have significant impacts upon their life, from not being offered or given a range of preventative testing measures, especially where disabilities have known high risk factors for co-morbidity of specific conditions.

QDN members have also reported that this can have significant impacts upon doctors and clinicians fully investigating the symptoms that people are presenting with and undertaking the clinical diagnostic testing.

QDN members have also reported a bias about their ability and capacity to make decisions and be involved in their own healthcare.

## **Health workforce capacity and communication**

A range of QDN members have reported that in their interactions with doctors, health professionals and clinicians that they are:

- Communicated with in a way that assumes they cannot understand and are seen as a 'disability' not as a person
- Ignored by doctors and health practitioners who will talk to their family member or support worker
- Not given information in a way that they can understand
- Not being included in the conversation and supported to make decisions about their health care
- Failing to involve people who know them best

Doctors, clinicians and health professionals report that as part of their professional learning, there are nil to limited opportunities for training and skill development to equip them with the skills to deliver appropriate specialist health care to people with intellectual disability. The focus on people with intellectual disability in university medical and nursing school curricula is very low, with a median of only 2.6 hours of compulsory content found across 12 medical schools (with one university standing out with 12 hours<sup>5</sup>).

### **Disability workforce capacity and communication**

The disability workforce broadly has limited knowledge, understanding and training in health literacy, in understanding the specific health impacts for people with intellectual disabilities, their role in recording and assisting individuals to maintain information and records about their day to day health conditions, and specialist information and training to deliver quality disability supports that are cognisant of people's health and wellbeing needs.

With the transition to the National Disability Insurance Scheme, and the limited funded opportunities for a range of staff development and training, the health literacy of the workforce has shifted. The system level shifts have also seen a change in the level of co-ordination and integration of supports, which for some people who experience a range of challenges and disadvantage because of their intersection across multiple systems and has left them more vulnerable. QDN members have also reported challenges with supports coordination. This role has lacked consistency with training and delivery, resulting in a range of critical disability and health supports being compromised. People with intellectual disability need a range of supports to be able to access quality, safe, affordable, timely health care and it is important moving forward that the safeguards and systems are put in place to facilitate and enable this to happen.

### **Diagnostic experience and knowledge**

Diagnostic overshadowing is increasingly recognised to contribute to health inequalities experienced by people with intellectual disability<sup>6</sup>. Diagnostic overshadowing for people with intellectual disability results in delayed diagnosis, treatment and misdiagnosis. For some QDN members, this is more prevalent in the area of mental health, meaning people with intellectual disability haven't been taken seriously when presenting with mental health symptoms. Instead, their experiences are minimised or sometimes not recognised, resulting in adverse treatment affects and outcomes.

The risk, mistreatment, additional complications, illnesses and mortality due to errors in diagnosis has catastrophic effects on people's lives. There are also flow on impacts on the health system, including functionality and costs.

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<sup>5</sup> Trollor, J.N., B. Ruffell, J. Tracy, J.J. Torr, S. Durvasula, T. Iacono, C. Eagleson, and N. Lennox, *Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught*. BMC Medical Education, 2016. 16(1): p. 105.

<sup>6</sup> Shefer G, Henderson C, Howard LM, *et al*. Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms—a qualitative study. *PLoS One* 2014;9(11):e111682.

Primary health care plays a critical role in preventative and direct treatment for people with intellectual disability and it is important that this is delivered in a way that builds the capacity of primary health care services, delivers connected care and improved diagnostic outcomes, which enable appropriate healthcare.

### **Treatment and care**

QDN members have reported a range of challenges with the medical treatment that they have received across primary, sub-acute and acute care at times including:

- Limited focus on preventative health care
- Use of psychotropic medication that is sometimes misused to manage behaviour arising from diagnostic overshadowing
- Poor access to mental health care
- Errors in diagnosis
- Patient pathways not being clearly explained with people receiving inadequate support throughout the transition stages of their care
- Not being given information about their illness, treatment options and what is happening to them in ways and language that they can understand
- Hospital discharge processes that are not connected, integrated and coordinated with an individual's disability supports and primary health care
- Where appropriate, and where a patient chooses, the use of telehealth, virtual care and hospital in the home
- Delivery of treatment in a 'status quo' approach without consideration of reasonable adjustments that would make a difference for the individual. For example, sitting in crowded waiting rooms for extended periods of time even when an individual has sensory processing issues

### **Advocacy and support**

QDN members with intellectual disability have identified the importance of having access to independent, individual advocacy and support when navigating their health journey. People have said the lack of access to dedicated resources like a liaison or navigators within the hospital environment impacts upon the individual's experience. QDN members and family have often reported that the only reason that the individual with intellectual disability received the right care and right treatment was that their family member, support worker, informal support or advocate was present, and was insistent and advocated on behalf of the person to get what they needed. QDN members with intellectual disability have said that it shouldn't have to be a fight for an individual to be believed and taken seriously. QDN members have also said the role of a Clinical Advocate to review and oversee care in clinical health settings would be helpful in terms of oversight and review mechanisms to improve clinical care and outcomes.

QDN also sees the importance of systemic advocacy in broader systems reform and systems change. Systemic advocacy is critical to bring about change to deliver improved health care for people with intellectual disability.

### **Safeguarding and oversight**

A system that puts protections in place, including safeguards and oversights is needed to ensure health care is easily accessible and user friendly to people with intellectual disability. The effectiveness of the

system would rely on data collection to identify people with intellectual disability within the system and monitor the healthcare and health outcomes that people are experiencing.

## **Prevention of violence, abuse, neglect and exploitation**

QDN members acknowledged that a key strategy to prevent violence, abuse, neglect and exploitation in health care settings is education. This includes:

- Education targeted towards doctors and health care staff on how to respond appropriately to people with intellectual disability
- Education targeted towards supporters and paid support staff on appropriate strategies to support people with intellectual disability to understand the role of disability supports when interacting with the health care system
- Education targeted at people with intellectual disability regarding:
  - How to understand, navigate and interact with the health care system in an empowered way
  - Recognising good health
  - Understanding your rights to health care
  - Recognising signs of violence, abuse, neglect and exploitation in health care systems and what to do if experiencing this

## **Inclusive person-centred accessible health care**

QDN members with disability and their families consistently raise access to quality, safe, affordable, accessible and timely health care as a major priority. People with cognitive disability have a diverse range of accessibility needs across primary, acute and sub-acute health services. Engagement with people with disability in the planning, design, implementation and evaluation of projects, including major infrastructure projects like hospital redesign, is critical to designing accessible health services. Incorporating functional accessible design features like dimmable lighting, private waiting rooms and breakout spaces for quieter areas, adult continence change equipment, continence bins, ostomy cleaning facilities in accessible toilets, accessible equipment, hoists and earing loops in the planning of this project will deliver improved services and patient experiences. Many of the access and inclusion issues are related to building design and structural issues are most easily addressed when designing major building works, rather than additional outlay to retrofit and re-design, which often results in higher costs and budget investments.

Delivering accessible, integrated and inclusive health services, environments and infrastructure starts with including the end-users from the beginning of the conversation. This includes people with disability who access public hospitals and community health services.

## **Conclusion**

QDN acknowledges that people with intellectual disability have both historically experienced abuse, neglect, exploitation and violence when accessing a range of health care services and acknowledges the impact that this has had on individual's lives, which continues today. QDN strongly supports reform and change that

leads to improved health care, delivered by a well-equipped health system, with appropriately trained and skilled clinicians and health professionals. This will ultimately reduce the number of preventable deaths of people with intellectual disability and ensure that people's rights to access health services are upheld. QDN strongly supports a system that is built upon evidence and data, and delivers coordinated, integrated and quality health care for Australians with intellectual disability.