Joint submission to the Mental Health Select Committee

Mater Intellectual Disability and Autism Service (MIDAS), Mater and the Queensland Centre for Intellectual and Developmental Disability (QCIDD), Mater Research Institute-University of Queensland

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Summary of our recommendations

Queenslanders with intellectual and / or developmental disability experience profound inequities in accessing mental health services. Mainstream mental health services have systemically poor knowledge of intellectual and developmental disability, and this contributes to the discrimination, inaccessible service, and care environments, and ultimately, disproportionately poorer mental health status this population experiences. While specialist intellectual and developmental disability services exist, funding and staffing constraints substantially limit capacity to meet the mental health needs of Queenslanders with intellectual and developmental disability.

We propose four key recommendations for improving mental health outcomes for people with intellectual and developmental disability:

(1) Training of mainstream mental health services and professionals in intellectual and developmental disability.

(2) Mandatory requirements for mental health services to make reasonable adjustments to enable people with intellectual and developmental disability to access mental health care (including consideration of suitable inpatient facilities).

(3) Funding research to better understand mental health service access issues in Queensland for people with intellectual or developmental disability.

(4) Expansion of specialist intellectual and developmental disability services to ease demand and enable timely care provision for individuals experiencing greater case complexity.

The responsibility for providing and meeting the mental health needs of people with intellectual and /or developmental disability has long been shunted and perceived as 'someone else's problem'. Combined, these strategies represent key systemic changes that could translate into the improved mental health wellbeing of this population.

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About us

The Mater Intellectual Disability and Autism Service (MIDAS), Mater and the Queensland Centre for Intellectual and Developmental Disability (QCIDD), Mater Research Institute-University of Queensland (MRI-UQ), welcome the opportunity to make a submission to the Mental Health Select Committee. This submission is made by Mater and QCIDD to advocate for improved outcomes for people with intellectual or developmental disability.

The Queensland Centre for Intellectual and Developmental Disability (QCIDD), University of Queensland was established in 1997 to deliver a clinical service, education, and conduct research on the health of people with intellectual and developmental disability. For many years, QCIDD was jointly funded by Disability Services Queensland and Queensland Health (Mental Health Branch). In 2018, the funding was transferred to Mater to establish the Mater Intellectual Disability and Autism Service (MIDAS) to continue delivering the clinical service.

MIDAS and QCIDD work alongside at Mater South Brisbane with shared team members and office space. Together, we work to improve the health of Queenslanders with intellectual or developmental disability. We acknowledge that we have limited capacity and clinical scope as we are small teams with most staff employed part-time.

MIDAS provides a state-wide outpatient clinical service for people with intellectual and developmental disability aged 16 and over. Mater receives approximately $800,000 per annum from the Queensland Health Mental Health, Alcohol and Other Drugs Branch to provide our service, that sees approximately 350 new patients a year. In 2021 we accepted 440 referrals, predominantly from General Practitioners (GPs).

QCIDD is a small team consisting of 0.6FTE researchers and, with no recurrent funding, is wholly reliant on grant funding. QCIDD is positioned within the Mater Research Institute-UQ and our research is strongly grounded in our clinical experience and expertise in the area of intellectual and developmental disability. We draw upon our strong background in applied research in primary care for people with intellectual and developmental disability and a growing body of work in mental health research in the last five years. Our research often actively involves people with intellectual disability and Autistic people.

Due to the vast need and small size of our service, MIDAS uses a consultation-liaison model (rather than case-management or ongoing care models) to provide specialised intellectual and developmental disability health and mental health services to the community. MIDAS has an outward focus, aiming to provide support to care in the community rather than to unnecessarily draw clients into the hospital system. The demand for our service is high and increases annually. High demand for MIDAS is compounded by the lack of services in the private sector related to the lack of mental health professionals trained in intellectual disability.

About intellectual and developmental disability in Queensland

There are approximately 80,000 Queenslanders with intellectual and / or developmental disability, including autism.[1] *Intellectual disability* is characterised by significant limitations in intellectual functioning, difficulties in adaptive behaviour, with the conditions manifesting before adulthood. *Autism* is a developmental condition associated with differences in social interactions and communication, repetitive patterns of behaviour and sensory sensitivities. Approximately 30-40% of people with an autism diagnosis will also have a co-occurring intellectual disability.[2] The term 'intellectual and developmental disability (IDD) is used to refer to intellectual disability and developmental disabilities including autism. **It is important to note, that intellectual disability, developmental disability, and autism themselves are not mental health conditions.**

People with intellectual or developmental disability experience some of the greatest health disparities in our country. People with intellectual disability die up to 27 years earlier[3] and autistic people die up to 17 years earlier[4] than people without disability. Much of this health gap is preventable with a recent Queensland review of the deaths of people with disability finding that 53% of deaths were preventable.[5] The accessibility of health services, or lack thereof, contributes to the significant health gap this population experiences, with key barriers including lack of capacity of mainstream mental health services and staff.

People with intellectual and developmental disability experience mental health conditions at an earlier age and at higher rates than the general population.[6] Mental health conditions are two to three times more prevalent for people with intellectual disability compared to the general population. Autism is associated with higher levels of mental illness and Autistic people experience a **nine-fold increased risk of suicide**.[7] Autistic people, particularly those without a childhood diagnosis, are commonly misdiagnosed as, or have comorbid major

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[1] Australian Institute of Health and Welfare. Disability in Australia: Intellectual disability. Canberra: AIHW; 2008.

[2] Baio J, Wiggins L, Christensen DL, et al. Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. MMWR Surveill Summ 2018;67(6):1–23. doi: 10.15585/mmwr.ss6706a1.

[3] Florio, T. and Trollor, J. (2015), Mortality among a Cohort of Persons with an Intellectual Disability in New South Wales, Australia. J Appl Res Intellect Disabil, 28: 383-393. doi.org/10.1111/jar.12190

[4] Hwang, Y. I., Srasuebkul, P., Foley, K. R., Arnold, S., & Trollor, J. N. (2019). Mortality and cause of death of Australians on the autism spectrum. Autism Research, 12(5), 806-815. doi:10.1002/aur.2086

[5] Office of the Public Advocate. (2016). Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland. In. Brisbane: Department of Justice and Attorney-General, Queensland Government.

[6] Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. Br J Psychiatry. 2007;190:27-35.

[7] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. British Journal of Psychiatry, 208(3), 232-238. doi:10.1192/bjp.bp.114.160192

mental illness such as chronic schizophrenia or bipolar disorder[8] and therefore, are likely to be over-represented amongst those accessing mental health services.

People with intellectual and/or developmental disability also experience **high rates of off-label prescription of psychotropic medications** to manage challenging behaviours. One Queensland study found 82.2% of psychotropic medications prescribed to adolescents with intellectual disability was off-label and inappropriate.[9] Additionally, 49% of individuals whose deaths were reviewed by the Queensland Office of the Public Guardian were administered psychotropic medication without diagnosis of a mental illness.[10] Compared with the general population, people with intellectual disability may be more vulnerable to adverse effects associated with psychotropic medications, including weight gain, other metabolic effects and neurological symptoms.[11] People with intellectual and developmental disability are also more likely to experience **polypharmacy,** sometimes taking five or more medications a day, which increases the risk of developing adverse drug events, drug–drug interactions and medication-related problems.[12]

Comments on the Terms of Reference

We have addressed the following Terms of Reference in our submission:

(b) the current needs of and impacts on the mental health service system in Queensland;

(g) service safety and quality, workforce improvement and digital capability;

(i) relevant national and state policies, reports and recent inquiries including the Productivity Commission Mental Health Inquiry Report.

Mental health services for Queenslanders with intellectual or developmental disability

The current mental health system service in Queensland lacks capacity to meet the needs of people with intellectual or developmental disability. Gaining access to services is a persistent and ongoing issue for this client group, most of whom rely on public mental health services,

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[8] Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., . . . Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. Lancet Psychiatry, 6(10), 819-829. doi:10.1016/s2215-0366(19)30289-5

[9] Song, M., Ware, R. S., Doan, T. N., McPherson, L., Trollor, J. N., & Harley, D. (2020). Appropriateness of psychotropic medication use in a cohort of adolescents with intellectual disability in Queensland, Australia. BJPsych Open, 6(6), e142. doi:10.1192/bjo.2020.125

[10] Office of the Public Advocate. (2016). Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland. In. Brisbane: Department of Justice and Attorney-General, Queensland Government.

[11] Matson, J. L., & Mahan, S. (2010). Antipsychotic drug side effects for persons with intellectual disability. Research in Developmental Disabilities, 31(6), 1570-1576. doi:10.1016/j.ridd.2010.05.005

[12] McMahon, M., Hatton, C., and Bowring, D. L. (2020) Polypharmacy and psychotropic polypharmacy in adults with intellectual disability: a cross-sectional total population study. Journal of Intellectual Disability Research, 64: 834– 851. doi.org/10.1111/jir.12775.

with a significant dearth of specialist intellectual and developmental disability mental health services. Therefore, it is imperative mental health services are accessible, safe, and free from discrimination to people with intellectual and developmental disability. From our experience as a clinical service (including a large project assisting complex clients of mental health services to access the NDIS), coupled with knowledge from the research literature, we observe the following key barriers that contribute to this situation.

Mainstream mental health clinicians have difficulty identifying and recognising mental health conditions in people with intellectual and developmental disability. When individuals with IDD attempt to access mainstream mental health services, they are frequently refused care, representing a particularly pernicious manifestation of the phenomenon of 'diagnostic overshadowing'. Diagnostic overshadowing means that clinicians mistakenly identify signs of mental illness as being due to behaviour or the disability itself, rather than a treatable illness - "it's just your disability". Autistic people also have the experience of health professionals equating autism with the presence of intellectual disability, despite only about 30-40% of autistic individuals having intellectual disability. Diagnostic overshadowing precludes the diagnosis of a mental health condition and subsequent access to care and treatment, contributing to increased morbidity and poorer health outcomes.

People with intellectual and developmental disability are refused access to services for treatment of severe mental illness. There is no data collection on the number of people with intellectual or developmental disability in mental health services, and no data on how many are refused or dismissed when seeking mental health services. However, we know from our patients in our clinic this is a very frequent experience, with at least one patient per 1-2 weeks reporting they were declined access to mental health services, even when referred by our service with severe mental illness. Concerningly, these patients are often experiencing psychosis or catatonia and are very unwell. Some are reasonably referred for ECT (electroconvulsive therapy, reserved for very severe mental illness, and are declined access. If they did not have an intellectual or developmental disability, they would qualify for access. Evidence from the MIDAS in-reach project found a concerning number of clients – almost half – had a new or missed diagnosis of a mental illness (e.g., schizophrenia, depression and post-traumatic stress disorder). To illustrate the risks and complexity of this group, two patients (of the 169 who were referred) died prior to assessment and one sustained a significant and preventable disabling self-injury.

Related to the issue of diagnostic overshadowing, as a clinical service, we witness **hesitation from mental health services to accept clients with intellectual and developmental disability**. We believe that mental health services reject patients with IDD due to legitimate concerns of long in-patient stays and that inpatient units are unsafe for people with intellectual or developmental disability. Research within the Australian context illustrates people with IDD encounter markedly greater barriers to receiving admission into mental health units, and longer stays once accepted. However, such treatment delays result in a deterioration in mental state. Moreover, it does not change the fact that the person requires inpatient care, regardless of the lack of capacity of the system to support this. Some of these patients will go on to commit offences as part of their illness, which then complicates issues further as they become subject to the forensic order (disability), which usually mandates treatment by a mental health service and which is often a long-term proposition.

People with intellectual and developmental disability who are subject to Forensic Orders are not well-supported by the mainstream mental health services. There was a review of the forensic disability service system in 2018[13] but little seems to have changed. In practice, once subject to a forensic order (disability), there is little in the way of rehabilitative options. Mental illness may or not be present and these clients must be managed by mainstream mental health services, who, as already stated (including by these services), lack the capacity to do so. This is also a group, since the advent of NDIS, that struggle to access NDIS-funded services due to their complexity, especially those who commit sexual offences, often in the context of lack of basic sexual education. The current service system does not adequately support this group, who remain of significant concern.

Barriers to accessing mental health services are amplified for people with intellectual and developmental disability from groups vulnerable to social disadvantage. Individuals living in rural locations, similar to those without an intellectual disability, encounter greater barriers to accessing mental health services. People with intellectual and developmental disability from Aboriginal or Torres Strait Islander backgrounds experience elevated rates of mental health issues and are over-represented in our clinic population. Barriers to accessing mental health services are further compounded for non-Australian citizens who are also ineligible for the NDIS. For those in rural or remote areas, telehealth represents an alternative for when services are geographically difficult to access, however, barriers to telehealth use are exacerbated in this population. People with intellectual and developmental disability experiencing higher rates of socioeconomic disadvantage which is often a barrier to affording and using technological infrastructure. Any future initiatives aimed at increasing access to services must consider the needs of people with intellectual and developmental disability and including individuals as part of the co-design process of policy design and implementation.

The roll-out of the NDIS has added another layer of complexity when attempting to access care. There are several gaps in service, particularly around how to access the necessary assessments and documentation in order to prove eligibility for the NDIS; these are often costly and difficult to obtain especially for those with borderline or mild ID. The adult space and autism space also lack clinicians who are trained and experienced in providing these assessments. There are still significant delays between application, plan meetings and plan approvals. Additionally, considerable time can be spent finding suitable services. There is a particular lack of services for people with severe challenging behaviour (i.e., services previously provided by Disability Services but now expected to be available in the NGO / private sector).

The underlying reasons for this lack of capacity relate to:

1. **Lack of staff knowledge and education in this area**
2. **Inaccessible health service environments**
3. **Lack of data to map the scale and service use patterns of people with intellectual or developmental disability in mainstream mental health services**
4. **Insufficient support by specialist intellectual and developmental disability mental health teams**

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[13] The State of Queensland (Department of Communities, Disability Services and Seniors) SECTION 157: Review of the operation of the Forensic Disability Act 2011 Final report. https://documents.parliament.qld.gov.au/tableOffice/TabledPapers/2018/5618T1581.pdf

1. Lack of mainstream mental health staff knowledge and training in intellectual and developmental disability mental health

Inadequate knowledge and training results in barriers to receiving diagnosis, and thus, care for mental health conditions. Mental health issues do not necessarily present differently in people with intellectual disability compared to the general population. Instead, it is clinicians misunderstanding of intellectual disability or autism (diagnostic overshadowing) coupled with their lack of skills around clinical examination and history taking that contributes to under-diagnosis and misdiagnosis of mental health issues in this population. Health professionals also report low self-efficacy in communicating with people with intellectual disability, causing a host of issues such as excluding individuals from decision-making, failing to consult their lived experience in the clinical interview, and an inordinate reliance on support people. Inadequate knowledge of IDD results in poor self-efficacy in working with this group and in a tendency for risk-averseness or inaction when providing care. It contributes towards mental health services hesitating to accept and provide services to people with IDD due to fears regarding treatment complexity. The disability sector can be complex, and this also contributes to poor access to services. Clinicians also have little working knowledge of the NDIS, preventing identification of patients eligible for receiving behavioural and social support.

Recommendation: **Support mandatory education and training for mainstream mental health staff about intellectual and developmental disability.** Upskilling mental health professionals in their knowledge of IDD forms a primary component of workforce improvement and is foundational to improving the mental health outcomes for this group. To understand and address the mental health needs of people with IDD, education and training will cover areas including diagnostic overshadowing, reasonable adjustments, and communication. Improving clinicians' knowledge of the NDIS to identify suitable participants is crucial for this group who may respond well to increased social and behavioural support. MIDAS is currently creating easily scalable training through an NDIS-funded grant which can potentially be mandated for mental health workers state-wide, but this will require support and resources to deliver state-wide.

2. Inaccessible health service environments

Autistic individuals and those with intellectual disability experience environmental and interpersonal barriers to accessing mental health services. Barriers span from environmental barriers such as harsh lighting and loud noises, and interpersonal ones such receiving inaccessible communication to being excluded from their healthcare decision-making. These experiences compound, leading to an increase or escalation of behaviours of concern and can result in longer admissions. This is particularly relevant to individuals on a forensic order. These barriers can be addressed through minor practice changes. Yet, uptake and implementation of such actions remain low due to individual- and service-level unawareness.

Recommendation: **Services should be required to make reasonable adjustments to enable people with intellectual and developmental disability to access mental health care**, similar to reasonable adjustments mandates enabling people with physical disabilities to access health care. This should include consideration of dedicated space for inpatient treatment of people with IDD, including those who require ECT.

3. Lack of data to map the scale and service use patterns of people with intellectual and developmental disability in mainstream mental health services

There is a lack of data and research about the mental health needs of people with IDD. We need to understand the service use of those with intellectual or developmental disability, including those who are declined from mental health services. This is necessary to quantify and characterise the extent of mental health service accessibility for this cohort. Research is required to establish a more robust and tailored understanding of the experiences within the Queensland context. Bolstering research capacity in this sphere could enable improved understanding of the barriers and facilitators of accessing mental health care due to state-based differences in mental health services. Opportunities for conducting process evaluations of existing services and areas for improvement are curtailed by limitations in funding. Enhanced research capacity will also support the development of scalable education programs covering mental health in intellectual and development disability, an area sorely lacking training and education programs.

Recommendation: **Mandate data reporting from mainstream mental health services in relation to how many people with intellectual and developmental disability access their services.** Commission data-based research to better understand the patterns of service usage for this population in order to inform services and target resources appropriately.

4. Role of specialist intellectual and developmental disability in mental health services

Specialist IDD mental health services in Queensland are currently positioned to relate to (i) mainstream mental health services (through the Specialist Mental Health Intellectual Disability Service - SMHIDS) and (ii) the community (primary care, private specialists) (through MIDAS). However, these services are too small to respond to the level of demand and the requirements of an area that has been long neglected. The scale of the problem exceeds the capacity of these two small services to respond. These services provide the vehicle to undertake the education and research to support these recommendations, should funding be allocated.

Recommendation: **Service capacity of specialist intellectual and developmental disability mental health services need to be expanded.** While we advocate for the upskilling of all mental health professionals, we recognise there will be clients who require specialist IDD input. There is high demand for our services and for the other IDD service in Queensland, SMHIDS. Specialist services are significantly limited and concentrated in Brisbane despite the geographic spread of Queensland. Our service is not resourced to provide care face-to-face outside of Brisbane. Increasing resources for specialist services is key to meeting demand and the mental health needs of this group.

Relevant national and state policies, reports and recent inquiries

The importance of treating mental illness and intellectual disability has been highlighted in several policies spanning disability, mental health and designated national round table meetings involving experts across health, disability, and NGO and government sectors. There is a significant gap in relation to autistic adults and mental illness. We would like to represent to the Select Committee that whilst there are numerous reports and inquires relating to people with IDD, we find recommendations are often not followed and there is a lack of financial commitment or oversight of relevant authorities to ensure they are enforced.

National

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2019-ongoing)[14] is currently running and is investigating widespread reports of violence against, and the neglect, abuse and exploitation of, people with disability. It is addressing systemic issues including those experienced in the healthcare system by people with intellectual and developmental disability. Key issues around access to health services were addressed in *Public hearing 4: Health care and services for people with cognitive disability.*[15] Relevant to the remit of this committee was the need for health professionals to communicate effectively with their patients, the attitudes health professionals hold about disability and how these negatively impact care, the impact of diagnostic overshadowing, the need for health and disability services to work together cohesively and the need to collect better data about people with disability in health systems. The findings from hearing four directly led to an investigation of the educational needs of health professionals which was explored in *Public hearing 10: Education and training of health professionals in relation to people with cognitive disability*.[16] The committee identified four key learning areas for health professionals and these are pertinent for mental health clinicians to have: diagnostic overshadowing and the misdiagnosis of health conditions in people with cognitive disability; cultural attitudes, assumptions and beliefs about the quality of life of people with cognitive disability; communication with people with cognitive disability and their families and carers, support persons, and; gaps in specialised knowledge in cognitive disability. Learnings from *Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern*[17] (where Dr Franklin was called as an expert witness) are also relevant to the committee including a thorough exploration of behaviours of concern, how they relate to individual's experiences of mental health services and chemical restraint, and the interplay between disability and health services.

In 2018, a Communique outlining key recommendations to improve the lives of people with intellectual disability and mental illness was released by the Department of Developmental Disability Neuropsychiatry (3DN) following the National Roundtable on the Mental Health of People with Intellectual Disability.[18] The Communique provides guidelines at provider and

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[14] Disability Royal Commission. (2022). Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from https://disability.royalcommission.gov.au/

[15] Disability Royal Commission. (2020). Public hearing 4: Health care and services for people with cognitive disability. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from https://disability.royalcommission.gov.au/public-hearings/public-hearing-4

[16] Disability Royal Commission. (2020). Public hearing 10: Education and training of health professionals in relation to people with cognitive disability. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from https://disability.royalcommission.gov.au/public-hearings/public-hearing-10

[17] Disability Royal Commission. (2020). Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from https://disability.royalcommission.gov.au/public-hearings/public-hearing-6

[18] Department of Developmental Disability Neuropsychiatry. (2018). Communiqué: Recommendations from the National Roundtable on the Mental Health of People with Intellectual Disability 2018. In. Sydney: UNSW 3DN. https://www.3dn.unsw.edu.au/sites/default/files/documents/Communique_Full.pdf

organisational levels to strengthen and improve the accessibility of mental health services for people with intellectual disability, and advocates for inclusive policy environments with robust and meaningful contributions from key stakeholders, particularly people with intellectual disability. Provider level recommendations are centred around reasonable adjustments, such as implementing appointment and referral documents, minimising environmental factors that cause pain or discomfort (e.g., bright lights, noises among others), developing frameworks facilitating interdisciplinary collaboration, staff are well-versed in communicating accessibly, up-to-date staff training on intellectual disability and identifying those with intellectual disability, and regular screenings for psychotropic side-effects for those prescribed psychotropics, among others. The guide underscores the importance of engaging the individual with intellectual disability in decision-making and means of maximising and ensuring their meaningful involvement.

The Fifth National Mental Health Plan (2017)[19] highlights the higher prevalence of mental illness in people with intellectual disability. The barriers are also recognised in national policy including that people with intellectual disability experience barriers accessing timely and appropriate mental health care services identifying communication deficits as a key barrier. Intellectual disability is often identified as the cause of dysfunctional behaviours which impedes appropriate mental health assessment and treatment. The Fifth National Mental Health Plan highlights the need for coordinated care between services and specialised services staffed with people who have training across mental health and intellectual disability.

The National Disability Strategy 2010-2020[20] covers the principles of Inclusion, Rights Protections, Justice and Legislation, Economic Security, Personal and Community Support, Learning and Skills and Health and Wellbeing. In particularly, the policy highlights that diagnoses that cross intellectual disability and mental health are often poorly detected and not managed appropriately further supporting access to specialist services to address these needs and increasing the skills of mental health clinicians.

Queensland

Within the Queensland context, there are several reports and inquiries that are important to consider and have impacted the mental health service landscape.

The Forensic Disability Service System review (2018)[21] initially aimed to investigate the treatment of people with intellectual disability involuntarily detained or declared unfit for trial (those subject to Forensic Order). There were sufficient concerns raised that this was

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[19] Australian Government Department of Health (2017). Fifth National Mental Health and Suicide Prevention Plan. Retrieved from https://www.mentalhealthcommission.gov.au/monitoring-and-reporting/fifth-plan/5th-national-mental-health-and-suicide-prevention

[20] Australian Government Department of Social Services (2012). National Disability Strategy 2010-2020. Retrieved from https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020

[21] The State of Queensland (Department of Communities, Disability Services and Seniors) SECTION 157: Review of the operation of the Forensic Disability Act 2011 Final report. https://documents.parliament.qld.gov.au/tableOffice/TabledPapers/2018/5618T1581.pdf

broadened to include a commissioned review of the broader forensic disability service system in Queensland. The commissioned review by Ogloff et al suggested wide-ranging reform, however, despite being tabled in Parliament in 2018, there has been no appreciable change in this area.

The Office of the Public Advocate investigated the cause of death of Queenslanders receiving disability services. The Deaths in Care report (2016)[22] found 59% of the deaths were preventable. Of the 74 deaths, a high proportion (49%) were being administered psychotropic medication in cases where, based on available information, few seemed to have a diagnosis of mental illness. Whilst not solely focused on mental health, the report made recommendations that need to be considered by mental health services; improvements in education and training for health professionals about disability, improved interplay and coordination between health and disability services, review of the use of psychotropic medication and overall improved access to specialised health professionals and services.

The Barret Inquiry (2016),[23] an investigation into the closure of in-patient services for young people, prompted by the suicide of 3 young people, one of whom had intellectual disability, recommended improved coordination between services designed to support young people with intellectual disability and mental illness. There has been no appreciable change in this area and no expansion of services to support this fragile cohort. The considerable amount of funding dedicated to reform following this report did not include any funding for services for young people with intellectual or developmental disability who continue to fall between the cracks of services whilst transitioning form child to adult services.

The Carter Inquiry (2006),[24] a seminal investigation into service responses to people with intellectual disability with severe challenging behaviours, also recommended a coordinated and cooperative relationship between health and disability services that took a comprehensive approach that incorporated both physical and mental health. Additionally, the Carter Inquiry also noted the need for a cooperative effort towards assessment, intervention and management for this population. In response to this report, the Queensland Government initiated a new service (SDSAOT, now SMHIDS) and a Centre of Excellence in Behaviour Support, however, these have since been defunded or shifted focus.

Conclusion

People with intellectual and developmental disability with additional mental health conditions are often perceived as complex patients in the mental health service. They often have communication difficulties, and they lack a voice in this service system. People with intellectual and developmental disability also have higher rates of severe mental illness. They deserve equal access to mental health services without discrimination.

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[22] Office of the Public Advocate. (2016). Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland. In. Brisbane: Department of Justice and Attorney-General, Queensland Government.

[23] Wilson, M (2016). Barrett Adolescent Centre Commission of Inquiry Report. Retrieved from http://www.barrettinquiry.qld.gov.au/Barrett-Adolescent-Centre-Commission-of-Inquiry-Report.pdf

[24] Carter, WJ (2006). Challenging Behaviour and Disability: A Targeted Response. Report to the Queensland Government.

We call on the Inquiry to make a finding that Queensland mental health services lack capacity in intellectual and developmental disability mental health and require additional resourcing to improve access to services for people with intellectual or developmental disability.

Our additional recommendations are to support and fund (where indicated):

- **mandatory education** and training for mainstream mental health staff about intellectual and developmental disability. Such education is already in development and would require high-level support for state-wide implementation as part of mandatory education in Hospital and Health Services.
- **mandatory requirements** for mental health services to make reasonable adjustments to enable people with intellectual and developmental disability to access mental health care (including consideration of suitable inpatient facilities).
- **mandatory reporting** of data from mainstream mental health services in relation to how many people with intellectual and developmental disability access their services. Supporting investment in research to better understand the patterns of service usage for this population in order to inform better targeting of services and resources.
- **expanding service capacity** of specialist intellectual and developmental disability mental health services.

The mental health services for this population remain dangerously inadequate despite this group experiencing distressingly poorer mental health outcomes. Mainstream mental health services all identify that they lack capacity in this area. This issue must be addressed. People with intellectual and developmental disability have equal rights to access mainstream mental health services but this is not the experience in Queensland currently.

Systemic change is overdue and desperately warranted.

Yours sincerely

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