Submission No 96

INQUIRY INTO EQUITY, ACCESSIBILITY AND APPROPRIATE DELIVERY OF OUTPATIENT AND COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH WALES

Organisation: Department of Developmental Disability Neuropsychiatry, UNSW

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Submission: Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

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Summary

- People with intellectual disability represent 1-2% of the overall Australian population. There is a higher prevalence of intellectual disability among First Nations peoples compared to non-First Nations peoples.
- People with intellectual disability experience poorer mental health than people without intellectual disability.
- People with intellectual disability represent a sizable proportion of community mental health service users, with substantial associated costs; people with intellectual disability represent 6% of NSW community mental health service users with associated costs per person being approximately two times higher than for people without intellectual disability (1).
- People with intellectual disability who are from diverse populations (e.g., First Nations peoples and people from culturally and linguistically diverse backgrounds) may experience compounding inequities in access to community mental healthcare.
- Specialist mental health services have an important role in coordination and engagement of community mental health services.
- Among people with intellectual disability and serious mental illness in custody in NSW, provision of community mental health support is associated with a substantial reduction in return to custody (2).
- Current mental health service provision to people with intellectual disability is inefficient; compared to people without intellectual disability, people with intellectual disability are more likely to return to the emergency department or have an inpatient stay after an initial hospitalisation for a mental health condition. Improved capacity in the public outpatient and community mental health sector would help to address this.
- Addressing the above issues from an equity perspective would require:
    - A significant enhancement to the mental health workforce capacity in intellectual disability mental health, including for generalist and specialist services
    - Significant training and education for all mental health professionals to equip them to meet the needs of people with intellectual disability
    - Uniform inclusion of clinical care pathways for people with intellectual disability in all community mental health services, including for children and younger people, adults, and older persons.
- Our submission addresses multiple points from the Terms of Reference for this inquiry including: (a) equity of access to outpatient mental health services; (d) integration between physical and mental health services, and between mental health services and providers; (e) appropriate and efficient allocation of mental health care workers; (h) accessibility of mental health services for people with disability.

About 3DN

The Department of Developmental Disability Neuropsychiatry, also known as 3DN, sits within the pre-eminent Discipline of Psychiatry and Mental Health at UNSW Sydney. Our website has detailed information about our activities https://www.3dn.unsw.edu.au/. 3DN is a world-leading centre for intellectual and developmental disability health care. 3DN's strategic plan outlines a vision for the "The highest standard of health and wellbeing for people with cognitive disability." 3DN works closely with nationally representative networks of people with cognitive disability, their supporters, and health professionals to inform opinions and directions. There are three main strands of work at 3DN. We *Build Capacity* through teaching, training, health promotion, development of educational resources and the conduct of other professional activities. We conduct Research with high translational benefit to the disability and health sectors. We provide Consultancy of the highest standard, including: providing clinical consultations, sharing expertise and advice, engaging in advocacy and making detailed contributions to policy and legislative reviews. 3DN leads ground-breaking national initiatives to improve the mental health care of people with intellectual disability. For example, we have produced a

detailed understanding of the population health needs of people with intellectual disability; we have scoped the need for, designed, implemented and evaluated health service system initiatives; and we have conducted detailed mixed methods research to better understand health and wellbeing of people with intellectual disability.

About the Authors

Professor Julian Trollor (MB BS (Hons 1), FRANZCP, MD)
Professor Julian Trollor holds the position of inaugural Chair of Intellectual Disability Mental Health at UNSW Sydney. He also heads the Department of Developmental Disability Neuropsychiatry within the Discipline of Psychiatry and Mental Health, School of Clinical Medicine at UNSW Sydney. He is a clinician in the local health district and an academic psychiatrist with neuropsychiatry and developmental disability subspecialisations. Julian leads national initiatives in health care for people with intellectual and developmental disability. He works with Commonwealth and State Government Departments to improve health services for people with an intellectual or developmental disability. He sits on multiple Commonwealth and State Government Committees and provides advice to regulatory bodies in his area of expertise. Julian also develops and delivers courses in mental health and intellectual disability. Julian is involved in diverse research programs that examine the health inequalities experienced by people with intellectual or developmental disability and design solutions to the issues arising. He is passionate about inclusive research practices and enjoys rich interdisciplinary collaborations.

Dr Janelle Weise (BAppSc (OT) (Hons), MPH, PhD)
Dr Janelle Weise is an Occupational Therapist and Senior Research Fellow with a background in public health who drives a translational program of research that aims to equip the health sector to meet the needs of people with intellectual disability. She has worked across clinical, service delivery and managerial roles within the disability and health sectors. She is passionate about addressing the inequitable access to healthcare and poor health outcomes experienced by people with an intellectual disability and other priority populations.

Dr Rachael Cvejic (BPsych (Hons), MBMSci, PhD)
Dr Rachael Cvejic is a registered psychologist and Senior Research Fellow who leads a program of translational research that aims to improve health outcomes for people with intellectual disability, progressive neurological conditions, and serious mental illness. She has worked across clinical and academic roles in the area of mental health.

Dr Pramudie Gunaratne (MD BMed BA MMed (Psychiatry) MSc (Pub Health) FRANZCP GAICD)
Dr Pramudie Gunaratne is a neuropsychiatrist and Research Fellow. She is passionate about understanding population-level drivers that affect mental health and improving access to mental health services for people with intellectual disability. In addition to her academic role at 3DN, she works clinically in intellectual disability mental health and co-founded Seriph Clinics, a specialist private service caring for people with complex neuropsychiatric disorders.

Background

People with intellectual disability represent 1-2% of the Australian population (3, 4) and face stark health inequalities and systemic neglect within the Australian healthcare system (https://disability.royalcommission.gov.au/public-hearings/public-hearing-4). There is a higher prevalence of intellectual disability among First Nations peoples compared to non-First Nations peoples; the 2018 Survey of Disability, Ageing and Carers found that 10.1% of First Nations men and 5.9% of First Nations women reported having an intellectual disability (5). As a signatory to the United Nations Convention on the Rights of Persons with Disabilities, Australia is committed to upholding the rights of persons with intellectual disability to the highest attainable standard of health. However, systemic inaction across all elements of the healthcare sector, including the mental health sector continues to delay the achievement of this right for people with intellectual disability.

People with intellectual disability experience two and a half times more health problems (6) and a higher burden of multimorbidity (7) than people without intellectual disability. The prevalence of mental health conditions is at least two to three times higher in people with intellectual disability compared to the general population (8). Many people with intellectual disability also experience a high degree of complexity and an atypical profile and presentation of mental health conditions (9), thus requiring a high level of psychiatric expertise, and coordinated approaches between services. The poor mental health status of people with intellectual disability, and commitments to address this issue, have been clearly articulated in the National Disability Strategy (10). Further priorities to address the mental health needs of people with intellectual disability were determined at successive National Roundtable on the Mental Health of People with Intellectual Disability (11-12), and in progressive documents such as the NSW Mental Health Commission's 10-year strategic plan (13) and the Fifth National Mental Health and Suicide Prevention Plan (14).

Despite the over-representation of mental health conditions in people with intellectual disability, people with intellectual disability continue to be inadequately represented in mental health policy (15) and face multiple systemic barriers to accessing mental health services, including a shortage of service availability, organisational barriers, poor quality services, and the scarcity of a skilled workforce (16). People from culturally and linguistically diverse backgrounds may experience compounding inequity related to accessing services and supports, as well as understanding and navigating systems and settings (17)

What we know about Australian mental health services for people with intellectual disability

- Research in NSW has found that people with intellectual disability:
    - make up 1% of the NSW population, but 6% of those who use publicly funded mental health services, and 12% of the public mental health costs (1)
    - are twice as likely than the general population to have services failure, as characterised by psychiatric readmission or emergency department re-presentation after their first psychiatric admission (18)
    - have 1.6 times more face to face contacts within ambulatory mental health services, and a total contact time which is 2.5 time longer compared to the general population (19)
    - are 2.5 times more likely to be given an 'unknown diagnosis when accessing ambulatory mental health services (19).
- The importance of provision of community mental health services is highlighted by our existing research focusing on people with intellectual disability and serious mental illness in custody in NSW. Our research shows that receiving community mental health support post-release was associated with a 42% lower reincarceration rate, and that receiving a combination of community mental health and disability support was associated with a 54% lower reincarceration rate (2).

- Our research shows that the public NSW mental health workforce has low confidence in key clinical areas, insufficient training, and inadequate resources to meet the need of people with intellectual disability (20). The mental health workforce requires unique and additional attributes to meet this need (21-23).
- Off label use of psychotropic medications is common in people with intellectual disability, especially in the management of behaviours of concern (24).
- Our work with Australian data in primary care shows that psychological reasons for encounters with primary care are significantly higher for people with intellectual disability compared to people without intellectual disability (25).
- Our secondary analysis of data collected by the Royal Australian and New Zealand College of Psychiatrists suggests a potential future shortage of psychiatrists with expertise in the area of intellectual disability mental health (26).
- There is a role for specialist intellectual disability mental health services in meeting the mental health needs of people with intellectual disability (27-28).

Gaps in current mental health programs and supports

There are significant gaps in current programs and support available for people with intellectual disability and cooccurring mental health conditions in NSW. These include:

- the lack of explicit identification of people with intellectual disability in mental health policy in Australia, despite the high vulnerability to mental health conditions in this group (15)
- inaccessible mental health-related information (29)
- the lack of preventative and mental health promotion programs which target, and are accessible to, people with intellectual disability (29)
- poor recognition of the specific needs of people with intellectual disability and their carers in clinical care settings, including lack of awareness about adaptations to clinical approach in mental health services and professionals (20)
- limited education and training of mental health professionals (10,30-31), and no mandatory expectation that mental health professionals obtain the attributes outlined in the Intellectual Disability Mental Health Core Competency Framework (32)
- a lack of clear articulation of role and responsibility between the National Disability Insurance Scheme and health sectors (33-34)
- very few specialist services in the area of intellectual disability mental health; there is emerging evidence of the important role of specialist services in meeting the mental health need of people with intellectual disability (27-28)
- the lack of specific identification of people with intellectual disability within routinely collected mental health data, and lack of ability to report outcomes
- inadequate support for people with complex behaviour support needs; people with intellectual disability presenting with complex behaviour require physical and mental health assessment in order to determine the aetiology of their behaviour. Further, they may require mental health input into decision making regarding treatment, including the need for psychotropic medication in this context (35).

Action to meet the mental health needs of people with intellectual disability

Our recommendations to improve health outcomes for Australians with intellectual disability are summarised in these key locations:

- Professor Julian Trollor's statement to the Disability Royal Commission
- https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0049.0001.0001.pdf
- The communique from the National Roundtable on the Mental Health of People with Intellectual Disability
    - Full version can be found here: https://www.3dn.unsw.edu.au/sites/default/files/documents/Communique_Full.pdf

- Easy read version can be found here: https://www.3dn.unsw.edu.au/sites/default/files/documents/Communique_EasyRead.pdf

In summary, key elements of action include:

- equipping mainstream mental health services to meet the needs of people with intellectual disability
- mandating training among all key stakeholders, drawing on the existing knowledge on the core attributes required of mainstream mental health professionals (32)
- introducing mechanisms that accurately identify people with intellectual disability within routine data collections
- mandating the need for services and professionals to make reasonable adjustments to meet the needs of people with intellectual disability. The Guide (36) provides a framework to base these adjustments on
- further development of specialised intellectual disability mental health services, drawing on the existing knowledge on specialist mental health services (27-28)
- introducing clinical pathways and coordination to respond to the needs of this people with intellectual disability, including for children and adolescents, adults, and older adults
- measuring and routinely reporting outcomes for people with intellectual disability and their support networks
- making mental health information accessible to people with intellectual disability. Examples of this can be found within our Department's Easy Read information sheets on accessing mental health services in NSW (https://www.3dn.unsw.edu.au/projects/making-health-informationaccessible-people-intellectual-disability) and Intellectual Disability Mental Health Connect website (https://idmhconnect.health/)
- considering cultural sensitivity and safety in the provision of community mental health care for people from diverse populations, including First Nations peoples and people from culturally and linguistically diverse backgrounds
- developing models of care that can better reach people from diverse populations that may experience compounding inequity in access to community mental health care.

Other points:

i) Members of our team are available to give evidence at a hearing.
ii) We consent to this submission being published with our names included.

We thank the Committee for this opportunity for input into this important issue. Should you wish to discuss the content of this submission please do not hesitate to contact us.

Sincerely,

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