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Inquiry into the opportunities to improve mental
health outcomes for Queenslanders

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Summary

- People with intellectual disability:
 - represent 1-2% of the Australian population.
 - face stark health inequalities and systemic neglect within the Australian healthcare system, including the mental health sector.
 - are two-three times more likely to experience common mental health problems but face substantial barriers to access and participate in mental health services.
- The Committee's consideration of the specific mental health needs of people with intellectual disability is critical to improving mental health outcomes for Queenslanders.
- The National Roundtable on the Mental Health of People with Intellectual Disability provides a blueprint of clear and actionable recommendations for the ongoing improvement in mental health services and outcomes for people with intellectual disability.
- Existing resources and insights from action in other states such as New South Wales provide tools for change.

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 "highest attainable standard of health and wellbeing for people with intellectual disability". 3DN works closely with nationally representative networks of people with intellectual disability, autism, carers, 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 of population health needs of people with intellectual disability; we have scoped the need for, designed, implemented and evaluated health service system initiatives for these populations; and we have conducted detailed mixed methods research to better understand health and wellbeing of people with intellectual disability.

About the Authors

Dr Janelle Weise (BAppSc (OT) (Hons), MPH, PhD)

Dr Janelle Weise is an Occupational Therapist 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 vulnerable populations.

Professor Julian Trollor MB BS (Hons 1, FRANZCP, MD)

Julian 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 School of Psychiatry at UNSW. 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.

Background

People with intellectual disability (ID) represent 1-2% of the Australian population (1, 2) and they face stark health inequalities and systemic neglect within the Australian healthcare system (<https://disability.royalcommission.gov.au/public-hearings/public-hearing-4>). 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 ID 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 ID.

Compared to people without ID, people with ID experience two and a half times more health problems (3) and a higher burden of multimorbidity (4). The prevalence of mental ill health is at least two to three times higher in people with ID compared to the general population (5). Many people with ID also experience a high degree of complexity and an atypical profile and presentation of mental illness (6), thus requiring a high level of psychiatric expertise, and coordinated approaches between services. The poor mental health status of people with ID, and commitments to address these problems, have been clearly articulated in the National Disability Strategy (7). Further priorities to address the mental health needs of people with ID were determined at successive National Roundtable on the Mental Health of People with Intellectual Disability (8-9), and in progressive documents such as the NSW Mental Health Commission's 10-year strategic plan (10) and the Fifth National Mental Health and Suicide Prevention Plan (11).

Despite the over-representation of mental illness in people with ID, access to mental health services in Australia is limited and falls far short of that for the general population. People with ID continue to be inadequately represented in mental health policy (12) 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 (13). In essence, the mental health services system, including that in Queensland, is currently unable to meet the mental health need of people with ID.

What we know about Australian mental health services for people with ID

- Research in NSW has found that people with ID:
 - 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 (14)
 - 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 (15).
 - 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 (16).
 - are 2.5 times more likely to be given an 'unknown diagnosis when accessing ambulatory mental health services (16).
- 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 ID (17). The mental health workforce requires unique and additional attributes to meet this need (18-20)
- Research using Queensland data found that off label of inappropriate use of psychotropic medications was common in adolescence with ID, especially in the management of challenging behaviour (21)
- Our work with Australian data in primary care shows that psychological reasons for encounters with primary care are significantly higher for people with ID compared to people without ID (22)

We note the limited knowledge about specific capabilities of the Queensland mental health sector to meet the needs of people with intellectual disability. However, the available evidence indicates that Queensland is similar in this regard to other Australian jurisdictions.

Gaps in current mental health programs and supports

There are significant gaps in current programs and support available for people with ID and co-occurring mental ill health. These include:

- the lack of explicit identification of people with ID in mental health policy in Australia, despite the high vulnerability to mental disorders in this group (12).
- inaccessible mental health-related information (23-24).
- the lack of preventative and mental health promotion programs which target, and are accessible to, people with ID (23).
- insufficient support from education and disability sector to promote mental wellness.
- poor recognition of the specific needs of people with ID and their carers in clinical care settings, including lack of awareness about adaptations to clinical approach in mental health services and professionals (17).
- limited education and training of mental health professionals (17,25-26), and no mandatory expectation that mental health professionals obtain the attributes outlined in the Intellectual Disability Mental Health Core Competency Framework (27).
- a lack of clear articulation of role and responsibility between the National Disability Insurance Scheme and health sectors (28-29).

- very few specialist services in the area of intellectual disability mental health. However, there is emerging evidence of the important role that specialist service plan in meeting their mental health needs (30-31).
- the lack of specific identification of people with ID 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 (32).

Action to meet the mental health needs of people with ID

Our recommendations to improve health outcomes for Queenslanders with ID are summarised in these key locations:

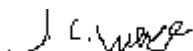
- Professor Julian Trollor's statement to the Disability Royal Commission
 - <https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0049.0001.0001.pdf>
- The communique from the National Roundtable on the Mental Health of People with Intellectual Disability
 - Full version can be found 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_Easy-Read.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 (27).
- introducing mechanisms that accurately identify people with ID 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 (33) provides a framework to base these adjustments on.
- developing of specialised intellectual disability mental health services. Drawing on the existing knowledge on specialist mental health services (30-31).
- introducing clinical pathways and coordination to respond to the needs of this group.
- 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-information-accessible-people-intellectual-disability>).

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 ([REDACTED]) or [REDACTED]

Sincerely,



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References

1. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Res Dev Disabil.* 2011;32(2):419-36.
2. Wen X. The definition and prevalence of intellectual disability in Australia. Canberra: Australian Institute of Health and Welfare; 1997.
3. van Schroyen Lantman-De HM, Metsemakers JF, Haveman MJ, Crebolder HF. Health problems in people with intellectual disability in general practice: a comparative study. *Family practice.* 2000;17(5):405-7.
4. Hermans H, Evenhuis HM. Multimorbidity in older adults with intellectual disabilities. *Res Dev Disabil.* 2014;35(4):776-83.
5. Cooper, S-A., et al., Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry,* 2007, 190(1): 27-35.
6. Fuller, C.G. and D.A. Sabatino, Diagnosis and treatment considerations with comorbid developmentally disabled populations. *Journal of Clinical Psychology,* 1998, 54(1): 1-10.
7. Council of Australian Governments. National Disability Strategy 2021-2031. Canberra: Commonwealth of Australia.
8. NSW Council for Intellectual Disability. National Roundtable on the Mental Health of People with Intellectual Disability – Communique, 2013.
9. Department of Developmental Disability Neuropsychiatry, UNSW Sydney (2018). Recommendations from the National Roundtable on the Mental Health of People with Intellectual Disability 2018. Department of Developmental Disability Neuropsychiatry, UNSW Sydney.
10. NSW Mental Health Commission. Living Well: A Strategic Plan for Mental Health in NSW. Sydney, NSW Mental Health Commission, 2014.
11. Australian Government Department of Health. (2017). The Fifth National Mental Health and Suicide Prevention Plan. Canberra: Commonwealth of Australia.
12. Dew, A., Dowse, L., Athanassiou, U., & Trollor, J. (2018). Current Representation of People With Intellectual Disability in Australian Mental Health Policy: The Need for Inclusive Policy Development. *Journal of Policy and Practice in Intellectual Disabilities,* 15(2), 136-144
13. Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2017). Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review. *Journal of Mental Health Research in Intellectual Disabilities,* 11(1), 69-102.
14. Srasuebkul, P., Cvejic, R., Heintze, T., Reppermund, S., & Trollor, J. N. (2021). Public mental health service use by people with intellectual disability in New South Wales and its costs. *Medical Journal of Australia,* 215(7), 325-331.
15. Li X, Srasuebkul P, Reppermund S, et al. (2018) Emergency department presentation and readmission after index psychiatric admission: a data linkage study. *BMJ Open* 8: e018613.
16. Howlett S, Florio T, Xu H, et al. (2015) Ambulatory mental health data demonstrates the high needs of people with an intellectual disability: Results from the New South Wales intellectual disability and mental health data linkage project. *Australian & New Zealand Journal of Psychiatry* 49: 137-144.
17. Weise, J., & Trollor, J. N. (2017). Preparedness and Training Needs of an Australian Public Mental Health Workforce in Intellectual Disability Mental Health. *Journal of Intellectual & Developmental Disability,* 1-10
18. Weise, J., Fisher, K. R., & Trollor, J. N. (2017). Establishing core mental health workforce attributes for the effective mental health care of people with an intellectual disability and co-

- occurring mental ill health. *Journal of Applied Research in Intellectual Disabilities*, 30(S1), 22-33
19. Weise, J., Fisher, K. R., Whittle, E., & Trollor, J. N. (2018). What Can the Experiences of People With an Intellectual Disability Tell Us About the Desirable Attributes of a Mental Health Professional? *Journal of Mental Health Research in Intellectual Disabilities*, 1-20
 20. Weise, J., Fisher, K. R., & Trollor, J. N. (2018). What makes generalist mental health professionals effective when working with people with an intellectual disability? A family member and support person perspective. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 413-422.
 21. 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).
 22. Weise J, Pollack A, Britt H, Trollor J. Primary health care for people with an intellectual disability: an exploration of demographic characteristics and reasons for encounters from the BEACH programme. *J Intellect Disabil Res*. 2016;60(11):1119-27.
 23. Trollor, J.N., It's time to address the mental health needs of people with intellectual disability. *Australasian Psychiatry*, 2018. 26(6): p. 575-576.
 24. Newman, B., Fisher, K. R., & Trollor, J. (2021). Right to Information for People with Intellectual Disability in Australian Mental Health Policy. *Journal of Policy and Practice in Intellectual Disabilities*.
 25. Trollor, J. N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T., . . . Lennox, N. (2016). Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught. *Nurse Education Today*.
 26. Trollor, J. N., Ruffell, B., Tracy, J., Torr, J. J., Durvasula, S., Iacono, T., . . . Lennox, N. (2016). Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC medical education*, 16(1), 1-9.
 27. Department of Developmental Disability Neuropsychiatry. (2016). *The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals*.
 28. New South Wales Parliament Legislative Council, Implementation of the NDIS and the provision of disability services in NSW. 2018. NSW Government: Sydney.
 29. Joint Standing Committee on the National Disability Insurance Scheme, Transitional Arrangements for the NDIS. 2018. Australian Government: Canberra.
 30. Weise, J., Cvejic, R. C., Eagleson, C., Trollor, J. N. (2020). A Scoping Study of a Tertiary Intellectual Disability Mental Health Service: A Family Member and Support Person Perspective, *Journal of Mental Health Research in Intellectual Disabilities*, DOI: 10.1080/19315864.2020.1753268
 31. Walsh, J. A., Weise, J., Eagleson, C., Trollor, J. N., & Cvejic, R. C. (2021). Expert consensus on the operation of an adult tertiary intellectual disability mental health service in New South Wales, Australia. *Australasian Psychiatry*, 29(6), 635-643.
 32. Council for Intellectual Disability. (2018). *A pathway through complexity. Report from the NSW Roundtable on Meeting Complex Behaviour Support Needs in the NDIS 2017*
 33. Department of Developmental Disability Neuropsychiatry (2014). *Accessible mental health services for people with an intellectual disability: A guide for providers*. Sydney, NSW: Department of Developmental Disability Neuropsychiatry.