Faculty of Medicine, The Department of Developmental Disability Neuropsychiatry 3DN

Submission to the Productivity Commission inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth

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About the Department of Developmental Disability Neuropsychiatry

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney supports the mental health needs of individuals with an intellectual disability (ID) through the education and training of health and disability professionals and by conducting research with a particular focus on the mental health of people with ID. 3DN's vision is to work with people with ID, their carers and families, to achieve the highest attainable standard of mental health and wellbeing. 3DN is led by UNSW's inaugural Chair of Intellectual Disability Mental Health, Professor Julian Trollor, who is supported by a dedicated team of researchers, project and administrative staff. Professor Trollor has over 20 years of clinical experience in the management of people with ID and complex health and mental health problems. He has had extensive experience with a range of disability service providers and professionals, and has led or contributed to numerous legislative, policy and service reviews in the disability arena. More information about 3DN and the work of the Chair IDMH can be found on our website: http://3dn.unsw.edu.au/

In 2018 3DN hosted, in collaboration with the Council for Intellectual Disability, the second National Roundtable on the Mental Health of People with Intellectual Disability. The Roundtable brought together 130 lead clinicians, academics and sector representatives from around Australia. The Roundtable provided a blueprint of clear and actionable recommendations for the sector, and acts as a catalyst for ongoing improvement in mental health services and outcomes for people with intellectual disability (6).

Background

People with ID represent about 1.8% of the Australian population, or approximately 450,000 individuals (1). People with ID experience very poor physical and mental health compared to the general population. They often have complex support needs, which arise because of complexity at the person level, at the service level or systems levels. The prevalence of mental ill health is at least two to three times higher in people with ID compared to the general population (2). Many people with ID experience a high degree of complexity and an atypical profile and presentation of mental illness (3), 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 (4). 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 (5-6), and in progressive documents such as the NSW Mental Health Commission's 10 year strategic plan (7) and the Fifth National Mental Health and Suicide Prevention Plan (8)

Despite the over-representation of mental illness in people with ID, access to mental health services is limited and falls far short of that for the general population. People with ID continue to face numerous barriers to service access, including a shortage of service availability, organisational barriers, poor quality services, and the scarcity of a skilled workforce (9), and research suggests that the rates of mental health service uptake do not match their health needs (10-13). These preliminary findings highlight the need for potential solutions that begin with the consideration of the needs of people with ID in all aspects of health policy and services development.

In the following we address the terms of reference for the Productivity Commission's inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth.

Consequences of mental ill health

- Research has shown that individuals with ID and co-occurring mental ill health have poorer quality of life, poorer health outcome, and higher mortality rates as compared to the general population (14-16).
- Emerging reports and studies have revealed that the health inequality in individuals with ID and co-occurring mental ill health can be partially explained by the low quality of healthcare provided to this minority population (17-20).
- Without adequate and sufficient support, individuals with ID and co-occurring mental ill health turn to acute healthcare and emergency services for support. An Australian data linkage study found individuals with ID were more twice as likely to have psychiatric readmission and ED presentation after the first psychiatric admission compared to the general population (21).
- A study investigated ambulatory mental health use in New South Wales Australia also found individuals with ID are significantly more likely to use ambulatory to access mental health services and were 2.5 times more likely to be given an 'unknown' diagnosis (22).
- In the criminal justice system, Individuals with ID and co-occurring mental illness were reported to be more likely to commit a crime or being a victim of a crime. Among the adult prisoners with ID, a high proportion also had comorbid psychiatric conditions (23).
- A systematic review conducted by Simpson and Hogg in 2001 found that the individuals who have ID and co-occurring mental ill health in justice system are 'a very complex group of individuals' who are often the 'most stigmatized populations with a 'psychiatric', 'disability' as well as 'offender' label (24).
- The frequent utilisation of healthcare and criminal justice services not only reflected the high cost involved with the service utilisation in this population but also the potential human costs on the individuals and their families including barriers to community and economic participations.

Effectiveness & cost of current programs and supports

- In a multi-disciplinary partnerships for better health project funded by the NHMRC (see Link https://3dn.unsw.edu.au/project/national-health-medical-research-council-partnerships-better-health-project-improving-mental) we worked together with key mental health, disability, education, justice and consumer agencies to improve mental health outcomes of people with ID. Key findings have include: much higher admission rates, length of stay and associated costs of mental health admissions for people with ID in NSW, compared to people without ID. Further, our analysis identified that:
    - individuals with ID represent 5.5% of people accessing ambulatory mental health care and 6.3% of people admitted to a psychiatric ward in 14-15 financial year.
    - people with ID constituted 12% of all mental health expenditure in 14-15 financial year.
    - the mean cost per person with ID for all mental health service utilisation was $24,878 compared to $10,587 per person without ID.
    - the cost differences in in-patient mental health care is more significant than the difference in all mental health services.

- In 14-15 financial year, the cost per person for in-patient mental health care was $ 81,321 for those with ID compared to $32,582 for all.
- The repeat service use pattern and the cost of current mental health services illustrated that current mental health services are ineffective in responding to the needs of those with ID.

Gaps in current programs and support available

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 (25).
- Mental health-related information that is not accessible to people with ID (26).
- The lack of preventative and mental health promotion programs which target and are accessible to people with ID (26).
- 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 (27).
- Limited education and training of mental health professionals (27-29), and no mandatory expectation that mental health professionals obtain the attributes outlined in the Intellectual Disability Mental Health Core Competency Framework (30).
- A lack of clear articulation of role and responsibility between the National Disability Insurance Scheme and health (31-32).
- Very few specialist services in the area of intellectual disability mental health.
- 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 (33)

Likely effectiveness of alternative programs and supports

Currently there is a paucity of research into the effectives of alternative programs and supports for people with ID. A Cochrane review into health service for people with ID found that there is an urgent need for high-quality health services research to identify optimal health services for people with ID (34).

The 2018 National Roundtable on the Mental Health of People with Intellectual Disability (6) identified eight elements of an effective mental health system for people with ID. Within each of these elements practical recommendations were made including:

1. Inclusion: The mental health needs of people with intellectual disability are specifically considered and accommodated in all mental health initiatives.
2. Prevention and timely intervention: People with intellectual disability and their families receive education and support to prevent, and to obtain early and timely assistance for mental illness.
3. Access to skilled services: All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

4. Specialist services support mainstream mental health services: A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.
5. Collaboration: Ongoing joint planning by disability services, schools and mental health and other relevant services including (a) identification of referral and treatment pathways; and (b) a framework and capacity for collaborative responses where intellectual disability and mental health needs co-exist.
6. Workforce development and support: Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.
7. Data: Collection and analysis of data that measures mental health needs, access to services, and outcomes of people with intellectual disability.
8. Multiple disadvantage: All Elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, culturally and linguistically diverse (CALD) background, and contact with the criminal justice system

The actioning of these recommendations will help to realise the right of people with ID to the achievement of the highest attainable standard of mental health.

We thank the Productivity Commission or 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. We can be contacted

Sincerely,

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