



Submission to the National Mental Health Commission's Review of Mental Health Services and Programs - Improving Mental Health Outcomes of People with an Intellectual Disability

Never Stand Still

Medicine

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Contents

Intellectual Disability: An Important Minority Group for Mental Health Services	1
Current situation in Australia	1
The need for improvement in Australia.....	2
Some progress in the right direction.....	2
Recommendations for the Review of Australian Mental Health Services.....	3
1. Specific consideration of the ID population group:.....	3
2. Specialised intellectual disability mental health services:.....	3
3. Enhanced training and education:	3
4. Mandated cross-portfolio collaboration:	3
5. Data Collection:	3
6. Research:.....	3
References	4

Intellectual Disability: An Important Minority Group for Mental Health Services

- Over 300,000 people in Australia have an Intellectual Disability (ID) [1].
- People with ID experience very poor mental health and physical health status compared to the general population. This is characterised by very elevated rates of mental disorders [4, 5] including the dementias [6-9], multiple chronic complex disorders and higher mortality [2, 3].
- The increased physical and psychiatric morbidity for persons with ID is compounded by difficulty accessing health and mental health services. Australian research followed a cohort of children and adolescents with ID for 14 years and demonstrated that just 10% of those with a mental disorder received access to an intervention [4] over that period. This compares unfavourably with access to mental health supports for the general population which has been estimated to be about 35% over a one year period [10].
- Potential barriers to accessing effective mental health care for people with ID include: communication difficulties; atypical and complex presentations; a lack of empirical data on the interaction between disability and mental health services; a lack of training and confidence of mental health professionals [11-14]; poor understanding by families, disability and mental health workers of the manifestations of mental disorders in people with ID [15-17]; and poorly developed interagency service models.
- The strong link between disability, physical and mental health in people with ID highlights the importance of policy and legislation which clearly addresses the complex issues for this population and articulates a joint framework for cross-agency service provision [18].

Current situation in Australia

- Despite the over-representation of mental disorders in people with ID, access to mental health services for people with ID is limited and falls far short of that for the general population.
- In Australia, comprehensive physical and mental health models, policy and services for people with ID await development. While pockets of expertise in ID physical and mental health exist across Australia, their scarcity and lack of integration with mainstream services limits accessibility.
- At a jurisdictional level, funding that attempts to meet the complex needs of this population is administered by two distinct government agencies- Mental Health and Disability. Consequently the organisation of services reinforces a 'siloing' of expertise, fosters inter-agency disputes regarding service provision and also limits the capacity for holistic mental health intervention.
- This separation engenders in staff of both services a reduced capacity to share resources, triage and assessment practices and knowledge [19], and does not facilitate staff to strive for a person centred approach.
- Potential barriers to accessing effective mental health care for people with ID in an Australian context: a lack of substantial Australian epidemiological data on prevalence of mental illness in people with ID; a lack of data on the interaction between, and distinct roles and responsibilities of disability and mental health services [18]; a lack of training and confidence of mental health professionals [20-23]; poor understanding by carers [24], disability and mental health workers, and allied health professionals, of the manifestations of mental disorders in people with ID [25-26]; a lack of coherent service models and funding for ID mental health services [18]; lack of coordination between services and treating agencies [27]; and a lack of specific inclusion of people with ID in mental health policy and service development nationally.
- Although outcome data is not available, it is a reasonable assumption that the relative lack of accessible and appropriately skilled mental health services and practitioners results in lower rates of treatment and recovery from mental illness for people with an ID. Furthermore, the lack of application of preventative mental health care means that vulnerabilities and risk of

relapse remain unchecked. For a person with ID, continuing symptoms of mental ill health often manifest as challenging behaviour, which if unaddressed leads to social and workplace exclusion [36] and high cost for services.

- A systemic cross-portfolio approach to improving mental health outcomes for persons with an ID is greatly needed.

The need for improvement in Australia

- Australian mental health services fall far short of its obligations to commitments made under the United Nations Convention on the Rights of Persons with Disabilities [28] and lag behind the international standards exemplified by the UK and other lead countries in the European Union (see the UK policy framework Valuing People [29] and Valuing People Now [30]).
- Australia's Fourth National Mental Health Plan highlights the vulnerability of people with ID to mental disorders, recognising that those with ID and co-occurring mental disorder are "overlooked, and access to appropriate treatment for both disabilities is limited" [31, p.70]. The National Mental Health Plan highlights the urgent need to address mental disorders in this group, and to do so in an inclusive manner (see Priority Areas 1 and 2) [31]. The National Standards for Mental Health Services mandate that Mental Health Services provide equal access and entry (Criteria 10.2 and 10.3 respectively) in an appropriate and timely manner. Entry to a Mental Health Service should represent "a defined pathway with service specific entry points that meet the needs of the consumer, their carer(s) and its community that are complementary to any existing generic health or welfare intake systems" [32, p.23].
- The pathways to mental health care for persons with ID are however, ill-defined and under researched. There is currently a clear mismatch between the expectations outlined in policy and the currently available services and expertise.
- The National Disability Strategy (Council of Australian Governments 2011) commits all governments in Australia to six key outcomes, one of which is: "People with disability attain highest possible health and wellbeing outcomes throughout their lives." To give effect to this outcome, the Strategy specifies policy directions and action areas including that expansion of national action on mental health should "explicitly meet the needs of people with disability" [33].

Some progress in the right direction

- There are a number of laudable National and NSW State policy initiatives in ID health and mental health, such as: the National Roundtable and the development of a National Guide on the issue (both funded by the Commonwealth Department of Health, formerly the Department of Health & Ageing); the NSW Health Service Framework on the Health of People with ID [34]; and the NSW Health ADHC Memorandum of Understanding on the Mental Health of People with ID [35].
- In NSW, there has also been some service development in this area, with the funding of three pilot multidisciplinary teams in ID health, each of which includes a mental health component. The most established of these is the MRID.net in the South Eastern Sydney and Illawarra Shoalhaven Local Health Districts, which is a specialist multidisciplinary health service led by the Kogarah Diagnostic and Assessment Service (DAS) at St George Hospital.
- While these laudable initiatives go some way to improving the system to better meet these needs, specific service and policy development within mental health is required at a national level.
- The lack of services and poor access to mental health services for people with ID has far reaching consequences, not just for the individual with an ID, but also carers, and services themselves.

Recommendations for the Review of Australian Mental Health Services

1. **Specific consideration of the ID population group:**

The needs of people with ID and a mental disorder should be specifically considered and accommodated in mental health policy and service development as a specific target group. This means that any new policies, services or funding of mental health services are to include a specific requirement that the policy or service will provide equitable access and appropriately skilled treatment to people with ID.

2. **Specialised intellectual disability mental health services:**

A national network of specialist ID mental health psychiatrists, nurses, psychologists and other professionals. These professionals would act as a consultancy, training and research adjunct to mainstream mental health services.

3. **Enhanced training and education:**

Improved training and education in the area of ID mental health is required for clinicians and disability workers, this would include:

- Mandated training in ID mental health to minimum standards, or core competencies, for front-line and other professional staff in mental health and disability services. Building the expertise and skills of clinicians and disability staff in Australia in the management of persons with ID (in assessment, triage, referral and treatment) is integral to improving mental health outcomes for this group. It is also integral to the success of this training that it is embedded in a work culture that supports its effective use in practice.
- Funding the establishment of a national training centre in ID mental health (either virtual or physical) that provides training in ID mental health, is a resource hub, and brings together key experts in ID mental health from across the country. This Centre would be the site where professionals will be skilled up; where staff, consumers and family will be able to access training modules, and multimedia and print resources.

4. **Mandated cross-portfolio collaboration:**

Enhanced joint planning by mental health and disability services including the development of a mandated shared case-coordination capacity where ID and mental health disorder co-exist.

5. **Data Collection:**

Enhanced data collection and data linkage methods are needed on a national level between health, disability and other administrative datasets (such as Centrelink, Education, Medicare and PBS data). Collating and interrogating epidemiological data is an important first step in improving the mental health of Australian adults with ID. However, epidemiological data relating to the prevalence and impact of mental disorders, the impact on families, and the direct cost to health services, is limited. Data evaluating the way in which Health and Disability sectors intersect, the impact of services on the mental health of people with ID, the specific mental health vulnerabilities of ID, and those with mental disorders who offend is very limited.

6. **Research:**

Investment is needed to develop the research base for good practice in intellectual disability mental health. This would include:

- Translational research investigating sub-populations of persons with ID, such as offenders with ID, and those who are ageing with ID.
- Qualitative research exploring the barriers of access to service use by people with ID, incorporating consumer and family perspectives.
- The feasibility of including specific initiatives that target people with ID should be explored for inclusion in targeted grant rounds of the National Health and Medical Research Council (NHMRC) and other relevant research funding opportunities.

Finally, building mental services and policy in a way that supports people with ID will ultimately reduce unnecessary hospitalisation and this is likely to be far more cost-effective in this tight current fiscal environment.

We welcome the opportunity to be further involved in the work of the Commission and your efforts in working towards improving the mental health outcomes for persons with an ID in the national mental health service system. Should you wish to discuss the content herein, please contact, Associate Professor Julian Trollor, j.trollor@unsw.edu.au or by phone on (02) 9931 9160.

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