Submission to the National Mental Health Commission - National Mental Health & Suicide Prevention Report Card: Mental Health Needs of Persons with an Intellectual Disability

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Background

- Over 300,000 people in Australia have an Intellectual Disability (ID) [1].[1]

- People with ID experience very poor health status compared to the general population. This is characterised by multiple chronic complex disorders, higher mortality [2, 3], and very elevated rates of mental disorders [4, 5] including the dementias [6-9].

- 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 an intervention [4] over that period. In stark contrast, about 35% of the general Australian population with a mental disorder receive a mental health service over a 12 month 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.

Current situation

- 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.

- Furthermore, Mental Health and Disability funding is administered by two distinct government agencies and 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.

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[1] It needs to be noted here that the systematic collection of data on intellectual disability at a State and National level is yet to be established and current prevalence estimates are not without their integrity issues.

- This separation engenders in staff of both services a reduced capacity to share resources, triage and assessment practices and knowledge [18] with the best possible outcome in mind for the person with ID.
- Both mental health and disability workers lack skills in intellectual disability mental health.
- A cross-portfolio approach to improving mental health outcomes for persons with an ID is greatly needed.

Impetus for Change

- Australia recently ratified the United Nations Convention on the Rights of Persons with Disabilities [19]. Article 25 of the Convention states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health", and that signatories should "take all appropriate measures to ensure access for persons with disabilities to health services" [19, p.18].
- Further, Article 31 of the Convention instructs that "States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention...the information collected in accordance with this article shall be used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights." [19].
- Australian health services fall far short of these obligations, 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 [20] and Valuing People Now [21]).
- 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" [22, 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) [22]. 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" [23, 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" [24].

Recent Developments in NSW

- The development of a "NSW Service Framework to Improve Health Care of People with ID" has seen the funding of three Specialist ID health pilot projects as well as for an ID Network as part of the Agency for Clinical Innovation. One of the three pilot ID health projects (MRID.net) is an outreach service run out of South Eastern Sydney Local Health District and contains a strong focus on improving mental health service outcomes for people with ID in the Illawarra region. The pilot serves as an exemplar of good practice in cross-collaborative effort.
- The "NSW Memorandum of Understanding between Ageing, Disability and Home Care (ADHC) and NSW Health on Provision of Services to Persons with ID and Co-occurring Mental Illness" has seen the establishment of Working Groups within each LHD, which report to a Joint (ADHC/NSW Health Mental Health) Committee. These Groups aim to case conference and resolve difficulties in cross agency service provision and improve local training initiatives in ID mental health [25].
- The establishment of a Chair of Intellectual Disability Mental Health at UNSW (funded until February 2014 by the Office of the Senior Practitioner, Ageing Disability and Home Care, NSW Department of Family & Community Services) has allowed the commencement of the following initiatives:

    i. Data linkage – linking health and disability data to establish the epidemiology of mental illness among persons with ID; to understand the service pathways engaged by this population and to draw comparisons with the general mental health population.
    ii. Education and Training - education and training modules have been and continue to be developed for mental health and disability staff, undergraduate and postgraduate students. Modules are currently being converted into an online course. Work is also

being undertaken to develop a package of Core Competencies for staff working with persons with ID.

iii. Research – research is being undertaken into various sub-groups of populations of persons with ID, such as those ageing with ID, offender populations, and genetic conditions that underlie ID, such as Fragile X and Tuberous Sclerosis.

iv. Lobbying and awareness raising– working with Consumer and Advocacy groups in the submission of proposals to State and Federal government, and responses to Policy initiatives.

What is required?

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 all mental health reform processes. This entails 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. Policies and services such as the ATAPs, EPPICC, and Headspace would all have an ID component embedded into them to ensure this population is specifically accommodated in the day-to-day running of these funded programs.

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

The Federal Government should fund 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.

The Department of Developmental Disability Neuropsychiatry and the National and NSW Council for Intellectual Disability would welcome the opportunity to be further involved in the development of annual Report Cards on Mental Health and in improving the mental health

outcomes for persons with an ID in the National Mental Health Reform process. Should you wish to discuss the content herein, please contact either, Associate Professor Julian Trollor, Department of Developmental Disability Neuropsychiatry j.trollor@unsw.edu.au or by phone on (02) 9931 9160, or Mr Jim Simpson, NSW Council for Intellectual Disability, jcsimpson@optus.net.au or by phone on (02) 9345 5504

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