3DN Submission
5th National
Mental Health Plan Draft

Never Stand Still | Medicine | Department of Developmental Disability Neuropsychiatry

Professor Julian Trollor MBBS, FRANZCP, MD
Chair, Intellectual Disability Mental Health
Head, Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
UNSW Australia
j.trollor@unsw.edu.au

Ms Janelle Weise, BAppSc (OT) (Hons), MPH
Project Officer, Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
UNSW Australia
j.weise@unsw.edu.au

Dr Simone Reppermund, Dipl.-Psych., PhD
Senior Lecturer, Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
UNSW Australia
s.reppermund@unsw.edu.au

UNSW AUSTRALIA | 3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

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About the Department of Developmental Disability Neuropsychiatry

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Australia leads National and State developments in Intellectual and Developmental Disability Mental Health through education and training of health and disability professionals and by conducting research with a particular focus on the mental health of people with intellectual disability (ID). 3DN's vision is to work with people with ID and Developmental Disabilities (DD), 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/

Background

People with ID represent about 1.8% of the Australian population, or approximately 400,000 individuals (1). People with ID experience very poor physical and mental health compared to the general population. They often have complex support needs, which can arise because of complexity at the person level, complexity at the service level or systems levels. The prevalence of mental disorders 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 disorders (3), thus requiring a high level of psychiatric expertise, and coordinated approaches between services. The poor health and 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 a recent National Roundtable on the Mental Health of People with Intellectual Disability (5), and in progressive documents such as the NSW Mental Health Commission's 10 year strategic plan (6). The lack of specific mention of people with ID in the current draft of the National Mental Health Plan is therefore out of step with the broad acknowledgement of this problem. Policy leadership from the Australian Government forms a core part of the solution to the poor mental health of people with ID.

Despite the over-representation of mental disorders in people with ID, access to mental health services is limited and falls far short of that for the general population. In a current 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 work together with key mental health, disability, education, justice and consumer agencies to improve mental health outcomes of people with ID. The partnership project aims improve access to, and quality of, mental health services for people with ID using an innovative multi-pronged, mixed method approach. The project uses large scale data linkage, comprehensive policy analysis and inclusive qualitative methodologies to establish an evidence base from which to guide the development of targeted, appropriate services as well as improving access to services for people with ID and mental health issues at both national and state levels. Key findings thus far 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; lack of explicit identification of people with ID in mental health policy in Australia, despite the high vulnerability to mental disorders in this group; and lack of recognition of the specific needs of people with ID in clinical care settings, including lack of awareness about adaptations to clinical approach in mental health services and professionals. 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. Hearteningly, Health Minister Sussan Ley as well as the NSW Minister for Mental Health, Hon Pru Goward, and their respective Departmental Staff and advisors, are aware of our work through recent discussions with them. As such, we make the following recommendations for the inclusion of people with ID within the fifth national mental health plan for your consideration.

Recommendations

People with ID need to be specifically included in the fifth national mental health plan. They have very high mental health needs which are inadequately met by the mainstream and specialised mental health services, and leadership in inclusive policy development is required by Government if this issue is to be addressed. Further, inclusion the right to full participation in all aspects of community life and should be able to access all components of mental health services, including mainstream and specialised mental health services. This can only be achieved by including people with ID in mental health policy and legislation.

More specifically, within each section of the draft plan we make the following recommendations:

Setting the scene

- When discussing the key issue of unmet needs, we recommend that examples are provided of groups who are more likely to experience unmet needs, including people with ID and co-occurring mental ill health.
- When referring to the issues faced by the workforce it is important to recognise that the existing requirements of the mental health workforce, as articulated in the National Practice Standards for the Mental Health Workforce and the National Mental Health Core Capabilities, do not meet the needs of people with ID. Our department has undertaken a significant body of work and has released the Intellectual Disability Mental Health Core Competency Framework, which articulates the additional skills that the generalist workforce require to meet the need of people with ID (please see https://3dn.unsw.edu.au/idmh-core-competency-framework for further details on this work).
- We recommend that the National Disability Strategy is acknowledged as one of the key policy documents that is driving national reform.

Values that underpin the Fifth Plan

- We note that the key principle of 'recognition of social, cultural and geographic diversity and experience' has been removed in this revised version of the plan. We recommend that it is an essential key principle that should be included in the fifth plan because it allows for the need of diverse populations to be recognised.
- When referring to the specific needs of diverse groups we recommend that people with ID are specifically recognised.
- Within the value of equity it is important that disability and more specifically ID are specifically acknowledged.

Priority Area 1

- Figure 2 refers to the need for PHNs and LHNs to lead service integration. We recommend that non-government organisations are also included. The inclusion of non-government organisations is critical given their growing role in the delivery of mental health support.

- Under Action 1, national data analysis/reporting should specifically identify people with ID and planning tools should specifically be applicable and cater to the needs of people with ID.
- Under Action 2, the document refers to the need to engage a range of different community groups. We recommend that people with ID are specifically listed as one of these groups.
- When referring to the joint development of plans and services we recommend that disability action plans should also be referred to.

Priority Area 2

- Under Action 3, the plan articulates that the Government will work together to develop a set of national guidelines "for people with severe and complex mental illness" but no specific information is given about the target groups for the development of "national guidelines". We recommend that specific examples of target groups, including those with ID and mental illness are included, as our data shows that such individuals are among those least adequately catered for in current service provision.

  To ensure that these guidelines are in line with best practice and build on other work funded by the Department of Health and undertaken by us (see The Guide: http://3dn.unsw.edu.au/the-guide), it is essential that people with lived experience are included in their development. As such, we recommend that people with ID and other key stakeholders such as 3DN, NSW Council for Intellectual Disability, Queensland Centre for Intellectual and Developmental Disability, Centre for Developmental Disability Health Victoria, Australian Association of Developmental Disability Medicine be involved in the development of these guidelines.

Priority Area 5

- The plan currently identifies some key groups that are at increased risk of cardiovascular disease. However, people with ID and co-occurring mental ill health are not specifically recognised. Our literature reviews indicate that people with ID have very high rates of cardiovascular risk factors, and our recent analysis of all deaths in people with ID in NSW indicates that the biggest proportion of potentially avoidable deaths in people with ID are cardiovascular deaths. We therefore recommend that people with ID are recognised in this section of the plan because they experience high rates of cardiometabolic disease and their risk factors differ from people without ID.

We have been funded to develop an extensive clinical tool to reduce cardiometabolic burden in people with ID, which was launched in July 2016. For more information on this area please see here: http://3dn.unsw.edu.au/project/postive-cardiometabolic-health-people-intellectual-disabilities-early-intervention-framework

Priority Area 7

- We recommend that people with lived experience, including people with ID be involved in the development of the proposed mental health safety and quality framework.
- We recommend that any such framework takes into account the requirements of soon to be released NDIS Quality and Safety Framework, which will also be off relevance to people with a disability.
- We recommend that any such framework seeks to resolve the issue of the conflicting conceptualisation (within mental health and disability services) of "restrictive practices" as they relate to people with intellectual disability who receive psychotropic medication for the purposes of treatment of a mental health condition, challenging behaviour or both.
- We recommend that other key stakeholders such as 3DN, NSW Council for Intellectual Disability, Queensland Centre for Intellectual and Developmental Disability, Centre for Developmental Disability Health Victoria, Australian Association of Developmental Disability Medicine also be involved in this process.
- The plan currently refers to using the 'Your Experience of Service survey tool'. It is essential that this tool is accessible to all potential consumers and carers, including people with ID.
- We note that in figure four there is no reference to the National Mental Health Core Capabilities developed by Health Workforce Australia. We recommend that this document is referenced as it includes some of the key attributes required to meet the needs of people with ID.

Glossary

- We recommend that the definition of severe and complex mental illness be modified to recognise disability and the complexity of co-occurring conditions.

We thank the Government 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. We can be contacted by phone on (02) 9931 9160 or by email, j.trollor@unsw.edu.au,

Sincerely,

Professor Julian Trollor

Chair, Intellectual Disability Mental Health

Signed on behalf of all authors

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