**Submission No 195**

# INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

**Organisation:** Department of Developmental Disability Neuropsychiatry (3DN)

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

# Submission to the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

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

Ms Janelle Weise, BAppSc (OT) (Hons), MPH
Project Officer, Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
UNSW Australia

**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 health and wellbeing of people with intellectual and developmental disabilities . 3DN's vision is to work with people with intellectual and developmental disabilities, 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 has over 20 years of clinical experience in the management of people with ID and complex health and mental health problems. He and his staff have extensive experience with a range of disability service providers and professionals, and have led or contributed to numerous legislative, policy and service reviews in the disability arena. More information about 3DN and the Chair IDMH can be found on our website: http://3dn.unsw.edu.au/

**Background**

People with intellectual disability (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 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 health and mental health status of people with ID, and commitments to address these problems, have been clearly articulated in the National Disability Strategy 2010-2020 (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).

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. 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. 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.

In the following we address the terms of reference for the inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales.

**d) The effectiveness and impact of privatising government-run disability services**

We have observed that the privatisation of government-run disability service has had a negative impact on i) leadership and equipping the sector, ii) interagency capacity building, and iii) research.

i) Leadership and equipping the sector

State based providers had exemplarity systems for the professional development of staff and monitoring of standards. To date these systems have been severely degraded under NDIS. An implication of this has been the erosion of quality and safety across disability services. Examples can be given if required.

ii) Interagency capacity building

Supports for people with intellectual and developmental disabilities lie across a range of government and non-government sectors. The former State disability provider Ageing Disability and Home Care (ADHC) negotiated strongly with other sectors and took a leadership role in brokering interagency partnerships and cooperation. Under the NDIS this has ceased, and significant gaps have emerged. While we acknowledge the attempt to address this through the Integrated Response Team, further initiatives are required to bridge the gap, re-establish and promote interagency collaboration.

iii) Research

Another impact of privatising government run disability services has been the removal of funding for research that enhances service delivery, access, and participation for people with an intellectual disability and mental health problems. Within NSW, ADHC played a central role in funding research and development in this area. For example, the development of on-line educational programs and funding for key positions such as the Chair of IDMH (UNSW), Chair of Disability Behaviour Support (UNSW), Fellowships in Intellectual Disability Mental Health for Psychiatry Specialist Trainees (Health Education Training Institute), funding for projects between academics and the sector to develop workforce capacity. Into the future alternative sources will need to be identified to fund this type of research.

**e) The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme**

Under the NDIS there has been a decline in both the quality and availability of behaviour support. In NSW, the state government provider had three levels of behaviour support available (local

community teams, regional teams and state-wide teams). Under NDIS many clinical leads in behaviour support sector have left, and the non-government sector has far less expertise available for purchase.

The situation is further complicated by inadequate funding through NDIS of behaviour support, so that a person with challenging behaviour is far less likely to be able to purchase the support they require at the intensity required. The end result is the emergence of worsening behaviour and outcomes for people with more complex needs, carer stress and burnout and risk/stress to disability workers.

**h) Challenges facing disability service providers and their sustainability**

For people with complex support needs the existing NDIS pathways and funding models are inadequate. This results in further difficulties in accessing appropriate supports for those with complex needs. Further, disability services for this group are likely to continue to erode as providers are unable to access appropriate remuneration for their services to this group; hence they will begin to look elsewhere for better business prospects.

**i) Incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services**

Our experience suggests that the disability workforce currently have insufficient knowledge and skills in the area of intellectual disability health and mental health. The lack of capacity in these areas present barriers to accessing health and mental health service for people with an intellectual disability. We recommend that core competencies are develop for disability professionals relating to both the physical and mental health needs of people with an intellectual disability.

**k) Any other related matter**

Our Departments work with ageing carers suggests that they are finding the paperwork and ongoing review processes overwhelming. Some of our carers reported needing assistance from others to complete the paperwork. They also reported that some services have become more expensive under the NDIS, and that there can now be longer waiting times for equipment and assessments.

We recommend that the Memorandum of Understanding between Ageing Disability and Home Care and NSW Health be revised to reflect the transition to the NDIS. This is particularly important because our research suggests that effective collaboration between disability and health services is a key element of providing services that meet the needs of people with an intellectual disability (see Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers https://3dn.unsw.edu.au/the-guide).

We also recommend that consideration be given to how interdisciplinary practice can be facilitated, both within NDIS providers and across sectors, especially health and mental health. The need for interdisciplinary practice, especially at the pre-planning and planning stages of an NDIS application

is a key recommendation of a recent National Roundtable on the Mental health of People with Intellectual Disability (Department of Developmental Disability Neuropsychiatry, 2018).

We also strongly recommend that people with an intellectual disability are involved in the design and development of services and systems relating to the NDIS.

We thank the Legislative Council 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 or by email,

Sincerely,

Professor Julian Trollor
Chair, Intellectual Disability Mental Health

Janelle Weise
Project Officer

## References


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