Submission to National Disability Insurance Scheme Quality and Safeguards Framework April 2015

Never Stand Still | Medicine | Department of Developmental Disability Neuropsychiatry

A Response to the Consultation paper:

Proposal for a National Disability Insurance Scheme Quality and Safeguarding framework

Dr Simone Reppermund
Senior Project Officer
Department of Developmental Disability Neuropsychiatry
School of Psychiatry, Faculty of Medicine
UNSW Australia
s.reppermund@unsw.edu.au

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

Introduction and Background

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Australia 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 an 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/

A significant minority (about 2%) of Australia's population have an ID[1]. People with an ID experience very poor physical health and mental health compared to the general population. 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 an 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. Furthermore, people with an ID are vulnerable to exploitation and abuse, including physical and sexual abuse[4], which can further magnify their vulnerability to mental ill health and highlights the need for an appropriate quality and safeguards framework.

3DN commends the National Disability Insurance Agency (NDIA) on the development of the consultation paper "Proposal for a National Disability Insurance Scheme Quality and Safeguarding framework" (the Framework). The vulnerability of people with ID and mental ill health, and the complexity of the needs of this population, makes it essential that the Framework ensures a high standard and level of accountability of disability service providers and their staff.

Further, 3DN would like to encourage the NDIA consider how the Framework intersects with supports and safeguard in other jurisdictions, especially health, to enable a more complete appreciation of safety and outcomes of people with an ID.

[1] Australian Institute of Health and Welfare (2003). Disability Prevalence and Trends. AIHW Cat. No. DIS 34. Canberra: AIHW.
[2] Cooper, S-A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. The British Journal of Psychiatry, 190(1), 27-35.
[3] Fuller, C.G. and D.A. Sabatino, Diagnosis and treatment considerations with comorbid developmentally disabled populations. Journal of Clinical Psychology, 1998. 54(1): p. 1-10
[4] McCarthy, M. (1996). The sexual support needs of people with learning disabilities: A profile of those referred for sex education. Sexuality and Disability, 14(4), 265 -279.

3DN Submission

We submit the following comments and recommendations for your consideration.

Part 1: Proposed quality and safeguarding framework for the NDIS

Principles guiding the development of a Quality and Safeguarding framework for the NDIS

Page 4 of the consultation document outlines the proposed Principles guiding the development of the Framework. We have concerns about the completeness of these guiding principles.

3DN recommends:

1. *That the Framework includes a principle related to the need for evidence based practice for any disability services providing an intervention.*
2. *That the Framework includes a principle that specifies integrated and holistic support- that is, that an important principle of service provision is willingness to work across agencies (health, housing, other social services, etc) to provide seamless support for people with disabilities. This will assist the better integration of complex support needs, especially for those with ID and complex physical and mental health support needs.*

Under the Developmental Domain, 'providing information for participants' (page 12-13)

The issue of 'providing information' is mentioned. However, the issue of accessibility of this information to people with intellectual and other cognitive disabilities has not been addressed. Further, there is substantial consideration to 'online systems' without due acknowledgement that, unless considerable steps are taken, positioning of resources here has potential to exclude many people with an ID.

3DN recommends:

1. *The need for materials to be made available in easy English and pictorial formats should be made explicit, in order to enable people with ID to access them.*
2. *An alternative, or adaptation to 'on-line' systems should be articulated for people with disabilities such as ID, who may struggle to access such systems*

Under the Developmental Domain, 'building natural safeguards'' (page 15)

Self-advocacy is viewed as an important aspect, but needs to be contextualised to people with an ID.

3DN recommends:

1. *Additional support for a person with ID may be required if the self-advocacy aspect of safeguarding is to be effective for a person with ID.*
2. *Additional and in-depth consultation on this issue is suggested with groups such as Intellectual Disability Rights Service; National and NSW Council for Intellectual Disability, Self Advocacy Sydney.*

Under the Corrective Domain, 'serious incident reporting', (page 23)

People with an ID experience reduced life expectancy and premature mortality, including from preventable causes[5, 6]. Further, as evidenced by the recent Winterbourne View scandal in the UK (see https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf) significant abuses of people with ID have occurred within private enterprises. It would therefore be critical to develop a system of complaints, notifiable incidents and adverse outcomes which is subject to independent review.

3DN Recommends:

1. *The establishment of a Quality Care Commission or similar as a means of hearing complaints, reviewing notifiable incidents, reporting use of restrictive practices and reporting adverse outcomes*
2. *That a provider portal for notification of all above issues and incidents is developed, and that the use of this portal is mandatory for service providers.*
3. *That data from the 'incident management system' be independently analysed and reported annually to the public.*
4. *That such incident data be made compatible with, and available for, linkage to a NDIS minimum data set, the Commonwealth health data (PBS, MBS) and State and Territory health minimum data sets, and the ABS mortality data. This would enable an analysis of incidents and adverse outcomes across major support systems, would assist in the addressing of harms associated with restrictive practices or failures to address care needs, and would form the basis for analysis and the development of strategies to improve outcomes and reduce preventable deaths in people with disabilities*.

[5] Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD. The influence of intellectual disability on life expectancy. Journals of Gerontology Series A-Biological Sciences & Medical Sciences. 2002;57(7):M470-2.

[6] Hollins S, Attard MT, von Fraunhofer N, McGuigan S, Sedgwick P. Mortality in people with learning disability: risks, causes, and death certification findings in London. Developmental medicine and child neurology. 1998;40(1):50-6.

Part 2: Detail of key elements of the Quality and Safeguarding Framework

NDIA provider registration

Given the risks, particularly to vulnerable populations such as people with ID, providers should be required to undertake rigorous quality assurance and improvement process and to meet recognised industry governance and management standards and achieve certification with a recognised certification/ accreditation body. This would instil confidence that the providers they choose are safe and competent.

An important part of improving the safety and quality of care is the collection, analysis and application of information on performance and safety standards of service providers. Quality evaluations provided by an independent evaluator will ensure that future and current care receivers and their relatives are informed about the strengths and areas of improvement of providers. The assessments should follow a systematic and standardised approach to ensure that all providers are being evaluated in the same way. The assessment reports should be published by the NDIA so that there are easily accessible. This will help participants to make informed choices and gives additional assurance that the service provider meets recognised industry standards.

If a service provider breaches critical requirements and rights, sanctions have to be included and a process should be in place to exclude individual service providers from the NDIS due to recurrent breaches.

3DN recommends:

1. *Option 4 (mandated participation in an external quality assurance system for certain providers of supports).*

Systems for handling complaints

It is important not only that complaints can be made, but also that a timely and effective responses are received. Service providers should therefore be required to demonstrate that they follow an effective complaints handling process which occurs in a standardised way. A uniform system for reporting complaints would be required (see earlier). Independent review of complaints will ensure that there is sufficient external scrutiny of issues raised.

3DN recommends:

1. *Option 3b (independent statutory complaints function with an independent disability complaints office).*

Ensuring staff are safe to work with participants

People with an ID in particular are at an increased risk of abuse, harm, exploitation and neglect. A nationally consistent approach is required to avoid problems simply 'moving interstate'. As already been implemented in South Australia, service providers have to ensure that staff undergo a screening assessment before commencing in a role and then every three years. This requirement applies to both paid employees and volunteers wishing to work in a 'prescribed position'.

3DN recommends:

1. *Option 3 (working with vulnerable people clearance).*

Safeguards for participants who manage their own plans

A model care for people with an ID should recognise the autonomy of individuals with an ID whilst acknowledging their age and capacity, and seek to work in manner that maximises their independence. The NDIS has a duty of care to ensure that all providers are safe and competent. Participants should therefore be able to choose their preferred service provider but there should be an onus on the NDIA to ensure the appropriateness of a provider by screening and approving that agency.

3DN recommends:

1. *Option 3 (Self-managed participants would be required to use a provider who has been approved or screened by the NDIA).*

Reducing and eliminating restrictive practices in NDIS funded supports

In order to protect the rights of people with an ID, there is a requirement for monitoring, auditing, regulating and public reporting on the use of restrictive practices. It is necessary to develop guidelines and standards, and provide education, training, information and advice on restrictive practices and on the rights of people subject to such interventions. Further, it needs to be acknowledged that the responsibility for restrictive practices cuts across service sectors- for example medical practitioners are responsible for prescribing of psychotropic medications which at times are administered for the purposes of behavioural control.

3DN recommends:

1. *Option 4 (Restrictive practices could only be authorised by an independent decision maker).*
2. *All providers of services to people with an ID should be required to ensure that their staff members have basic training in positive behaviour support practices and effective communication skills and awareness of restrictive interventions restrictions.*

3. *That in the review of restrictive practices which involve the administration of psychotropic medications, it should be mandatory that a medical practitioner with appropriate skill in psychotropic drug prescription is an active participant.*
4. *That all restrictive practices should be subject to reporting and review through the portal mentioned earlier.*

Concluding Remarks

People with ID and complex needs (including those with multiple and complex needs e.g. comorbid mental disorders, physical health disorder and those with challenging behaviour) represent a highly vulnerable population whose needs are prone to being unmet and who are at high risk of abuse. This makes it essential that the Framework ensures a high standard and level of accountability of disability service providers and their staff. We thank the NDIA for this opportunity for input into this important framework. We would welcome further liaison regarding the issues raised in our submission.

Sincerely,

Professor Julian Trollor
Chair, Intellectual Disability Mental Health

Dr Simone Reppermund
Senior Project Officer