

**Submission  
No 300**

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

**Organisation:** Being  
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Mental Health & Wellbeing  
Consumer Advisory Group

## Submission

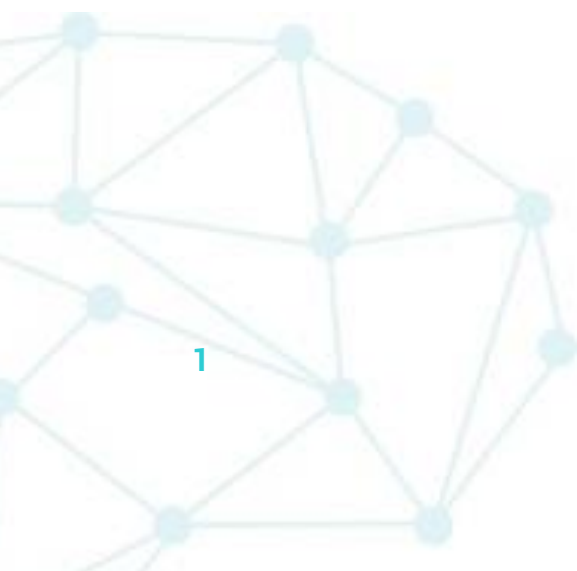
# Inquiry into the Implementation of the National Disability Insurance Scheme and the Provision of Disability Services in NSW

Legislative Council – Portfolio Committee No. 2 – Health  
and Community Services

17 August 2018

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## Introduction

Being | Mental Health and Wellbeing Consumer Advisory Group (*Being*) is the independent, NSW peak organisation for people with a lived/living experience of mental health issues and emotional distress. Our primary focus is to ensure the voices of people with mental health issues are heard by decision makers, service providers, and the community. With a long-standing history of operation, *Being* is in a unique position to influence NSW policy, legislation, and service delivery, to improve the outcomes for the communities we serve by providing advice to the mental health sector on people's views and experiences of the way mental health services are delivered. We support people to advocate and provide input into decision making at all levels through a co-design process and peer-led activities.

*Being* has a strong focus on human rights, and as such advocates for the rights of people with mental health issues and emotional distress to live and participate in the communities they choose. We are a value based organisation whose work is underpinned by Recovery-Oriented and Trauma Informed principles including respect, social justice, and transparency, and a belief that recovery is possible for every individual.

*Being* engages with their members, Government, Community Managed Organisations, and the community through the provision of resources and information, consultations and submissions, research and evaluation, and education and training.

Our work is guided by eight principles:

- Principles of recovery underpin all our work
- Recognition of the importance of a holistic approach
- Collaboration and team work
- Flexibility, responsiveness and innovation
- Consultative and participatory processes that have consumers at the centre
- Promoting equity and positive images to address discrimination and prejudice
- Accessible and approachable for all
- Promotion of professionalism and quality practice

**Being** receives core funding from the Mental Health Commission of NSW, and project funding from the Ministry of Health – Mental Health Branch, and FairTrading NSW.

We would like to thank the people of NSW for sharing their time and experiences with us, in a way which assists us to advocate for change at a systemic level.

We would also like to thank the NSW Legislative Council, *Inquiry into the Implementation of the NDIS and the Provision of Disability Services in NSW* for the opportunity to contribute.

## Recommendations:

1. **Being** is strongly supportive of providing training to all staff who administer the NDIS application and management process to ensure that they fully understand recovery focused and trauma informed paradigms of mental health.
2. **Being** recommends implementation of a robust peer workforce who are trained and embedded in services to support people with psychosocial disability. **Being** has been advised by consumers that they face significant barriers when applying and managing NDIS funding without support including:
  - Difficulties applying due to the complexity of the process.
  - Having past traumas and other mental issues triggered by the application process.
  - Generally finding the application process a barrier to accessing funding.
3. **Being** recommends that embedded peer workers are provided with appropriate and adequate infrastructure to develop and maintain their skills.
4. **Being** recommends that the Government of NSW advocate for early psychosis services to be included as an expansion of the early intervention processes already included in the NDIS.
5. **Being** recommends that the NSW Government work in collaboration with the NDIA to ensure that those consumers who have significantly fluctuating mental health issues are able to rapidly change their available funding when required.
6. **Being** encourages the Government of NSW to consider ways to ensure that the training of staff who assist people to access NDIS funding includes a clear understanding of the ways psychosocial disability differs from physical, neurodevelopmental and intellectual disabilities regarding the profile of disability over an individual's lifetime.

7. *Being* recommends that the NDIA and the NSW government ensure that people with psychosocial disabilities be provided with advocates who are as much as possible uninvolved in the provision of support services and more generally supports service provision models that allow for greater consumer choice.

## Definition of Disability and Recovery

Section 24 of the *National Disability Insurance Scheme Act 2013*, defines disability in the terms of the act as permanent impairment. By contrast the most innovative examples of mental health policy in NSW and Australia, use the language of recovery. The whole of Australian Government *National Framework for Recovery-oriented Mental Health Services* defines recovery as “...being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues” (Commonwealth of Australia, 2013(a), Pg.17). In the framework Health Ministers from across Australia committed to ensuring that “... all Australian jurisdictions ... promote and implement the framework...” and as much as possible facilitate and support the recovery journeys of those people living with mental health issues. The NSW Government also committed to ensuring that future mental health policy and legislation development in NSW would be informed by lived experience and recovery-oriented principles (section 4.3, Living Well).

The funding provided by the NDIS to people living with psychosocial disabilities should be understood by those administering the funding as a means of supporting recovery in the broad sense described above and not as support provided because of a permanent and unchanging disability. Recent research into the provision of NDIS services to people living with psychosocial disability has found that the idea of permanent disability has been a barrier to individuals self-identifying as potential users of NDIS funding despite high levels of need, as well as discouraging some professionals from providing supporting information for NDIS applications (The University of Sydney, 2018, Pg. 12).

## Fluctuating mental health issues

A further difficulty with the notion of permanent disability in the context of psychosocial disability, is the fact that for many people mental health issues are chronic, but episodic, rather than chronic and persistent. Having mild or no disability

between acute episodes, should not exclude people from support when they are experiencing an acute relapse which may cause significant disability over extended periods of time.

As noted in *Contributing Lives, Thriving Communities* across the spectrum of mental illness in Australia people experience a variety of different impacts from their mental health issues. The report distinguishes between mental health issues that are mild and moderate, severe and episodic, severe and persistent and severe and persistent and requiring complex multiagency supports (National Mental Health Commission, 2014, Pg. 5).

Further to this, the Royal Australian College of Psychiatrists also advises that it is not possible to determine the level of disability caused by mental health issues simply by referring to the diagnostic label given to the individual. A severe anxiety disorder, or episode, or a severe major depressive episode can be just as disabling as mental health issues such as bipolar disorder and schizophrenia (Royal Australia and New Zealand College of Psychiatrists, 2016, Pg. 9).

Consumers have told **Being** that if available funding is not used over any given year, funding will be reduced during the next funding period. Whilst this has so far been successful for that consumer, in some cases fluctuating mental health will mean that the same consumer may require different funding levels depending on the state of his, or her mental health.

However it is also true that for some people with psychosocial disabilities, a lack of individualized community support, even when they are not currently experiencing an acute relapse, will place them at greater risk of an acute relapse.

## NDIS Peer workers

Peer workers are widely employed within mental health systems in New Zealand, the USA, Canada, the United Kingdom and Hong Kong (State of NSW, 2016, Pg. 20). The evidence collected to date confirms that peer workers are at least as effective as employees without psychiatric histories in roles such as case managers, rehabilitation staff and outreach workers. (State of NSW, 2016, Pg. 20).

Peer workers could make a useful contribution in a number of areas in which the NDIS is not yet achieving optimal outcomes. Aboriginal and Torres Strait Islander (ATSI) people, for example, currently face significant barriers to accessing NDIS packages. The lack of culturally

specific support services to assist in the application process and in the development of plans is a significant challenge for ATSI people (University of Sydney, 2018, Pg. 17). ATSI peer workers could provide culturally specific support, to assist with both identifying individuals who would benefit from NDIS services in ATSI communities and to provide individual advocacy and support to people with psychosocial disabilities while they are applying for funding, accessing and managing their funding packages and accessing services.

Other potential target groups for NDIS support would also benefit from peer support. These include people from Culturally and Linguistically Diverse (CALD) communities and people with psychosocial disabilities who live with cognitive challenges and find unsupported decision-making challenging.<sup>1</sup>

If peer workers are engaged to support people living with psychosocial disabilities to navigate the complex administrative processes needed to set up and negotiate changes in an NDIS plan, it is also important that they are provided with specialist training in relation to NDIS application and management processes and embedded in service provision organisations like Centrelink. Achieving the best outcome will only be possible if peer workers have both lived experience as consumers and a solid understanding of bureaucratic policy, processes and culture that allows them to advocate with and for the NDIS applicants who they are supporting. Skilled and knowledgeable peer support workers would benefit all of those who are only having their first contact with the NDIS.

## Early support for young people experiencing first episode psychosis or at Ultra high risk of psychosis

Currently early intervention in the NDIS focuses primarily on very early childhood.<sup>2</sup> One group of young people that is not effectively supported or identified by the NDIS currently are those young people at ultra-high risk of psychosis.<sup>3</sup> Identification of and provision of additional supports to the young people who fall into this group would ensure both a significant reduction in suffering and a likely reduction in the number of people who experience acute

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<sup>1</sup> For an overview of supported decision making for people with disabilities, see (University of Melbourne, 2017). Mind Australia is also currently progressing research into choice making under the NDIS (<https://www.mindaustralia.org.au/about-mind/research-mind/please-tell-us-your-experience-making-choices-under-ndis>)

<sup>2</sup> The 0 to 6 year age group. See for example *Early childhood, early intervention – How the NDIS can help your child* (NDIS, 2017).

<sup>3</sup> For a brief overview see *Evidence Summary: Identification of young people at risk of developing psychosis*. Available at <https://headspace.org.au/assets/Uploads/Evidence-Summary-Identification-of-Young-People-at-Risk-Developing-Psychosis.pdf>



episodes of psychosis and their debilitating after effects. KPMG have projected in *Investing to Save* (KPMG, 2018, Pg. 68), that the estimated long-term health savings per person resulting from early intervention for psychosis would be approximately \$74,437. A significant part of this cost would result from access to both NSW Health emergency and public acute care services.

## Failure to access services

Some Consumers have told *Being* that the NDIA is not pro-active enough in engaging with people who have psychosocial disabilities, but who do not see themselves as being unwell, as is sometimes the case with people living with psychosis. The University of Sydney's recent report, *Mind the Gap* (University of Sydney, 2018, Pg. 13), has also noted that anxiety, fear and illness related barriers and social isolation can make self-identifying as someone eligible for services and going through the application process for funding very challenging.

## Choice

Some consumers who participated in the initial pilot of the NDIS and have been accessing services for four years, have expressed specific concerns about the ways in which choice is facilitated and limited within the current NDIS process.

Discussions with these stakeholders made clear that having choice while you develop an NDIS plan can be a challenge when the support coordinator works for the same agency which will provide the services. There is clear potential for a conflict of interests when it is in the interests on the support coordinator to recommend the services of their own organization.

Although it was recognized that provision of Local Area Coordinators (LACS)<sup>4</sup> can in some cases provide a more neutral advocate during the plan development process, it is not uncommon for LACS to not have a strong understanding of psychosocial disability.

There are some examples of companies which are trying to provide a greater amount of choice to users of disability support services. *Hireup* for example, allows people living with disabilities to individually choose their support worker on an individual basis, rather than having the process mediated by a larger organization who assigns a support worker.<sup>5</sup>

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<sup>4</sup> See <https://www.ndis.gov.au/about-us/our-sites/NSW.html> for an overview of local area coordination services in NSW.

<sup>5</sup> See <https://hireup.com.au/>.

# Complaints processes

*Being* has also been informed that it is difficult to make complaints within the current NDIS system. To support freedom of choice and planning, more support should be given by the both the NDIA and other organisations providing services to NDIS recipients to make complaints in situations where they are unsatisfied. Consumers feel free to make complaints when organisations make clear that they value and welcome engagement as an element of their ongoing service improvement processes.

# Acronyms

ATSI – Aboriginal and Torres Strait Islander

CALD – Culturally and Linguistically Diverse

LACS – Local Area Coordinator

NDIA – National disability insurance agency

NDIS – National disability insurance scheme

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