

Submission

Productivity Commission Position Paper: National Disability Insurance Scheme (NDIS) Costs

Orygen, The National Centre of Excellence in Youth Mental Health (Orygen) welcomes the opportunity to provide feedback to the Productivity Commission's Position Paper on the Costs of the National Disability Insurance Scheme (Position Paper).

Orygen is the world's leading research and knowledge translation organisation focusing on mental ill-health in young people. At Orygen, our leadership and staff work to deliver cutting-edge research, policy development, innovative clinical services, and evidence-based training and education to ensure that there is continuous improvement in the treatments and care provided to young people experiencing mental ill-health.

This submission provides commentary on the impact and implications of the NDIS where relevant to mental health, and more specifically, young people (12-25 years) experiencing severe, complex and potentially enduring mental ill-health. In particular Orygen is concerned that:

- The application of the current eligibility criteria for the NDIS may exclude access to important psychosocial supports for a significant majority of young people with severe and potentially enduring mental illness as their primary disability.
- Currently there is little known about the assessment and nature of supports provided to young people with secondary psychosocial disabilities.
- Without specific psychosocial disability assessment tools and instruments (and skilled professionals to administer these) young people who are accessing the NDIS for primary or secondary psychosocial disabilities may not receive plans that incorporate effective and evidence-based psychosocial support and care as part of their package.
- Opportunities to provide cost-effective early interventions which respond to life-long functional impairment as a result of severe mental illness among young people are being missed in the roll out of the NDIS. This has the potential to exacerbate current gaps in care and compromise the sustainability of the scheme as a result of future downstream costs.

Orygen would also like to reiterate the challenges previously identified through NDIS consultations with the mental health sector regarding the implementation of the NDIS. The Position Paper already acknowledges a number of these including:

- The large numbers of people who will require community mental health services but who will fall out of the scope of the NDIS Individually Funded Packages (IFPs): currently expected to service 64,000 Australians with a psychosocial disability at full implementation.¹

¹ Mental Health Australia (2017) Submission Joint Standing Committee on the NDIS – Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

- The ongoing lack of clarity on the eligibility criteria for the NDIS as it relates to individuals experiencing a psychosocial disability and the difficulties applying current NDIS language, such as 'permanent' to determine eligibility. Particularly for individuals experiencing fluctuating mental ill-health with an expectation of clinical recovery.^{1,2}
- The experience at trial sites where many people with mental health conditions have found it difficult to understand and navigate the NDIS, suggesting the need for further advocacy and care coordination support.³

Orygen notes that a parliamentary inquiry on the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition has recently occurred. The report is due on 10 August 2017. It is important that the findings of this inquiry are considered in the final recommendations from the Productivity Commission.

Young people in Australia experiencing severe/complex mental ill-health

In 2015 the resident population of young people in Australia aged 12-25 years was approximately 4.3 million.⁴ One in four young people will have a mental disorder, of which an estimated 17% will experience severe impairment.⁵ Utilising these statistics and what we know from recent epidemiological research, Orygen estimates that upwards of 200,000 young people across Australia are experiencing a severe mental disorder, over three times those with a psychosocial disability (across all ages) who are expected to receive individualised supports through the NDIS.

We also know from the demographics and clinical characteristics of young people seeking help at youth mental health services in 2013-14 that around 11,000 were experiencing recurrent or chronic mental ill-health⁶, while 16,337 young people aged 16-24 years with a primary psychological/psychiatric condition received the disability support pension in 2013.⁷

Within headspace centres around one in four young people assessed on the Social and Occupational Functioning Assessment Scale (SOFAS) experienced a serious impairment in functioning on their first presentation and 1.9% experienced an inability to function in almost all areas.⁸

Young people with mental illness: assessment and NDIS eligibility criteria

The Independent Advisory Council (IAC) advised that it will be difficult for young people with a psychiatric condition to enter the NDIS (via the IFPs) because most of these young people will not receive a diagnosis of a permanent disability.⁹ Even for young people experiencing severe and

² Independent Advisory Council (2014) Advice on implementing the NDIS for people with mental illness, <https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-mental-health>

³ Mental Health Coordinating Council (2016) Navigating the NDIS: Lessons learned through the Hunter Trial, http://mhcc.org.au/media/85852/ndis_lessons_final_200117.pdf

⁴ ABS (2015) 3101.0 - Australian Demographic Statistics, Jun 2015, Table 8.

⁵ ABS (2007) 4840.0.55.001 - Mental Health of Young People.

⁶ Purcell R, Jorm AF, Hickie IB, Yung AR, Pantelis C, Amminger GP, et al. Demographic and clinical characteristics of young people seeking help at youth mental health services: baseline findings of the Transitions Study. *Early Interv Psychiatry*. 2015;9(6):487-97.

⁷ Services DoS. Characteristics of disability support pension recipients. Canberra: Australian Government; 2013.

⁸ Hilferty, F., et.al. (2015). Is headspace making a difference to young people's lives? Final Report of the independent evaluation of the headspace program. (SPRC Report 08/2015). Sydney: Social Policy Research Centre, UNSW Australia.

⁹ Independent Advisory Council (2014) (ibid.)

functionally disabling mental illness, current NDIS eligibility criteria could exclude access on the basis that it may not be possible (or clinically advisable) to diagnose the illness as a 'permanent' condition.

In the March 2017 NDIS dashboard data, it appears only approximately 200-300 young people aged 15-24 years were active participants with an approved plan primarily for a psychosocial disability (or around 2% of all young people in this age group on approved plans). This suggests that the NDIS individualised supports can be provided to young people with mental illness, although these are being applied sparsely (compared to the over 20% of people aged 25 years and over on approved plans primarily for psychosocial disabilities).¹⁰

Orygen appreciates the cost implications for the NDIS to change the eligibility criteria from 'permanent' which, although would address issues in relation to psychosocial disabilities, could potentially open up the scheme to a much larger cohort of young people with mental ill-health. We also acknowledge that the Position Paper clearly states the Productivity Commission does not support a change to the eligibility criteria (p24). However, at present, the criteria can be applied in such a way that could effectively restrict access to the NDIS for young people with severe and complex psychosocial disabilities – as shown in the data available to date.

To improve access to the scheme for young people with severe psychosocial disabilities, Orygen supports Mind Australia's recommendation that a set of psychosocial assessment tools are developed to assess levels of functional impairment and the likelihood of ongoing illness to determine eligibility and define the supports required.¹¹ Orygen would also propose that the NDIA intake workforce includes professionals with expertise and a comprehensive understanding of psychosocial disabilities.

As found in the Hunter region pilot site, people with psychosocial disabilities have found it difficult to navigate the scheme, leading to poorer outcomes. Young people with severe mental illness may be even less likely to access in a service that requires a certain amount of self-directed referral and phone contact for assessment. Young people are already a group reluctant to present to primary care or access mental health services¹², although those with severe experiences of mental ill-health appear more likely to use a mental health service (51%) than those with mild-moderate conditions (18%).⁵

Orygen recommends:

- 1. Development of psychosocial instruments and tools to assess functional impairment which can then be used to determine eligibility and support to be provided. These need to be appropriate and accessible for young people aged (12-25 years).**
- 2. Providing assertive outreach and assistance in service access and navigation, particularly to identify and support young people who are eligible for the NDIS but may not make contact.**

Early intervention criteria and the NDIS

Early intervention to support functional recovery at this life stage (12-25 years) for severe and potentially enduring mental health conditions is cost-effective in the long term.¹³ The World Health Organisation has identified that mental disorders pose the greatest threat to economic output globally

¹⁰ NDIS (2017) National Public Dashboard, 31 March 2017.

¹¹ Mind Australia (2017) Response to the Productivity Commission inquiry into NDIS costs

¹² Rickwood, D., Deane, F. & Wilson, C. (2007) When and how do young people seek professional help for mental health problems. The Medical Journal of Australia, 187, 7, 35.

¹³ World Health Organisation (2013) Investing in mental health: Evidence for action

of all non-communicable diseases¹⁴. Orygen believes excluding young people with severe mental illness, either assertively or indirectly, from early intervention services which address reduced functioning in social and economic life could be costly in the long term. Therefore, it is important that safeguards are developed within the NDIS to ensure young people with severe mental illness are considered part of the insurance schemes eligibility group ‘comprising of individuals for whom there is good evidence that the intervention is safe, significantly improves outcomes and is cost-effective’.

The Position Paper identifies that where an unexpected cost escalation was occurring in the NDIS, with children under 6 years, an Early Childhood Early Intervention (ECEI) approach was designed as a gateway to the scheme. This emphasised providing the right level of support, at the right time, for the right length of time (Box 4, p22). Orygen also notes that the NDIA is also developing an early intervention approach like this for the 7-14 years cohort.

This approach is congruent with approaches in early intervention for youth mental health and Orygen believes there is potential for a similar program to be developed for young people aged 12-25 years with a psychosocial disability. This would also ensure the advice on eligibility for care plans is provided by service providers with specific skills and understanding of the stages and severity of mental illness and impacts on functioning. Regular assessments by these same providers would also ensure early exit from the NDIS where recovery of function was assessed.

As identified by the IAC, headspace and other early intervention services for young people experiencing mental ill-health will play a key role in determining the future demand for NDIS programs. This includes the provision of evidence-based interventions for mental ill-health which will ensure the illness does not become permanently disabling. It noted that “(s)tronger investment in such services will reduce demand for National Disability Insurance Agency (NDIA) services over the medium and longer and will be a factor in (the) Schemes financial sustainability.”¹⁵

Orygen recommends:

- 3. Investigating the development of a similar gateway program to the ECEI to ensure that young people with social and functional impairment due to a primary psychosocial disability: are appropriately assessed; that access to the NDIS is facilitated where appropriate; and participants are supported to exit the scheme once functional recovery is assessed.**
- 4. Continued and increased investment by all governments in youth mental health services such as headspace, youth early psychosis program and other interventions for young people experiencing severe and complex mental ill-health with a focus on increasing access to care.**

Young people receiving NDIS individualised support with secondary psychosocial disabilities.

The co-occurrence of mental ill-health with physical, intellectual, sensory and cognitive disabilities with mental ill-health is well documented. For example:

- Almost half (48%) of people with severe or profound disability have mental health problems.¹⁶

¹⁴ Bloom, D.E. et al. (2011) The Global Economic Burden of Noncommunicable Diseases. Geneva: World Economic Forum.

¹⁵ Independent Advisory Council (2014) (ibid.)

¹⁶ AIHW (2010) Health of Australians with disability: health status and risk factors. Bulletin 83.

- More than 70% of mainly young adults with autism identified a clinical mental health condition.¹⁷
- Mental health problems among young people with intellectual disability are 3 to 4 times higher than typically developing children.¹⁸

Orygen acknowledges that a number of young people on NDIS individual support plans for another primary disability will also receive support through their care package for a co-occurring psychosocial disability. However, at present it is difficult to derive this information from publicly available NDIS dashboard data. Reports from trial sites suggest that for every two people accessing the scheme for a primary psychosocial disability, there was another accessing with a secondary psychosocial disability.^{19,20} Given the high prevalence of co-occurring mental health issues with physical, cognitive and intellectual disabilities, this would suggest an under-reporting or under-assessment of these secondary conditions across the broader group accessing NDIS individualised supports.

In regards to the cost implications for the NDIS, intervention to provide supports for young people across a range of disabilities that address reduced functioning as a result of mental health issues early in onset is critical. For example: co-occurrence of depression with a physical disability could be a significant barrier to functional, economic and social participation. Therefore the supports and services provided need to address the psychosocial disability. These should be evidence-based, effective, well targeted and given appropriate weighting within the plan provided.

Along with the need to develop psychosocial specific instruments and tools to determine eligibility and support requirements, Orygen recommends:

- 5. That information is collected and published through the NDIA to improve our understanding of: a) the numbers of secondary mental illnesses that are identified through individualised supports; b) the quality and efficacy of assessments utilised; and c) the appropriateness of the supports provided.**

Boundaries and interfaces, including the Information, Linkages and Capacity Building Framework

Given young people experiencing mental ill-health will mostly likely encounter difficulties accessing the individualised supports, the role of the Information, Linkages and Capacity Building (ILC) Framework and associated funding will be of critical importance. The NDIS Scheme Actuary estimates this platform could provide services to 2.4 million people with a disability under the age of 65 years and 800,000 primary carers.²¹

Orygen supports the Productivity Commissions Recommendation 5.1 that funding for the ILC should be increased to the full scheme amount during transition as this could potentially improve outcomes

¹⁷ Autism Spectrum Australia, 2012, We Belong: Investigating the experiences, aspirations and needs of adults with Aspergers disorder and high functioning autism. 15 May 2012

¹⁸ Einfeld S, et al. 2006. Psychopathology in young people with intellectual disability. Journal of American Medical Association 296 (16):1981–9.

¹⁹ Mental Health Sector Reference Group (2015) Communique, December 2015. <https://www.ndis.gov.au/document/mhsrg-dec15>

²⁰ MHCC (2015) Further unravelling psychosocial disability: Experiences from the NSW Hunter National Disability Insurance Scheme Launch Site, Issue 4, July 2015.

²¹ NDIS A Framework for Information, Linkages and Capacity Building <https://www.ndis.gov.au/html/sites/default/files/ILC-Policy-Framework.pdf>

for people who may not be eligible for individualised supports. It will also address the need, as identified in the Position Paper (p33), to urgently clarify what supports will be made available to people with a mental illness who are not eligible for an individualised care plan.

Orygen believes that in designing and implementing the ILC Framework activities (such as community and individual awareness raising and capacity building, and facilitating linkages and referrals into community-based mental health supports) particular consideration should be given to the addressing the needs of young people. This would require the involvement of education settings, employment providers, as well as young people and their families. These activities will also need to identify and utilise technologies and other platforms that young people engage with.

The Position Paper identifies the potential role of the ILC and Local Area Coordination to identify and respond to the emerging gaps in care which could impact on the overall sustainability of the scheme (p34). Young people experiencing severe and complex mental health conditions which significantly impact their functioning are already a group for whom gaps in care exist. Orygen is currently working with the Australian Government and the Primary Health Networks (PHNs) to provide guidance and support in the development of innovative and novel service responses to young people experiencing severe and complex mental health conditions.

Orygen believes that in regards to mental health, the PHNs will also have an important role working with and supporting the NDIA to assess demand for regional services and facilitate pathways through the NDIS, youth mental health primary care (headspace) and state and territory youth mental health services. Particularly for young people experiencing severe and complex mental ill-health, PHNs will need to be involved in assertively identify any existing or emerging gaps in care and work with the functions of the NDIA to present the case to government for additional funding, resources and service coordination at a Commonwealth and state/territory level.

Orygen recommends:

- 1. That a commensurate proportion of resources available through the ILC Framework are provided to support individuals experiencing psychosocial disabilities, in particular young people and their families who are likely to be ineligible for the individually funded packages.**
- 2. Prioritising improvements in service coordination between the NDIS, primary care service platforms and state and territory youth mental health systems with a focus on reducing and preventing duplication of responses.**
- 3. That the NDIA, LACs and the regional implementers of the ILC Framework engage Orygen and the PHNs to identify existing or emerging gaps in care for young people with severe and complex mental health conditions, coordinate responses and advocate for more resources where required.**

Further information

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