

SUBMISSION

FROM: the Independent Advisory Council to the National Disability Insurance Agency

TO: the Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

General Comments

The Independent Advisory Council welcomes the opportunity to make a submission to the Joint Standing Committee. The Independent Advisory Council (IAC) to the National Disability Insurance Agency is an independent Council appointed under the NDIS Act 2013 to provide advice to the National Disability Insurance Agency. S. 144 of the NDIS Act 2013 emphasises the complementary role of the IAC as a conduit between core governance of the NDIS and people with a lived experience of the Scheme and the broader community.

The NDIS Act 2013 establishes the Independent Advisory Council (IAC), its membership and independence. The purpose of the IAC is to provide advice to the Board of the National Disability Insurance Agency (NDIA) on how the NDIA delivers the Scheme. Crucially, the majority of IAC members must have a lived experience with disability.

The IAC embodies the principle of co-design through its membership and strong connections to community. The IAC is committed to maintaining the integrity of objectives and principles of the NDIS Act 2013. In particular, IAC work focuses on people with disabilities becoming more independent, included in the community and 'mainstream' services, participating socially, economically and leading self-directed lives.

To support this fundamental work, the IAC established expert subcommittees including the Innovations in Housing and Supports Working Group (Innovations) and the Intellectual Disability Reference Group (IDRG). Additionally, work of the IAC provided the impetus for the establishment of a [National Mental Health Sector Reference Group \(NMHSRG\)](#). IAC subcommittees ensure that IAC advice is robust informed by lived experience and sector expertise. IAC subcommittees also assist in building critical partnerships between diverse sector representatives, the community and the NDIA.

Since its establishment in July 2013, the IAC has had a strong focus in its work program on improving the responsiveness of NDIS for people with disabilities related to mental health conditions. Through its work it has raised this issue at its community consultations, approved research on issues of the assessment of eligibility to facilitate a more evidence-based and informed approach to the interpretation of eligibility and maintained a line of sight on the responsiveness of the planning and access approval processes. Its feedback to the Agency's annual work plan report to the IAC and suggestions on priorities for the next year's work plan is the mechanism through which it offers input on an on-going basis to the NDIA.

The IAC recognised early on in its term, that there were a number of design and implementation issues specific to people with disabilities related to mental health conditions. It undertook a significant program of work in 2014 and provided advice to the NDIA Board on these matters in December 2014, 'Issues paper: implementing the NDIS for people with disabilities related to mental health issues' (IAC 2014). The paper can be accessed at the following location: <https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-mental-health>. This paper offers an analysis of a range of design and implementation issues in regard to the NDIS and people with mental health conditions relevant to term of reference 1a. We recommend it to the Joint Standing Committee for consideration. This paper was considered by the NDIA Board in early 2015.

The IAC have noted that the NDIA has developed and implemented a more targeted approach to improve the responsiveness of the Scheme to the needs of people with disabilities from mental health conditions. The establishment of a specific mental health team to co-ordinate and manage this strategy, the effective leadership of the NDIA Special Adviser on mental health, Eddie Bartnik and an annual mental health work plan are tangible evidence of this more targeted approach. While IAC recognises that additional reform is necessary, it considers that significant progress has been made over the past two years in improving the responsiveness of the Scheme for disabilities related to mental health. At its February 2017 meeting, it was briefed on the draft 2016-17 work plan and provided input to this. In 2016, it completed a report that focused on difficult to reach people with mental health conditions who may be eligible for the Scheme. This report which was presented to the NDIA Board in late 2016 is attached to this report. The IAC is pleased that the Board has adopted consideration of an annual mental health work plan as part of its deliberations each year. This was a recommendation from the IAC in its 2014 report and the Board's adoption of this recommendation has proven to be effective.

While recognising this progress, our submission is that further work is required in refining and standardising the approach of the NDIA to the assessment of permanency and the degree of impairment.

IAC Comments in regard to specific terms of reference

1(a): Eligibility Criteria for NDIS and people with a psychosocial disability

The IAC work in 2014 identified the need for a more informed evidence base to assist in addressing the complex issues involved in implementing the intent of the NDIS Act 2013 in regard to the assessment of eligibility and determinations of reasonable and necessary. Our analysis at that time identified that while there were reasonably robust assessment tools in many areas of disability which had been developed over many years, standardised and validated instruments for the assessment of functional impairments due to mental illness were not available. Indeed, one of the significant issues for the Scheme was that much of the data is based on diagnostic assessments of mental health and not functional impairments. Reliance on diagnostic rather than functional criteria may put pressure on the financial sustainability of the Scheme. IAC was aware of a major literature reviewed commissioned by Mind Australia for the IAC to the NDIA and undertaken by the School of Population Health at Melbourne University on mental health and the NDIS (Mental health and the NDIS: A literature review). This literature review was very helpful to it in its understanding of the complexities of eligibility assessment issues and it considered that this review was an important resource for the Agency, government and the general community in understanding of these issues. It recommended this report to the Agency and the then Minister. Both endorsed this literature review and the paper was placed on the NDIA website.

This literature review summarises the current research evidence in regard to the assessment of functional impairments due to mental illness. It provides in our submission a clear presentation of the issues and consideration of the manner in which judgements about permanency of functional impairments have been dealt with in jurisdictions in Australia and internationally. The IAC have recognised the technical complexity in interpreting the intent of the NDIS Act in the assessment of eligibility based on severe and permanent functional impairments. It acknowledges the work that

has been undertaken in improving assessment practices and considers that there are strong grounds for moving towards a validated assessment instrument and standardised processes.

The IAC has recently reviewed the recommendations from IAC's 2014 advice 'Issues paper: implementing the NDIS for people with disabilities related to mental health issues' (IAC 2014) and consider that these recommendations continue to remain relevant to this terms of reference. The IAC recommended as follows:

- a. That the Agency monitors patterns of eligibility and ineligibility in relation to permanency of disabilities related to mental health issues to develop an informed approach to the robustness and consistency of practice across the Agency.
- b. The Agency develops its own working definition and guidelines of permanency of disabilities related to mental health issues.
- c. That the Agency promotes its working definition of permanence of disability related to mental health issues within the Agency and to staff in external agencies who make judgements about diagnosis and functional impairments upon which the Agency relies.
- d. That the Agency monitor patterns of eligibility and ineligibility in relation to functional impairment and a psychiatric condition to build a picture of who is being included and excluded, track compliance with the requirements of the legislation and the consistency of the assessments being undertaken.
- e. That the Agency invest in the development of a validated instrument for identifying an evidence-based approach to the determination of functional impairments and support needs for people with an impairment related to a psychiatric condition.

Eligibility should be evidenced based, based on the eligibility criteria as defined in the NDIS Act 2013. Many areas of disability do have accepted criteria for the determination of serious and persistent functional impairments. However, such criteria are not established in regard to psychosocial disabilities due to mental health conditions and need to be developed. The 2014 paper and the literature review noted the pattern in some social insurance schemes internationally to tighten eligibility criteria based on funding rather than social needs grounds. Our comment at the time was that the NDIS may be subject to the same pressure in the future and that developing a stronger evidence-based and validated instrument was a strategy for providing more transparency and measurable indicators; the balanced judgement approach that is currently being used by the Agency.

1b: Transition of community mental health funding to the NDIS

The IAC is aware of the concerns about the transition of long and short term mental health Commonwealth funded services amongst some consumer, carer groups and community mental health service providers. It has been briefed on the arrangements that the Department of Social Services is putting in place for a phased level of reduction for Phams, Day to Day Living and some mental health respite services, consistent with the NDIS roll out time table. Funding flexibility and revised program guidelines have a clear focus on preparing people for the NDIS and assisting their transition to the NDIS.

It recognises from a diverse range of research in particular the Review of the Mental Health system by the National Mental Health Commission of major structural issues in the provision of mental

health services across Australia. There are many Australians who are not able to access an adequate level of mental health services including support co-ordination and psycho-social disability support. The focus of the IAC is on effective use of and financial sustainability of the NDIS. Adequacy of commonwealth mental health policy and funding are issues for the Department of Health, Department of Social Services and the Commonwealth, State and Territory Governments. These are issues being considered in the Fifth National Mental Health Plan.

The IAC acknowledge the issue, but considers that it is not within our terms of reference as a Council. Rather this is a matter for Commonwealth, State and Territory Governments. Our focus as the IAC is on how to improve responsiveness within the Scheme.

1e: Planning process for people with psychosocial disability and the role of primary health networks in that process

Planning processes

The IAC has played an active role in listening to community feedback about planning processes in the NDIS trials and with the roll out of Local Area Co-ordinators (LACs). It has provided advice and prepared a number of papers on the planning processes generally. In particular, it has highlighted the critical importance of capacity building, main-streaming and effective support co-ordination. This work has had a NDIS wide focus.

IAC identified major variations in the knowledge and skill base of the NDIS teams and more recently in regard to LACs in relation to mental health expertise. It has encouraged the Agency in its workforce strategy and contracting guidelines to aim to achieve a balance of knowledge and skills across a range of disabilities. It has been encouraged by a range of initiatives within the Scheme to develop specialist teams with a focus on mental health, mental health access initiatives such as the Psychiatric Hostels project in Western Australia, and the building of mental health capacity in the national access team. It considers that increasing expectations of LACs in this area in future expectation setting, and service agreements, is an area for focus.

The IAC 2014 report identified some issues in regard to the appropriateness of language for potential and current participants with mental health conditions. Considerable work has been undertaken over the past two years in reviewing existing documentation and operational procedures to improve the sensitivity of the language used. A key theme in this work has been translating the intent of severe and permanent mental health disability into more accessible and service user friendly language. This issue is an on-going aspect of the NDIS Mental Health Team's work plans. The NDIS Mental Health Reference Group facilitated by the NDIA is an important national forum for feedback and discussion of appropriate language and presentation.

Role of the PHNs

The IAC has noted that the Department of Health guidelines for PHNs restrict the role of PHNs in regard to psychosocial disability and focus their role on clinical mental health services. They have a significant role to play in regard to service planning and co-ordination of primary health services with a strong priority on mental health. However without substantial expansion in scope and more flexible guidelines that do not exclude psychosocial disability, then commissioning of services

through PHNs alone will not meet the support needs of people needing psychosocial disability support who are not eligible under the NDIS.

System interface issues between primary health services and NDIS services will gather increasing recognition and prominence over the next five years and effective open communications between the two programs would be very constructive. We note that the Special Adviser on Mental Health Eddie Bartnik has spoken at several national and state forums on the NDIS and PHNs. However without substantial expansion to the scope of and more flexible guidelines, the commissioning of services through PHNs will not meet the psychosocial disability support needs of people who are not eligible for the NDIS.

1g: Role and extent of outreach services to identify potential NDIS participants with a psychosocial disability

The IAC has recognised that given the nature of severe mental illness and its impacts there will be some people who are eligible who may not use the standard access pathways or may need special assistance to do so. It has received briefings on a number of initiatives in the trials sites that have built in outreach components. These include joint liaison positions between public mental health services and NDIS trial site teams, innovative access initiatives such as the Psychiatric Hostels project in Perth and identification of potential participants through liaison between NDIA and service provider staff.

IAC has identified access issues for a specific group of potential participants, that is people living in “supported” residential facilities, psychiatric hostels and private boarding houses. It completed a report on this issue in November 2016 and forwarded this to the NDIA Board.