

25 May 2017

The Hon Kevin Andrews MP
Chair, Joint Standing Committee on the NDIS – Mental Health
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Andrews

I thank the Joint Standing Committee for inviting me to appear at the hearing on Friday 12 May 2017 to further discuss my submission to the inquiry into services under the NDIS for people with psychosocial disabilities related to a mental health condition.

During the hearing you asked a question to which I now offer additional comment. The question (and lead-up to the question) reads:

Two things came out of your evidence. One is what seems like an inherent tension between, on one hand, the approach of mental health in Australia, which is a recovery oriented framework that has a focus on functionality, and, on the other hand, the NDIS, which is an impairment oriented framework that has a focus on the permanence of that impairment. This is an area where those two things clash and it leads to a lack of services, I suppose, potentially in the future. The question for us is a practical one: how do we resolve that? Do we resolve it by saying that the permanence required otherwise should not be a feature in terms of assessment of the psychosocial condition? Do we suggest modifications to the NDIS rules in this regard so that there is, more or less, an exception to that underlying principle that applies to the NDIS? Or is there some other solution?

The concept of ‘permanence’ is embedded in many, if not most, definitions of disability. To remove ‘permanence’ from the definition of psychosocial disability for the NDIS would risk subjecting people with mental health impairments to possible criticism within Australian society regarding the validity of mental health related impairments and may discredit the experience of living with a psychosocial disability. Additionally, removing the concept of permanence may lead to gatekeeping between social service systems (particularly the health and disability systems), diminishing access to necessary supports for those people who have a mental health condition that has, and is likely to, seriously impact their long-term ability to participate in Australian society. I therefore do not recommend that the concept of permanence be removed from the definition of disability for people with psychosocial disability seeking entry into the NDIS.

In my view, the *National Disability Insurance Scheme Act 2013* (the Act) has sufficient flexibility in its provisions for a sophisticated synthesis by NDIA assessors and planners of three of the key concepts central to this dilemma: ‘permanence’, ‘fluctuation’ and ‘functionality’. The Act adopts a nuanced approach the definition of disability in that it recognises that there can be variability in the nature and intensity of a person’s disability. While s. 24(1)(b) of the Act requires that “the impairment or impairments are, or are likely to be, permanent”, s. 24(2) allows for variability within the concept of permanency. This section states: “an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person’s lifetime, despite the variation.” The Act further requires that the

impairment must result in substantially reduced functionality in one or more of six life domains (see s. 24(1)(c)). On the basis of these provisions, I am of the view that the Act recognises that people whose need for support due to reduced functionality is likely to last a lifetime, can be eligible for NDIS funding irrespective of the changing nature of their impairment and subsequent experience of disability.

While I do not consider the expectation of permanency in the definition of psychosocial disability to be problematic, I do, however, acknowledge that determining 'disability' (and thereby permanency) for such a group will bring challenges to NDIS assessors. Diagnosis – which may play a major role in determining the eligibility of some NDIS participants – should have less weight in determining eligibility for people with psychosocial disability. A diagnosis of Down syndrome is, I understand, always permanent; clinical depression can be treated successfully in some people and will not necessarily lead to a permanent impairment. Thus, while the identification of an impairment is required under the Act (see s. 24(1)(a)), the critical issue for people with psychosocial disability, in relation to determining eligibility for the NDIS in accordance with the Act, is that of **assessing functionality and capacity to participate in Australian society over the long term** (see ss. 24(1)(c)-(d) and 24(2)).

Predicting functionality over the long term is difficult, however, even in highly controlled environments, and is even more so for people whose life course has been seriously disrupted by fluctuating mental illness. Using sound and sensitive evidence-based strategies, it is possible, however, to gauge what reasonable and necessary supports a person might need during the life course in order to sustain participation in Australian society. For example, assessing functionality could be identified through extensive discussions with participants and their supporters (not a single telephone call with the applicant as is currently being done by many NDIS planners), and a review of services they have received to date in response to their mental health condition. Such a review should also identify the types of supports that have historically addressed crises and optimised the person's functionality. For example, if people with mental illness have decades-long histories of periodic housing instability, ineffective (or no) management of critical health needs when they arise, and/or failure to maintain supportive familial and social relationships, it would be reasonable to assume that they may require lifelong access to supports to assist them with managing housing, health and relationships. These (and other) supports should be built into the person's NDIS plan, and access to those supports should not be ceased simply because the participant is sometimes able to sustain housing tenancy, sometimes takes essential medications and shows up for specialist appointments, and sometimes engages positively with supportive family members.

The issue is not, therefore, whether a person with fluctuating psychosocial disability should be 'in' or 'out' of the NDIS on the basis of permanency of their condition or diagnosis, but how the NDIS responds to their varying functionality and changing life circumstances. No life remains static irrespective of disability, yet once NDIS plans are in place, participants are currently being advised that they may have to wait as long as 12 months between reviews (as reported to my office). For participants with widely varying functionality who are provided with plans based on maximum functionality (and thus minimum funding), such a long period between reviews may be disastrous, particularly if they experience a sudden downturn in wellbeing. Plans for participants whose disability fluctuates may need to be reviewed on a much more frequent basis, even on an as-needed basis, to ensure they reflect the supports needed to optimise functionality and participation in Australian society, and receive timely access to these supports. This approach aligns with the principle of reasonable adjustment as outlined in the *United Nations Convention on the Rights of Persons with Disabilities* and is also in line with what was originally promised when the NDIS was first introduced (the Australian public was told that NDIS plans would be reviewed on an as-needed basis).

I therefore recommend that the NDIA consider how the NDIS planning regime and resulting plans can more accurately optimise functionality for those participants whose ability to live an ordinary life in the community is expected to change on an ongoing basis. There are a range of ways this could be done and I offer the following as possible options. I stress, however, that the actual regime adopted by the NDIA should be based on evidence-based research where possible, and informed by data collected about participants with psychosocial disability during the roll-out of the NDIS trial sites and launch locations.

1. Plans for participants whose primary disability is of a psychosocial nature should be reviewed on a much more frequent basis than those who are assessed as having a more 'stable' disability. This period could initially be as frequent as bi-monthly and eventually adjusted to suit participants' individual 'recovery' and personal circumstances. Participants with psychosocial disability should also have access to an emergency review should they experience a mental health (or other) crisis. This review should be able to be triggered by any of the participant's service providers (as long as the participant consents, or is supported to consent, to the review being conducted).
2. Participants with psychosocial disability could be offered funding at the maximum level of potential supports required. However, service providers would only claim the services that are used by the person. A review of the plan could be undertaken when actual supports delivered vary significantly from those identified in the plan – such a review would not, however, result in the removal of supports if they are not used: it would simply serve as a way of establishing baseline functionality and usual societal participation for the person. This approach would be less costly (fewer formal reviews may be needed) but may result in a perceived budget 'blow out' for the NDIS (although actual service delivery costs would be lower because not all of the allocated supports would be used). There is also potential for it to be taken advantage of by unethical service providers who lodge claims for supports that are not delivered or are not required by the participant at the time. Mechanisms to address this risk would need to be considered.

A further issue that also needs to be addressed by the NDIA is how it will respond to participants with psychosocial disability who become mentally unwell or are placed on Involuntary Treatment Orders (ITOs) or Forensic Orders (FOs). I recommended that in these circumstances, participants' NDIS packages be placed on hold and immediately reactivated once the orders are revoked or the patient returns to living in the community. I also recommend that the NDIA continue funding support for individuals on ITOs or FOs at a minimal level during the period of operation of the orders, or while the person is detained in a mental health facility to ensure that participants' critical systems (housing, informal supports, finances etc.) are maintained during this time and people do not return to their lives to find themselves homeless, facing financial crisis, or experiencing a breakdown in their informal support network.

If the NDIS is to uphold the principles of "choice and control", "reasonable and necessary supports" and "social and economic participation", it must focus on maximising the long-term functionality of Australians with psychosocial disability who have clearly demonstrated a need for ongoing supports, rather than being preoccupied with gatekeeping on the basis of the perceived permanency of their condition. We have learned in various trial and launch sites throughout Australia that sound plans based on robust evidence and methodology are much more likely to lead to successful outcomes for NDIS participants. I similarly propose that a planning system, based on reviews that take into account the person's individual circumstances, and undertaken by knowledgeable and competent

planners, would be one way to manage the issue of varying functionality over the life course of participants with psychosocial disability.

I thank the Joint Standing Committee again for inviting me to participate in the recent hearing. I hope these additional comments assist the Committee to identify options for addressing the complexity associated with determining eligibility and responding to the variable impairment of NDIS participants with psychosocial disability.

Yours sincerely

Mary Burgess
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