

28 October 2019

Review of the NDIS Act and the new NDIS Participant Service Guarantee

Dear Sir/Madam,

I feel the NDIS has the potential to improve the lives of people suffering from a disability, and allow them greater opportunity to participate and contribute to, and help create a more prosperous society. However to do this serious omissions in the NDIS Act need to be addressed. In addition the inconsistencies in interpretation of the Act and its Rules by NDIS staff have and still are causing considerable and unnecessary stress and constraints for Participants, and will continue to do so until the core issues preventing the successful implementation of the scheme, as intended, are addressed.

The INTENT of the Act is unquestionable. The Legislation, scope, and subsequent budget do not allow the intent to be fulfilled. This review will do little to assist in seeing the intent realised, as the board instructs the Agency to ensure the scheme remains within the constraints of the numbers ESTIMATED to be eligible, thereby ensuring the scheme remains in budget.

An Insurance scheme can only be effective if it uses accurate forward estimates.

The estimated numbers eligible to access the scheme have been questioned by amongst others:-

1: Productivity Commission:

“The NDIA is tasked with ensuring the NDIS is financially sustainable. The insurance approach involves identifying and managing emerging cost pressures. The NDIA has identified five early cost pressures that need to be managed for the full scheme going forward (figure 6).

- ⌚ The number of children entering the scheme is higher than expected.
- ⌚ The number of people approaching the scheme in trial sites that have been operating the longest (since 2013) is higher than would be expected if only people with newly acquired conditions were approaching the scheme.
- ⌚ The number of participants exiting the scheme is lower than expected (particularly for children entering under the early intervention requirements).
- ⌚ Levels of committed support tend to increase as participants move to their second and third plans (over and above the impacts of inflation and ageing).
- ⌚ There is greater than expected variability in package costs for participants with similar conditions and levels of function (suggesting inconsistencies in planners’ decisions). “

(<https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf>)

2: Suncorp:

“It has been estimated that 64,000 Australians (14 per cent of total expected participants)³⁴ with psychosocial disability would be eligible for IFP, but this has been challenged.³⁵ A lack of reliable data in Australia has been argued.³⁶

Current estimates suggest that the projections for IFP eligibility resulting from psychosocial disability is more likely to be 230,000 (of the 690,000 Australians who experience severe mental illness each year).³⁷ This suggests that the application of the eligibility rules or the eligibility rules themselves need enhancing to capture those who should access the scheme.

Hard empirical evidence is crucial to understand the extent of the problem. This would inform policy settings and designate policy responsibility with the appropriate government bodies. As stated previously, funding an updated National Survey of Mental Health and Wellbeing should be seriously considered.” (<https://www.aph.gov.au/DocumentStore.ashx?id=171c3ad5-34df-4831-9d1a-4de4ec2096f8&subId=464569>)

These are just two examples. I have also personally raised this issue with Former Prime Minister Malcolm Turnbull, my current Federal MP Fiona Philips, Former MP Ann Sudmalis, and had correspondence between former Ministers and Shadow ministers. All acknowledged the veracity of the data I presented.

NDIS Legislation, Rules and Interpretation is based on Medical rather than Disability

“people suffering from PTSD or cPTSD, Chronic Depression,, Chronic Anxiety, to name a few diagnosis under DSM 5, are being told they do not meet the eligibility requirements because the condition is not on the list of acceptable disabilities, and is a Medical Condition.”

<https://www.aph.gov.au/DocumentStore.ashx?id=2953a492-cecf-4637-a1e7-e6aeef65be72&subId=463822>

This is another critical factor that is being ignored, not only in the discussion paper but also by Politicians, NDIA, Academics, purported experts, and media. The NDIA has an expectation that the provision of supports will result in an improvement in the persons disability, and with that improvement supports can be reduced or the person will be exited from the scheme as they have suddenly been “cured”. Psychosocial Disability is the most obvious example of this. The NDIA legislation and rules clearly does not meet United Nations Health Criteria.

The Special Rapporteur on Health, in his comprehensive assessment of the right to highest standard of health and wellbeing, has emphasised the removal of 3 kinds of “obstacles” in addressing the “global burden of obstacles” facing persons with psychosocial disabilities. (a) Dominance of the medical paradigm and overmedicalization; and complete neglect of psychosocial aspects (b) Power asymmetries with psychiatrists playing a unique, but powerful role within all medical disciplines, to take away or subvert the decision making opportunities of people with psychosocial disabilities and finally (c) Presenting a partial view of “evidence base” and the role of powerful actors who shape and determine outcomes of research agendas on mental health. To gain access to the NDIS requires a Psychiatrists diagnosis of Mental Illness, whereas The Mental Health and Human Rights Resolution of the OHCHR (2017), defines persons with psychosocial disabilities as, “persons who, regardless of self-identification or diagnosis of a mental health condition, *face restrictions in the exercise of their rights and barriers to participation* on the basis of an *actual or perceived* impairment.”

To quote from <http://disabilityrightsfund.org/our-impact/insights/psychosocial-disability/>

“Much of the discourse on psychosocial disabilities is also couched in medical and health terms. There is still a strong push from parts of the psychiatric community to view psychosocial disabilities as largely biomedical and health issues. Many people have expressed strong concerns about the increasing push to over-prescribe anti-psychotic drugs, mood stabilisers and other pharmaceuticals

in a well-orchestrated global push to increase medication of mental health problems, which blatantly promotes an expansionist agenda of the mental health industry and not the rights of individuals.”

Why am I highlighting Psychosocial Disability? I am doing this simply because it is the Disability that has the most inaccurate Estimated number of participants. Psychosocial, along with Autism Spectrum Disorder, are the disabilities that are driving the NDIA to slash funding to plans as the numbers entering the scheme far exceed those estimated. The Federal Government, States and territories slashed Mental Health services when the NDIS rolled out . This is Professor Pat McGorry’s “missing middle’, currently fuelling the escalating Mental Health crisis.

“the NDIS was never designed to accommodate mental health, and this is now even more evident. To remove it, or not undertake proper scoping to allow for sufficient funding, will result in an economic and social disaster as far as the group is concerned. The government need to engage with actual members of the psychosocial cohort and not the many agencies supposedly representing us if they want to have any chance of averting this disaster.” <https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=COMMITTEES;id=committees%2Fcommjnt%2F059c91a1-649a-45c3-ac94-4cc15f12e7e1%2F0001;query=Id%3A%22committees%2Fcommjnt%2F059c91a1-649a-45c3-ac94-4cc15f12e7e1%2F0000%22>

I have not addressed specific issues as outlined in the Discussion Paper simply because these issues are simply playing around the edges. To address the Dogs Breakfast that is the NDIS requires going to the heart of the matter. This is undoubtedly Politically unpalatable for all sides of politics, given the partisan support the NDIS has. There has been Productivity Commission reviews, Joint Standing Committee enquiries, State Enquires, and countless representations by people such as myself that have all gone unheeded by the Government. The Government continually falls back to the same purported experts to map a way forward. This Review the latest exercise in trying to be seen to be doing something.

The NDIS was a much needed revolutionary reform, that would have propelled Australia to the forefront of Disability reform. Sadly, just like the NBN, it has failed. The NDIS must be fixed, but to Quote Albert Einstein:

“We can’t solve problems by using the same kind of thinking we used when we created them.”

I have been a participant of the NDIS for three years. I have family members who are participants. I have battled the NDIS through the AAT, and am still confronted every day with the consequences of what should have been a life changing innovation that has been destroyed by people without any direct experience of dealing with the NDIS at a grassroots level.

The NDIS can be fixed, and “give the Australian People Value for money”, but not by the current so called experts and advisers, but by engaging those such as myself with Lived Experience, not those who's careers depend on the status quo being maintained, or self proclaimed experts.

Yours Sincerely