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To whom it may concern

The purpose of this document is to provide input concerning the National Disability Insurance Scheme (NDIS) Independent Assessments.

1. The Joint Standing Committee on the National Disability Insurance Scheme are to be congratulated for considering submissions to this very important, somewhat contentious, and significant change to how the Australia Government, Minister for NDIS and National Disability Insurance Scheme Agency proposes to streamline access to, and planning for people living disability to have allocated NDIS funding for support.
2. My experience with disability systems and the diversity of disability culture in Australia is personal, professional and political. This submission is written by a NDIS Participant living with a significant and complex physical disability. Furthermore, I have had considerable professional experiences with the Scheme from proposal development before legislation phase through to implementation as a former employee of the Agency and then as a co-founder and director of NDIS registered, independent Support Coordination business and now in academic research and education.
3. As a person living with significant and complex physical disability, there is no doubt the NDIS has changed my life for the better. I have access to the appropriate funds to engage essential personal care supports, aides and equipment so that I am able to continue with my academic research, consulting and employment.
4. However, I am concerned about the sustainability of the NDIS in its current form. For example, the NDIA and Governments have neglected to invest appropriately and accordingly, in the Tier 2 approach of the original NDIS, as recommended by the Productivity Commission report (2011). Without appropriate investment into community development and capacity building and mainstream services to include people with disability, the only way people with disability are able to access support is to apply for an individualized funding package through the NDIA.

Lack of accountability, transparency and trust by the former Minister and the Agency

“Well, the average Australian I speak to is aghast that we’d be paying billions of dollars for the services of prostitutes. Now, if people wish to use any services that are lawful in this country, they can do so with their own money. But you can’t bill it to the Commonwealth.” (Department of Social Services, 2021).

5. Unfortunately, the former Minister Stuart Robert MP has caused significant damage to the reputation of the Commonwealth and the NDIS in by his authoritarian and paternalistic approach to communicating about people with disability and the Scheme. He displayed a complete lack of understanding concerning people living with disability, our barriers to participation, human rights, dignity and respect. In fact, the former Minister pitched NDIS Participants as wasting taxpayers funding and spending valuable funds on ‘prostitutes and yachts’. He went on a national media agenda promoting misunderstandings which totally framed people living with disability as welfare cheats, misusing federal funds to have our needs met; of the very scheme which



gives us a lifeline. It was extremely distressing and upsetting, but most of all, it damaged any trust people with disability, our community has with the federal government.

6. This was exacerbated by tokenistic consultation to reform the NDIS including independent assessments. Arnstein (1969) discusses tokenistic consultation in a framework of citizen power in 'determining the end product', whereby tokenism may see us having a voice or being informed yet, we 'lack the power to ensure that our (sic) views will be heeded by the powerful...the powerholders continue right to decide' (Arnstein, 1969, p. 217).
7. Further fueled by the lack of accountability and transparent process of appointing the independent assessor panel, and consultation methods with the diversity of people with disability and communication needs.
8. As a consequence, we have felt really powerless, and a robust discussion and engagement whereby we are included as key stakeholders in the co-design process to reform the NDIS is almost lost. Independent Assessments, scheme sustainability and reform and change, must include us in a meaningful consultation and co-design process. This is an imperative.

Disability Policy Imperatives

9. It is timely to refer back to United Nations Convention of the Rights of People with Disability, of which Australia became a signatory in 2008. International policy imperatives such as the United Nations Convention on the Rights of People with Disability (UNCRPD) (Fleming et al., 2019) is one step towards valuing people living with disability as equal citizens and sets a range of articles to improve the way nations and states respond to people with disability.
10. The UNCRPD is incredibly powerful as it sets a human rights agenda for global nations to facilitate the right to self-determination and meaningful participation of all citizens living with disability as equal to their non-disabled peers enjoy. For example, Article 3.a of the UNCRPD proclaims 'respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons.' (United Nations, 2006 p.3).
11. In 2009, prior to the introduction of the NDIS, people living with disability and their important others shared their lived experiences to shape a National Disability Strategy, as a result of Australia Government signing its commitment to the UNCRPD. However, the National Disability Strategy 2020-2030 is yet to be finalized and this important and vital document provides the blueprint required to keep governments accountable and transparent in investing in legislation, policy and programs to improve the mainstream, community services required for all people and their quality of life and enact human rights.
12. At the heart of the NDIS is a spirit of, and processes falling into the social model of disability framework which promotes a rights-based framework. Disability studies scholars have long advocated for the social model to replace outdated medical models of disability support which truly had a detrimental impact on the lives of people living with disability in Australia that has perpetrated a culture of devaluation. For example, Goggin and Newell once describe the former disability support system based on medical model as 'Australia's social apartheid' (Goggin & Newell, 2005, p. 217).



13. International disability scholars have argued that the social model of disability denies functional impairment and thus informed and supported a model of support such as the World Health Organisation's International Classification and Functioning to better capture and provide tools and resources to address individual impacts. Considering the personal and environmental factors which influence self-determination, equal rights, participation and inclusion is vital. For example, see Abery and Standcliffe's ecological theory of self-determination (2003).

Independent Assessments

'...the introduction of mandatory IA (Independent Assessments) represents the largest and most fundamental changes to the Scheme since its conceptualization and introduction.' (Bonyhady, 2021, p. 4)

14. There is no doubt that since Australia began its nationalisation of providing disability support services that placed the individual firmly at the centre, there have been significant improvements in quality of life, economic and social participation of people living with significant and permanent disability. However, not everyone has benefited from the national individualised funding scheme and it is widely reported that since the launch of the scheme, navigation of the complex system has exacerbated health and wellbeing inequalities (Malbon et al., 2019).
15. It is well understood in the public sphere and in research that the NDIS planning process currently, is very complex to navigate, disadvantages peers living with disability, particularly cognitive disability, and culturally and linguistically diverse groups, remote and rural, and those individuals who experience trauma, neglect, abuse and exploitation because of communication barriers, systemic professional control and powerlessness.
16. Too many people still experience bias, inadequate or inappropriate plans because the current planning process is clunky and does not fully capture the true extent of the personal and environmental factors of the person living with disability. For example, in supporting people during planning meetings, in most circumstances, it is somewhat extremely difficult for a Participant or their plan nominee to discuss very confronting consequences of functional limitations and/or for a Planner to recognize there may be situations of violence, abuse, neglect or exploitation occurring to the participant.
17. It is also reported that the need for evidence-based assessments to assess need and allocate 'reasonable and necessary' funds to pay for supports, has 'resulted in inconsistent decision-making and a high volume of reviews' (National Disability Insurance Agency, 2020, p. 5; Tune, 2019).
18. The National Disability Insurance Scheme (NDIS) does require a more streamlined, accessible and timely planning process to ensure reasonable and necessary support is targeted to assist people living with significant and permanent disability more fairly and promptly. By doing so would assist people with disability to reach equal opportunity for meaningful participation as members of Australian society.

What are the advantages

"Experience has shown where a person lives, their access to health professionals and a focus on diagnosis, has led to inconsistencies in how people are assessed for the NDIS, and the funding they receive." (Department of Social Services, 2020, p. 12)



19. The following points summarise the advantages of Independent Assessments as framed by the Minister and the NDIA, including the Department of Social Services:
- Giving effect to the 2011 Productivity Commission report into Disability Support and the Tune Review consultation and subsequent recommendations.
 - Ensuring participants have the right assessments to inform access, planning and review decisions and promoting equal opportunity (as opposed to some participants paying for functional assessments personally to prove disability).
 - People will have choice about who they work with from a panel of Independent Assessors who will then assess their functional capacity and inform decisions on their access request or development of their plan.
 - Evaluation of the pilot determined that the use of consistent functional assessments resulted in improved decision-making and more equitable plan outcomes for participants with similar characteristics (Department of Social Services, 2019).
 - Influence the financial sustainability of the NDIS into the future.
20. Another advantage of independent assessments would ideally be to eliminate the ‘professional control’ often seen across our disability service industry. At times, people with disability are at risk of somewhat powerful others who may manipulate advice and services to keep their consumers locked in to receive services. For example, ‘professionals actually perpetrate dependency’ (Thomas, 2007, p.24). In Fleming et al.’s (2019) review of individualised funding, he discussed tensions of ethical obligations of the support professional’s practice ‘to promote empowerment and self-determination whilst honouring their legal obligations’ (Fleming, et.al., 2019. P.17).

What are the disadvantages

“...Being grilled about my disability for 3 hours left me feeling traumatized, incredibly sad, exposed, exhausted and very concerned about the impact this will have on people with disabilities should it become compulsory.” Dr George Taleporos, NDIS Grassroots Discussion forum, 19 March 2021.

21. There are widespread concerns across the Australian disability support sector regarding the NDIS Reforms including the Independent Assessment process. On 11 March 2021, a Joint Sector statement was released to voice concerns about ‘how people with disability will access the NDIS and, most importantly, how they will receive support’ (Australian Disability Sector, 2021).
22. There is a perceived lack of co-design by the NDIA with all interest stakeholders to implement the Independent Assessments (Advocacy for Inclusion, 2021; Australian Disability Sector, 2021). These perceptions are supported by the fact that the Independent Assessment pilot occurred in 2018, before the Tune Review took place and presented findings. In reference to implementing any significant change to planning processes, the Tune Review states ‘this change of approach will require extensive consultation with participants, the disability sector, service providers and the NDIA’ (Tune, 2019, p. 66).
23. The proposal to introduce Independent Assessments has raised concerns that:



- The proposed assessment tools ‘are based on standardised self-report items linked to conceptual domains, as opposed to the client’s individual circumstances, needs and/or goals’ (Occupational Therapy Australia, 2021, p. 6).
- Bonyhady identifies ‘the absence of rigorous evidence to support the validity of the Independent Assessment tools and are not fit for purpose.’ (Bonyhady, 2021, p. 4),
- The process of functional assessment as prosecuted by the NDIA, ‘impinges on the rights of people with disability and limits their choice and control’ (Occupational Therapy Australia, 2021, p. 5).
- the right to appeal decisions made by the Independent Assessor is denied even through the Administrative Appeals Tribunal (AAT). The only right to appeal is the funded support established by the NDIA after the Independent Assessment. For example, ‘independent assessment results will not be directly reviewable by the AAT’ (National Disability Insurance Agency, 2020, p. 25).
- The implementation of independent Assessments as proposed with the NDIA may severely disadvantage prospective participants and existing participants ‘based on the use of predetermined self-report(ing) measurement tools, implemented in an impersonal way by an assessor who may not know the client’ (Occupational Therapy Australia, 2021).
- There are significant concerns about the Independent Assessment process interview – which will include a direct meeting with the individual, and a separate meeting with a significant other or provider of your choice, without you present (which raises significant concerns about respect, dignity, rights and choice and control).
- Credibility, capability, accountability and governance concerning the privately contracted organisations who will carry out the independent assessments and fully capturing the true and authentic needs of an individual living with disability in time limited assessment process.

The important role of independent support coordination.

24. Key assistance for individuals to navigate complex systems and build individual capacity towards self-determination behaviour, is the ideal role of independent support coordination. Traditionally known as case management, support coordination can play a vital role in building the skills, abilities and capacities for individuals to navigate complex systems to access personalised, self-determined support needs to be met. Support Coordination is a funded support allocated within NDIS Participants’ Plans if it is seen as ‘reasonable and necessary’. However, there lacks a framework for providers of support coordination to ensure NDIS Participants are appropriately supported to exercise their self-determination and express their will and preferences, choice and control and access independent living and meaningful social inclusion.
25. In my opinion, this independent support coordination role is vital and essential to build capacity of NDIS participants at either Tier 1 or Tier 2 of the original NDIS design. Linking individuals to mainstream services, empowering them to understand their rights and responsibilities in a time limited model. This would occur to such point where the participant has the confidence, tools and resources to navigate their own life, make decisions or have the support for decision making and accessing mainstream and community services (that have lifted their game in being more responsive to diversity of our society and inclusive of people with disability).

Conclusion

26. The introduction of Independent Assessments proposal has caused concern across the Australian Disability Support Sector including participants, support organisations and allied health professionals. A national joint



statement urging the government to halt the introduction of Independent Assessments was released in March 2021.

27. It proposed that there is not enough evidence to support claims by government this initiative will not resolve the current problems (Australian Disability Sector, 2021) with NDIS Planning and navigation of the system until there is an appropriate, 'rigorously tested and independent evaluation' to support its implementation.
28. Further, the statement highlighted 'rushed consultation' by the NDIA (Australian Disability Sector, 2021, p. 2). A more co-designed consultation process piloted across regions, which meaningfully includes all stakeholders is one part of an ideal solution to fixing some of the design issues with the present NDIS Scheme.



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