

[REDACTED]

Monday 23rd December 2019

To the Committee Secretariat,

As the father of [REDACTED] children, three of whom have complex Autism Spectrum Disorder diagnosis (along with a plethora of associated disabilities) and as an experienced primary school teacher specialising in teaching children with disabilities, I feel that my opinion is well informed by research and lived experience to comment on what it is like to be involved with The National Disability Insurance Agency (NDIA). The NDIA is a behemoth that requires a great deal of patience, resilience and fortitude to engage with and as I have been dealing with them now for three years I am shocked at how they seemingly operate based on 'secret knowledge,' completed by 'secret people,' who have 'secret credentials.' I am compelled to make a submission to the inquiry and I thank you for your time.

From the very beginning, three years ago, my eldest son was given a plan that was grossly inadequate and I was forced to fight for 'reasonable and necessary' supports. My complaints can all be boiled down to several personal observations that need to be addressed.

1) NDIA staff are not qualified to make the judgements that they are making. I have presented evidence to each and every planning meeting from a range of health professionals that talk of the critical supports that my children need and each and every time I have a nameless 'planner' at the NDIA make judgements contrary to my children's medical advice. I sought information from a high level director within the NDIA three years ago and she confirmed to me that the life-changing decisions for participants are made by clerks who are not trained medical and/or health professionals. *I ask that plans require formal sign-off from independent and appropriately qualified health professionals to ensure that the rights of the participant are upheld.*

2) There is no additional support provided that takes into account that household complexity compounds participant need. *I request that an additional "complexity levy" be added to plans where there are two or more people in the same household on NDIS plans which factor in that there are less informal supports available to the household, which means you require much more formal support to balance this deficit.*

3) Participants of the NDIA have too many barriers accessing and using the scheme to its full. Let me elaborate on the most obvious barrier that affects me - computer hardware and associated resources. There are over one-million Australians who do not have access to the internet, let alone have access to a reliable computer. While I understand that many of these people are under the age of 18 (who have parents and carers who may have adequate resources) or over the age of 65 (and are therefore ineligible to participate in the NDIS), it fails to acknowledge the tens of thousands of Australians who are below the poverty line or who need to prioritise food and shelter over IT hardware and are at a significant disadvantage which is compounded by their disability. And yet to access the NDIA portal it requires a high level of computer literacy and a stable internet access with provision to upload documents (that requires a camera and the ability to use it). *Critically, the NDIA forbids you to use your funds to purchase a computer to allow you to facilitate case-management. I ask that this be changed immediately and resourcing for applicable participants be added to plans.*

4) Plan success is either optimised or hindered based on the quality of the Local Area Coordinator (LAC) that you happen to be allocated. My most recent experience was harrowing when the appointment was rushed, I was asked hardly any questions and when I rang to enquire of the draft plan she had already submitted it without checking that the goals I had suggested (based on the many

health professionals I had consulted) were accurate. *It is critical that the rights of the participants are placed over the KPIs of the LAC. It is the right of the participant to review the proposed plan prior to submission to the NDIA.*

5) Young participants are viewed with prejudice when trying to access short-term accommodation. As my wife and I have three sons who access the NDIA, we have consistently requested adequate resourcing to short-term accommodation. Each and every time I have been told by LACs that they are not eligible for respite due to their age. I have insisted that this be a goal as it is critical in our complex situation that respite takes place to ensure the longevity of their informal supports. *I would like to see that NDIA allow equality of access to all resources for all participants.*

6) NDIA staff don't liaise with participants prior to plan approval to seek clarification or to maximise participant outcomes. I still don't understand how if my son requires 26 speech pathology, 26 occupational therapy and 15 psychology appointments per annum at the NDIA pricing recommendation (amongst the many other needs recommended by the many health professionals at the planning meeting), how the plan is approved by an NDIA Planner with funding levels significantly lower than required! *I want to see the NDIA compelled to fund participant supports exactly as health professionals recommend at planning meetings.*

If you require any further information on the above submission please do not hesitate to contact me at your earliest convenience.

Thanking you,

████████████████████