

As someone who has a lifelong, permanent and severe disability, I have vested interest in ensuring the ongoing and long-term health and viability of disability supports in Australia, the industry that supplies them and the funding mechanisms by which they are funded. The following submission is a summation of my thoughts and input into the proposed changes to the NDIS Act, Rules and other supporting and subordinate legislation.

First please let me bring attention to the format that the consultation has been presented in. Upon superficial inspection, a layperson would be forgiven for having the mistaken belief that the proposed changes are quite benign. However, it is only upon closer inspection going line by line comparing the current act and rules etc. with the proposed changes that the true nature of what is being proposed can be truly seen. This coupled with the extremely short period of consultation, only 20 business days (the National Disability Advisory Council recommended 2 months and only 14 days given for DSS to work through the considerable body of submissions in order to facilitate a report for subsequent necessary changes before the act and supporting legislation is brought before the parliament for consideration can only be seen as a very clear message of intent to limit the opportunity of the disability community and their supporters (friends, family, service providers, peak bodies and states governments) to give meaningful input into the process. I will also note that by the governments own admission, these proposed changes are as a result of a process that has been ongoing within government for no less than 2 years with literally scores of draft versions having been worked through in that time, however, only now is the disability community and its supporters being somewhat superficially engaged in the process, virtually moments before the government intends to bring the changes before parliament for discussion and ultimately a vote. This is in fundamental opposition to the co-design process (that should see scheme participants and other relevant parties consulted from the very beginning to work together in finding or crafting a solution that works for everyone) that any proposed changes to the Act are supposed to utilise.

At least 24 times throughout the proposed changes to the Act, the word "MUST" has been replaced with the word "SHOULD" this has the impact of decreasing the responsibilities the National Disability Insurance Agency (NDIA) and the government have towards participants and prospective participants of the National Disability Insurance Scheme (NDIS).

There are no protections in the proposed legislation to prevent the CEO / NDIA from triggering a plan variation which reduces funding and/or changes how the funding is managed. This needs to be rephrased to ensure that the participant is consulted prior to plan variations occurring. Preferably, there should be a clause stating that only a full review (reassessment) can result in reduction of funding.

The ECEI Intervention Reset Paper and recent discussions regarding providers in the Positive Behaviour Support Plan space refers to funding selected providers delivering evidence-based intervention. This is of concern as it is likely to significantly impact Choice and Control, particularly in regional and remote areas and areas where thin markets exist and choice is already significantly impacted by availability.

There is also significant concern regarding the ECEI Reset Paper's recommendation that 'Children enter exclusively through s.25, with clearer focus on prevention and early support'. The majority of children accessing ECEI have permanent disabilities and should continue to be assessed under s.24. This also lines up with concerns regarding the proposed removal of the NDIS Eligibility lists. While I can fully appreciate that the government and the NDIA are eager to see the day where children would enter thru the ECEI catchment, receive intensive Early Intervention and by the completion of their time funded under ECEI

find that sufficient capacity has been built that they are no longer dealing with significant developmental delays etc. and are able to then make their way through life without depending upon formal funded supports through the NDIS, a few things must be noted. 1. It will always only be a percentage of children who access ECEI who are able to gain sufficient capacity so as not to require ongoing formal funded supports through the NDIS. 2. Current funding under ECEI is significantly below optimum levels for good clinical outcomes. 3. Because ECEI finishes when a Child reaches school age, a lot of developmental delays and other issues that serve to seriously impact social and economic inclusion are yet to be identified at that age, a better approach would be to recognise that most of the children who enter ECEI will continue to require at least some funded supports throughout their schooling with an objective to have sufficient capacity by the end of school so that they are able to have social and economic participation in their community with fewer funded supports because the investment has been made early in life where it counts. Even then one must acknowledge that this will not be possible for all participants who enter via ECEI but is certainly a more useful goalpost than currently exists. 4. In order to achieve this the NDIS will need to embody true insurance principles instead of the welfare approach that I currently being used to ration supports and attempt to exert influence over participants and their families rather than to focus on who best to achieve good long-term outcomes. 5. The NDIS was never intended to operate in a vacuum but rather to work together with new and pre-existing mainstream supports. In failing to develop a healthy, diverse and resilient Tier 2 supports network, participants are more reliant on ongoing funding through the NDIS and more people on the edge of eligibility are being forced to either fight their way into the scheme or go without the supports they require. The original architects of the NDIS understood that disability supports must exist on a spectrum so that everyone is able to access the supports and services they require in a timely and cost-effective manner. As currently stands with Tier 2 supports being non-existent in much of the country and a massive shortfall in both scope and capacity where they do exist, we now once again have a system of the have's (those who are able to access the NDIS) and the have nots (those who fall short of meeting the eligibility criteria.) Until this is adequately addressed we will not see this issue improve. 6. Finally, there is still much work to be done by both government and communities to systemic and deeply ingrained hurdles that exist in Australian society that serve to limit access to "an ordinary life" for very many disabled people in this country

Drip feeding of funding in monthly / quarterly instalments will put participants with complex needs at significant risk. Not to mention that in living an ordinary life, a person's support requirements may quite naturally and reasonably change overtime for a variety of perfectly valid reasons such as disabilities that are episodic in nature or due to changes in social and economic participation opportunities that may vary significantly from week to week or month to month leading to some months where support requirements are less and other months where support requirements are significantly greater. This kind of Choice and Control over being able to use the supports that best fit the need at the time are inherent to the intent of the scheme and are essential in ensuring that people have the best opportunity to 'live an ordinary life'. To remove this flexibility will not only relegate many participants to a 2<sup>nd</sup> class existence having to simply settle for a scheme that is no longer responsive to their needs but also serves to infantilise NDIS participants by effectively saying that we should not be entrusted to manage the ebbs and flows of a good life. This coupled with efforts to severely limit available service providers in certain support segments and change the way that services are supplied and paid for through the scheme are a massive step backwards that is eerily reminiscent of the old "block funding" model that the NDIS was created to replace.

Removal of Eligibility Lists is extremely problematic – Australians need some guidance on who may or may not be eligible, and there are specific diagnoses which should be deemed automatically eligible.

Many of the new powers afforded to the CEO and the minister lack appropriate scope and means of review which leaves this new powers open to abuse.

The proposed Participant guarantee is fundamentally good however while the agency and the government continue to attempt to operationalise the scheme according to a welfare approach instead of pure insurance principles the outcomes are not likely to significantly improve.

The addition of a risk assessment for plan management means that many people would then be denied plan management which is an integral part of successful service delivery particularly in regional / remote areas and where thin markets exist as in many cases there are simply no NDIS registered service providers available. Plan managed should also not be constrained by the price guide as this further limits choice and control and properly funded participants who have the correct supports where needed (for example support coordination) should be entrusted to be able to make decisions that are in the interest of achieving good outcomes while operating within the plan budget. Contrary to what appears to be this current governments opinion, the more constraints that are placed upon a participant or their NDIS funded supports, the worse the outcomes are likely to be.

Proposed changes to Self-management in terms of having to either use an “NDIS Card” that might take the form of a virtual credit card or other format or to upload invoices to the portal and have the provider paid directly by the NDIS also serves to seriously limit choice and control as currently people may purchase supports from a range of mainstream providers (eg. supermarkets and pharmacies for continence supplies, department stores for low cost / low risk AT) in some cases people have been able to purchase goods second-hand at significant discount (eg. Particularly where NDIS has funded a piece of AT for one participant and then due to changes beyond the control of that individual that equipment no longer suits their needs soon after it is supplied) and in a number of cases where either goods or services are supplied from overseas (eg. Where certain consumables / low cost low risk AT is not readily available from an Australian supplier or where someone receives funded supports while temporarily out of the country and supplied by someone in the country they are visiting).

By renaming plan reviews to re-assessment and creating a multitude of opportunities for plan variance without re-assessment the government is attempting to limit the right of reply by people with disabilities and their subsequent access to external review by AAT. All processes which would serve to vary a plan either in terms of budget or scope of supports available to be used must involve consultation with the participant and their rights to review and subsequent access to the AAT or other means of external review must be protected.

Finally the proposed “King Henry VIII powers” to be granted to the NDIS minister by allowing the minister to update the rules (which “MUST” then be considered by the CEO when interpreting how best to operationalise the scheme) without consultation from participants, the states or the industry would allow the Minister to fundamentally change the scheme beyond recognition and are open to serious abuse. These changes cannot therefore be allowed to stay in their current form.

This submission is in no means intended to exhaustive but instead represents the issues that myself and those near to me see as of most serious concern.