



# Changes to the NDIS Act & Rules Submission

October 2021





**“Timeframe is  
much too short to  
allow promised  
meaningful  
consultation  
with disability  
community.”**

**Every Australian Counts thanks the Department of Social Services for the opportunity to make a submission into proposed changes to the NDIS Act and Rules. The changes proposed are a far cry from the changes we were expecting to see this time last year, when the Minister for the NDIS was planning to legislate independent assessments, and make changes to Reasonable and Necessary. Our community is relieved and grateful that they have been listened to - and those changes have not been included here. And they are grateful to see some of the welcome recommendations from the Tune Review being introduced (although not exactly as expected).**

**However, our community is still feeling battered and bruised from the experiences of the last 12 months or so - in addition to the stresses of the pandemic. And they are disappointed about the short consultation timeframe. As a result, people in our community continue to feel cautious and sceptical about many of the proposed changes.**

But before we get into the detail, let us tell you a bit about who we are...

Every Australian Counts is the grassroots campaign that fought for the introduction of the NDIS. It is a community of people with disability, their families and carers, people who work in the sector, as well as ordinary Australians who want to see a better and fairer deal for people with disability in this country. In the ten years since EAC was established, it has amassed thousands of supporters from all over the country.

Unlike other campaigns, Every Australian Counts didn't end with the introduction of the NDIS in 2013. The EAC community has stayed active and engaged as the scheme has rolled out all around the country. Our community continues to fight to make sure the NDIS stays true to its original vision, and delivers on its promise to people with disability.

We want to begin by acknowledging our support for the NDIS. We have had the opportunity to both see and hear firsthand the incredible difference it has made to many lives. When it works well, it does change lives for the better – as we always hoped it would.

But our community is also all too aware that it is not working well for everyone. Too many people are falling through the gaps, and not getting the support they need. Even those who are ultimately happy with the outcome express constant frustration with NDIS processes and policies. In short – the scheme is not yet working the way we all want and need it to.

We have had the privilege of speaking to thousands of people across the country about their NDIS experiences. Whether face-to-face or online at one of our community forums, or through social media, phone calls and emails, or through surveys and submissions, we are constantly collecting people's experiences, feedback and ideas for change. We do this because we are concerned that in the maelstrom that has become the NDIS, the voice of people with disability and their families – the people who use and need the NDIS the most – is often lost. We want to make sure they are front and centre, as they should be.

No changes to the NDIS should ever be made without first consulting the people who matter most. It is their experiences and priorities which should drive change.

We therefore wanted the review team to have the opportunity to hear from people in our community who may not have otherwise engaged. Not everyone has the time or resources to make an individual submission directly to DSS – and many feel intimidated by the formality of the process. Others reported finding the DSS submission process inaccessible.

So we opened a small page on our website asking people to make submissions that we would collate and pass along on their behalf in this submission.

When we used a similar process to collect stories for the Tune Review in 2019, we received more than 600 individual submissions in just a few short weeks. But this time we received little more than 100. Members of our community have primarily responded to the news of this submission with a mixture of disappointment and cynicism about the very short consultation timeframe. They told us the amount of information to consider was far too much, far too complex and far too time-intensive to read, understand or respond to. This was exaggerated by the exhaustion resulting from the consultation occurring during the peak of the COVID-19 pandemic in Australia. And exaggerated again by the short passage of time since the long and traumatic fight against independent assessments – a process that left our community feeling exhausted, anxious, and distrustful of the Federal Government and National Disability Insurance Agency's intentions for the NDIS both now and into the future.

You will find the stories, statements and ideas about people's experiences with the NDIS legislation, the ways it could be improved, as well as specific feedback on the proposed changes attached in the Appendix. They are as they have been submitted to us – swear words and all. The only editing has been for typographical errors or information that clearly, and potentially dangerously, identifies a person, their family, the person they support, or their employer.

So the focus for this submission is on the voices of people with disability, their families, and the people who support them.

And while we know your team will read every single one of the stories in the following pages, what follows is a very brief summary of their valuable insights, concerns and suggestions for a better way forward.

We've left the substantive legal analysis to our colleagues from PIAC who have provided sound recommendations on the NDIS legislation. EAC endorses their submission.

As you read through the statements people have shared you will see key themes emerging that are consistent with what we have heard again and again from people over the years - that they want a fair, easy to use scheme that is flexible and that puts them in the driver's seat.

Every Australian Counts would usually provide a thorough summary of the issues raised before jumping to the Appendix. But just like our community, we have also found that the volume and complexity of the materials combined with the very tight timeframe has meant we needed to leave our submission form open right until the last minute, and leave the analysis to DSS.

But in short - these are some of the most common types of responses:

- The consultation timeframe was much too short.
- The CEO has way too much discretionary power, especially when it comes to changing people's plans without their awareness or consent.
- Plain and clear reasons should always be provided for decisions, by default.
- Self and plan managed participants are very worried about losing choice and control.
- The word 'reassessments' is too closely associated with independent assessments - but giving clarity to the different forms of 'reviews' is welcome.
- Participants must be able to request their own reassessments, not just the CEO.
- Undefined terms need clarity. People want to know what "appropriate treatment", "unreasonable risk" and "substantial improvements" mean exactly.
- People want more individual advocacy to help them navigate the NDIS.
- People don't want to do S100 and AAT appeals, they are far too slow and distressing.
- Plain, clear language is needed for the NDIS Act, Rules, policies and communications.
- People want to see a draft of their plan before it is approved, by default. And have the opportunity to correct mistakes.
- People want genuine, meaningful engagement. They want to be heard and respected. Trust has been broken and will take time and effort to regain.

**Every Australian Counts urges the Government to give careful consideration to these critical issues and make amendments before the legislation is presented to Parliament.**



## Appendix

**"It concerns me greatly that a CEO has the power to make decisions about a plan without the request, consultation or consent of a participant."**

## **Sam**

### **Vic**

As a current NDIS participant I have some concerns about some of the proposed changes to the NDIS Act and Rules.

Firstly, section 47A also allows plans to be varied on the CEO's own initiative, without request, consultation, or consent from the participant. Plans should not be changed without the consent or knowledge of participants.

Secondly, Rule 8 of the Becoming a Participant Rules requires that, to access the NDIS, a person must be undergoing or have undergone 'appropriate treatment'. The treatment that a person pursues must be up to the individual. What does "appropriate treatment" mean? What if the person cannot access or afford that treatment? What if that treatment comes with significant risks?

I underwent "appropriate treatment" for my Dystonia and suffered a stroke as a result of that treatment, leaving me significantly more disabled. I wouldn't have pursued that treatment if I had access to appropriate support at the time.

I would hate for someone else to be pushed into pursuing a risky treatment in order to receive necessary NDIS funding.

## **Vicki**

### **NSW**

I support only positive changes. The word reassessment needs to be dropped.

## **Victoria**

### **NSW**

- 1/ Stop the CEO from having full control.
- 2/ Drip feeding buckets of funding will not work.
- 3/ Self managed needs to stay as it is.
- 4/ Open up capped staffing numbers.



## Chanelle

### Qld

The proposed amendments also have the potential to make NDIS participants worse off, such as giving the CEO of the National Disability Insurance Agency very broad powers to change participants plans without consent.

The proposed legislation also provides the NDIA with the ability to apply the very broad term of 'unreasonable risk' in relation to plan management rules.

## Rochelle

### Qld

There are many areas of open language which allows the NDIS CEO and or Minister to move goal posts at whim.

They don't define what is involved in say, the extended assessment for 'who should not be allowed to self manage'.

And, I feel this change can be used to 'discipline' participants by forcing them into all or part Agency Managed. Where is the additional training, where is the cautions that one would think NDIA should be providing when they determine a person isn't using funds correctly. Not all of the misuse is fraud, for heavens sake. Most is honest mistakes trying to navigate a complex, biased and discriminatory service.

Unless assessors and planner are given adequate medical and disability training, even box ticking personas won't help.

What needs to be overcome is the misinformation and personal bias from the LAC role, all the way up, the chain.

I'm still being told by LAC and the like that my "condition" is not accepted. I have impairments that are physical, neurological, cognitive and sensory. I have BEEN accepted with severe functional loss in ALL 6 domains, but an LAC says "No!! I don't think you need that!!!"

This change in planning and the wording to allow further abuse is just unconscionable.



## Anon

Hi, I think there needs to be removal of sustainability in the legislation as that is currently the driving force behind cuts in plans or decline in finding supports. Inflation of plans is a major controversy for us in the NDIA with plans not being approved due to this inflation amount and not based on R & N.

As an employee of the Agency and someone with a disability I feel at times we plead for these participants and sound decisions are not being made or rushed. We know that participants are given more and more reasons and given extra red tape to jump more hurdles to provide more and more evidence.

Lived experience is effectively ignored and any learnings from other sources eg AAT are ignored. We have no risk based decisions and executive leadership teams make decisions to the detriment of participants and not in accordance with legislation. For example, psychology supports are deemed the responsibility of the mental health system regardless if a person with a disability does not have a mental health condition ie you can still suffer anxiety that is short lived without having a mental health condition.

The NDIS is failing the pub test - participants and their families don't want the earth they just want a chance and not be scrutinised and perceived as dodging the system.

## Greg

### NT

NDIS has been an absolute terrifying experience for myself not one plan has ever been completed correctly, had 6 reviews in 2yrs, my currently plan has been halved over a 2yr period not 12mth as well as AT equipment in last plan not purchased now rejected in new plan or doesn't even exist on it.

Been awaiting an electric wheelchair for 3yrs now only recently rejected the manual chair I'm sitting in 24/7 isn't one built for that and is a fold up hospital style chair.

I've been left with absolutely no MH, PHYSICAL, NUTRITIONAL Supports all of which I had regular contact with PRIOR to NDIS roll-out. Also our Highly Trained Service Dogs are still not recognised under NDIS as to their importance of them in our lives.

## **Libby and John**

### **Qld**

We want to be able to have person-to-person interviews at Review Meetings and to be present with our son to be able to interpret the questions and answers for him as he needs help with that. Every intellectually impaired person needs an advocate with them at Review Meetings.

Before the Plan is set in concrete it would be great to see a Proposed Plan so adjustments could be made to ensure the Plan is really what is needed for the Participant.

## **Victoria**

### **Vic**

I have read the 'explainer' copy by the PIAC, and agree very much with their concerns.

## **S**

### **SA**

I cannot thoroughly read through these documents as I'm currently at AAT for my Autistic-PDA teenager and also have [diagnosis] myself so there's only so much cognitive energy-processing I can have right now. But here's my concerns based on my experiences managing my teens plans since 2016.

First up reviews, S100 and AAT. I did my teens review last December whilst my teen was in crisis, plan approved in April, S100 Decision end of June, first AAT conference end of September.

Now firstly it took 4 months for plan to be approved which is not good enough.

It was very disappointing so I was trying to gear myself up to do a S100, LAC called me briefly and said she was going to put in a request on my behalf and that she will contact me when she hears something.

I found this to be a problem, I never saw the request so did not know what was in there. I think this needs to be changed. If LAC puts an S100 through it should come to us first for approval, there needs to be some form of collaboration in writing.

When the Review officer called me briefly late June wanting to clarify what was requested before sending to delegate. I was taken by surprise as I wasn't expecting his call and also I had to try to remember back to December right there on the spot and I didn't know what the LAC had requested. This was difficult for me though I feel I got most of it across. I was also disappointed in that my preferred communication is by email and wasn't being used.

I think this should be improved on and that once Review officer has begun communicating with PWD/Nominee that they should then send an email at the very least summarising what they are sending to delegate to ensure everything is understood appropriately as well as then giving opportunity in case something was missed. I noticed S100 outcome entry was in the documents upload in the portal the very next day but didn't get decision for at least a week. I have read in groups some PWD aren't even being contacted by review officer before decision is made, this should NEVER be allowed.

Now the Review officer was nice and respectful and when I look at the documents he supplied to the delegate from the portal in the T-Documents - I can see that he tried but there were some miscommunication which could've been corrected - if I had the opportunity, which I would blame on NDIS processes rather than the review officer.

I had lots of issues with the S100 decisions by the delegate. For example denying psychologist who has built up a therapeutic relationship with my teen since early 2017 which is very important in Autism let alone PDA (Pathological demand avoidance). Instead wanting to push someone new (an agency managed behaviour therapist and PBSP) which has potential for disaster let alone how few there are. We live in the country and there are issues around the behavioural profile of Pathological Demand Avoidance that requires very different approaches. Not only that many adult Autistics will say they were harmed by behavioural approaches like ABA and PBSP. There needs to be more choice and control here. We do not use restricted practices which goes against the basic needs of PDA - self autonomy.

After that I applied to AAT and also for an advocate.

I also put in a FOI request which I am still waiting on a decision. This is very disappointing.

The tribunal staff have been very nice and respectful, no issues with them.

The statement of issues, this is a huge document, very overwhelming and invasive. Not only that they send it at the last minute.

I think this should be improved on both the document itself and the timing of when they send it. I can't help but wonder how many give up based on this document. I nearly did!

Next conference is late November. Let me remind you that the initial review was in December. So it will already be almost a year when the second conference comes around. My teen was 15 at the time of review, 17 next year. Lots of changes are happening for them in this time and near future. I have read about a recent decision at AAT in regards to tribunal not considering additional supports outside of initial review. This is very concerning considering my teens age.

There needs to be processes that protect against this.

This also leads me to the changes in legislation in regards to plan variation. Variations should never be made without consent, period. This needs to be protected. The CEO is open to too much power and control. Nothing about us without us.

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Another concern I have is changes to self managing. I self manage and I am very concerned about potential changes that could be made after this goes through. I am always spotting mistakes on invoices which would never be picked up if a third party was managing this. This removes accountability from providers and provides more opportunity to fraud.

I am also concerned about being funded in instalments. I would like flexibility to when we use supports, there may be periods that may require more support then other periods like STA/sickness/Covid or doing groups that are not year long. Their proposal would not allow this and be a hindrance to one's choice and control.

Another issue is registered providers, we don't always use registered providers especially as PDA requires a lot of out of the box/flexibility planning.

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I am concerned about changes to the becoming participant rules.

Let's use me as an example, say I decide to torture myself with applying to NDIS for my [diagnosis], what is stopping them from denying me based on false and already debunked treatments such as [treatments] which has already been proven scientifically to be harmful?

My mother applied to NDIS before her 65th birthday, She has very reduced functioning in her shoulders, neck, arms, hands. Now neglect by the public health system aside she finally after 4 years reached the end of the long line on a waiting list to see a specialist who was shocked by my mums shoulders being so badly bone on bone. They have offered to operate on one shoulder and if it works she will get some (not all) functionality but get this she's on yet another waiting list (as non urgent) and has been told she needs to see a physio to improve functionality enough so they can even operate on it but Medicare only supply 5 physio sessions a year. She's on a disability pension!

There is also the issue that due to my mums other health conditions she is at risk in surgery so there's issues in even going ahead.

If this day ever comes and she survives the operation and there's some functionality returned then it's the same if not longer wait for the next shoulder, then after that it's the hands and then the neck. Of course in all this time my mums functioning is deteriorating even further. She already struggles to do basic personal care.

All because of a whiplash injury over 40 years ago!

But NDIS say it's not their problem and public health just barely exists. What support is there for my mum and people like her. NDIS should be responsible, this is very clear physical disability that is permanent .

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I am concerned about the changes in the legislation and reliance on future rules. I think there needs to be more protection for PWD in the legislation and less rules.

That's the best I can do right now, I hope it's helpful.

**Kathryn**

**SA**

Plan management – section 45

Self-management 'tap and go' only works if you are using a larger business.

I use individuals who have an ABN but don't have payment facilities of a normal business. I choose to maintain a float of funds and pay them immediately then do my claims once a week or fortnight. It saves me messing around constantly with claims and my service providers are happy. Clarification required on this.

S100 – reasons for decisions should be mandatory provided to the participant – not on request. There is significant emotional and physical stress involved in dealing with the NDIA and to not have any transparency about decisions adds to this and flies in the face of accountability for those decisions. Surely any participant service guarantee should include transparency around decision making.

For example – I received funding for a powered wheelchair around three years ago. At the time getting it in and out of my house was not a major issue as my son was studying and at home a lot so it didn't occur to me to seek funding for a ramp. However, since then he has started work full time is no longer available to assist. As well, my condition has deteriorated and I have come to accept that I cannot keep falling over within my home without risking breaking bones or worse – that I need safe access to my house and to use a walker within it. I have been trying for nearly two years to either get modifications to my home to remove hazards and a build a ramp for safe access with a walker and to be able to use my wheelchair. OR for the NDIA to assist me with the cost of a move (mainly the taxes) – provided for within the guidelines - where I sell my home and buy something more suitable. Not only would this be more cost-effective in the short and long term, but it would provide me with much desired autonomy and far less stress than dealing with the NDIA for future modifications.

However, I've been refused assistance with a move and all modifications, including a ramp with no real explanation or justification and now have to go through the appeals process. Over the last two years I have endured poor or no advice from the Local Area Coordinator provided by the NDIA, unprofessional conduct by the NDIA delegate and/or the LAC (there has never been an explanation for some of the early and inaccurate comments made by one of them, despite my requests for clarification). I am now being told that I don't meet the clinical justification for a ramp and yet I have to use a wheelchair for any distance more than about 100 metres, but can't get it out of my house? I have used NDIA preferred providers as OTs and even had quotes from NDIA preferred builders but they have not been able to satisfy the NDIA delegate that is assessing this? Two years of mental strain and effort on my part, as well as thousands of dollars in costs of OTs has come to nothing with no logical explanation, nothing in writing, and no end in sight!

## **Carol**

### **Vic**

Reasons should be given automatically, as a matter of course, for all participants when a decision is made about them. And details must be given when a review of the reviewable decision has been made.

**Martin**

**Vic**

**Introductory statement:**

The process, the time, the way things are being done by the NDIA with respect to a lack of consultation, or around the trust that exists in the community, illustrate why the NDIA and Government needs to go back to the drawing board. Recommendations from the recent August 2021 Submission to the Joint Standing Committee on the NDIS titled Unreasonable and unnecessary harms: Joint submission regarding the NDIS internal review and external appeals processes, found on pages 5-8 (source: <https://villamanta.org.au/documents/Joint%20Submission%20to%20the%20Joint%20Standing%20Committee%20NDIS%20re%20internal%20and%20external%20reviews.pdf>), provide clear guidelines on how the NDIA and Government can do so. There needs to be a number of areas in the NDIS Act and Rules that provide clear definitions and circumstances if there are to be changes. This is best to be done in a consultative manner, and to ensure that people with disabilities, their families and the wider disability sector is engaged. Four weeks for consultation doesn't cut it, and this shows a contempt for the majority of stakeholders. Add to that that it is done in the middle of a global pandemic, when little time or opportunity for real consultation is possible, and it seems to be merely an exercise in rubber stamping changes without meaningful engagement and the building of partnerships with the community.

The old version of the NDIA's Operational Guidelines re s100 Internal Reviews (also known as Review of a Reviewable Decision or RORD), had a provision that stated "The reviewer will take all reasonable steps to speak to the person who has requested the internal review to provide them with the opportunity to explain their reasons for requesting a review. The reviewer will also give the person the opportunity to explain why a different decision should be made, to provide additional information or evidence and respond to any adverse information". This source for this was 5.7 Who can request an internal review?, and used to be on the website [That page can't be found. | NDIS](#).

The above process no longer exists on the above NDIS website. As the above Operational Process was an important one, and as s100 Internal Reviews are increasingly not involving or contacting participants and their nominees, it is important to have such provisions and inclusions in the future NDIS Act and Rules.

**Attachment:**

Introduction



This is an extremely short and inadequate consultation with the disability sector. It continues to cause distrust and harmful relationships between the NDIA, Governments and people with disabilities and the wider community.

#### Methods and timing of consultation

Disability Intermediaries Australia (DIA), is disappointed with this consultation and states “Despite the level of the proposed change, DIA is disappointed in the extremely short and inadequate consultation with the disability sector” (source: [NDIS DRAFT LEGISLATION | Disability Intermediaries Australia](#)). This short timeframe and consultation, as well as the lack of information and engagement sessions available to a variety of people with disabilities, communities, and with resources, continues to create distrust between the community and the NDIA and Government.

#### An important provision and inclusion in future NDIS Act and Rules

The old version of the NDIA's Operational Guidelines re s100 Internal Reviews (also known as Review of a Reviewable Decision or RORD), had a provision that stated “The reviewer will take all reasonable steps to speak to the person who has requested the internal review to provide them with the opportunity to explain their reasons for requesting a review. The reviewer will also give the person the opportunity to explain why a different decision should be made, to provide additional information or evidence and respond to any adverse information”. This source for this was 5.7 Who can request an internal review?, and used to be on the website [That page can't be found. | NDIS](#).

The above process no longer exists on the above NDIS website. As the above Operational Process was an important one, and as s100 Internal Reviews are increasingly not involving or contacting participants and their nominees, it is important to have such provisions and inclusions in the future NDIS Act and Rules.

#### Why might it be important?

The Commonwealth Ombudsman has reported many issues with NDIS reviews (see [NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf \(ombudsman.gov.au\)](#)). Having such provisions and inclusions in future NDIS Act and Rules would help ensure a person's rights for a fair review, and that this is done with people actually being contacted and transparency. Without it being in legislation, there is no provision or guarantee that this will be done.

A recent August 2021 Submission to the Joint Standing Committee on the NDIS titled Unreasonable and unnecessary harms: Joint submission regarding the NDIS internal review and external appeals processes, specifically identified issues with NDIS internal and external reviews. This submission available at [Joint Submission to the Joint Standing Committee NDIS re internal and external reviews.pdf \(villamanta.org.au\)](https://villamanta.org.au/wp-content/uploads/2021/08/Joint-Submission-to-the-Joint-Standing-Committee-NDIS-re-internal-and-external-reviews.pdf), and recommended “To repair the system and improve the experience for people with disabilities exercising their right to request a review or an appeal we make the following recommendations” (source: last sentence, page 4 of [Joint Submission to the Joint Standing Committee NDIS re internal and external reviews.pdf \(villamanta.org.au\)](https://villamanta.org.au/wp-content/uploads/2021/08/Joint-Submission-to-the-Joint-Standing-Committee-NDIS-re-internal-and-external-reviews.pdf)). This submission then followed up on pages 5-8 with 28 recommendations. Again, having such provisions and inclusions in future NDIS Act and Rules would help ensure a person’s rights for a fair review, and that this is done with people actually being contacted and transparency. Without it being in legislation, there is no provision or guarantee that this will be done.

## Summary

The process, the time, the way things are being done by the NDIA with respect to a lack of consultation, or around the trust that exists in the community, illustrate why the NDIA and Government needs to go back to the drawing board. The below recommendations from the recent August 2021 Submission to the Joint Standing Committee on the NDIS titled Unreasonable and unnecessary harms: Joint submission regarding the NDIS internal review and external appeals processes, found on pages 5-8 (source: [Joint Submission to the Joint Standing Committee NDIS re internal and external reviews.pdf \(villamanta.org.au\)](https://villamanta.org.au/wp-content/uploads/2021/08/Joint-Submission-to-the-Joint-Standing-Committee-NDIS-re-internal-and-external-reviews.pdf)), provide clear guidelines on how the NDIA and Government can do so. There needs to be a number of areas in the NDIS Act and Rules that provide clear definitions and circumstances if there are to be changes. This is best to be done in a consultative manner, and to ensure that people with disabilities, their families and the wider disability sector is engaged. Four weeks for consultation doesn’t cut it, and this shows a contempt for the majority of stakeholders. Add to that that it is done in the middle of a global pandemic, when little time or opportunity for real consultation is possible, and it seems to be merely an exercise in rubber stamping changes without meaningful engagement and the building of partnerships with the community.

“RECOMMENDATION 1: The Joint Standing Committee to initiate a specific inquiry into the NDIS internal and external review processes to understand the issues discussed herein and the level of participant distress, distrust and anxiety being experienced as a result. An inquiry will enable the Committee to understand the different barriers and impacts experienced by the diversity of NDIS participants and prospective participants which prevent access to justice.

RECOMMENDATION 2: DSS and the NDIA to commission an independent report using a co-design strategy to investigate how the reviews and appeals system can be improved to be more efficient, effective and promote the rights of persons with disabilities.

RECOMMENDATION 3: The NDIA to co-design a 'Guiding Principles on the Conduct of NDIS Appeals' document. This is necessary for the NDIA's accountability during the NDIS appeals process and to build trust with persons with disabilities and the disability community. Such a document should include, but not be limited to, principles concerning: timeframes, reporting obligations, applicant feedback surveys, the conduct of internal and external lawyers and case managers, training requirements on disability rights and awareness, approach to evidence, addressing equality of representation, approach to settlement offers and approach to diverse groups such as Culturally and Linguistically Diverse and First Nations applicants.

RECOMMENDATION 4: Continuing from 'Recommendation 3', the 'Guiding Principles on the Conduct of NDIS Appeals' document to ensure the NDIA addresses equality of representation at the AAT. The NDIA must provide equal legal representation when it chooses to be legally represented. In addition, there must be sufficient resources for advocacy support where this is requested to ensure applicants have effective access to justice".

## **Kerry & Tony**

### **Vic**

We would like to strongly oppose any attempt by the NDIS to make changes to the existing Legislations. We have a son with a disability who has been in the NDIS since its beginning. During this time we have come up against some obstacles with the NDIS to do with our sons plan which we could not have managed without the help of a good support coordinator. We want to be able to make our own choice of who our sons support coordinator should be whether they are registered with the NDIS or not.

Also we strongly disagree that a plan can be changed at any stage by an NDIS CEO at their own discretion without consultation and not having to give reasons for their decisions.

Thanks for letting us have our say.

## **Lynne**

### **Qld**

Please leave it alone, you are causing so much worry and concern to people living with all kinds of disabilities and very importantly their aging parents who thought we could relax knowing that financially their sons / daughters were final secure and receiving the supports that they need.

## **Harvey**

### **Vic**

We are perfectly happy with the current set-up but do agree there is some room for improvements. Regardless of anything else, the current methods of evaluation and assessment must be maintained. Only properly qualified people with specific experience in the field of disability should be involved in decision making. Giving this role to unqualified people would be disastrous. In addition any changes to client's plans should not be allowed without consultation (other in perhaps, an emergency). Funding should be based on need not on accountants' decisions.

## **Brian**

### **Qld**

I have tried to get my head around this, these or those documents that are supposed to make it easier for participants and their nominee's and just as I think I have the gist of it, them or those I lose it again. I feel this is designed to suck more life and time from the lives of participants and nominees and I would like to challenge the CEO of the NDIS as an individual to be able to make head or tails of them as well.

What is apparent to me is that each and every nuance of these planned amendments would have had the hand of a individual public servant, assistant or secretary under the control of the CEO to reach this stage of confusion. So how do they or anyone for that matter expect one person with reasonable capacity for decision making, someone deemed to fit in the guidelines by the CEO of the NDIS to be deigned as a nominee for a participant to get a grasp of the current raft of changes.

Seems a whole expanding department of servants to the public are getting paid a lot of money to oversee another expanding department just to ensure \$10.00 is spent to save \$1.90 getting to participants.

## **Heidi**

### **Vic**

Participants in all stages need to be included in the decision making about themselves and the plan and in a way that they understand.

The CEO should NEVER make a decision on participants plan without consultation, explanation and discussion on participants plan without full consent with participant and or advocate present and agreeable to decisions being made.

Participants need more flexibility and understanding in funding that is received to have clear understanding of the services to be able to make a decision for the better use their funding.

Participants may need advocates to advocate for them in decision making about their plans and best for choices in their personal development physically, mentally and over all health and wellbeing.

CEO, NDIA need to be more clear in there decision making and the results to the Participant, advocate, Local LAC and if they are Plan managed, or NDIA managed and have documents given to the Participants in detail of the discussions, decisions that are made about the Participants in there plan and why not things are approved.

Any changes whatsoever need to be documented and participants are always to be included in the decision making of their plan and about them.

Participants need to be given a draft of their NDIS Plan before it is approved as this will help participants and advocates, local LAC of what plan is like and if things need to be twigged before final plan goes ahead.

## **Patricia**

### **Qld**

There are very strong inferences that participants are going to be further controlled and limited in their NDIS programs.

This further leads to a genuine perception that we are being manipulated.

This whole situation negates our freedom and independence; a fundamental of NDIS in its inception.

## **Alicia**

### **Qld**

There's a huge need to clarify and define terms used to determine funding access and funding allocation, which if clarified and defined would allow participants to understand and build capacity in managing their plans and accessing the scheme.

So much money from plans is spent to access assessments and reports as 'evidence' of support needs, but often even the people writing these reports don't have clear understanding of how the NDIS evaluates or decides on funding levels, and this is frustrating and exhausting to all involved and often sees the money spent on assessments and reporting wasted, leaving participants with poor experiences and a mistrust for the Agency.

## **Dr B**

### **Qld**

The term reassessment has an embedded meaning that the person's impairment will be under review.

Given the more recent concept of the social theory of disability purports that barriers encountered create the disabling moment, the question is ... does reassessment refer to the environment, social, and cultural barriers ... or are we regressing to the old model where the individual owns the problem?

## **Jenny**

### **ACT**

Changes to the NDIA could mean that I would no longer have someone managing my Plan and the organisation which pays my bills, (p.19 Easy Read document).

The NDIA would be deluged with service creditors' wanting to be paid.

Surely the small organisations that currently do this serve the community and ensures employment.

## **Marj**

### **Vic**

Plan variation without consultation

S47a will allowing Planning to be varied by CEO.

Its extremely concerning that CEO has power to make changes of the plan, funding restrictions and funding will be used without firstly consulting the participate. It takes away all of the participates rights of consultations and ensuring their needs are meet.

Changes to becoming a participant - permanent impairment.

What will the guidelines be to determine a participant has made substantial improvement and if this is ongoing? What is set in place should there be significant changes again to the participant during their plan period.

And what is a reasonable period of time to declare there is substantial change?

Reasons for Decision

This should be given automatically without the participant or advocate requesting these reasons as a routine process per the Tune Review.

## **Kerry** **NSW**

Submission Proposed Changes to NDIS Legislation and Rules

I submit that the information from the Public Interest Advocacy Centre (PIAC) below represents my views about the concerns I have with the proposed changes to the NDIS Legislation and Rules. My son is a complex needs very high support NDIS Participant. In the past I have had to commence Reviews of wholly inappropriate Plans and utilised the AAT to rectify wholly inappropriate levels of funding leaving him without essential supports. I am currently waiting for a new NDIS Plan to be built. It has been 5 weeks since the Plan meeting. The NDIS Planner had no experience at all in high support complex needs disability. I requested a complex needs high support NDIS Planner for 3 months prior to the NDIS Plan meeting.

“Plan variation without consultation

First, proposed section 47A allows participant plans to be varied without a ‘reassessment’.

This may be a positive change in as far as it allows plans to be amended or fixed where the amendments are not significant – such as where there are technical mistakes, changes to a participant’s goals and aspirations, or changes following an AAT decision.



However, s 47A also allows plans to be varied on the CEO's own initiative, without request, consultation, or consent from the participant. This appears to be broader than the Tune recommendation, and raises a number of concerns.

We see no reason why the NDIA should be able to vary plans without consultation or consent by the participant, except in rare cases of urgency where the participant cannot be consulted within a reasonable time. This is especially so because the CEO already has power to conduct reassessments on their own initiative (meaning that if a participant declines to have their plan varied, the CEO can still undertake a full reassessment if that is needed).

The CEO's power to vary plans is also not constrained. Rule 10 of the new Plan Administration Rules sets out a non-exhaustive list of matters the CEO must consider when deciding to vary a plan on their own initiative. But these matters do not limit the CEO's power. This leaves it open for variations like changes to funding amounts or restrictions on how funding could be used. These variations could be made without consultation with participants.

## 2. Changes to the 'Becoming a Participant' Rules

Second, changes to the Becoming a Participant Rules include new requirements for determining whether a person has a 'permanent' impairment or 'substantially reduced functional capacity' for the purposes of accessing the NDIS.

The clarification of what these phrases mean, especially in relation to psychosocial disability, is welcome. A longstanding issue has been fitting people with psychosocial disabilities into the language of 'permanence', especially when it comes to episodic or fluctuating impairments. While the language of 'permanence' remains, the clarification around what this means for psychosocial disabilities is helpful.

However, people with disability and advocates should consider the new requirements carefully.

Rule 8 of the Becoming a Participant Rules requires that, to access the NDIS, a person must be undergoing or have undergone 'appropriate treatment' for the purposes of 'managing' their condition, and that the treatment has not led to a 'substantial improvement' in their functional capacity after a reasonable period of time. Alternatively, there must be no 'appropriate treatment' 'reasonably available' to the person. These terms in inverted commas are not defined.

In practice, it will be the CEO and delegate considering in each instance what 'appropriate treatment', 'managing' a condition, 'substantial improvement' and 'reasonably available' means.

It would assist if the Rules provided guidance on these terms, especially given the highly personal decisions involved in medical treatment, and the subjective nature of these thresholds. 'Appropriate treatment' for instance, should take into account matters like a participant's risk appetite for treatments and personal choices over medical procedures. 'Substantial improvement' should include subjective assessments of a person's functional capacity. The absence of these considerations would reduce a person's choice and control over their own health.

Similar considerations apply in rule 9(2)(b) of the Rules. This rule requires that there are no 'known, available and appropriate evidence-based clinical, medical or other treatments' that would be likely to lead to a person's impairment no longer resulting in substantially reduced functional capacity. Again, the term 'appropriate' is vague and should include respect for bodily autonomy. 'Other treatment' is also vague – what non-clinical, non-medical treatment should a participant be required to undergo? Should those treatments in any case be funded under the NDIS – for example, capacity building supports?

### 3. Changes to Plan Management and Payment of Supports

Third, changes to plan management and payment of supports should be closely examined.

The change to plan management, under amendments to sections 43 and 44 of the Act and the Plan Management Rules, essentially impose a risk management process for participants who request to have their funding plan managed.

Under the existing rules, in considering a request for self-management or management by a nominee, the CEO must be satisfied that management of the plan in this way does not create an 'unreasonable risk' to the participant. This is not currently required for participants requesting their plan be managed by providers.

The proposed rules bring this into alignment with the risk assessment process for self-management. This change reflects the Tune Review recommendations, however we note that some advocates are concerned by what this change may mean. We encourage participants and advocates to consider the criteria for 'unreasonable risk', set out at section 10 of the proposed Plan Management Rules.

In addition to plan management, there are also proposed changes to the way in which supports are paid by the NDIA. These changes are set out in the proposed amendments to section 45 of the Act. The Government has indicated that these changes are intended to make it easier for self-managing participants to make claims, by using a 'tap and go' system on smartphone apps with their service provider, rather than paying out of pocket first and seeking a reimbursement.

These changes appear to be broadly sensible. However, we understand some people may be concerned by the inability for self-managed participants to opt out of this system and pay for their own supports first, or to mix-and-match their preferred payment method.

The drafting of new section 45 states that payment is to be made 'to the person determined by the CEO'. While the Government has clarified that this change is not intended to remove the ability for self-managed participants to continue their existing payment method, the drafting does not make this clear. We would recommend a clarification to the drafting of section 45.

#### 4. Reasons for decisions

Finally, proposed s 100(1B) and (1C) of the Act allows participants to request reasons for decisions made by the NDIA which are subject to review. This is a welcome change, as it can empower individuals to understand decisions made about them at the initial stage – for example, initial decisions about access or participant plans.

However, we suggest this could be improved in two ways. First, the provision of reasons should not be on request by the participant. It should be given automatically, as a matter of course, for all participants when a decision is made about them. This is consistent with the Tune Review, which said (at [3.59]):

Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions. However, in the event this does not occur, the Participant Service Guarantee should empower the person with disability to require the NDIA provide this information in a manner that is accessible to them.

This is important as it will enable all participants to receive reasons for decisions made about them, not just those who are willing or able to go through the further process of making a request.

Second, there is no corresponding requirement for reasons to be provided once a review of the reviewable decision has been made under s 100(6). In practice, we understand that reasons are often – but not always – provided in relation to internal reviews.

We consider that a provision should be inserted to make this a legislated requirement. That is, every decision made by an NDIA reviewer must be accompanied by a statement of reasons. Again, this is consistent with the intentions of the Tune recommendation, and with good administrative decision-making principles.

The Federal Court.

This is a technical problem about what the AAT can and cannot decide about a participant's plan on appeal. The easiest way to resolve this technical problem is by legislative fix, to ensure that the AAT can consider all matters concerning a participant's plan on appeal. The failure to do so ties up participants as well as AAT, NDIA, legal and advocacy resources in costly jurisdictional disputes that leave participants worse off.

There is also a missed opportunity to simplify the NDIS framework. While attempts have been made to simplify and modernise the drafting of some of the rules, the NDIS framework remains extremely complex, and this package of changes only adds to the complexity, with new rules and principles in disparate locations. For example, when making a decision about specialist disability accommodation (SDA) supports, the rules that need to be considered for that one decision include (at least):

- the 'reasonable and necessary supports' rules under s 33 and 34 of the Act;
- the principles which underlie decision-making in the Act, including under s 4, 5, 17A and 31;
- the Participant Service Guarantee Rules;
- the Support for Participants Rules;
- the SDA Rules; and
- the NDIA's Operational Guidelines.

Many of these rules overlap and are not entirely consistent. This is unwieldy and makes it impossible for participants to navigate and follow the process.

I hope that Parliamentarians understand the important points made by PIAC when considering the new NDIS Legislation and Rule changes.

## **Lyn NSW**

Upon reading through proposed changes to the NDIS Act, a few proposals worry me significantly.

Chief of these is that NDIA would be able to vary plans at any time without consultation or consent from the participant.

We go through an annual review where copious data and input is presented and considered before a plan is handed down. We then have a right of review if we do not agree with the decision.

(Which by the way should be much more open - not like a secret, uncontactable society).

We assemble a lot of evidence and examples to present our case. (Detailed explanations should likewise be presented for any variance handed down by NDIA.)

If all this can then be simply overruled and undone without consent or consultation, what is the point? Is it all just window dressing at our expense?

This is not care and compassion in any sense of the words, it is tyranny.

My second worry is with proposed changes to Plan Managed budgets. Having a budget Plan Managed gives us the "choice and control" that we were promised when NDIS was first envisaged. This is extremely important. If we can direct the money to the services that we wish through our plan manager/support coordinator (legitimate, registered services naturally) then we have true choice and control. Not just a choice within the Agency which oversees the funds - which amounts to no choice at all really. It seems that NDIA wishes to take away that Plan Managed control for itself. This is not what was guaranteed to us.

If the correct safeguards are in place, then the money cannot be utilised illegally by any unscrupulous people. (We all know that these users do exist, but don't confine us all because of them please.)

My third worry is that all decisions should be based upon what we already know works well for a person in NDIS.

When the correct scaffolding is put in place to support a person and their life starts to get on a better track, then that case needs to be looked at carefully.

I am very tired of the "one size fits all" mentality that many agencies have towards disability.

Every disability and every person pigeonholed in any particular disability, remains an individual. What is good for one, or even most, can be disastrous in individual cases.

In some cases the scaffolding needs to remain in place to support that person - maybe for a long time, maybe forever.

If it's working - fantastic - but please don't start dismantling it to save \$\$\$.

In many cases, the person is improving because the support is there and it needs to remain or the whole thing falls in a heap once again, with disastrous results.

## **Kristen**

### **Tas**

From your explainer: "The Government has indicated that these changes are intended to make it easier for self-managing participants to make claims, by using a 'tap and go' system on smartphone apps with their service provider, rather than paying out of pocket first and seeking a reimbursement."

This is in effect a way of controlling the therapies and consumables used by self managed participants.

We're currently self managed for both plans and have items/therapies that are not listed in the NDIS schedule but have been approved by our LAC/NDIA. These would not be included in the app because that would be unwieldy and impractical so we would have no way of paying for these.

## **Joe**

### **Vic**

I am concerned about the statement that this new legislation will be "co-designed with disability representatives". How is this going to happen? And when?

How will "re-assessments" be made? And, by whom?

Section 47A says "plans can be varied on the CEO's own initiative without request, consultation or consent from the participant". This could be particularly dangerous as it could depend on the CEO, their integrity, and the "needs/wants" of the Government of the time!!

Finally, reasons MUST be given if a plan is reviewed/varied by the NDIA reviewer. To not give reasons, would lead to all manner of confusion & lack of transparency!!

## **Andrea**

### **Qld**

I am one of the people who would be directly affected by this as I am in a rural area and this means that I would loose my package and I am one of the people who are slipping through the cracks I am disabled but at a point where I am stable but not stable enough, to not never need support, this would push me back into mainstream supports and these acutually make my conditions worse. There is stories even from providers about how there mental health is suffering due to the changes as well.

## **Vicki**

### **SA**

I'm sorry but the NDIS is a joke. I have clients that need extra funding for 1:1 time because of serious mental illnesses and they are being cut back. Then there those in allied health that are meant to be assisting my clients but are just there to take the money from these vulnerable people. Not happy, there are a lot of support workers out there that really want the best for our clients but this doesn't seem to be happening.

## **Samuel**

### **ACT**

Many thanks.

Regarding Chadwick Wong's "1. Plan variation without consultation", will CEO's power be delegated?

See <https://everyaustraliancounts.com.au/opinion/explainer-what-are-the-proposed-changes-to-the-ndis-act/>

## **Michelle**

### **Vic**

1. The word reassessment for a plan review is confusing and traumatising - plan update would better explain what the process is actually about.
2. Recommendation 25d of the Tune Review talks about draft plans but the government wants to put the responsibility of getting a draft plan before finalising on the participant to know to ask for one. It should be mandatory to offer one and the participants choice to look at it or not. Being part of the scheme since it started, draft plans were a logical step to ensure the plan was correct before finalising it, avoiding the need for internal reviews and AAT appeals. Time and cost saving process - isn't that what the participants and the agency want!



**Celia**

**Vic**

It is essential for participants to be given reasons for any decisions made by the NDIS concerning their plan. This allows them to understand and know about reasoning behind decisions and would surely ultimately save time in answering follow up enquiries and allow participants to address issues raised.

I am also concerned by the suggestion that plans could be altered without consultation and view this as potentially damaging and unnecessary.

**Joyce**

**Vic**

Re: Proposed changes to the NDIS Act and Rules - Plan Management Rules. It is imperative to my daughter [middle age] with ID and grandson [young adult] Autism & ID that they can access Plan Management. Because of their cognitive ability will never be able to Self Manage or use Tap and Go. We use some excellent unregistered providers with whom they have gained trust with and assist them with daily activities. Their support coordinator who advocates brilliantly for them is unregistered. As an elderly mother/grandmother I plead that the option of Plan Management is not taken away from them, allowing choice and control of their supports within the NDIS.

**Sharee**

**NSW**

My thoughts on NDIS Changes (by a participant's nominee/mother)

In regard to 2 new rules

1. PARTICIPANT SERVICE GUARANTEE

Timeframes must be added to the Bill to eliminate distress to participant and their supports when delays have been experienced in the past causing much distress. And timeframes should be checked for adherence constantly by overseeing body for adherence.

2. PLAN VARIATION WITHOUT CONSULTATIONS – in regard to 47A (to be varied without assessment)

It concerns me greatly that a CEO has the power to make decisions about a plan without the request, consult or consent of a participant.

Would this not render essentially that CEO to a position of nominee status which is in opposition to the "nominee rules/act"

That CEO, potentially, would have little grass-roots knowledge of how even a seemingly insignificant change to a plan can grossly impact a participant's life. Granted, that sometimes it may be suitable to consult with major care-givers or nominees first to grasp a better understanding of plan funding (for accountability purposes)

This variation however does have merit where changes are not significant and would be able to avoid a whole plan-review process. But "Not significant" would need to be defined. And participant, caregivers, nominees, I contend, should still be consulted in the idea of any changes, small or large, initiated from the NDIS end.

So I would like to see specifics to this drafting and the elimination that any one person or body, not physically associated with the daily life of the participant, to be able to make potentially life changing decisions to a plan without consultation and due process if there is a legitimate concern.

### 3. REASONS FOR DECISION

I would like to see that every participant is automatically informed of the reason/s why negating decisions are made in regard to requests to plans [s 100(6)]

Provided rather than a participant having to undergo a very laborious search for an answer by phonecall to an ambiguous source who usually struggles to find an answer from an "up the line" source (IN MY EXPERIENCE).

In regard to the amendment of rules (only which apply to my daughter)

### 4. CHANGES TO PLAN MANAGEMENT AND PAYMENT OF SUPPORTS

I think there should be the same "risk management" process applied to the Plan Managers. Does an accountability process exist for plan managers?

I think that there should be flexible options regarding payment for supports.

So I would like to see clarification to the drafting of section 45

In regard to update of rules (only which apply to my daughter)

## 5. SDA

To simplify the SDA supports process by consolidating the various acts and rules which currently overlap and provide some inconsistency.

In doing this it should simplify and speed the process for decision making in this regard

### SUMMARY NOTES

I WOULD LIKE TO SEE the defining of the terms:

"in kind supports", "appropriate treatments", and "unreasonable risk".

## **Penny**

### **Vic**

The choice to use unregistered service providers is part of my choice and control to use who I see fit to best work in with my lifestyle and choice. Creating the tap and go card takes away from my choice and control and it does not sit right with me at all!

## **Debbie**

### **Qld**

Re PAYMENTS: I am a blind senior who lives in a regional area with limited direct access to providers. Therefore, most of my purchases are made online and/or via phone conversations with groups such as Guide Dogs Qld; Humanware etc. For that reason, I would not be able to use 'tap and go' facilities on my mobile to pay. I need to be able to pay upfront, then be reimbursed as is the current situation.

Re CHANGES TO PLANS: I believe it is essential that plans can only be changed with consultation with the participants - it is THEIR plan. No-one, not even the CEO should be able to change a participant's plan without their knowledge and full understanding of such changes.

Thank you.

## **Steve**

### **Vic**

Everyone needs to remember what this government stands for and does at the election.

## **Valerie**

### **Qld**

There is a need to look at Service Providers and how some are manipulating the system. I would prefer to visit museums, aquariums etc during the week when it is quieter, i.e., no school age children. Some providers only offer these outings on weekends so they can charge maximum hourly rate. My suspicion is the support workers are the service providers, they work another job during the week and provide community access outings on weekends only as a very profitable money making scheme.

## **Taya**

### **Qld**

Truly? SO furious at how the "gov't" abuses folk on the NDIS! Even Covid - the PM PROMISED vaccination of disabled folk would be a priority. & didn't THAT go down the drain quicksmart!?! I have friends so traumatised by the sheer effort of TRYING to get on NDIS that they've given up, and are now back to struggling on ridiculously low incomes. In short, the only changes to NDIS I have seen are NOT benefiting the majority of people with disability, but are meant to save the government money. [Angry face emojis]

## **Marilyn**

### **SA**

Dont you think the NDIS should have been thought through before implementing it so there should be no changes. Is all you do is confuse people from the ground up. Parents cant keep up with the changes and with all the extra work involved for parents its a nightmare. There is either a plan or not. If it's not organised properly and is not working STOP MESSING AND DO IT PROPERLY ONCE.

## **Paul**

### **NSW**

As a Support Worker going on 5 years of service I have a very relevant story to share for the Minister Linda Reynolds and the NDIS abroad.

I support a [middle aged] man with [disability type] and severe Epilepsy. I have been with this man for the entire time I started in disabilities. His name is [Name] and I am totally dedicated to his care.

Unfortunately [Name] was admitted to hospital recently due to yet another turn with his Epilepsy. This left [Name] in hospital for up to 3 months under the advice of his treating Doctors.

For the first month of [Name's] stay, myself along with my fellow co-workers were told that our shifts to support [Name] are cancelled by our employer [service provider].

They told me the funding was stopped due to the NDIS claiming NSW health were caring for [Name] at this point on.

Now although the nursing staff themselves agreed 100% they are not staffed to sit with [Name] 24 hours to oversee the constant seizures that needed to be witnessed/recorded & supported through and [medication] administered after [x] minutes. [Name] also needed a NGA tube inserted and tried to pull it out at any given chance he would get, which again prompted the 24 hour support need for [Name's] care while in hospital.

As [Name's] support worker, I was left with none of my regular 72 hours a fortnight. I had to ask my employer to find me the 15 hours a fortnight [provider] have only commented in contact for me since starting with them back in 2019. At this point I had to explain to [provider] I will have to leave to find work elsewhere if I can't pay my bills.

Meanwhile, [Name's] poor mother, an elderly woman [in her 70's] was forced to continue sleeping on the couch in [Name's] room to keep watch on her unwell son for almost 2 months 24/7.

The main issues here was while NSW Health nurses, as well as their supervisors agreed they could not watch over [Name] 24/7, the NDIS continued to tell [provider] & [Name's] mother that his funding was not able to cover his stay in hospital with support staff. [Name's] mother, while sitting by his bedside was day-in, day-out phoning the NDIS and [provider] to get the right answers on [Name's] rights for better support while in hospital.

The mother was told No from many people at the NDIS, but she found one very helpful & compassionate NDIS person who found the piece of legislation stating the fact [Name] is covered by the NDIS to be supported by his regular carers while in hospital. But! this still got disputed by others at the NDIS who obviously had zero concerns for [Name's] quality of care while in hospital, his mothers state of health & efforts to return to her own home, the Nursing staff trying their best to care for 30+ other patients in the ward, not to mention us Support Workers being forced to look elsewhere for work if something wasn't going to be decided on soon.

Eventually all concerned did end up doing the right thing for [Name], but it was not without unnecessary stress that dragged on for too long.

If that wasn't bad enough the story does not end there. Once the NSW Government ordered stronger lockdowns on Covid19, [Name's] mother was then told everyone had to leave [Name] in the hospital as directed by NSW Health. His mother was left to take up the fight for her son again & told the treating Doctors [Name] would just have to go back home and be left with support workers to try care for [Name's] now high care needs they are not trained in.

[Name] & his mother were back to square one again to support him correctly. The hospital did their best to extend the extra support from [provider] staff with [Name], and during this time I personally witnessed another gentleman with a disability I know personally emitted into the room next door to [Name]. This man was refused extra support by his disabilities provider due to the hospital lockdown & was left by himself in the room with the lights left on 24 hours, and only check on when nursing staff had time or medication times. Luckily for him there was a Support Worker with special exemption to be there that could go in to check on him, that being myself.

I understand the Government's wanting to use the umbrella effect upon all citizens of NSW, but we are all with individual needs with grounds for exemptions that need to be taken into stronger consideration moving forward.

The man next door & the lack of supervision from nursing staff highlighted my arguments laid out here that the NDIS need to straight up support all people with a disability that need to attend a hospital & get the care they deserve & not left to the nursing staff or family members alone.

That the NDIS also needs to make measures to implement clauses in their legislation that expeditions are made for support workers to continue their caring roles right through any difficult times and not be pushed to the side that risk them having to go look elsewhere for work. That new work may not be still in the disabilities field.

I hope this story can be heard and understood by those who are given the powers to act & improve a much need service in our communities.

Final words on my views on the running of the NDIS, is that there is still a long way to go to get it right if not better than it is reported to be at this stage.

## Michelle

### NSW

[Note: Michelle spoke to EAC over the phone after being referred to us by DSS, after she was referred to DSS by NDIS Minister Linda Reynolds' office. Michelle was unable to provide a written response because of her disability. The following is a transcript of the main concerns Michelle wanted to raise in her submission.]

DSS or the Minister's office were unable to find an accessible way for me to make an individual submission. They should really be leading by example (and following the law!) if they expect other agencies or departments to be accessible and inclusive.

The Agency does not understand the fluctuating needs of people with chronic conditions.

The Agency is ignoring the medical advice in front of them.

AAT decisions don't seem to effect the day to day policy - they don't seem to make changes to how things operate after the AAT has made a decision.

Decisions on reviews should be given automatically and in clear words like:

- "This is the decision we made."
- "This is why we made this decision."
- "This is the law or policy that we used."

This would make it much easier for people to understand things, and they would have the information they needed if they wanted to take further action.

Therapists often disagree with each other.

I need someone to work through it - like a specialist case worker.

Then it should be what does the participant want - they should be able to decide.

That is choice and control.

Someone else shouldn't be deciding what appropriate treatment is.

I feel the NDIS are marginalising and discriminating against people with learning disabilities.



Or learning impairment. People might get put under guardianship when what they really need is more support. For example I have not put in a tax return in 10 years and may potentially be facing jail time or being put under a Guardianship order. What I really need is more help to manage my financial paperwork.

Plans

Flexible as possible, so that funds can be used across a range of areas.

For example - sometimes when a support worker can't come, I get items delivered instead, but I can't claim delivery on these items - even though it is cheaper than having a worker do the task.

Plans should be developed without having to go through full reviews.

I'd like to see SDA or SIL longer concrete timeframes set in budgets. Some budgets have rubber stamped in concrete in a long term provision of support, but then with an additional flexible amount that can be called upon quickly if needed, without going through a whole review.

SDA is funded for a lifetime.

With regards to payments people need to have the option to have both - tap and go and invoicing. Similar to what medicare does.

Support before Guardianship.

Proactive support should be given before Guardianship is an option. A stepped approach could work.

Yes to the AAT being able to review more than the one item that is up for review when it gets to the tribunal. It takes ages to get there and things might have changed and they need to look at the whole situation.

**Maria**

**Vic**

Reasons for decisions in plans should be mandatory and means participants are not forced to request it.

Every decision made by planner should include the factors considered when arriving at a decision and should be worded in clear language.

## Michael & Suzanne

### NSW

#### NDIS draft changes to legislation – comments

1. Section 47A allows plans to be varied on the CEO's own initiative, without request, consultation, or consent from the participant. This appears to be broader than the Tune recommendation and raises a number of concerns.

a. There is no reason why the NDIA should be able to vary plans without consultation or consent by the participant, except in rare cases of urgency where the participant cannot be consulted within a reasonable time. This is especially so because the CEO already has power to conduct reassessments on their own initiative (meaning that if a participant declines to have their plan varied, the CEO can still undertake a full reassessment, if that is needed).

b. The CEO's power to vary plans is not constrained. Rule 10 of the new Plan Administration Rules sets out a non-exhaustive list of matters the CEO must consider when deciding to vary a plan on their own initiative. But these matters do not limit the CEO's power. This leaves it open for variations like changes to funding amounts or restrictions on how funding could be used. These variations should not be made without consultation with participants.

2. Changes to the Becoming a Participant Rules include new requirements for determining whether a person has a 'permanent' impairment or 'substantially reduced functional capacity' for the purposes of accessing the NDIS.

a. The clarification of what these phrases mean, especially in relation to psychosocial disability, is good. A longstanding issue has been fitting people with psychosocial disabilities into the language of 'permanence' especially when it comes to episodic or fluctuating impairments. While the language of 'permanence' remains, the clarification around what this means for psychosocial disabilities is helpful.

b. Rule 8 of the Becoming a Participant Rules requires that, to access the NDIS, a person must be undergoing or have undergone 'appropriate treatment' for the purposes of 'managing' their condition, and that the treatment has not led to a 'substantial improvement' in their functional capacity after a reasonable period of time. In some cases such treatment may not have made any improvement. Alternatively, there must be no 'appropriate treatment' 'reasonably available' to the person. These terms in inverted commas are not defined.

c. In practice, it will be the CEO and delegate (question whether the delegates have the same training and understanding) considering in each instance what 'appropriate treatment', 'managing' a condition, 'substantial improvement' and 'reasonably available' means.

d. The Rules should provide guidance on these terms, especially given the highly personal decisions involved in medical treatment, and the subjective nature of these thresholds. 'Appropriate treatment' for instance, should take into account matters like a participant's risk appetite for treatments and personal choices over medical procedures. 'Substantial improvement' should include subjective assessments of a person's functional capacity. The absence of these considerations would reduce a person's choice and control over their own health.

e. Similar considerations apply in rule 9(2)(b) of the Rules. This rule requires that there are no 'known, available and appropriate evidence-based clinical, medical or other treatments' that would be likely to lead to a person's impairment no longer resulting in substantially reduced functional capacity. Again, the term 'appropriate' is vague and should include respect for bodily autonomy. 'Other treatment' is also vague – what non-clinical, non-medical treatment should a participant be required to undergo? Should those treatments in any case be funded under the NDIS – for example, capacity building supports?

3. Changes to plan management and payment of supports should be closely examined.

a. The change to plan management, under amendments to sections 43 and 44 of the Act and the Plan Management Rules, essentially impose a risk management process for participants who request to have their funding plan managed.

b. Under the existing rules, in considering a request for self-management or management by a nominee, the CEO must be satisfied that management of the plan in this way does not create an 'unreasonable risk' to the participant. This is not currently required for participants requesting their plan be managed by providers.

c. The proposed rules bring this into alignment with the risk assessment process for self-management. This change reflects the Tune Review recommendations, however some advocates are concerned by what this change may mean. Participants and advocates should consider the criteria for 'unreasonable risk', set out at section 10 of the proposed Plan Management Rules.

4. In addition to plan management, there are also proposed changes to the way in which supports are paid by the NDIA. These changes are set out in the proposed amendments to section 45 of the Act. The Government has indicated that these changes are intended to make it easier for self-managing participants to make claims, by using a 'tap and go' system on smartphone apps with their service provider, rather than paying out of pocket first and seeking a reimbursement.

a. These changes appear to be broadly sensible. However, we understand some people may be concerned by the inability for self-managed participants to opt out of this system and pay for their own supports first, or to mix-and-match their preferred payment method.

b. The drafting of new section 45 states that payment is to be made 'to the person determined by the CEO'. While the Government has clarified that this change is not intended to remove the ability for self-managed participants to continue their existing payment method, the drafting does not make this clear. We would recommend a clarification to the drafting of section 45.

5. Proposed s 100(1B) and (1C) of the Act allows participants to request reasons for decisions made by the NDIA which are subject to review. This is a welcome change, as it can empower individuals to understand decisions made about them at the initial stage – for example, initial decisions about access or participant plans.

a. However, we suggest this could be improved in two ways. First, the provision of reasons should not be on request by the participant. It should be given automatically, as a matter of course, for all participants when a decision is made about them. This is consistent with the Tune Review, which said (at [3.59]): "Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions." However, in the event this does not occur, the Participant Service Guarantee should empower the person with disability to require the NDIA provide this information in a manner that is accessible to them.

b. This is important as it will enable all participants to receive reasons for decisions made about them, not just those who are willing or able to go through the further process of making a request.

c. Second, there is no corresponding requirement for reasons to be provided once a review of the reviewable decision has been made under s 100(6). In practice, we understand that reasons are often – but not always – provided in relation to internal reviews.

d. A provision should be inserted to make this a legislated requirement. That is, every decision made by an NDIA reviewer must be accompanied by a statement of reasons. Again, this is consistent with the intentions of the Tune recommendation, and with good administrative decision-making principles.

6. Additional action required: There is a technical problem about what the AAT can and cannot decide about a participant's plan on appeal. The easiest way to resolve this technical problem is by legislative fix, to ensure that the AAT can consider all matters concerning a participant's plan on appeal. The failure to do so ties up participants as well as AAT, NDIA, legal and advocacy resources in costly jurisdictional disputes that leave participants worse off.

7. There is also a missed opportunity to simplify the NDIS framework. While attempts have been made to simplify and modernise the drafting of some of the rules, the NDIS framework remains extremely complex, and this package of changes only adds to the complexity, with new rules and principles in disparate locations. For example, when making a decision about specialist disability accommodation (SDA) supports, the rules that need to be considered for that one decision include (at least):

- the 'reasonable and necessary supports' rules under ss 33 and 34 of the Act;
- the principles which underlie decision-making in the Act, including under ss 4, 5, 17A and 31;
- the Participant Service Guarantee Rules;
- the Support for Participants Rules;
- the SDA Rules; and
- the NDIA's Operational Guidelines.

Many of these rules overlap and are not entirely consistent. This is unwieldy and makes it impossible for participants to navigate and follow the process.

Part of the reason for this complexity is the continued expansion of the NDIS Rules and the Minister's rule-making powers.

## **Robert** **NSW**

There are positive aspects to the proposed NDIS changes, but it should not be possible to vary participants' plans without consultation. That power is very concerning.

**Peter**

**Vic**

Minister Reynolds. We write to express our deep concerns about the proposed changes to the NDIS Act and Rules.

Specifically we are very concerned that the denial to allow clients the right to choose who provides services to them is very concerning. We strongly believe that people with a disability should be allowed to choose non NDIS registered service providers as this was the original intent of the NDIS.

Over the years we have relied very heavily on non NDIS registered service providers and the denial to continue to use them would remove our choice and control. Minister Reynolds, please do not make these changes.

**Leonie**

**WA**

My main concern is the fact that the CEO may make changes to my sons plans. We have had 7 years of planning and alterations first with WANDIS and then with the national scheme.

We have finally got the ideal plan for our younger son and it is working perfectly. If anything were to change, he would go backwards and lose any skills and improvements he has made.

It isn't easy having all this doubt and uncertainty all the time. The NDIS should settle down and allow things to run for a while to see what happens when continuity is guaranteed.

**Judy**

**NSW**

If NDIA can vary plans without reassessment.

Would this person be aware of the town and the services that are available to the client? E.G The person who assessed my sons plan resided in Melbourne which is a far cry from northern NSW [Town]. Did not understand how his disability would fluxuate and more services would be required.

The rules need to be simplified and less repetition.

## Joshua Qld

The changes are obsolete before they've even been implemented.

Change how service manufacturers of specialist disability equipment can overcharge on they're products.

Change how people can authorise an independent registered/unregistered support coordinator to be plan nominee; resulting in the participants that don't want to put up with NDIS jargon, don't have to.

Reviews and plan developments would be done and dusted in a matter of minutes, obviously having the participant and nominated plan nominees verbally accept and acknowledge their understanding of their plan changes.

But empowering of support coordinators to bridge the gap between NDIS and participants at current level.

Be rid of PITC program its persons with either their own or experienced disability referring to how they deal with disability not how the participants and their families are dealing with their disability, and what they feel is more appropriate for participants from their own experiences.

Change the funding for support coordinators to actually undertake what they need to, not currently; where support coordinators are limited by the funding allowance for each participant.

## Roger SA

RESPONSE TO DRAFT NDIS ACT AND RULES – Roger [Surname] [Date] Oct. 2021

1. Having a reasonable time frame would be a big improvement to NDIA processes.
  - a. We had a planning meeting for the [date] August to put in place a new plan for August [about a week later]. We were promised a quick response from the planner. Nothing has happened since then. The file is sitting on someone's desk higher up – with no response from the NDIA in the last 2 months. Being treated without any respect and worse absolute contempt by the NDIA, and being held in limbo, with no understanding of when a plan will eventually be put in place and what that plan will contain - is very difficult for us to comprehend.

- b. My son has the dual disabilities of Down syndrome and [mental illness and other diagnosis]. We are [very elderly] and finding it difficult to cope with the complexities of the NDIA rules – especially around application for SDA funding. Our application has been with the NDIA for many months with no response from that team.
  - c. Contacting the NDIS planner assigned to our son seems an impossibility. The files sent to the planner for the planning meeting took weeks to arrive so that information needed for the planning meeting, was not read, digested and analysed beforehand. If you want to depress people and upset them no end, this is the way to do it.
  - d. Being able to have a planning meeting a month ahead, so that everything can be put in place on time, does not seem to happen any more.
  - e. Being able to have a response from the planner to what has been decided and put in place, (let alone them sending a copy of the plan, so that we do not have to wait months, before having to repeatedly request that one be sent) – does not seem to happen any more.
  - f. Being able to interact with the planner about planning meeting decisions - to discuss and negotiate any fine adjustments, does not seem to happen anymore either. Being able to do this, would save months of wasted time, and relieve a lot of the anguish and heartache of everyone concerned.
2. Reasons for decisions - should be given automatically. This should be a routine operational response for the NDIA when making access, planning and plan review decisions, and should be legislated for. We should not have to make requests, and then have to wait for more months for some or no response. Every statement made by the NDIA reviewer / planner should be accompanied by a statement of reasons.
  3. Plan variation without consultation - the proposed section 47A, allowing plans to be varied on a CEO's own initiative without request, consultation or consent from participants, (such as changing funding amounts and how funding may be used) is to say the least, untenable.
  4. When is the NDIA going to act professionally - and start to treat people with the respect and human decency that they deserve. People want an accessible NDIA with a human face and a bottom line of compassion and service to community, rather than an organisation several times removed and a law unto themselves, able to act with impunity, and take absolute power unto themselves to do as they please, without reference to the people they act for and serve.



## **Graham**

### **Qld**

It would appear the Commonwealth lawyers for the NDIA when drafting the recommendations for a review decision have conveniently left out common law principles in that they will only advise the basis for the decision if applied for by the applicant. This is becoming all too common with Commonwealth legislation.

Natural Justice is denied when a decision is made without giving the recipient the basis of the decision.

Further, the time for review which is never timely could place the recipient in financial difficulty accessing necessary supports.

I would envisage that data will be put into a computer and a standard response will be sent to the recipient.

This process was only been implemented to reduce staff numbers in the NDIA with the hope that a majority of recipients will not know how to challenge the decision.

## **Katherine**

### **Qld**

I would like changes made for Plan Management. They all need to be doing the same thing and not holding the participants, service providers and support coordinators to ransom. Plan Managers should pay the invoices within 7 working days the max and notify the service providers when funding is getting very low.

Also can NDIS providers work with DVA participants? We as providers should be able to help these people as well.

## **Terry**

### **Qld**

I think more discussion is required with NDIS participants and NDIS support groups.  
Thank you.

## Peter

### Vic

Hello, thank you for this update. I have some concerns in the proposed changes.

1. S 47A allows plans to be varied on the CEO's own initiative, without request, consultation, or consent from the participant. If the NDIA proposes to make any changes to a participant's plan, then it must be made in consultation and consent of the participant, except in rare cases of urgency where the participant cannot be consulted within a reasonable time.
2. Proposed changes to payment of Supports suggests the Government wants to introduce a "tap and go" functionality through a smart phone app rather than a participant pay out of pocket and then gets reimbursed. What if the participant is unable to physically get to a "tap and go" POS terminal and makes the majority of their transactions online? This proposed method of payment should be optional and the participant can choose how they want to make a payment.
3. Reasons for decisions. Providing people with disability with an explanation of a decision should be a routine/mandatory operational process for the NDIA when making access, planning and plan review decisions. This decision making process must be recorded somewhere and so it must be provided to the participant as part of the process. However, in the event this does not occur, the Participant Service Guarantee should empower the person with disability to require the NDIA provide this information in a manner that is accessible to them.

## Wendy

### Tas

It was so difficult to get my NDIS plan in place the first time. So many hoops to jump through. So much money spent on getting reports and assessments to prove what I needed. I don't want this to be any harder than it was.

I was trying to maintain my full-time employment and setting up my plan took so much time and so many phone calls that it was embarrassing at work and could have put my employment at risk.

## **Elizabeth**

### **Vic**

Nothing about us without us remember, we need to be involved in decision making changes - parents, carers, participants.

## **Marjorie**

### **NSW**

As older carers for our son, who is [in his 30's] we self manage his plan. Parent carers have a tough time often navigating a system that doesn't value us as it should, putting much emphasis on the participant. Providers are catered for, but we feel our role is as a partner with the participant.

## **Nancy**

### **Qld**

I read the explainer and agree with its recommendations.

Also, it would be great if NDIS could get rid of its excessive bureaucratic language.

Even better if it could publish a simple map of its decision making structure so we can where a decision gets made, where it gets stuck and who should unstick it so we don't have to keep going to the Minister after waiting months.

This happens with SIMPLE home mods all the time.

## **Geraldine**

### **Vic**

I don't think the CEO should have so much say/power in reviews/reassessments. All new proposals or changes to a plan should be given to the participant or carer so that they can understand any changes made and a clear reason as to why.

**Lisa**  
**Vic**

"Nothing About Us Without Us!" (Charlton, 1998).

The proposed section 47A 'Plan variation without consultation' is in direct violation of the Tune Review (2019, NDIS Act) that promised reform in communication, transparency and better disability advocacy and representation.

This rule is UNACCEPTABLE as it is an overreach of practice that allows for NDIS Plans to be varied at the CEO's own initiative; WITHOUT request, consultation, OR consent from the participant!

If this policy is approved as part of the changes in the NDIS Act, then it will undoubtedly harm all NDIS participants and add further detriment to the long-term health implications that people with disabilities are already disproportionately facing in this current era of uncertainties and constant change.

The limitless power for the CEO to make open variations to a participant's Plan like changing funding amount or restrict access or how or what the funding can be used for (and done so without ANY consultation with the participant), means participants will be forced to live in a CONSTANT state of fear and panic as their NDIS Plan is only guaranteed on a day-to-day basis; WITHOUT any long-term security, assurances or consistency on WHAT, WHEN or even IF certain changes may next occur to the Participant's Plan, or whether accessibility to certain services or EXISTING supports will continue to be approved for ongoing use at any moment in time!

This rule provides NO control or independence for the participant and it also LIMITS the TYPES of goals people may choose when creating their NDIS Plan in the first place, especially given that the looming threat of unexpected change only further challenges one's ability to emotionally and psychologically have confidence (if not PHYSICAL and financial as well!) that the necessary supports will exist long enough to pursue or even CONSIDER "big dreams" or choose goals that "aim high to reach our greatest potential."

This is also amplified if participants want to select ambitious goals that heavily rely on the STABILITY and UNWAVERING budget of a NDIS Plan that set the funding and supports for appropriate accessibility AND opportunity for LONG-TERM use so that people with chronic disabilities can realistically achieve goals and succeed more in life ONGOING!

If NDIA truly wish to assist people with disabilities effectively live a constructive life and bring out the best for each participant and individual, then people with disabilities need to know and trust that any goals created together or funding that was agreed upon in the NDIS Planning assessment, will hold up fairly and be honoured moving forward; WITHOUT the impending threat that the CEO can make variations WITHOUT any warning at their own initiative to the Plan, and WITHOUT request, consultation, OR consent from the participant at all!

^This is NOT a healthy policy that promotes inclusion, independence, choice, control or trust.

"Nothing ABOUT us, WITHOUT us!"

Thank you.

## **Peggy**

### **Vic**

Reasonable and necessary needs to be clearer and allow the participant to make their choice on supports using legislation they can understand.

Mainstream technology should be considered as AT like accessibility features on iPhones.

Over 65 age group should be considered to make access to the scheme.

## **Diana**

### **WA**

I love the NDIS system, to me it is precise and simple, I self manage my son, he is well covered and living a full and wonderful life, thanks to the funding I receive and the team of quality carers I am fortunate to have.

I don't think the changes will have any effect on our family.

I am extremely grateful to have this help!

## **Gail**

### **Vic**

I am writing in response to the proposed NDIS legislation changes which will impact on the NDIS Act and NDIS Rules. The introduction of a 'Tap and Go card' has been proposed to facilitate payment of providers. If this is the only method for NDIS participants to access the payment facility then participants will be restricted from accessing their chosen services if this card only caters for NDIS registered providers.

If the legislative changes restrict access to non-registered NDIS providers, I wish to object strongly to these proposed changes. My comments are based on my experience as both mother and carer to our [adult age] son who suffered a severe Traumatic Brain Injury (TBI) following a fall in [year] and is therefore non-compensable. After hospitalisation and rehabilitation it was 6 months before he returned home with multiple cognitive and physical issues which, as a parent, were totally overwhelming. The hospital informed us that he would spend his life either in a nursing home or at home under the care of a full time carer.

The strength of the current NDIS system is the flexibility for those closest to the participant to investigate a broad range of options and identify the most effective pathways to improvement/recovery. A significant challenge, but I believe the motivation of a parent or family member to find the most effective pathways can rarely be matched by others.

When the enormity of this task was realised I resigned from my paid employment. It took a couple of years of painstaking and expensive trial and error, but after extensive research and consultations with many practitioners our son now has a talented team of professionals working with him, some of whom are not NDIS registered. It's impossible for someone removed from the daily experience to achieve this. The criteria were always to identify those therapies that would improve his functional ability, thereby leading to an increase in capacity and independence.

From the beginning I have attended appointments together with our son, enabling us to evaluate the therapy and whether or not the practitioner also had the ability to relate to and motivate him. His current therapy team not only treat his disabilities, they counsel and motivate him to strive for both improvement and greater independence, which are equally important. If an obstacle seems insurmountable they are often able to provide practical strategies. To his credit, our son does the prescribed homework to ensure ongoing improvement in his capacity and independence.

From very early days my husband took our son to his office a couple of days a week for a few hours to maintain connection to a workplace and the associated discipline. Because of the severity of his injury, even alphabetical filing was a challenge. He has come a long way in the past [number of] years and we know further improvement lies ahead.

My semi-retired husband is [senior ages]. We are striving to push our son to independence while we still can. We have recently moved into a purpose built property which provides a fully independent living area for him, including a separate entrance. Having directed our financial resources to this major project, our son is now totally reliant on his NDIS funding to maintain his current therapy program.

Being in the driver's seat has been the strength of our son's self-managed program. Choice and control provide the flexibility to create a customised program ensuring a future with greater capacity and independence. Our family is very grateful for the NDIS funding we have received from 2017 to date as it has enabled our son to continue his highly effective therapy program. Our son's therapists are not all NDIS registered, but they are all highly skilled and leaders in their field. If we have to change any of his current providers because they are not NDIS registered, the effect on our son's motivation and progress would be nothing short of devastating.

The most recent Physio report submitted to the NDIS states "For several years [Son's name] has engaged with a [health] practitioner which has given him significant benefit in terms of pain relief and improved flexibility. This in turn has a very positive benefit to his quality of life and engagement in activities."

These words from our son:

"I am fast approaching [time period] since my unfortunate accident which resulted in a traumatic brain injury, a stroke and [other diagnosis]. My life has changed dramatically since that fateful day and it has sadly become truly apparent just how difficult it is to find effective treatments/practitioners.

"One thing I have been very fortunate with is my family. The initial diagnosis was that I may never walk or regain continence again. I am eternally grateful to my mum who was studying [health discipline] at the time, she brought in a [health] practitioner who turned things around for me.

"Today I am still seeing two different [health] practitioners who are driving me forward in the pursuit of returning to work and functional life activities. Courtesy of the stroke I suffer from [functional impairments]. One of the practitioners provides a session of [therapy] which goes above and beyond anything I receive at [other] sessions. This provides a phenomenal [improvement in symptoms] and allows me to continue through the week without the constant hassle of [symptoms].

"Without these practitioners I would not be anywhere close to where I am right now. They have been and still are critical to my recovery and are able to achieve things which are well above the goals set by other practitioners."

Thank you for taking the time to read our submission.

## **Christine**

### **Vic**

I am very concerned at NDIS staff ability to state what disabilities are permanent and what treatments are appropriate. I work with child who has been denied entry to NDIS despite very low IQ, 0.4% working memory, auditory processing problems, concentration problems, severe oral language disorder, learning impairments, and eye sight problems. Despite all of these issues, they were told they were not eligible because surgery for the eye problems had not been explored despite eye specialists not recommending surgery as a treatment option. Why should this child - requiring speech, OT, psych services be denied because they don't have labels like ASD, ADHD, to help NDIA rep understand the difficulties are permanent/lifelong!!

## **Marion**

### **Vic**

I really can't work out the NDIS. I know people on it because of their [diagnosis] but the NDIS denied my application. Told me degenerative [condition] and chronic disabling pain from [other condition] isn't a disability that will get worse over time, even though it has.

I don't trust this federal government at all. They terrify me.

## **John**

### **Qld**

The NDIS should cover people over 65. Disability is not vanquished by a birthday.



## **Mikaela**

### **Qld**

I think the upcoming changes are more about saving money and less about human rights. I'm fighting the NDIS to receive the correct SDA and even that's a challenge since it's "value for money".

Why should my life be decided by strangers? It's not fair and needs to be thoroughly changed.

## **Elsbeth**

### **Vic**

Given that funding for therapies have been redirected towards NDIS - meaning that access to therapies is often dependent on access to NDIS funds - the participant rule requiring that therapy is conducted to prove that there is no change to the condition - is unreasonable and high risk.

People may not have sufficient funds for a sufficiently long period of therapy to prove that their condition is not 'cured' by therapy.

## **Teresa**

### **Vic**

NDIS is for permanent disability with a view to participants increasing their participation over time. The current review system is working well in achieving this. Our son is increasing his independence (he is profoundly disabled) and this will reduce costs over time. It also allows his parents to both work and employ others.

We are able to have a positive impact on the community and economy by improving others people's ability to work and providing work through our jobs.

We cannot do this if the NDIS system is inconsistent and our son's care fluctuates greatly from one "assessment" to another. He is complex. No professional can understand his needs in a couple of hours.

This system benefits the economy. Talking about the NDIS only in terms of "what it costs" is not an accurate reflection of the NDIS system.

It provides and enables people to participate in a huge number of jobs.

**Diane**

**Vic**

Whilst initial reading of the proposed change to the NDIS look quite good, there are still a few adjustments needed if it is to truly represent those it was meant for- namely the disabled, their family/carers.

1/ It is unjust that plans can be altered without the participants input, fore knowledge of such adjustments, any/all changes must be made with consultation from the participant to ensure their needs are met.

2/ As we all have the right to make our own medical decisions based on informed consent, who are the ones who will decide on the participant having reasonable treatment?

**Max**

**NSW**

Have the ALP finalise the draft before it is voted on

**Karen**

**WA**

My worry with the changes is that my daughter will receive less funding and hours...

This has happened to my families and as myself and my husband are older Australians and both have chronic health issues.

It worries me that she will be stuck at home unable to enjoy her Community participation as she has done for many years...

Out of the week we currently get 27 hours the remainder is spent with us.

I am Carer for my Mum since my Dad passed.

These hours are an absolute blessing...

Her anxiety and panic attacks prevent her sometimes from doing what she loves.

Her dementia is another stress for us.

Thank you for your time.

## **Penny**

### **Vic**

The choice to use unregistered service providers is part of my choice and control to use who I see fit to best work in with my lifestyle and choice. Creating the tap and go card takes away from my choice and control and it does not sit right with me at all!

## **Shiva**

### **NSW**

Your Handy Explainer is really very well written by Chadwick Wong.

\* One of main concerns was about "Independent Assessments" - I hope they NEVER introduce it as it was too arbitrary without proper medical input of the NDIS participant. From the Handy Explainer I believe this is NOT being introduced.

\* I do applaud the Government for the many Positive changes that is listed by Chadwick.

\* I do have concerns about "Plan variation without consultation" I would like this to be clarified and to be used only in the most dire cases.

\* I agree that NDIA must provide "reasons for decisions" without the Participant having to ask for it.

\* The different types of reviews (Less and more significant) is highly overdue. I personally had to spend an enormous time in getting NDIS to make a simple correction (which was an error on their part in the first place but nobody would own up to it).

## **Julie**

### **Qld**

Of course its crazy its politics. I can get someone to clean my house, mow the lawns, take to the dump what I need to get rid of, but I can't get someone to wash n polish the car because that's "daily living" and that isn't included in NDIS. I'm having more and more issues making a basic meal, I can get someone to help me but not do it for me. They will pay for the meal but not delivery (cant find anywhere to fit my diet). Community access?? Who can afford that, let alone access it physically??

## **Sabrina**

### **WA**

My 26 year old son has severe intellectual disability and severe phobia of needles. His provider was not able to assist with vaccination as the staff were instructed they could not assist and hold his arm for the injection due to the NDIS restrictive practices . Whilst these are there to safeguard vulnerable individuals like my son it meant that we had no support in getting him vaccinated . We spoke to our GP and the provider and GP recommended slight sedation. How ironic that chemical restraint is more accepted than holding his arm. We trialled [sedative] but it has little impact due to it being a very low dose. We now have booked him in ourself at a GP practice but we are not sure how things will go. What can we do to keep our son safe and where can we go? Vaccination hubs are too daunting for him and I am just praying that we can distract him enough and have competent staff who have some disability training/competency to give the injection quickly. This whole process has been very stressful and not because of a lack of trying. individuals like my son who have severe intellectual disability fall through the cracks .

Our son is also in a group home and his contact specifically identifies him as a boarder. Given boarders are not captured in tenancy legislation he has very little if any security of tenure.

During a previous post traumatic stress episode, bought on by physical assault of a staff member, the provider threatened to remove our son from his home. The royal commission must recommend security of tenure for all modes of disability accomodation.

And thirdly with NDIS covering a large diversity of disabilities the current model does not cater for individuals like my son with chronic ongoing disability with no improvement - yearly reassessment is highly stressful for families with no sense of security that their loved one will receive long term guaranteed services.

## **Zara**

### **Vic**

I am a carer for an NDIS participant. I think the proposed changes are mostly good, and am very happy that the proposed 'independent assessments' have been excluded - this was a huge concern for me and the person I support.

I am concerned about a couple of the changes:

1. Plan Variation without consultation - I like that this may help variations of small things be more smooth, however, I am concerned about plans being changed without consulting the participant. For participants to have choice and control over their supports, they need to be consulted on changes and have ample time to respond. More clarity about this would be helpful.

2. Becoming a Participant - I appreciate the clarification around this in terms of psychosocial disabilities - this will be helpful for some participants. However, I am unsure of the change to require potential participants to have been undergoing 'appropriate treatment' - this might be reasonable for people with certain disabilities (e.g. physical or psychosocial), but for people with intellectual disability, there is no cure or treatment that could change their disability diagnosis (i.e. make it not permanent), so this seems irrelevant. Many people with intellectual disabilities do not have access to 'treatment' (such as therapy) because they don't have money or support to access them. Intellectual disability is life-long, so this shouldn't be something that they need to spend money on to prove they have it. I've recently been going through the process of helping someone with an intellectual disability apply for NDIS, and the only supporting evidence they can provide is from their GP or reports from their childhood. I worry that the changes may require them to pay for therapies out of pocket (which they cannot do) in order to prove their life long disability. I feel that more clarification around the changes to reflect this circumstance is needed.

## **Sarah**

### **NSW**

Will give participants less choice control and flexibility if a plan is plan managed and is made similar to self managed where it is looking at the risk and that participants are not using funding for something that is not reasonable and necessary.

Supported decision making style process to be used when NDIA make a decision on approving a plan and what is funded.

There are too many people going to the AAT to get a decision overturned for supports previously funded under the state system leaving people with disabilities worse off and disadvantaged under the NDIS.

**Kathryn**

**Qld**

Too unwell to be able to consider and provide submission, sorry. Timeframe is much too short to allow promised meaningful consultation with disability community.

**Sophie**

**WA**

"Reassessment" of Plans and supposed "Person-Centred Assessment" cannot be rushed through without proper consultation and approval by people (with lived experience of) disability.

**T & E**

**Vic**

#### **Introduction**

Dear Representatives,

We are glad that the NDIS legislation is currently being reviewed. For the most part, an excellent achievement for our nation and the disabled members of our society. It is not however respectful or affirming of the critical role of families in some important aspects. We and other supportive, loving families of NDIS participants with BSPs are let down and hindered by the legislation in providing care for some of the most vulnerable in our society.

Section 4 General principles guiding actions under this Act states that "(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected"

Section 31 Principles relating to plans, states the intent to: "... (d) where possible, strengthen and build capacity of families and carers to support participants who are children;"

Sadly, in regards to providing behavioural support, families seem to be completely out of the picture in the legislation! Instead of loving families (with help of funded supports), it is assumed that registered legal entities provide the supports. It assumes second best and it fails many people!

Our request for consideration and legislation change: Regarding the NDIS Commission, enabling a Family-centred model (or Service for one) where behavioural supports are in play – the NDIS Act needs to be updated to enable family-centred supports to thrive.

The current system is set up for institutions and large services and does not accommodate a family-centred model. Onerous registration hurdles and outdated paper-based safeguards appear to force the use of large and unsuitable organisations.

Attached documentation: Our submission to the Parliamentary Inquiry into the NDIS Quality and Safeguards Commission

Specifically, the legislation fails many participants with complex needs and behaviours, who may have a supportive, loving family around them. As soon as they have a BSP with regulated restrictive practices, lodged with the Commission, the registration requirements make it almost impossible for a family-centred model to operate. Supports are limited to registered service providers, of which there are almost none who are prepared or able to provide suitable support. [Name] has amazing specialist Support Workers, sole traders providing the necessary bespoke model of care, but registration is not feasible for these people.

While registration provides an important safeguard for some, we do feel that those supportive families of NDIS participants with BSPs are let down and hindered by the legislation. It seems that this is recognised by the NDIS, shown by the efforts to make audits 'proportional'. We are involved with a such an effort, involving VALID and the NDIS Commission. Disappointingly, this initiative doesn't look to be enabling family-models with light touch registration for small providers or another means of safeguard. The stated obstacle continues to be the legislation, the NDIS Act! Surely it would be better to encourage families that provide well-functioning, loving, supportive environments for the most vulnerable rather than push them to the point of giving up, with onerous requirements imposed presumably due to the actions of others. We know many families that have set up separate legal entities to try and meet the requirements, but none that we know of have achieved registration. It really feels like some sort of collective punishment that is highly inappropriate to the supportive families. We can readily think of much better safeguards, many of which are already in place.

We are fortunate to have found ways to avoid Support Workers needing to use restrictive practices, but of course if this changes, then we face the additional challenges and bureaucratic burdens of setting up, registering and running a legal entity, on top of the already huge responsibilities of caring for [Name]. It certainly doesn't seem right, and if anything it looks more likely to make [Name] less safe than more safe! It is surely unreasonable and even discriminatory to place such additional burdens (including creating a legal entity and registering with Commission) upon those supportive families who have got a family member with a BSP, and not for those with less complex, more straight forward support needs. It is not proportional at all!

Instead of burdening such families, who already invest huge amounts in providing support, we suggest that the Government should take this burden and revise the legislation to enable supportive family-centred models to thrive. Specifically to recognise other means to achieve safeguarding and/or to make it feasible for small providers to register with the Commission.

While the NDIS Commission staff seem supportive of families, they are constrained by the legislation which works against the family-centered model. We write to you with the hope that you can update the NDIS Act to enable family-centered support models to thrive.

## **Attachment**

Parliamentary Committee Submission

Inquiry into the NDIS Quality and Safeguards Commission

[Names], [date]-2020

Introduction

[Name] is our beautiful [age] severely autistic son, who faces a mountain of adversity each day. Full of energy, with a cheeky glint in his eye, he enjoys a wonderful, unique sense of humour. Alex spends his days reciting his echolalic phrases, delighting when a trusted carer joins in. He struggles to be in the same space as other children and only accepts certain adults. When anxiety and sensory overload combine, as they do frequently, [Name] will communicate his profound distress through biting, grabbing, kicking, hair-pulling and devastating self-harm – often banging his head on corners, windows or brick walls. His daily existence is a fragile balance between contentment and pleasure and chaos and utter distress.



In diagnostic terms, [Name] has a complex neurodevelopmental presentation of multiple co-morbid conditions including Autistic Spectrum Disorder (ASD) Level [number] in association with a Severe Intellectual Disability (ID), a severe communication disorder, severe sensory processing difficulties and Generalised Anxiety Disorder. [Name] also presents with multiple behaviours of concern that have been present since he was a toddler and are frequently resistant to intervention. Despite support from highly skilled staff in all settings, an environment which is fully adapted to meet his needs and attentive, devoted parents and carers, [Name] continues to present with behaviours of concern daily. He displays high frequency, high intensity behaviours that present significant risks to himself and others on several days each week.

[Name's] physical health issues combine with his neurodevelopmental conditions to result in these severe behaviours. [Name] experiences intense distress due to digestive pain which escalates when he needs to move his bowels. [Name's] bowel movements are not regular despite medical interventions to alleviate this. As a result, [Name] experiences extended periods of discomfort and pain even over several days, and this is a significant trigger for his behaviour. Despite following medical advice and treatments to address [Name's] bowel issues and the pain that they cause, all interventions to date have been ineffective.

Over the last [number of] years we have adapted our lives, re-setting our priorities, limiting our involvement in almost all areas of life to be able to do what we can to care for our precious son, born with such overwhelming and complex support needs. [Name's] number one goal on his NDIS plan is to continue living with his family for as long as possible and for us all to feel safe. This is an all-consuming challenge. We don't go on holidays as a family, or join extended family for Christmas, birthdays or other occasions, or partake in so many other typical family activities. What we do is pour our lives into trying to make [Name's] quality of life better. At times it seems that he lives with daily torment and distress that breaks our hearts and stretches our resolve far beyond what we thought was possible for us.

Key points in submission

NDIS: The support needs of severely autistic participants with complex needs must properly be considered and managed ancillary to general approaches regarding autism. Restrictive practices rules and guidelines need a common-sense approach so as not to reduce freedoms of highly vulnerable people.

Family-centred model: Behaviour Support safeguards need to change to enable more flexible and family-centred models to thrive. The current system is set up for institutions and large services and does not accommodate a family-centred model. Onerous registration hurdles and outdated paper-based safeguards appear to force the use of large and unsuitable organisations.

TOR d) The adequacy and effectiveness of provider registration and worker screening arrangements, including the level of transparency and public access to information regarding the decisions and actions taken by the Commission.

#### NDIS Quality and Safeguards Commission

We trust that the Commission will serve well and protect [Name] and many others over their lives. Unfortunately, it currently presents bureaucratic red tape and delays, as well as driving a reduction in services and opportunities available to [Name] with his complex behaviours. Almost all providers of day care and respite do not offer these services to clients with complex behaviours and this market has become even thinner with the introduction of the restrictive practices rules and guidelines. There are now no day services that we know of in Victoria that will provide care for [Name]. The one service that did exist has been rendered impractical since the provider's response to restrictive practices rules involved removing door locks at the premises. From this point they could no longer cater for [Name's] needs and behaviours of concern given that they were no longer able to keep him separate from others when dysregulated.

[Name] is now on the Complex Needs NDIS stream. Although this stream appears to still be finding its feet, we do trust that this will result in much greater expertise and more transparent and informed decisions. The NDIS needs to continue to invest in developing expertise specifically with severe autism, severe/profound IDs and complex needs and behaviours. The needs of these participants must be considered ancillary to general considerations regarding autism, which in almost all advocacy and policy situations does not adequately include or represent someone like [Name], and frequently inadvertently works against his best interests.

Behavioural Support and a Family-centred (or Service for one) model

We and other families in similar circumstances seek flexible options that might work for a family-centred support model to care for our son and give him his best life. This contrasts with a support model based on large service providers which have proven consistently to offer very poor options for someone with complex needs like [Name]. With his extraordinary anxieties, building trust with a few highly attuned and trusted communication partners provides [Name] with a source of security and is vital to his wellbeing. People who can't 'read' [Name] expertly fail very quickly in trying to support him. The Support Workers who can work effectively with [Name] are a very small percentage of the market, but there are some who are highly focussed and motivated to work with [Name].

[Name's] number one goal on his NDIS plan is to continue living with his family for as long as possible and for us all to feel safe. This is a substantial long-term challenge, but one that we believe offers [Name] the potential for his best life.

We now have a wonderful "Team [Name]" around [Name] and his safety, wellbeing and quality of life have improved significantly as a result. Working together with his parents, it includes specialised health professionals (Psychiatrist, Psychologist, OT, Paediatrician, etc.) and a small handful of skilled, competent and highly dedicated Support Workers that we have found who love [Name] and are committed to the long term to make his life as good as it can be. These people are very hard to find and have the required specialised focus and desire to work with severe cases/complex needs to help families to stay together. [Name's] Clinical Behavioural Psychologist has prepared a thorough and insightful Behavioural Support Plan (BSP).

Unfortunately, the family-centred model does not readily fit the current Behaviour Support safeguards, where regulated restrictive practices are used. Registration requirements are onerous and appear very much suited to large organisations or agencies with substantial administrative structures, including an Authorised Program Officer (APO). Registration has proven virtually impossible to individuals and small businesses, including most of the specialists that wish to work with [Name]. Most of these are not expert administrators and bureaucrats, nor should they need to be, but they are the most capable, trustworthy and best suited people that we have found to work patiently and skilfully with [Name] as he journeys through each day. They support [Name] to manage the daily challenges he faces, to enable self-regulation and build resilience, to stay safe, to build life skills and to expand his participation in the community. That is their passion and area of speciality; that is where they make a huge difference to [Name's] life.

The relevant laws need to change to enable more flexible and family-centred models to thrive and not be thwarted or supports re-directed via much less appropriate services by a mountain of bureaucratic red tape that seems to sit between Alex and those who can provide essential support services. Safeguards are of course essential, but there are certainly more effective and appropriate ways that this could be achieved within a family-centred arrangement for [Name] than those in the current requirements.

Registration with the Commission for individuals, such as sole traders and small businesses, needs to change from being onerous and virtually impossible to being simple and more appropriate to the purpose. The purpose may be to provide dedicated and specialised support to a disabled person with complex support needs who lives with their family. It cannot be assumed that the disabled person be in full time care of a service.

The function of APO also needs to be made readily available in a means suitable to a family structure. We are informed that the current Disability Act in Victoria doesn't allow a family member to be an APO, but rather the APO must be linked to a provider. To have [Name's] mother as APO would make perfect sense to us and is essentially what happens now. No one else will have the intimate knowledge, ultimate care responsibility and same level of protective instincts for [Name]. Other good options that we have proposed are his Behavioural Psychologist or another of the health professionals already on 'Team [Name]'. However, during our interactions to date with the office of the DHHS Senior Practitioner, it has become apparent that there is an assumption that everyone with a BSP will be using large registered service providers with APOs and that the family centred 'Team [Name's] model that we are committed to, and are sure it is by far the best approach for [Name], doesn't fit their way of working. During these interactions with the DHHS Senior Practitioner team, it felt very much like we were in the wrong place and that the APO policies may in fact prove an unnecessary stumbling block that works against [Name's] best interest.

We need clarity and help navigating this space as parents. [Name's] complex needs and choices rarely fit into standard boxes in most aspects of life, including how he stays safe and how he expands his community participation. A common-sense approach, allowing pragmatic application of the guidelines is necessary in order to avoid politically-driven over-reaction, with unintended consequences that work against [Name] and others with severe autism and comorbidities including severe/profound IDs and presenting with behaviours of concern. When [Name] is breaking windows with extreme force of repeated impacts with the back of his head and carers stand back watching, too frightened to intervene due to fear of breaching a restrictive practice rule, clearly [Name's] best interests are left smashed with the pile of broken toughened glass.

## Conclusion

We currently experience well-intentioned but poorly informed implementation of laws and policies that reduce freedoms of vulnerable people like [Name]; ironically those that they try to protect. It seems clear that the laws need to be refreshed to enable more flexible and family-centred models to thrive.

## **Arahi** **NSW**

Why is the Agency proposing to pay the bills for self managed people? Does not make sense.

Why is plan managing losing some of its choice and control?

Why does the CEO have the power to determine what providers a person can use?

Why does the CEO have a lot of discretionary power?

## **JOE** **SA**

PLEASE MINISTER REYNOLDS, DO NOT CHANGE ANYTHING ON THE NDIS. IT IS WORKING JUST FINE NOW. WHY IS THE GOVERNMENT TRYING TO MAKE CHANGES TO SOMETHING THAT IS GOOD FOR PEOPLE WITH DISABILITIES.

MY DAUGHTER IS ON THE NDIS AND INDEPENDENT ASSESSMENTS ARE NOT NECESARRY.!

SHE HAS COMPLETELY IMPROVED HER INDEPENDANCE SINCE THE INCEPTION OF THE NDIS.

## **Nathan** **Qld**

I am legally blind and don't wish to receive another assesment. My condition is perminant and has been since I was [infant age]. I also do not want to be mandated into vaccination.

## **Rohinton**

### **NSW**

Positive changes are always welcome.

Also I feel very strongly about a new plan being approved at a substantial reduction over the previous plan even when a participant's medical condition has not changed. This in my opinion is unethical and immoral particularly when the planner or case managers do not discuss and explain the plan to the participants before it is released.

## **Shane**

### **SA**

I am concerned about the undefined terms used throughout the document. When dealing with people's lives, you cannot just leave such things open for interpretation. Leaving such things as 'appropriate treatment' vague worries me especially in regards to autistic children, as evidence-based research is still out on certain therapies and treatments, and I do not wish for these individuals - two of whom I know - to be forced into experimental and dangerous treatments such as 'Applied Behavioural Analysis' - which are currently being pushed by non-autistic parents, teachers and therapists despite the resounding and unified voices of autistic adults warning of the damage it does - as a condition of receiving NDIS support.

## **Jacqui**

### **NSW**

I'm a person with MS who receives NDIS funding. I'm not a lawyer (I was once a technical writer, communications manager, and even an art teacher). I haven't read all the proposed changes to the legislation, nor can I easily understand all that is being proposed.

There has been a very short timeframe for consultation and submission. Inadequate I think for participants to fully understand what is being proposed and the ramifications.

Having attended a few sessions run by DSS and various advocacy groups I can see there are some good things coming from the new legislation.

HOWEVER my trust in anything the NDIA do at the moment is incredibly low. I'm sure there are some sneaky things in this proposed legislation which will come back to bite me (ie will be misused by the agency/abused)!! I'm sure an agenda(s?) is being enabled by these changes..I just don't know what agenda(s?)!

I've listed the specific areas of concern I have below:

1. Plan Variation without consultation (47A) - seems positive on the surface but there's devil's work in the lack of detail around this. It gives a lot of unconstrained power to the CEO. I think this should be tightened up significantly in the legislation .

2. Changes to Plan Management & Payment of supports (S43 and 44) and section 10 of Plan Management Rules.

I have concerns about (as a self managed participant) I will be able to pay for some of my supports. That is for my supports that are independent contractors or businesses that aren't NDIS registered (like my cleaner, gardener, oven cleaner) or for low cost AT purchases I make from a variety of retail stores or online business.

2. Trickle release of funding. I'm concerned that if there is underspend in a quarter, the agency may then not release any further. I have already had such arguments made as to why my continence funding wasn't included fully in my plan at an s100 review.

3. Additionally s45 states that payments are to be made "to the person determined by the CEO". This should be clarified. Could this be used to force me into only using set providers for my therapy for example. A bit like workcover. Instead of my established providers.

4. Reasons for decisions on S100 (1B & 1C). I think these should be automatically be provided to the participant, rather than on my request. This should be the same for ALL decisions made on a person's plan.

5. Access Changes - my concerns with this section are

a) could this be a requirement applied retrospectively for existing participants, and

b) is part of this a veiled way to remove a participant's funding for CB daily activities as no longer being an NDIS responsibility but the Health system (eg around therapies I must have tried before being given access to NDIS, or be booted off)

Overall, there are a lot of new powers in the proposed legislation, with not enough detail provided on when and how they will be exercised. The reliance on Plan Management Rules also raises the issue of governance. I want to ensure any changes to this scheme are included in the main legislation so that it can be voted on in parliament.

The devil is in the detail!

Thankyou.

**Carmelo**

**NSW**

Not good





## Lorraine

### NSW

Please include request to change the rules to allow in line with the UN Accord "Independent Self Determination with choice and control" of what Service Provider Deaf Auslan Users over 65 whom have been Disabled all their lives and ineligible for NDIS by Age not disability. Please change the rule that excludes them from NDIS by age not disability. Australian Deaf Elders (ADE) Group have 830 members and 2016 census stats state that only 874 Over 65 Auslan users wrote Auslan as their home language. Hence ADE are the voice of Deaf Auslan users the nation wide.

Please include over 65s Deaf Auslan users whom have been disabled all their lives yet excluded by deliberate choice of rule by Federal Government knowing that it is not provided in Age Care System when they created that rule, upon age not disability.

Federal Minister for Age Care allocated \$20 million dollars to one Organisation 23/9/2021 free over 65 Auslan interpreter in Age Care as a direct result of ADE lobbying yet the allocated it by "I TENDER FUNDING" Over 65s have no "independent and control of what Service provider they choose for Auslan Interpreting un equal to under 65 Auslan Users whom have "choice and control via a 'self managed, plan managed, or NDIS managed. We want the rule of NDIS changed to include Auslan users over 65s to have the same as under 65 Auslan users. Via Self managed, plan managed, Age Care managed under DSS equal to NDIS Auslan Users.

Our current lobbying for "Equity to NDIS for Tech Assistance for our Deaf Auslan Users Over 65 for life saving equipment such as Visual communication technology, fall alerts , Nursing Home Technology training equal to NDIS Recipients under 65 whom have been disabled all there lives likewise . Thank you Lorraine [Surname]

Australian Deaf Elders Group Admin

**Attachment next pages**

To:

The Hon Greg Hunt MP.  
Minister for Health and  
Aged Care.

Senator the Hon Richard Colbeck  
Minister for Senior Australians and Aged Care  
Services.

Your Ref No. MC21-000233

**29th September 2021**

Dear Ministers,

ADE Admin Group thank you for your letter of 25 February 2021 to Lorraine Mulley of the ADE Admin group.

874 Australian Deaf Elders over 65 years old, according to the 2016 ABS census, do not consider themselves to be "functionally impaired". Compare this number of 874 with the under 65 year olds NDIS Australian Deaf Elders of which there are currently about 15,000. Australian Deaf Elders know and see themselves born congenitally deaf, attended schools for the deaf, tested by audiologists, over the years since birth, to be deaf. Australian Deaf Elders's deafness is congenital not a deafness acquired by natural normal ageing processes. Many over 65 year olds ADEs have over 99% deafness. Many hearing persons acquire deafness through ageing but is nowhere near 99% deafness.

These hearing people with functional hearing impairments have fully developed speech and clear voiced speaking unlike most congenitally deaf people who battle daily to make themselves understood by the general hearing population. The congenitally deaf people today use Australian Sign Language, known as AUSLAN, to communicate with interpreters their messages to the hearing persons. Very rarely do Australian Deaf Elders find one or more of themselves able to lipread and speak well with other hearing people.

Daily congenitally Auslan deaf over 65 year olds see fellow deaf elders under 65 year olds use their non-means tested self managed, plan managed NDIS plans to purchase their much needed technology assists to enable them live out their lives to the best of their abilities. NDIS plans are currently managed by the capable staff at the Department of Social Security. As stated on 4/4/2018 the ADE Admin Group meeting and providing Minister Ken Wyatt with an "Independent choice and control, with self determination where-ever possible, the Pre-MyAgedCare Supplement Proposal " to be managed by the Department of Social Security equal to NDIS , is required. Covid 19 pandemic presently has reiterated this need, and the adverse impact of the single choice tender service provider, Auslan Connections's inability to reach its customers that you funded. Whereas the NDIS users continued to use their funding both for tech assists and Auslan INTERPRETING ONLINE for life saving matters of communication during the Covid19 lockdown.

Sirs, you both need to stop labelling our Auslan users as pathological constituents who have "functional impairments due to ageing". The Department of Social Services Staff overseeing NDIS ...understand the needs of these deaf people. These staff members understand the needs of these deaf persons. For the rest of the Australian deaf elders who are the over 65 year olds they are really struggling in the MyAgedCare sector.

This MyAgedCare caters very well for the hearing people many of who have "functional impairments". The Department of Health staff care for them via means-tested MyAgedCare plans. The ADE Admin group have found that the staff generally have no understanding of congenital deaf elders over 65 year olds and their real needs.

As an example of urgent technology assist needed by any congenital Australian Deaf Elders over 65 years old living alone at home, inside or outside, would find that Smartwatches with emergency falls detection are an absolute life saving tool 24/7 time during covid 19 lockdowns. This tool and a corresponding Smartphone would serve to connect them with emergency services



in an instant while they are lying unconscious or immobile on the floor/ground including the paramedics clicking on the fallen person's watch to communicate quickly with family inside the speeding ambulance because of the paramedics's lack of AUSLAN to communicate with the congenitally deaf patient before reaching the emergency department at a nearby hospital.

Ministers Hon Hunt and Hon Colbeck you have stated in your letter that there is access to technology for the congenital deaf persons living in Australia via the Commonwealth Home Support Programme [CHSP]. Living in regional/rural areas of Australia comes with great difficulties accessing this CHSP as the funds are nil and depends in which regional shire you live in. Some CHSP funds maybe available in adjoining shires but is totally lacking in your own shire. Sadly if you don't live in the Shire with the funds you get no technology assists.

ADE Admin Group are always very concerned about this lack of technology care that is seen shown to the over 65 year olds congenital deaf persons which does not exist with the under 65 year old congenital deaf persons. It would be wise to transfer the congenital deaf over 65 year olds to the NDIS scheme where the Staff understand best their real technology needs.

With regards to the \$20,000,000 that you, sirs, allocated to your selected single service provider, Auslan Connections, instead of the ADE Admin Group's preferred multiple free choice service providers, on 23 September 2020 just over 12 months ago .. a \$20 million trust fund could have been set up in the Australian Government Reserve Bank to provide for the Free interpreting services to the congenital Australian Deaf Elders over 65 year olds that you announced last year on International Sign Language day, 23/9/2020. It can be calculated as follows:-  
\$20,000,000 x 2% RBA interest rate (approximately) on that trust account over 12 months equals \$400,000 dollars interest divide that by 800 elders is \$500 per elder and concerning a useful life tool tech assist would purchase a real life-saving smartwatch with emergency falls detection. Any other "funding slippage" that was not used in the first year from your original \$20,000,000 allocation would be added for a corresponding purchase of a smartphone to support this smartwatch.

Yours sincerely,



Euan Pescott  
Per The ADE Admin Group

## Content/language warning

### G

#### WA

1. Stop the coalition cornification with NDIS immediately, stop handicapping recipients' choice and control in accessing services and supports;
2. How can one CEO dispense equality independently vary 470K recipients plans per annum?
3. Participant's interactions in establishing meaningful plan and accurate for the future are handicapped by unqualified, inexperienced, anonymous individuals making assumptions and passing judgements on individuals against a matrix system without being prepared to explain or justify their decisions or clarifications to the recipient.
4. Currently there is zero accountability by anonymous agency staff when seeking clarification of details for the dispersal of funds contained in their plans, ie: eligibility criteria, reimbursement refusal, decision making by the agency of the participant.
5. AAT must have the power to stop the belligerent abuse of power, the recipient blame and shame game tactics used by legal professionals which prolong and fail to come to a speedy resolution within a specific time frame, therefore subjecting the taxpayer to unreasonable and unnecessary expense which cannot be considered fair and reasonable cost to the taxpayer;
6. The internal review process lacks transparency, demands resubmission of evidentially documentation which is not processed with due diligence and duty of care under the disability standards. The anonymity and accountability of internal reviewers must be able to be questioned more than a simple statutory number and sub number must be accompanied with a more detailed explanation not dismissed with only a legislative reference number. This must be done before escalation to the AAT level or above proactive and with recipients would result in greater benefit for recipients and a significant reduction.



7. It is not conceivable or possible for anonymous bureaucrats to have a significant understanding of the applicants requirements when they refuse to meet other standards in the Act ie: access to information in a suitable format able to be independently accessed by recipients, their arrogant and dismissive attitude towards the requirement by providing duty of care, their demands for private personal information which is irrelevant to assessment requirements, the disempowerment and removal of independence through complacent incompetence are all standards currently unmet by the NDIA and the AAT therefore rendering the Agency incapable of dispensing my basic rights to choice and control section 34.
8. The blatant willingness of NDIA case managers wilfully and deliberately fraud misrepresentation of engagement with participants, the unconscionable decisions to change the participants medical diagnosis without consultation or authorisation. Their complacent dismissive attitude when pulled into line and request their unprofessional conduct be amended.
9. The NDIA/NDIS lack of transparency in providing the relevant documentation required for evidence for the said: AT, capacity building and consumables is remiss in the system and on website. Prevents and disempowers the participant with NO process and transparency to support the participant in moving forward.
10. The NDIS must stop the gauging in the price setting to preference to parasitic providers.
11. A stop to the systematic corruption and dysfunctional structure of the NDIA as it has been made clear with the changes the new intent of the Agency is to first meet the budgetary constraints imposed on them by the minister and her congregation deceitful disciples.
12. Minister Reynolds : "STOP"! raping the resources out of the recipients plans as this conduct is unconscionable.

## Content/language warning

**M**

**Vic**

Everyone is different on everyday and not everyone can work on 1 tactic or rule.

I want self management to continue as this is a bonus to help those who want to stay in control and have self respect and knowledge for themselves.

The fees of these therapists is a joke and should be reduced by half.

This government funding is for the sick and disabled not for the provider companies nor therapist to our funding as they financial escape.

I am disgusted and hope they use the funding they are robbing us off on their health.

And hope soon they end up being sick and disabled and no NDIS funding is allocated to them.

Yes I'm very pissed off.

## Content/language warning

**D**

**WA**

1. Cut back on the bullshit.
2. Cut back on the bureaucracy, cut way back, way way back.
3. Cut back on crazy high hourly rate pricing schedules.
4. Cut back on the rorting.

Pretty simple when you apply common sense.

**"I underwent "appropriate treatment" for my Dystonia and suffered a stroke as a result, leaving me significantly more disabled. I wouldn't have pursued that treatment if I had access to appropriate support at the time.**

**I would hate for someone else to be pushed into pursuing a risky treatment in order to receive necessary NDIS funding."**



Every Australian  
Counts

