



NDIS Planning Inquiry - Submission

September 2019



Every Australian Counts thanks the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make a submission into its inquiry into NDIS Planning.

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 eight years since it was established, it has amassed thousands of supporters from all over the country.

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 rolls out 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 once again 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 experience. Whether face-to-face at one of our community forums, or through social media, or through phone calls and emails, or through surveys and submissions, we are constantly collating people's feedback, experiences and ideas for change. We wanted the committee to have the same opportunity to hear from everyone in our community. Not everyone can attend one of the committee's public hearings, and not everyone has the time or resources to make an individual submission.

So we opened a small page on our website asking people to contribute to this submission. In just a couple of weeks we received almost three hundred stories, statements and ideas about planning in the NDIS. That is what you will find attached in the Appendix. They are as they have been submitted to us – the only editing has been for typographical errors or information that clearly, and potentially dangerously, identifies a person or their family.

And while we know you will read every one of the stories in the following pages, what follows is a brief summary of the most common issues raised. This summary is very similar to the summary we provided the last time made a submission to the committee. That is because the experiences, stories and ideas submitted to us this time match almost exactly the feedback we received last time.

Which prompts us to say ...

We are all trapped in Groundhog Day

If the committee feels a strong sense of déjà vu when reading the submissions there's a good reason for that – you have indeed heard it all before. The experiences and stories you will find on the following pages echo the feedback provided at community forum we hold, the same feedback provided through emails, phone calls or on social media, the same feedback provided through surveys. Seeing a pattern here? And the feedback we receive is the same feedback other organisations in the sector receive when they survey their members. It is also consistent with feedback provided directly to the NDIA through their pathway review.

And if the committee is feeling a sense of déjà vu spare a thought for the people with a disability and their families who are stuck living it every day. We are all trapped in some NDIS version of Groundhog Day where we keep identifying the same problems and potential solutions – but each day we wake to find very little has changed. And while we want to acknowledge the NDIA's commitment to listening and responding, and the changes they have made through their pathway program, we feel compelled to say that progress on the ground is agonisingly slow.

And now we find ourselves faced with the prospect of the Tune review into the NDIS Act and Rules. The recently released discussion paper asked many of the same questions the NDIA asked during their review of planning pathways. Many are the same questions asked by the committee as part of this inquiry. We have now provided the answers every way we know how. The issues are well known. The solutions are well known. What's missing is some action.

If we sound fed up it's because we are. If we could make a single plea to the committee it would be to state that the time for talk has well and truly passed – in fact it passed long ago. It is now time for some action. And we do not believe it is necessary to wait for the Tune review to be completed for some concrete change to occur that would really help people on the ground.



So at the risk of repeating ourselves – what are the most common issues?

Quicker, simpler and easier processes – and more help for everyone

The resounding message from all around the country is that people still find NDIS processes too complicated, too confusing and too difficult to navigate. And as a result everything just takes far, far too long. And as will become abundantly clear when you read the stories that follow, the stress of trying to navigate the scheme has pushed many to breaking point. NDIS processes MUST become clearer, simpler and quicker so that no one misses out or is left waiting for support.

And there needs to be more help for people to work their way through every stage of the NDIS - from application, to planning, to finding supports and services, to finally getting funds out the door. Everyone needs a hand to get their plan up and running and make sure it is working for them – well beyond the small number that currently receive support coordination. Local Area Coordinators cannot be relied upon to provide this help – they are clearly overwhelmed and do not possess the necessary skills and experience. Help must be provided by organisations that people know and trust.

Draft plans

Yes everyone would like to be able to see a draft of their plan. This would allow people to correct simple mistakes and make sure it accurately captures the information they have provided. But the draft plan has become the unicorn of the NDIS – a magical mythical creature that everyone would love to see but so far no one has.

Improved communication

Communication from the NDIA needs to be simple and consistent. Often things that participants and their families need to know are still lost in complicated jargon. The NDIS must use language everyone can understand. They need to use consistent language on the website, the plan, the portal and the price guide. And they must make sure they give consistent answers regardless of who asks the question – or who answers it.

There have been significant improvements to both the NDIS website and the portal. But both still require further changes so they are much more user-friendly and easier to navigate. Everything being online just doesn't help – there are lots of people who don't have access to the internet or who don't use it.

And finally while call centre waiting times have undoubtedly been reduced, unfortunately there has not been a corresponding increase in usefulness – you still can't speak directly to someone who can answer your question or fix your problem. Answers are also often inconsistent – call multiple times, get multiple answers. Everyone would like a direct line to local offices so they can speak to a real person who can resolve their issue. That's kinda the point of calling.

More staff and improved training

Everyone agrees that planners and LACs need better training. Good intentions are no substitute for the experience and knowledge necessary to work effectively and respectfully with participants and their families. Navigating complex NDIS processes is hard enough – but poorly trained and inexperienced staff who are unable to answer important questions or who treat people badly just makes things even tougher.

Participants and their families understand that LACs and planners can't be experts in every single different type of disability – but they should have information they can refer to at their fingertips or experts they can call upon to make sure they make informed decisions. There are many calls for creation of specialist planners who can build up expertise in particular types of disability – this was a feature of some trial sites in the early years of the scheme which has since been lost in the speed of full scheme roll out.

There are also many frustrating examples of LACs and planners not reading material provided by participants and their families. This is particularly galling when people have gone to considerable trouble and expense getting reports from specialists or allied health professionals. Participants and their families expect the reports of experts should stand – decisions should be made based on their considered professional opinions rather than the outcomes of google searches by planners or LACs.

Consistent and transparent

People are frustrated at a lack of consistency between NDIS plans. They want to be reassured that things are fair. They also want to know that plans really are individualised – not just cookie cutter. And if people are really only going to get the amount contained in the relevant NDIS reference package, the NDIA should be upfront about this so people know what to expect.

There is also much frustration at a lack of accountability within the NDIA. People want the NDIA to not only be clear and consistent in their decision making but also explain the reasons for their decisions. It should not take an FOI request to find out why and how a decision was made. People need to know and understand the why of a decision because it will determine how they will respond and what action they will take.

More flexibility

People are frustrated by the continued lack of flexibility in managing their NDIS funding. People want to use their funds in a way that works for them. At the moment the fundamental principle of choice and control is being undermined by poor policies and processes and inflexible rules that just don't make sense. There are too many stories of people running out of funds in one area but having funds left in another – but no ability to move money around. This was never the way the scheme was intended to work.

At the moment self-management offers participants the most flexibility – but lots of people say they feel the leap into self-management is too big without more support. They would like more tools and help to be available so more people can take advantage of the opportunities self-management offers.

And finally people in regional, rural and remote areas want a fundamental rethink of the way the NDIS model works. You can't just tinker at the edges – the NDIA and the government need to redesign how the scheme works outside metropolitan areas, particularly in remote communities. There needs to be much more flexibility for the scheme to have any chance of meeting the needs of people who live far from cities and towns.

Set timelines – and stick to them!

The length of time everything takes in the NDIS is one of the most common complaints. Waiting for plans, waiting for assistive technology, waiting for answers, waiting for reviews, waiting, waiting, waiting.

There needs to be some serious elbow grease to clear current backlogs, particularly in early childhood, assistive technology and plan reviews. And while many people support the idea of set timeframes for key processes such as access, planning and reviews, they argue they will only be effective if the NDIA have the staff to implement and if they are held to account for failing to deliver. A number of people also support the idea of introducing online tracking of applications, approvals, reviews and complaints so people can log in and be able to see where they are in the queue.

Most people find yearly plan reviews stressful, time consuming and unnecessary. They also come with an annual fear of a reduction in support. But while people are generally supportive of the idea of longer plans, many are also concerned that they must be accompanied by the introduction of an effective triage process. People are only happy with longer plans if they are confident there is a clear and simple emergency triage process which allows participants to fast-track their requests if circumstances change. It is something of an understatement to say that confidence does not exist at the moment.

Reviews and the need for advocacy

Like the rest of the NDIS, people consistently report they find the review process complicated and confusing. There are too many concepts and processes that sound like each other but which actually mean completely different things. Who on earth thinks a “review of a reviewable decision” is a clear and simple way of explaining the need for change?

People would like the opportunity to change simple things with their plan without triggering a full blown review. At the moment this can sometimes be done when the plan first lands but not always consistently.

Many people who would like to seek a review of one part of the NDIS plan are warned that the review may result in a reduction of support in other areas. To many participants and their families, that warning can sound much more like a threat. As a result it can deter some from challenging decisions they do not agree with. Reviews should be confined to the part of the plan which is being challenged – it should not trigger a wholesale review of the entire plan.

The considerable backlog in reviews leaves many seeking them stuck between a rock and a hard place. If you are seeking a review because you do not believe you have sufficient support what should you do? Spend your funds as you believe you need them and risk running out before your review is resolved? Or eek them out slowly and risk that being taken as evidence you do not require the support? An unpalatable devil and deep blue sea choice.

And like the rest of the NDIS, there is very little help for people seeking a review. Disability advocacy groups play a critical role in ensuring people with disability and their families have a safe space where they can voice their concerns with the NDIS and get help to resolve problems. While they absolutely doing the best they can, at the moment they are stretched beyond breaking point. As a result they are only able help those most in crisis. That leaves everyone else with nowhere to turn. More funding needs to be allocated so they can continue to empower people with a disability to understand their rights and stand up when things aren't going well.

Attention to groups who are missing out

The complexity of the scheme means people are increasingly concerned it is really only working for the people who have the capacity to navigate and are able to speak up for themselves – and even then good outcomes are far from guaranteed. They are really worried about all those who are really missing out – people with complex needs, people with psychosocial disability, people who don't have family members or advocates in their corner. They are also really concerned about people from an Aboriginal or Torres Strait Islander background or who come from a Culturally or Linguistically Diverse background – the numbers for these two groups are still low, and people think not enough is being done to reach out and help people navigate a complex and bewildering scheme.

Many people also mentioned they were concerned about what was happening to people who weren't eligible for the NDIS. There were too many examples of programs being wound up and leaving people without support. The NDIS was never meant to work in isolation - other programs and services must continue to so people get the help they need.

Support for families

Everyone is in furious agreement that the scheme should be focused on the person with disability. But families also need support as they work their way through the scheme. They also need support so they can continue their vital role. There are many submissions in the following pages that talk about the significant additional stress and anxiety that has resulted from the introduction of the scheme – ironically the very opposite of what was intended. These pleas and cries for help cannot be written off as “teething problems” or “transition issues” – they have existed for far too long and are too widespread.

So to wrap things up ...

Again, we would like to thank the committee for the opportunity to have input into the inquiry. We want to finish by strongly urging you to carefully consider the views expressed here and the suggestions for change. In our view, it is people with disability, their families and carers and people who work in the sector who have the best understanding of what needs to change, and what will and what will not work on the ground. Please listen to what they have to say – they are the ones who matter most.

And finally if we could repeat our earlier plea – the issues are well known. The solutions are well known. What is required now is action.

People with disability and their families deserve nothing less.

Yours Sincerely

Kirsten Deane on behalf of Every Australian Counts

