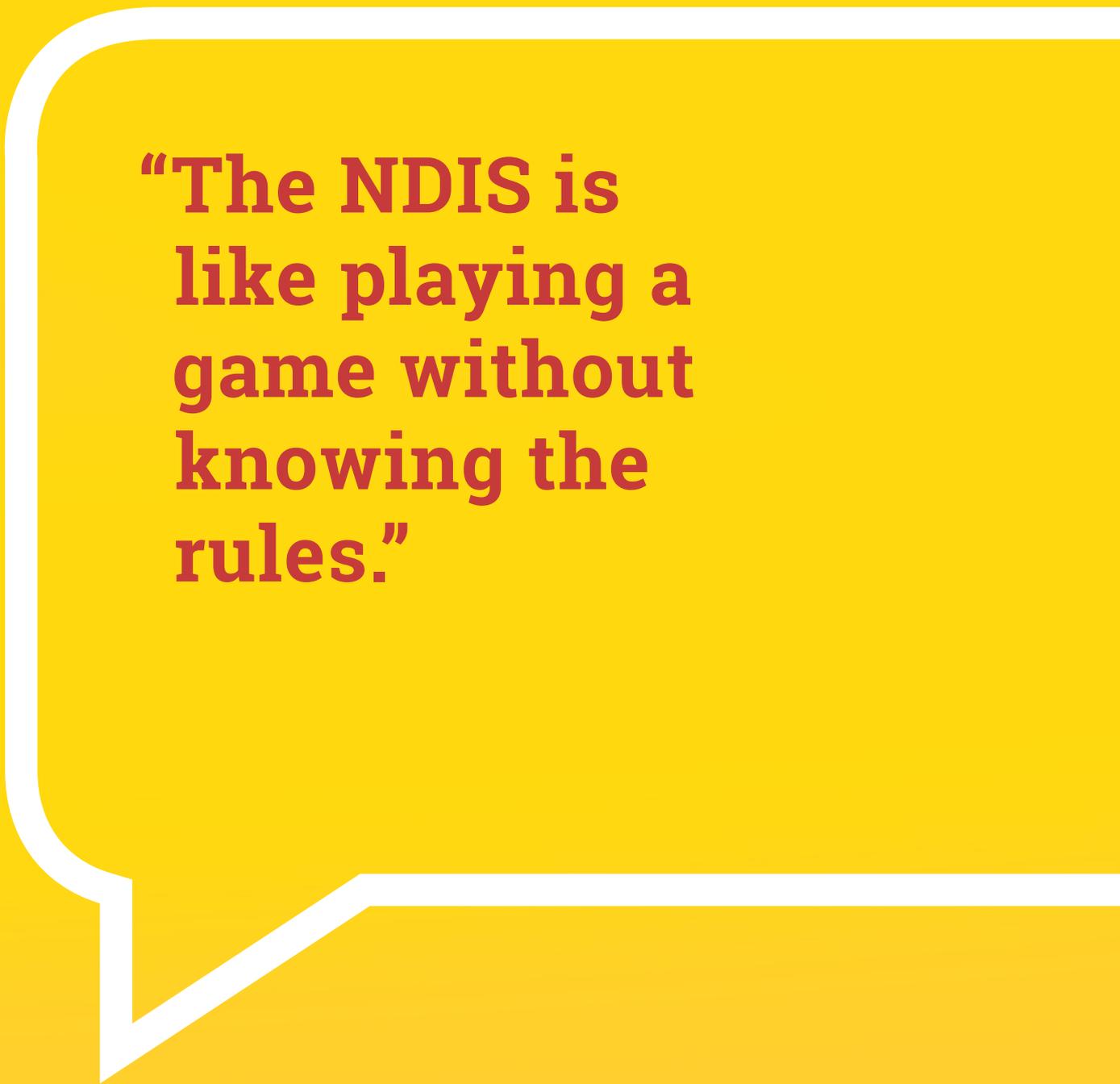




# Tune Review Submissions Summary

October 2019





**“The NDIS is  
like playing a  
game without  
knowing the  
rules.”**

**Every Australian Counts thanks Mr David Tune and the review team for the opportunity to contribute to the development and introduction of a Participant Service Guarantee for the NDIS. We also thank the team for the chance to move beyond changes required to the NDIS Act and Rules to a broader conversation about the ways in which the National Disability Insurance Scheme could be improved.**

**But before we get on to the PSG (it wouldn't be the NDIS if there wasn't a new acronym every day) let us tell you a little bit about ourselves.**

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 all 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.

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 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 stating 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 thousands of people. 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 at one of our community forums, or through social media, or through 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 is often lost. We want to make sure they are front and centre – as it 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 everyone in our community. Not everyone can attend a workshop, 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. This time, we also opened a phone line so people could quickly and easily leave us a message – just talk about the one burning issue they wanted to see addressed.

In just a few short weeks we received more than six hundred stories, statements and ideas about people's experiences with the NDIS and the ways it could be improved. 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 and your team 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 recently provided to the Joint Standing Committee on the NDIS as part of their current inquiry into planning. It is also very similar to a submission that we made to the last general inquiry conducted by the Joint Standing Committee held earlier this year. It is also very similar to a book of messages we recently provided to the Minister for the NDIS, the Shadow Minister for the NDIS and the Greens spokesperson for Disability.



And that is because the experiences, stories and ideas submitted to us this time match almost exactly the experiences, stories and ideas we received the last few times we asked for contributions. It also matches the feedback we receive every time we hold a community forum or survey our community. Or in the emails and phone calls we receive.

We note that the discussion paper released as part of this review asked many of the same questions the National Disability Insurance Agency (NDIA) asked during their review of planning. They are also the same questions asked by the Joint Standing Committee as part of their inquiry into NDIS planning. They are also the same questions as asked by the Productivity Commission into their inquiry into the NDIS, completed all the way back in 2017.

Which prompts us to say ...

## **We are all trapped in Groundhog Day**

We are sure that many of the issues raised in this submission will echo many of the issues raised in other individual and organisational submissions. And we are sure they will echo the issues raised in the community workshops held as part of this review. And in the responses to the online survey. In fact, we would hazard a guess that many things the review team will hear will be the same over and over again.

And if the review team 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.

If we could make a single plea 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. We do not believe it is necessary to wait for legislative amendments to be made before introducing some changes that would make a real difference to people on the ground.

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

## **Problems with access**

### **The mystery of the ARF ...**

The most common piece of feedback Every Australian Counts receives is that the NDIS is too complex, too complicated, too bureaucratic and too confusing – and this all begins with the process of applying for access to the scheme.

And it is little wonder the process is a mystery when the form you are required to fill in is hidden from view.

The Access Request Form (ARF) is only available when you call the NDIS – something of a problem for potential participants who are deaf or hearing impaired. Even a sample form is not available on the NDIS website. Calling for a copy of the form sets the clock running on the amount of time you have to return the completed form. For many people, one month is not enough time to gather all the evidence they need to demonstrate the impact their disability has on their daily life. If people require reports from medical specialists or allied health professionals, one month is rarely enough time to make appointments and get reports.

The focus of the ARF is on outlining the ways in which disability affects everyday life. The focus on functional impairment rather than diagnosis is a fundamental principle of the scheme. People with disability have fought hard over many years to move away from the medical model of disability to the social model of disability. Making sure the scheme focuses on functional impairment rather than diagnosis is therefore an important part of challenging the dominance of the medical model and changing attitudes towards disability.

But, unfortunately, this very important shift in focus has not been communicated well to either people applying for the scheme or the medical professionals who are responsible for completing the form. Medical and allied health professionals are used to the language of diagnosis. They are not used to describing the ways in which a diagnosis or a disability might have an impact on everyday activities.

One of the reasons medical professionals may not focus on the impact of disability has on a person's daily life is not just because little in their training prepares them for it. It may also be because they don't know. Like many other application processes, the access process for the NDIS favours those who have regular health care and regular providers delivering it. If you rely on a revolving door of bulk billed GPs, you are unlikely to have built up the kind of relationship that would allow the doctor to know much about your everyday life. However skilled or well-untentioned the GP is. And it is not the kind of thing you can get through in a quick "in and out" standard visit.

Through Every Australian Counts we are aware of people who have initially been rejected by the NDIS – only to be granted access after applying again or appealing. This suggests there were issues with the way the form was completed and the evidence provided, rather than the person's eligibility.

## **Counting the cost ...**

And then there is the significant cost of required assessments. We are aware of people who have paid hundreds even thousands of dollars for assessments and reports. Some people have even gone into debt to pay for them. For those who cannot afford to pay, the only alternative is long public waiting lists to see specialists or allied health professionals. Again, the process favours those with regular health care providers who can afford to pay. This is very far from the fair scheme we fought for.

## **Only for those in the know ...**

While it might sound a bit silly to say, you can't apply for something you don't know about. The NDIS is relatively new and not everyone knows about it. Or, frankly understands what it is all about. The NDIS relies heavily on people finding their own way to the door. That is not easy for a whole range of people – people who have multiple forms of disadvantage, people who come from a culturally or linguistically diverse background, people who come from an Aboriginal or Torres Strait Islander background. Then there are those who have very good reason to fear government services. We need to use trusted networks and organisations to reach these people – and then give them a hand to work their way through the maze. It is the only way to make sure the scheme reaches those who really need it but for lots of good reasons might fall through the cracks at any point.

## **What about everyone else ...**

And finally, while it is beyond the scope of this review, we cannot finish without saying something about people with disability who are not eligible for the NDIS. The NDIS was never intended to work in isolation. It was expected that other programs would continue for those whose were not eligible but who still required some form of support. We are beyond frustrated that vital programs have been, or are in the process of being wound down and the money “tipped” into the NDIS with little regard for the impact on those who are not eligible. We are also worried about those with lifelong disabilities who turned 65 before the scheme reached their area and who are not getting what they need from the aged care system.

We are the people who fought for the NDIS – and we are worried about our brothers and sisters who are not eligible but who still need help. We fought for things to be fair – at the moment they are very far from being fair. We want – and expect – that to change.

## So what's the solution?

- Fund active and assertive outreach by trusted organisations to reach people with disability who may be eligible and who will need assistance through the application and planning processes.
- Allow people to request or download the Access Request Form so they can begin preparation without the clock running.
- Provide more comprehensive guidance on what evidence the NDIA requires for access – for both participants and medical professionals.
- Provide more information, training and resources for medical professionals to complete the Access Request Form.
- Establish a Medicare line item to cover the time required to complete the Access Request Form.
- Provide independent assessment of functional impact where required or provide funding to participants to cover the cost of assessments with specialist professionals of their choosing.
- Allow applicants to track progress of their applications.
- Provide more detailed information when access is denied as to reasons and what further evidence may be required to demonstrate eligibility.

## **Problems with planning**

### **It's complicated ...**

The resounding message from people all around the country is that NDIS processes are too complicated, too confusing, too bureaucratic – and as a result, just too damn difficult to navigate. As one person commented – “the NDIS is like playing a game without knowing the rules”.

Because it is so complex and there are so many steps, there are also lots of ways for it to go horribly wrong. And it also means everything takes a really, really, really long time. While we are really pleased the NDIA is now making a concerted effort in some areas, wait times are still lengthy. Particularly for plans, for equipment and for reviews. And as will become abundantly clear from the stories that follow, the combination of trying to navigate the scheme and the length of time everything takes has pushed many to breaking point.

People consistently say that there needs to be much more help for people working their way through this maze. They want help with every part of the process – from application, through planning, through to finding supports and services, to finally getting funds out the door (more about that to come). Local Area Coordinators (LACs) cannot be relied upon to provide this help – they are clearly overwhelmed and many do not possess the necessary skills and expertise. Help must be provided by independent organisations that people know and trust.

### **Lifting the bar on training ...**

Again the resounding message from everyone all around the country is that LACs, planners and NDIA staff need better training. Many people are at pains to say they understand the difficult task LACs and staff have and the challenging environment they work in. And many often say they feel staff really are trying their best. But frankly good intentions are a poor 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 basic questions or who treat people badly just make things even tougher.

Participants and their families understand that LACs and planners cannot 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 good informed decisions. Lots of people like the idea 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 but it seems to have been lost in the maelstrom of full scheme roll out. The new pathway for participants with a psychosocial disability apparently features planners with specialist expertise and training. It would be great if this approach was extended to other disabilities.

### **Listen to the experts ...**

There are also many frustrating examples in the stories that follow of LACs and planners not reading material provided by participants, their families or the professionals that support them. This is particularly galling when people have gone to considerable trouble and expense to get reports from specialists or allied health professionals. People are also increasingly concerned at the cost of these reports when they seem to go nowhere. People with disability and their families expect that the reports of experts should be read and followed – decisions should be made based on their considered professional expertise rather than the outcomes of google searches by LACS and planners (and yes that is a thing).

Despite its lofty aspirations and intentions, the scheme appears to have degenerated into an old deficit-based model where people are forced to describe their lives in the worst of terms in order to access much need support. Ironically people fought for the introduction of the NDIS in order to get away from the “misery Olympics”. To find ourselves here again is a profound disappointment and a source of deep resentment and anger.

As you will see from the stories that follow, lots of people are both worried and frustrated that the scheme has become so adversarial. At best, people feel like they are not being listened to. At worst they feel they are being judged. And worst of all some feel like they are being treated like they are somehow gaming the system. Ignored, dismissed, disrespected – these are all words that people have used to describe their interactions with LACs and planners. Far from being valued, they feel the judgement of others overrides their own judgement and experience every time.

## **Cut out the middle man ...**

Many, many people tell us they want to cut out the middle man and speak directly to the person who will be making decisions about their lives and their future. They feel like they have to convince two people of their needs – and one isn't even in the room to hear it. Most people believe being able to speak to the planner in their own words and providing them with the information they need would clear up many issues. And while lots of people have heard this process is being trialled in a couple of areas, they are frustrated it appears to have moved no further than trial.

## **Drafting yet another draft ...**

Yes everyone would like to see a draft of their plan. This would allow people to correct simple mistakes and make sure it accurately captures their needs before it is submitted for approval. But the draft plan has become the unicorn of the NDIS – a magical mythical creature that everyone wants to see but so far no one has. We hear they are on their way – people wish things would move a little faster.

But beyond draft plans people are also really keen to have the chance to build their plan with someone else they trust and simply submit for approval. This would obviously suit people on later plans but would save everyone a heap of time and money.

## **Consistently inconsistent ...**

As you will see from the stories that follow, one of the things people with disability and their families find most frustrating about the NDIS is that it is consistently inconsistent. Both in simple things like answers to questions, and much more important things like access to the scheme, outcomes of plans, and outcomes of reviews. From the outside looking in it appears that people who seem to have quite similar needs can sometimes get quite different results. Everyone understands the scheme is supposed to be individualised – and no one wants to see that change. But people also expect it to be consistent and fair.

People are also increasingly concerned that in the rush to meet deadlines and in an attempt to cut costs, the scheme is not as individualised as it should be. At the moment the NDIA appears to be having its cake and eating it too – there appears to be a lot of pressure on LACs and planners to keep plans to the relevant Typical Support Package (TSP). But ... people don't know that TSPs exist, what their function is, how they are constructed or the assumptions which sit behind them. All that information is not made available to participants and their families.

### **Primary diagnosis ...**

The scheme was never intended to be based on diagnoses but always on functional impairment. Requiring participants to identify a primary disability not only goes against scheme intent but also has a number of practical consequences. The first is that it forces people to choose – many participants have more than one disability. Which one is primary depends on many factors including timing, circumstances, environment. The one that has a greater impact on may vary from day to day, or from circumstance to circumstance. Identification of a primary disability also takes no account of the way multiple disabilities may interact. As a result, the decision to commit to primary disability means people are missing out on vital support.

### **Tell it like it is ...**

Communication from the NDIA is much like the rest of the scheme – complicated, confusing bureaucratic and very, very slow. Often things that participants need to know are lost in complicated jargon. The NDIS has developed a language of its own that everyone needs to learn in order to have any chance of making it through. Fail to use the “magic words” and you might miss a critical piece of information – or even worse fail to get the right support in your plan.

And when it comes to communication, the NDIS is consistently inconsistent. Ask the same question and you can get wildly different answers. Too many people have shared frustrating stories of running around in circles to try and resolve an issue – either because people were given incorrect information or no one was clear on who was responsible for what.

The NDIS really like to keep everyone on their toes. Sometimes they use the same term to mean different things – like the word review for example. It might mean an annual review, an internal review, a light touch review or a review of a reviewable decision. Or in this case, it could mean a legislative review! On the other hand the NDIS also likes to change things up by using different terms for the same things. For example – the same terms are not used consistently on the NDIS website, the plan, the portal and the price guide. As a result a number of guides have sprung up around the community to help everyone keep it straight. This differences are more than simply annoying – for those who are plan or self-managed it is vital to ensure funds are being allocated appropriately.

Communication is not only inconsistent it is often rather slow (a bit like the rest of the NDIS). The NDIA is also guilty of releasing information for providers but not releasing the same information developed for or targeted at participants. For example – the NDIA released a new price guide earlier in the year with information for providers but with no specific information for participants. Only this week the Minister announced important changes to Specialist Disability Accommodation (SDA) – but the information was located on the provider section of the NDIS website.

There have been some big improvements to both the NDIS website and portal. There are for example many more guides and videos on the website, and the portal has recently made a few changes to make tracking your budget easier. But both still require further changes to be truly user friendly and easier to navigate. The website for example does not have an easy to use search function that locates the information people really need to see. Search for a term and you received a dump of everything that features that word. The engine does not prioritise most frequently accessed documents or participant fact sheets and booklets which are most likely to be helpful. In a similar way, the portal does not have key features that people would find much easier to keep track of their funding. And finally, while some of the more recent changes are most welcome, having everything online doesn't work for everyone. There are people who do not have regular access to computers or the internet.

This overreliance on online communication becomes even more critical in the face of continuing problems with the NDIS call centre. While call centre waiting times have reduced in recent times, there does not appear to have been a corresponding increase in usefulness – you still can't speak directly to someone who can answer your question or fix your problem. Everyone would just like a direct line to a local office so they can speak to a real person who can resolve their issue. That's kinda the point of calling?

### **More help ... again**

The NDIS is built around the idea of people with disability as well-informed, well-resourced and highly engaged consumers, able to clearly articulate their needs, search for appropriate services and negotiate the terms of engagement. Given the striking lack of opportunity for choice and control in the past, it is impossible to believe this will happen without a significant investment and a considerable period of time to build the capacity of people with disability, as well as their families, to become just those consumers. While recognising recent projects funded through Information, Linkages, and Capacity Building grant rounds, this is an investment that has yet to be made in a coordinated or consistent manner. As a result people with disability and their families consistently say they need more help at all stages of the NDIS process – before access, during planning and beyond to get the plan off the page and into action.

And they want that help to be provided by organisations they trust – particularly user-led organisations. People with disability and their families value the independence of these organisations and see them as a trusted source of information and support. People want the chance to learn alongside people they view as peers.

### **Support for families...**

Everyone is in furious agreement that the NDIS should be focused on the person with disability. It is as it should be. 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 stories in the following pages that talk about the significant additional anxiety, stress and sheer hard work that has resulted from the introduction of the scheme – ironically the very opposite of what was intended. People now talk about the scheme as yet another job on top of many others – robbing them of time they would rather spend with their family member. Or at least getting some sleep. Aging parents in particular are very worried about who is going to take on this incredible workload when they are no longer around – again ironically one of the very problem the scheme was intended to solve.

## So what's the solution?

- Improve training for LACs, planners and NDIA staff.
- Development of teams of specialised planners.
- Engage people with disability, families and carers in the development and delivery of training programs.
- Provide tracking of planning processes so individuals can see where they are in the "queue".
- Participants to plan directly with planners who will approve their plan.
- Simple, plain, and timely communication in language everyone can understand.
- Further work to improve the useability and functionality of website and portal.
- Consistent language across the website, plan, portal and price guide.
- Removal of the "no caller ID" and ability to call LACs and staff directly.
- Ability to book call back times so participants and families can resolve issues at times convenient to them.
- No announcements or changes made without timely, specific information for participants to explain what has changed and what it will mean for them.
- Participants able to view a draft of their plan before being submitted for approval.

- Participants able to develop their plans with support from an independent individual or organisation and submit for approval by NDIA.
- Greater funding for user-led and peer support organisations to support and assist people through the access and planning processes.
- Removal of the need to identify a primary diagnosis.
- Professional reports to be read when submitted.
- Professional reports to stand when submitted.
- Participants to be offered the opportunity to roll over plans without the need for review if circumstances have not changed.
- Development of simple effective triage processes to escalate requests for reviews when necessary.
- Public release of Typical Support Packages and the assumptions behind them.

## Problems with using your funding

### Please explain ...

According to the NDIS pathway, once people have a plan, the next step is for someone to explain it to them and help them get on their way. For most people that someone is supposed to be a LAC. In practice this does not always happen. And even when it does it is often so brief as to be of little assistance. People often report to EAC that they were not sure what to do once the plan arrived because no one explained what to do next. Sometimes the plan just sat on the kitchen bench. Sometimes it just sat in the portal. In other cases people were unaware a plan had even been allocated to them.

Beyond simply explaining what is in the plan, people with disability and their families need a clear understanding of what has been funded, what has not, and the reasons behind the decisions that have been made. They need to know what supports have been funded, and how the amounts have been calculated. For example – how many hours of support, and at what hourly rate. While they may not need to know line by line, they do need to know on a global level to understand better how they may use their funding. Even agency managed clients need to understand in order to inform their decision making and contracting of services. But it is even more important for increasing numbers of plan and self-managed participants.

Without any explanation of the types of supports they can purchase with their funding many people are uncertain about which way to turn. And frightened of doing the wrong thing they end up doing very little. There are multitudes of closed groups on social media where people tentatively ask such questions as “I have been funded for social participation. What kinds of things can I do?” These very basic questions suggest very little explanation of the funding in the plan and what it can be used for has been given at the time the plan is approved.

## **More flexibility...**

People want to be able to use their funds in a way that works for them. They also want to use them in way they believe will be most cost effective. Evidence from models and programs in other countries consistently demonstrate that when people have genuine control over their funds, they use them in economical and efficient ways – often requiring less, rather than more support.

At the moment however the fundamental principle of choice and control is being undermined by poor policies and processes, and inflexible rules that just don't make sense to people. There are too many stories of people running out of funds in one area, having funds remaining in another area, and no capacity to move things around. While core funding is more flexible, capacity building funding is not and there is no capacity to move funds between them. This was not how the scheme was intended to work.

At the moment self-management offers participants the most flexibility – but lots of people say they feel like 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 it offers.

## **More help ... again**

Everyone needs a hand getting their plan up and running and make sure it is working for them. Most people we speak to argue everyone needs a support coordinator in the first couple of years to help them get used to this complicated new beast called the NDIS. In particular people want more help understanding what kinds of supports and services they are able to purchase with their funding and where they might find them.

The Provider Finder on the NDIS website is only of limited assistance, spitting out a long list of providers with little guidance or useful detail. If people have not been previous recipients of services or are not linked in to good peer networks, it can be difficult to find out simply what services are available in any given area, let alone assess their suitability.

## **Let the market rip ...**

Sometimes people can't find services because there just aren't services to find. Or when they finally do find a service, they are confronted with closed books and long wait lists. People with disability and their families report lack of services (or thin markets in NDIS jargon) in all areas, but particularly in rural and remote areas. This scarcity of support is also true for particular population groups in metropolitan areas. Families with a son or daughter with complex needs, for example, frequently report that there are limited services available just equipped to deal with the complexity of the participant's life. Families also consistently report shortages of allied health therapists. To finally make it into the NDIS, to finally make it through planning, to finally get a plan – only to find that there is nothing available in your area is immensely frustrating.

People want the NDIA and government to pay much more attention to how the “market” works. They don't think “set and forget” is working. This is not a market like any other – buying services and supports to facilitate your inclusion or provide personal care is not the same as buying a fridge or a TV. There is so much more at stake. Everyone wants more active intervention to ensure there really is a diversity of services out there for people to purchase. You can't assume “if you build it they will come”. And they are also vitally interested in what we can do to make sure we actually get truly individualised and innovative services – rather than just dressing up the same old models and programs with buzz words and new branding.

## **Regional, rural and remote ...**

And if things are grim in the city, spare a thought for those in regional, rural or remote areas for whom the idea of choice is just a concept in a brochure. People in regional, rural and remote areas want a fundamental rethink of the way the NDIS model works – or doesn't work as the case may be – in areas outside the big cities. People are over mere tinkering at the edges – they want the NDIA and government to fundamentally redesign how the scheme works. This is true for all regions outside metropolitan areas, but is particularly pressing for remote communities. There needs to be much more flexibility in how scheme operates if there is any chance of meeting the needs of people who live far from cities and towns.

## **Approvals for equipment and mods ...**

The process for approving equipment and home modifications is complex and confusing. As a result, it is also often also lengthy. People are waiting months, even years, for vital equipment and even longer for home modifications. Often the process takes so long quotes “expire” and the process needs to start all over again.

People are also increasingly concerned that valuable and much needed NDIS plan funds are being spent on expensive assessments for simple pieces of equipment or equipment that has been used for many years. This seems to everyone to be a waste of valuable time and money, benefiting no-one – except perhaps the occupational therapists who write the reports. People like the changes the NDIA have made recently to allow direct purchase of low cost, low risk equipment and the decision to allow purchase of “like for like” without the need for further assessment. But they would really like to see the process for more expensive equipment and home modifications follow suit and become much more streamlined and quicker and easier for everyone. And like other areas of the NDIS they would like to see the introduction of a tracker to see how approval is progressing – and where any hold up might be.

## **Transport ...**

At every single forum, in every single survey, in every single call out for stories we hear about transport. Lack of funding for transport is consistently reported to us as one of the critical reasons why participants are unable to make the most of their NDIS funding. Many report having funding and support for activities – but no transport to get there. As a result, funds remain unspent. The recent decision by the NDIA to no longer allow participants to spend core funding on transport if they receive a transport allowance is exactly the opposite of what people with disability and their families consistently call for. People would like the flexibility to manage their funding in a way that works for them, including devoting additional funding for transport if that is what they choose to do.

## So what's the solution?

- All participants to have a "handover meeting" to explain the contents of the plan.
- Give people more help and assistance to get their plans up and running. Support coordination is one form of help but there are other ways to help people make the most of their funding. Training, resources, workshops, funding for one-on-one help are just some of the methods that should be considered.
- Development of a more effective, targeted and user-friendly provider finder to help participants locate services in their area.
- E-market. Much talked about but still yet to become a reality. While an online platform would not suit everyone, it would be a good place to start for many.
- Fund disability led and peer support organisations to help people explore how they might use their funding and imagine different kinds of models and approaches.
- Simplify the process for approval of assistive technology and home modifications. Require assessments and quotes for new or complex equipment only.
- Tracking of approval processes for equipment and home modifications so participants can see where they are in the "queue".
- Allow greater flexibility in use of funding including moving funding between categories.
- More resources, training and support for self-management.
- On a macro scale much greater attention to the development of market and workforce to ensure there are diverse range of services for people to purchase.
- Resolve issues with transport. Give people greater flexibility to use their core funding where necessary.

## **Problems with reviews**

### **Longer plans ...**

Yearly reviews are stressful, time consuming and can lead to gaps between plans. They also come with the annual fear of potential cuts to support. As a result, most people like the concept of longer plans. It cuts down on administrative red tape and gives people certainty about the future.

But ... there is always a but. People are only happy with longer plans if they confident there is a clear and simple emergency triage process which allows participants to fast track their requests if circumstances change. It would be something of an understatement to say that confidence does not exist at the moment.

### **Accountability and transparency ...**

As you will read on the following pages, there is a great deal of frustration at a perceived 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. At the moment reasons given for decisions are usually only general in nature. It should not take an FOI request to find out how and why a decision was made. People need to know and understand the why of a decision – because it will determine how they respond and what action they might take. This is particularly critical in deciding whether to challenge a decision and seek a review.

### **Review the reviews ...**

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. What is the difference between a “light touch” review and an interval review? How do you ask for one? And who on earth thinks that a “review of a reviewable decision” is a clear and simple way of explaining a 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. People have spent much time and energy trying to change small things on their plan that have big consequences – for example the wrong kind of plan management can prevent people from getting the supports they need for months.

Many people who would like to make a change to one part of their plan are warned that the review may result in a reduction of support in other areas. To many participants and their families this warning can sound much more like a threat. As a result, it deters some people 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 long delays with reviews leaves many participants between a rock and a hard place. If you are seeking a review because you believe you have insufficient funding what should you do? Spend your funds as you believe you need them and risk running out before your review is resolved? Or stretch them out slowly, use fewer services, and risk that being taken as evidence that you do not require the support? An unpalatable devil and the deep blue sea choice.

### **More help ... again**

And again like the rest of the NDIS there is very little help for people to navigate this stressful and complicated process. Disability advocacy groups play a crucial role in making sure people with disability and their families and carers have a safe space where they can voice their concerns with the NDIS and get help to resolve problems. And while they are absolutely doing the best they can, at the moment they are swamped by demand and stretched beyond breaking point. Every single organisation we speak to has closed their books to new cases long ago. And they cannot refer anywhere else because everyone else is in the same boat. As a result they are only able help people who are in the deepest of crises. This leaves everyone else with nowhere to turn. At the moment many advocates – including here at EAC – are recommending people speak to their local MP to try and resolve problems. It goes without saying that this is no way to run an effective or fair review and appeal system.

### **Changing policies and procedures ...**

One of the reasons many people pursue a review all the way to the AAT is to not only resolve the issue for themselves but for others who may be experiencing the same problem. They wear the cost both monetary and emotional in the hope that they can help others. They also do it in the hope that the scheme becomes simpler and easier for those that follow. Unfortunately it is not always clear that the NDIA modify or amends their own procedures and processes after specific rulings at the AAT. This suggests that decisions that were made on “merit” at the AAT do not always result in change beyond an individual participant.

## So what is the solution?

- Longer plans – up to five years.
- Ability to roll over plans if circumstances have not changed.
- Easy, simple, and well communicated triage process if circumstances change.
- Clarify terminology so each type of review has its own term.
- Allow participants to make small changes to a plan without requiring a full plan review.
- Allow participants to seek a review of one aspect of their plan while the rest of their plan remains the same.
- Explain all review decisions in writing, including the reasons for decisions.
- Independent complaint process and transparent reporting of outcomes of complaints.
- Allow participants to track where they are in the “review queue”
- Greater funding for advocacy.
- Additional funding for legal support for participants involved in AAT hearings.
- NDIA to publicly report on outcomes at AAT hearings including how policies and procedures have changed as a result of decisions made.

## **So to wrap things up ...**

We thank the review team again for the opportunity to have a say on the way the NDIS is being rolled out and the ways it could be improved.

We want to finish by strongly urging you to carefully consider the stories, experiences and ideas that you will find on the following pages. In our view, it is people with disability and their families who have the best understanding of what needs to change and what will and wont work on the ground.

Despite the promise of the NDIS and the rhetoric that has built up around it, people with disability and their families strongly feel that they are not yet at the centre of this landmark scheme. In stark contrast they feel like the scheme is driven by the dictates of bureaucracy rather than their own needs, experiences and ideas. People with disability and their families report that they don't feel engaged with – more talked to and at. They don't feel they are part of the process of implementing the scheme – just numbers to be processed, KPIs to be met rather than people whose experiences and ideas are valued and will drive change. They are beyond frustrated that their valuable experience and expertise is routinely ignored while highly paid consultants deliver “solutions” that will not work for them.

People with disability and their families feel a strong sense of ownership of the scheme – they fought hard for it. They built the political and public support for it from the ground up. They want to be partners in its delivery. But they feel sidelined by government and corporate priorities that do not align with their own.

They want that to change. This review offers a crucial opportunity to turn that around. We sincerely hope it does.

We are counting on it.

**Yours Sincerely**

**Kirsten Deane on behalf of Every Australian Counts**



