

# NDIS Act Review and NDIS Participant Service Guarantee Discussion Paper Feedback.

### Oct 31<sup>st</sup> 2019.

The Disability Trust welcomes the opportunity to provide feedback to the NDIS Act Review and NDIS Participant Service Guarantee Review. As a provider of a broad range of services to over 4000 participants across NSW, the ACT and Vic we are acutely aware of the challenges faced by participants with access to and engagement with the National Disability Insurance Scheme (NDIS). Our responses are focused around planning, use of funds and review of plans as these are the areas that participants are most vocal with when it comes to anxiety and frustration as they navigate the new framework. Reducing red tape is essential for both providers and participants particularly at the access and initial planning phases.

As a service provider, our commitment is to ensuring that people with disabilities are able to live the life that they choose whilst being empowered to exercise choice and control over their services. Many times, we hear that participants are instead feeling more frustrated, and sometimes less empowered as they navigate webs of red tape and misinformation. We often find that we are providing significant amounts of unfunded supports to people who require essential supports.

### **Feedback to Specific Questions**

### Creating a Plan

# What are some of the significant challenges faced by NDIS participants in the planning process?

The requirement to undertake planning every year, or even two years, puts strain on participants and carers as they gather, generate and input information into the process. The benefit of these regular plan reviews for NDIS participants is still unclear, indeed such short term planning inhibits individual capacity building. One year is not long enough, in most cases, to reach a goal, but then plans are reviewed and capacity building supports are removed for the next plan.

Participants and carers are often overwhelmed by the ongoing need to provide evidence of the disability, how it impacts on their life and what constitutes evidence. The ability to actually access this support is also an issue due to the lack of understanding in the medical community and wait lists for therapists who understand disability

People with disabilities and their families are not aware of the requirements for providers under Quality and Safeguarding. While families may have in place restrictive practices in their own homes, providers cannot offer services where RPs are required unless there is Behaviour Support funding in the plan. Lack of awareness of the Quality and Safeguarding framework means families will experience challenges when attempting to utilise their plans fully.

There often appears to be a lack of consistency and transparency in decision making. LAC's and Planners with a better understanding of the functional impact of a participants particular disability tend to produce better quality plans and budgets that optimally reflect actual need. The Scheme needs more LAC's and Planners with this level of understanding of participants, the legislation and familiarity with all aspects of planning and plan implementation. Participants and their families often become quite anxious as they prepare for plan reviews, wondering if they will get a 'good plan' that genuinely reflects their support needs, whether they will be allocated adequate budget to maintain supports and achieve plan goals, or whether there plan budget will be slashed for apparently no reason. The uncertainty experienced from plan to plan / year to year can be very distressing for people.

Reliance on technology to access the resulting plan. Plans are now only available on the portal, which is a challenge for participants and carers without the skill or capacity to access the portal unassisted.

Participants new to the scheme generally enter the planning process feeling anxious and unsure of what will happen and what the expectation from them is. There are planning resources available on line through the NDIS website, however a person does not receive experienced support in preparing this documentation and advice on the relevance. Clarity is required on the following;

Understanding and accessing the level of evidence required by the NDIS:

- What areas require evidence
- Who can provide this evidence
- What is considered appropriate evidence
- How frequently/up to date does the evidence need to be
- Where do I get the evidence if I have no funding for it?

### Are there stages of the planning process that don't work well? If so, how could they be better?

Preparation is key to ensuring that planning meetings produce successful outcomes. The initial phase of the planning process requires the participant to articulate goals and for the planner to understand the outcomes associated with these goals. Setting goals in line with supports required can be challenging for participants and their carers, particularly where there are no support coordinators involved. The NDIA could provide more support to participants to understand the link between goals and items within the plan. When participants are not prepared with goals, this often results in plans that are inadequate to meet the reasonable and necessary service needs of an individual.

The opportunity of supported pre-planning for those working towards a first plan would be very valuable. This would provide individual support in identifying their goals, if current services meet their needs and other options available across disability specific, mainstream and community supports. The resources available are adequate, however not accessible for some.

Clinical Supports; On a very frequent basis, clinical Staff provide detailed summary reports and letters outlining the previous service and the recommendations for future service provision, however the plan returns with nothing at all reflective of the recommended supports, funding in the incorrect categories or a much reduced level of funding. It seems planners make decisions not in line with the documents provided at plan review.

Funding is not provided in the correct categories for services required; frequently- despite letters of request for funding in Category 11 for Improved Relationships to provide behaviour support services, the plan returns with only funding available in Category 15 – Improved Daily Living.

There is not accurate understanding of Restrictive Practices at the planning stage; adequate funding is not provided in the plans to undertake the work that is required by the Quality and Safeguards commission, the planner will not release funding for services/ practices that are restrictive without Behaviour Support Plans in place, even though the plan will follow.

Employment Supports; Supports available to participants to help them achieve their employment goals is typically not working well. There remains a great deal of confusion about the interface between DES and NDIS funded supports, and rarely do we see funding included in the employment category, even where participants present clear evidence of need.

Similarly, consideration of a participants transport support needs are poorly addressed in the planning pathway, which particularly impacts on people with a disability who live in country areas and need to travel long distances to access their disability supports. Transport funding needs to be calculated based on evidence of individual need, rather than application of 3 arbitrarily determined levels of funding.

There appears to be an increasing inequity issue emerging between participants who self-manage and participants who are either portal or plan managed and therefore bound to the NDIS price guide. Understandably, the intent of self-management is to optimize flexibility with plan implementation — which is fantastic, but for participants who are unable to self-manage due to the functional impact of their disability or lack of informal support, the lack of flexibility imposed by having to adhere to the NDIS price guide is becoming more and more noticeable. The gap in how the capacity of these two groups to respond to the current transport guidance is a case in point — self managed participants will have the flexibility to hire staff, negotiate for supports to be inclusive of travel assistance, and pay them an hourly rate above that prescribed in the price guide. Participants with plan and portal managed budgets are constrained to using only their Level 1,2 or 3 Category 2 transport budget — which in rural areas typically goes no where near covering actual costs incurred and is leading to clients having to withdraw from services because they can't afford the level of private contribution to transport required to cover actual costs.

# How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

The planning process for participants should be tailored to the individual. Some participants will be able to prepare and participate in the planning process easily and in some cases with few changes to previous years. Others however need more time in both the preparing and the planning stages. Not all participants will have a supports coordinator to assist them with this process.

The NDIA needs to consider complex needs and allow adequate time for participants to collect and prepare reports, assessments and evidence of need to support their NDIS plan. We support many participants who feel rushed into planning meetings or to provide information over the phone. The NDIA may consider contacting people prior to the plan review being scheduled as a prompt for them to start collecting information and reports. This could be by email or text message as appropriate to the participants support needs.

Likewise, when booking the planning meeting, participants should be given adequate time to arrange to attend. Participants often need to arrange childcare or support people to assist them to attend. We support participants who have been contacted one or two days away from the planning meeting which has increased their anxiety about the process.

Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

The lack of a policy and practice framework that is transparent and easily accessible means families are using informal participant networks to try work out how to "navigate the system". These networks are unreliable as sources of information but have sprung up due to the information void experienced as a participant. The question of evidence and information requirements in the planning process is broader however with some planners placing heavy reliance on external reports and documents and others giving greater credence to interview and goal setting. The training of planners and LACs in evidence based assessment and a more transparent set of criteria around the level of detail required in reports would enable greater confidence amongst participants

Participants and their plan nominees / support people would benefit greatly from clear and consistent guidelines and information that provides clarity on what information is needed at planning meetings.

# Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

In the experience of some of our participants, the rationale behind decisions is not always clear, particularly with the regard to the "reasonable and necessary" test. This process could be improved by ensuring that participants are provided with more information about why decisions were made, this would allow the participant and their support person / nominee to identify whether any further information could have been provided. In some cases participants have received plans that do not reflect the discussions in the planning meeting.

### Example

A participant and carer attended a planning meeting and throughout the meeting discussed how much enjoyment, support and value the participant received at a group support based around creative arts. The carer was under the impression that the planner understood the importance of this activity to the participant's social goals and community participation. When the plan arrived there were inadequate funds for this activity. No explanation was provided.

In the above example, had the planner been more transparent through discussions at the planning meeting the participant and their carer may have been able to produce more information to support this activity or been prepared for it to not be included in their plan with an understanding of why not. The ability for participants to review draft plans will assist this process.

The information around why decisions are made in relation to reduced funding for Therapeutic supports is not available. In fact, when plans are returned with funding reduced, it would be helpful for a rationale to be provided as to why the NDIA has made those decisions (often in contrast to the supporting evidence provided).

If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?

While the knowledge of planners, LAC's and providers has increased there is still inconsistency across what and how services are funded.

For every plan participants and carers are required to provide up to date assessments, diagnosis and resources supporting the process for a disability that is permanent and the person or carer has not identified any change in support needs. This requires individualised assessment of the person to determine what is actually required as part of the review process. Common feedback is that people are providing the same details for each plan. A person's primary diagnosis is generally not going to change. For new users or those with major changes in circumstance the process can still be difficult and confusing. The information required and the outcomes need to be more consistent with easier options for contacting the NDIA to get information on the process, progress and outcomes.

### Using and Reviewing Plans.

# What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

- Inadequate support with the implementation phase of the pathway experience. It is still a common issue that participants have a relatively poor understanding of their NDIS plan – what's covered in the different budget categories, how to connect with providers and access supports that best match their needs, current guidance about transport, their rights and responsibilities with requesting reviews etc. This is particularly an issue for people with cognitive disabilities and limited informal supports, especially of support coordination is not included in their plan.
- Availability of services and capacity of providers to adequately resource the workforce, particularly therapy and other supports with large waiting lists.
- Some participants require restrictive practice authorization prior to accessing supports. Where participants do not currently have a behavior support plan (BSP) they must engage with and be assessed by a practitioner prior to engagement of supports. In some cases the funding for behavior support in plans has not been adequate to support development of a plan and review of restrictive practices. This combined with delays in accessing behavior support practitioners due to large wait lists often means that participants are late to engage with supports.
- Participant choice is limited by provider choice. In some areas, particularly rural
  areas there is no local provider of specialist supports. In other cases there is only a
  single provider offering the type of service and they may have limitations that make
  this less than ideal for an individual participant. The lack of flexibility in use of
  transport from core supports means that changes in provider availability and
  offerings can limit the ability to access services.
- Pricing around one to one supports has led to many providers exiting that part of the service system. The TTP decision has bought some time in slowing market contraction but ultimately individual support remains the least viable part of the pricing model. Complexity due to rostering and claiming and the impact of the further planned changes to the industrial award will have a further impact. Already

- unrecoverable payment for some elements of staff transport costs are continuing to see a reduction in this element particularly again in rural areas. Transport.

  Particularly in rural areas, participants struggle to access transport to connect with providers and participate in supported activities of their choice.
- Administrative processes and delays related to the Agency processing quotes for AT, home modifications and SIL especially for participants seeking SIL for the first time.

Availability of Providers for 1:1 Supports – It is well known that providers have many challenges with providing sustainable community access based 1:1 supports. A number of factors contribute to this, particularly pricing workforce capacity issues. Additionally, It is a high risk support (with staff often working unsupervised). The withdrawal of some providers from these services reduces the availability of 1:1 supports and contributes to the underutlisation of plans.

## Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?

This remains a significant challenge for participants accessing the scheme. Participants and carers receive minimal practical or individualized support to understand and implement their plans, unless they receive funded support coordination. For those with cognitive impairments and minimal informal support understanding how the categories can be used to fund services, or who can provide those services is a challenge. Local Area Coordinators do have the role of assisting people to implement plans, however the required level of support is very rarely provided. The response from a local LAC when questioned about support was:

"I am supposed to have ten hours available to help you get your plan and services organized. I can tell you honestly that you will be lucky to get a couple of phone calls from me. We just don't have the time"

Acknowledging that the information on using a plan is available through the website, the crus of the issue is with the communication and understanding of the information. Not all participants have capacity to access or understanding of technology and do not have the informal support to assist them in reading and implementing their plan. For reasons unknown they are generally excluded from Support Coordination funding.

#### Example

A man, hearing impaired and diagnosed with a moderate intellectual disability resides independently (and alone). He has no funded support coordination – familiar support workers assist him with his NDIS and other essential needs. His provider contacted the NDIA to advise that due to his hearing impairment he is unable to use the telephone and does not access a computer. The request (with his consent) was for the agency to contact a long term familiar worker and organize his plan review meeting. The NDIA continued to phone him directly with no success, then deemed him uncontactable. His plan ended with no

planning meeting and he was unfunded for three months while his providers advocated to the NDIA to arrange his planning meeting. The providers are still awaiting payment for services during this period, and the participant went through a period of stress and reduction to essential services only while it was rectified by his providers. He has no support coordination, despite meeting the LAC guide for funded support coordination services.

Support Coordination or similar is needed by more participants than it is provided to.

### Example

A single parent family from a non-English speaking background with 3 adult children with severe disabilities attended their initial planning meeting with support from their service provider. During the meeting it was made clear that the mother had no informal networks, a limited grasp of the system and a history of closing down supports when things became difficult for the family. The need for Support Coordination was emphasized but was not put in the plan. It was not until the third plan that 1 of the 3 siblings received a small allocation for support coordination and only then because the mother said she had been unable to find an alternate provider for in home supports since the previous provider pulled out early in the plan period.

Support the NDIS can offer is a base line amount of Support Coordination funded hours for any first plan, or subsequent plans with significant changes in support. Suggestion would be the ten hours that has been identified as required and being provided by LAC's. This would provide a participant with opportunity to build their skill and capacity in understanding and maintaining services, then support to prepare for their planned review. Those with stable services and support needs would not necessarily need this support in subsequent plans as supports would just roll over under continuity of services.

Clear and consistent information is key to minimize confusion and to ensure that participants understand the scheme with information provided in formats that meet various communication needs.

# What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?

Advice – Information on available providers, however this provision of advice is difficult for LAC's or planners to provide, as they must not be deemed to providing information that demonstrates a preference for a particular provider and must be kept up to date. The new NDIS Registered Provider data base is of great assistance, as long as the person has access to technology, knows the names of local providers and is familiar with the service names under NDIS. There is no "official list" of unregistered providers, who make up a large degree of support in many areas.

Resources – resources available through the online NDIS Planning page are excellent, however, again only available for those with IT access and knowledge. Understanding and

completing them would be very challenging for any person with literacy needs or vision impaired. In my experience, even those without support needs have required skilled experience to complete them. Access to the MyPlace portal is another serious issue for a large cohort of people who do not regularly use or have never accessed a MyGov account. There is much of the NDIA process that is only available on line.

Support – funded, set and reportable assistance in achieving plan implementation and engaging providers is essential. Hence, previous recommendation of all participants receiving a minimum amount of funded support to coordinate their services, then additional hours for more complex needs.

# What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

The review process remains a continuing issue for clients and families with many people reporting that the urgent review they requested to address an inadequate plan does not happen and when the scheduled plan review happens it is based on the lesser plan the person has now been living with for 12 months, not on their actual needs

Lack of notice, or the review not in expected plan review periods – preparing for a planned review requires the completion of review report documentation and often the compilation of therapist and other supporting reports.

Unused funds – particularly in first plans participants experience unused funding due to engagement and implementation issues.

Unplanned Review – delay in the review being carried out. From roll-out to current there are extensive delays in participants receiving support from the agency for reviews where funding is inadequate to meet reasonable and necessary support needs. Delays are up to twelve months.

Lack of communication of changes to participants – there appears a large gap in the agency communicating changes that affect participants, for example, recently TTP and Transport. Instead the agency appears to rely on providers to disseminate and share this information, which often comes as a shock, particularly when it has a negative impact.

### What can the NDIA do to make this process easier or more effective?

- The NDIA could amend the process to enable a more nuanced approach to reviews, so just the particular item / section of the plan that needs to be reviewed is reviewed rather than having to review every element of the plan.
- The ability for participants and their nominees to be able to see progress of plan reviews or to be kept informed about delays in the review process would greatly assist this area.
- Allow for plan rollover where it is demonstrablyworking to reduce the churn and the pressure on the agency and participants alike. This will allow participant generated review requests to be handled in a timelier manner.

### How long do you think plan reviews should take?

Some participants are waiting in excess of 12 weeks for a plan review to be returned. As with the planning process, reviews should not be defined by time but rather by consideration of the participants individual needs. Reviews any longer than 4 weeks have the potential to impact the participants ongoing attendance at a program or engagement with therapeutic supports and can therefore be detrimental to progress towards goals. Having said this, the increasing time for reviews is contributing to the anxiety and frustration of participants with the planning process. If the NDIA were to define a length of time for plan reviews, there needs to be open and transparent communication with the participant and their nominee about any additional delays. Participants and nominees should be able to access information about their review throughout the process and understand the reasons for any delays.

### Appealing a Decision by the NDIA

### What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

Delay in the response time, regardless of the urgency. Experience is that only those with excellent self-advocacy skills and the capacity to engage other influencers obtain timely support

Funding for the therapy based evidence is not available in their current plan, and this cost cannot be "back dated" from their plan review

The dialogue from the NDIA that a participant risks having their funding reduced as the agency looks at all funding during the review and may determine that areas are over funded and the person may end up with less funding than they started with. This frightens participants and carers and results in an extra degree of anxiety for already very stressed people.

### Are there other issues or challenges you have identified with the internal and external review process?

Participants provide feedback that they submit their request for review and then typically hear nothing for many months – so they aren't sure what to do, how to proceed with their inadequate but approved plan. Advocacy support is short supply, especially in rural areas; it is a very stressful and frustrating experience for many people.

Participants and plan nominees are not automatically provided with a "declination" document, and very rarely are people aware that if their request of reviewable decision is declined and there is no change to their plan they must be provided with written details from the agency as to the reason for the rejection of increase in funded supports. All applicants should receive this.

### How could the NDIA improve the decision review process?

Consider the impact of time on participants, and implement the soft touch review option more frequently for participants requiring a variation to funding in only one area.

Provide support for participants to prepare to the review process – should they require evidence, funded support to engage the person essential for review reports, for example therapists.

### How long do you think reviews of decisions should take?

Maximum of six weeks, or less if a person is at risk of losing or having to reduce reasonable and necessary services within that time frame.

### **Removing Red Tape**

# Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?

**Timeframes:** It is essential that the NDIS Act 2013 retains clear statements about timeframes in relation to access, planning and review decisions, although at the moment, these timeframes are rarely adhered to by Agency staff. The typical experience is that decisions take much longer than the timeframes prescribed in the Act. Resourcing within service delivery teams in the Agency is clearly a major issue impacting on staff capacity to meet the timeframes dictated in the Act.

Evidence of Disability: Section 24 describes disability requirements to access the Scheme; while it is not stipulated that access needs to be reviewed at every plan review, and yet this is the reality for many clients where they are asked at every plan review for 'updated evidence of disability'. This is costly, time consuming and very frustrating for all concerned, especially considering that for individuals over 7 years of age, their disability needs to be confirmed as permanent to meet eligibility in the first place. Clients and their families are struggling to understand why they are repeatedly asked to produce evidence of disability by NDIS staff &/or LAC partners and frustrated that despite a person's disability being ratified as permanent, they are constantly being questioned, and asked to produce more evidence that their disability hasn't resolved. Reviewing disability at every review adds unwarranted red tape and distress for participants and their families. Once a person is determined as eligible for support under the NDIS, requests for updated evidence of disability (diagnosis) to inform a revocation decision should be by exception rather than the rule. Ongoing monitoring would be better achieved through utilisation of effective / standardized outcome measures.

Reviews: As outlined in the changes proposed in 2015, the terminology in the Act relating to reviews is confusing, particularly with the same term 'review' being used for the very different processes covered under Sections 48 and 100. It would be useful to have terminology that reflects a clearer delineation between Section 48 and Section 100 reviews.

Interface with other service systems: This is addressed in the Rules relating to Supports for Participants, but significant confusion still remains about the interface between the NDIS and other service systems. Recent clarity about health supports has been welcomed. Clarification is also needed with other service systems, particularly in the areas of employment and justice.

What changes could be made to the legislation (if any) to:

### a. Improve the way participants and providers interact with the Scheme?

 NDIA service delivery teams need to be resourced appropriately to manage workload demands and adequately assist and follow through pre-planning, planning, implementation and monitoring phases. At the moment, teams (NDIA and LAC partners) do not have the staffing resources to cover all aspects of the participant pathway, which is having a huge cost to participant outcomes and reported levels of satisfaction.

### b. Improve the access request process?

- Targeted support to assist people to submit access requests and to initially connect with providers once eligible;
- Clarity about what constitutes appropriate evidence;
- Clarity about consequences when responses from the NDIS in relation to access decisions fail to comply with legislated timeframes.

### c. Improve the participant planning and assessment process?

 It would be good to see legislation clearly reinforce the responsibility of the NDIA to ensure the Scheme is resourced sufficiently well to address the need of participants. Current wait times and the frequency of plan review requests in response to poorly developed plans are indicators that the Scheme is currently under resourced.

### f. Improve the internal merit review process?

• It would be beneficial to change legislation to enable 'merit reviews' to address single issues of concern rather than having to review every decision in the plan. The prospect of having a full plan review to address a single issue in an approved plan is sometimes used by planners to intimidate clients and encourage them not to proceed.

### Comments on timeframes included in Appendix.

The timeframes outlined in Appendix B set out timeframes for CEO and NDIA decisions. It appears that in many cases the Agency is unable to meet these timeframes. Feedback to participants around delays or reasons for decisions not being able to be made within timeframes is not happening. Greater accountability and transparency around timeframes is required to ensure that participants are fully informed of the progress of their application or appeal.

### Plan Amendments

### What are the significant challenges faced by NDIS participants in changing

#### their plan?

Lack of availability of planners, changing a plan outside of a formal review can be challenging. For minor changes, (such as allocation of funding between categories or

adjustments to SIL) perhaps the NDIA could consider a more streamlined, faster pathway where participants can request a change online?

# How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?

Having a streamlined pathway for participants to request an amendment to plan would ensure that participants and nominees felt in-charge and empowered to make decisions about the supports in their plans. By empowering participants to amend plans {with oversight from the NDIA} this ensures that plan can respond to the changing needs of the participant as their support needs change. This process would increase choice and control.

# How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?

This needs to be as simple as possible, whilst ensuring that there are adequate opportunities to support different communication styles. Provision of documents online, or within an app are obvious choices, however being able to provide verbal evidence is important to many participants in the scheme. Uploading to MyPlace is another option however would require support from the NDIA to ensure that there was adequate information and access to information on using this function.

# Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?

• Assessment and approval of AT, equipment repairs, orthotics, home modifications and SIL requests.

### How else could the NDIA improve the process for making changes to a plan?

Many participants report that it is impossible to follow up on any previous contact due to the use of the centralized phone/email system and the high turnover within both NDIA and LAC's. Improving communication pathways will assist every stage of plan development, implementation and review.