

To whom it may concern,

Cara is one of South Australia's leading disability-services providers. We work with more than 730 children and adults with disability, we employ more than 1000 staff and our revenue is in excess of \$80M per annum.

We operate all over South Australia including in Adelaide, Mount Barker, Murray Bridge, Mount Gambier, Kadina, Port Augusta, Port Pirie and Port Lincoln, as well as supporting people with disability in surrounding areas.

We provide support to empower people for greater independence. Cara's services include Supported Independent Living (SIL), home and community support, Short Term Accommodation (STA), getaways, holidays, camps and kids club, personalised day options and specialist capacity building services.

In this context, Cara makes a written submission to the Department for Social Services review of the National Disability Insurance Scheme (NDIS) Act (2013) based both on our recent experiences of supporting existing customers to transition from State governed, block grant funded services to NDIS arrangements, and our current experience in providing services to people living with disability, many of whom have complex needs, who are now participants of the scheme.

Our responses have been provided under each of the key questions asked in the Discussion paper.

Cara's Submission
on the
Review of the National Disability Insurance Scheme (NDIS) Act (2013)

1. National Disability Insurance Agency (NDIA) service standards –
Timely; Engaged; Expert; Connected; Valued; Decisions are on Merit, Accessible

1. Which of the above principles do you think are important for the NDIA to adhere to, and why?

All of the principles listed should be adhered to because they are all valid in showing respect for people living with disability (their families, carers or nominees who act on their behalf,) and their entitlement to seek access to NDIS funding for reasonable and necessary services related to their disability.

Below are more specific comments for each of the categories.

Accessible –

Very little effort has been put into explaining the NDIS to people with complex disability by the Agency. Participants are often confused and unsure of what they need to do. More personalised interactions by Agency staff with participants would support their participation and therefore the success of the scheme.

There is an assumed level of computer literacy to access information on the NDIS website by the Agency. Very rarely are notifications or other information posted out to participants or their nominees, and even then, the participants often require a higher level of literacy to be able to interpret what the letters are saying. Easy English requirements should be provided as a matter of course.

In addition, a large number of participants can't afford electronic communication devices and are being denied funding to purchase an iPad for electronic communication in their plans.

Every time customers with intellectual disability are encouraged to telephone the NDIA, they are referred to the website, which is not accessible for them. This process is frustrating and unhelpful when they are seeking information and are encouraged to be as independent as possible, and to feel empowered to liaise with the NDIA.

The NDIA call centre does not act to support the inquirer i.e. call centre staff do not or cannot put calls through to a particular office. The only way to access office staff is in person by visiting an Agency office or via email.

Valued –

The process of supporting participants through the transition from block grant funding arrangements for accommodation to NDIS SIL funding was driven by service providers assisting their customers, rather than driven by the NDIA. The NDIA's involvement was not

clear nor was their role understood by participants. As a result, participants and their families, carers or nominees do not know where to go if they need further assistance. More information from the NDIA to the participant, to personalise the Agency's service, is required.

Some participants don't know how to engage with a support coordinator and they don't know how to go about getting the services that are in their plan. This results in underspend and a risk of reduced access to services in the future.

Engaged –

There has been very little evidence of the agency aiming to meet this standard. It appears that planners are directing and influencing the goals of a participant in their plan according to the scheme's ambitions.

Service provider quotes for some elements of service delivery are not being approved, e.g. continence aids, gastrostomy support (lines and training for feeding support).

Expert -

NDIA planners and their Local Area Coordination (LAC) representatives need to be more knowledgeable about disability and the needs of people living with disability.

NDIA staff need to be skilled in engaging with participants and their nominees to thoroughly explore the needs and goals of the individual in the planning process. At present there is too much reliance on the service provider (who has also been asked to attend meetings) to assist the participant in their planning conversations.

Planners are very different to one another. From one meeting to another the needs and outcomes that are recorded for the same participant can vary greatly. Also, the information provided by different planners varies incredibly. The attitudes and approaches of planners are very different. Some provide telephone numbers and direct email, others are not traceable.

NDIA planners and their LAC representatives should embrace the advice provided by other professionals regarding the support needs of a participant and not impose their own value judgements on that information. Planners should not ignore the advice provided to them.

There is no reliable and/or consistent approach to providing a quality service.

Connectedness -

The State-based in-kind support coordination service in South Australia did not have the capacity to take on all of the participants that had been referred. Consequentially, participants still are not receiving all of the services for which they have in in their plan. There have been lengthy delays in getting the in-kind coordination funding released, which has meant participants have not been able to access additional services.

When a service provider is requested to return a call that they have received from the NDIA regarding a participant (and customer of the service), it is not possible to do so because a direct contact number is not provided and staff who answer the 1800 number are unable to put calls through to the Agency staff member who initially made the call. Then, the reply to the service provider is they do not have a role to act on behalf

of the participant because they are not the nominee. Nominees have received unhelpful responses when they would like to add another support nominee, as only one nominee can be listed in the system. Flexibility is required here.

The complex participant pathway requires a broad roll out across the nation with a new approach. There has been no information provided to explain the benefit of this approach for participants with complex needs even though a trial has been undertaken.

Decisions are made on merit –

Some planners don't meet with participants in the planning process, this should not occur. Planners are meeting with the family, carer or nominee only. This can be misleading about the needs of the participant when only a short period of time is available for discussion and there is no observation of the person living with disability. There are many assumptions and judgments made by the planner. Therefore, there is a risk in the NDIA dictating what the plan for a participant should be without the participant having the opportunity to be involved in the consultation.

The NDIA does not make any contact with the participant or their nominee to discuss their plan in its final draft form. Participants should be notified of the final plan and have the time to review and accept it. This would lessen frustrations and extra work when plans are not designed well to address participants' goals.

During transition and the roll out of SIL, in most cases, the NDIA did not involve the participant in the planning process. There have been a number of examples where participants only realised they had been accepted by the NDIS because they saw a change in services.

Timely –

The time taken for the process of approving NDIS funding for services is not stipulated and has not been consistent.

At present, there is no agreed process to escalate an urgent review of services due to a change of circumstance and there is no timeframe stipulated for this type of unplanned review.

The date of request for additional services (unplanned review) does not guarantee the funding will be approved and available within the current plan period. What do participants do if there is a gap period?

There is no opportunity for participants to receive a draft plan and check that it is adequate to meet the goals that have been agreed.

2. In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?

See the above responses to question 1 in each of the principle areas.

3. What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?

PARTICIPANT CENTRED

This means understanding the individual needs of each participant and responding appropriately to their goals and support requirements. Do not group people according to their disability type – e.g. autism = x hours of therapy or physical disability = x amount for transport etc.

When participants have multiple needs e.g. multiple providers, multiple life domain requirements, and multiple carers, consideration needs to be given as to, how much support coordination, service provision or equipment is truly required e.g. children of blended family arrangements and multiple homes may require multiple pieces of equipment for different home settings.

4. One way to measure these principles is through a set of 'Service Standards'.

Some ideas for what these Service Standards could be are listed in Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?

RESPONSIVE

CONTACTABLE

CONSISTENT

PARTICIPANT CENTRED

5. Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?

Explain how the levels of satisfaction that are reported in the NDIA quarterly reports are currently measured.

Measure satisfaction based on all of the elements set out in the service standards in quantitative and qualitative format.

Publish the methods by which the NDIA is receiving information from participants and encourage their involvement through a variety of methods.

2. The NDIS participant experience –

Getting started: Eligibility and application

6. What are some of the significant challenges faced by NDIS participants in the access process?

See earlier comments regarding participants' experiences highlighted in response to question 1.

7. The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?

The application date is separate to the required evidence date. It is possible that the timeframe can start again if a participant has missed one piece of information. This drags out the processing time unreasonably.

Twenty one calendar days is a reasonable timeframe, however there is a risk of the participant not receiving a decision because the NDIA may restart the commencement date of accessing the request. For example, an application may be submitted then seven days later there is a request from the Agency for more evidence, and the timeframe is reset.

8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

The NDIA needs to provide accessible information in all forms including easy English documents. The Call Centre should act as a Help Line providing answers to questions and have the ability to transfer callers to other staff that can progress issues or resolve complaints.

9. Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?

Not able to comment.

10. Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

Participants should be able to ask Service Providers to speak on their behalf about their needs so the Agency can fully understand the current service provision and the needs of the person with disability.

3. The NDIS participant experience –
Planning processes 1: Creating, your plan

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

There is a lack of consistency between plans for participants with similar type and level of need. This could be due to inconsistencies between planners, the amount of information available or the level of advocacy by the participant's decision maker.

Some participants receive an excess of supports while other's needs are not met. Unmet needs can place undue suffering on the participant and their personal network. Further, it can put pressure on other government departments and service providers as emergencies arise.

More needs to be done to understand how variations arise and a tool developed to ensure consistent assessment of reasonable and necessary funding. This is regarded as a core role of the NDIA.

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

When the Agency meets with participants who are eligible for SIL they expect service providers to arrange appointments with people and then only meet with each participant for a short time frame and move on to the next person living in the shared

home. There is no flexibility for the participant to set the time or day the meets are occurring.

13. 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 goal of the planning process shouldn't be driven by time but by success of the plan for the participant. A clear process to address the current challenges needs to occur along with a participant centred approach to the development of the plan. Therefore, planning processes need to be flexible and will look different for each participant.

14. 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?

Service providers continue to participate in the planning process on behalf of participants as participants are nervous and want the support and knowledge of the provider about critical service provision. It is expected that this arrangement will be ongoing because it has come to be expected by participants and their nominee's. The Agency needs to understand why this is happening to then provide participants the information they are lacking.

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

See earlier comments in response to question 1 and the principle that decisions are made on merit.

Planners need to ensure they have the right information in the first instance prior to the planning session so the planner can be informed about the needs of the participant and shape an appropriate conversation to create a successful plan that will meet the needs of the participant.

Participants' funds have been reduced purely because they had unspent funds. Even where they articulated the specific reason it was unspent and why it wasn't indicative of future use. This, further disadvantages participants who already experience significant disadvantage. The NDIA planning and approvals process should consider personal circumstances and the reason for unspent funds.

16. 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?

There has not been consistency of improvement in the planning process in South Australia.

4. The NDIS participant experience – Planning processes 2: Using and reviewing plans

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

See earlier comments in response to question 1 under the principle of valued, regarding difficult access to support coordination and underspend of plan funding

The NDIA must acknowledge that the market is immature as are the consumers and respond appropriately. Participants and their decision makers can find it particularly hard to navigate the complexities of the NDIA including understanding what funding they have been allocated, how flexible the funds are and which services they can and should access. It is very hard for them to get the answers they need from the NDIA. A support coordinator would assist; however, they rarely have this included in their plan.

Plans are sometimes written in a way that seems to further limit the participant's flexible use of the plan. Training and guidance for staff would help to ensure a consistent approach by planners that maximizes participant flexibility.

A clearer break down of what funds have been allocated for which items should be included in the plan rather than one bulk figure for multiple items. For example, the core supports amount could be broken down to show community supports, group based activity supports, continence supplies etc., so an amount can be booked for specific supply of services or goods while retaining flexibility if the participant needs it.

Some providers block out funding which can confuse participants and limit other providers to offer services. Support Coordinators are not being engaged when a change of funding allocation needs to occur. Service providers are expected to negotiate this between themselves.

Service providers are having to use their resources to not just promote their products/services but to assist the participant to understand the plan and navigate the NDIS. This should be the role of the Agency or its assigned partner. This would help participants understand the different role of both the Agency and the provider.

18. 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?

There is still confusion on the part of the participant about their plan. A confirmation of a draft plan is required by the participant after a further conversation with the planner to explain the outcome.

Plans could break down what the approved funding is for. Core supports is the most difficult to understand.

When participants or nominees don't have access to the portal they are not informed of how much funding remains in their balance. As well as having access, participants have not been advised in a timely manner about how to set up their portal access. Often information via a letter has been received after the due date for setting up the portal.

On occasions the NDIA has misinformed participants of the amount of funding left in participant's plan. They have provided information without knowing what has already been allocated for future service and this has not been clarified.

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

After a planning meeting and when the plan is approved, there should be another meeting with the participant/nominee to review the plan and implementation requirements i.e. setting up the portal, setting up the nominee and confirming that the set-up is correct and the participant understands this.

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

A plan review because of a change in circumstances can be emotionally challenging for participants. Even annual reviews can be stressful as participants need to revisit deficits to receive the appropriate supports.

The Agency needs to ask the question why have a plan review at all unless something has changed? Especially for adult participants.

The question needs to be asked- Why is a SIL plan reviewed independently of other aspects of the plan and it involves the service providers. This seems to be a duplication of the planning process.

21. What can the NDIA do to make this process [plan review] easier or more effective? How long do you think plan reviews should take?

Plan reviews if required should be implemented prior to the old plan finishing. Individual circumstances should govern how long a review should take. If a plan review passes the date of the cessation of the current plan, funding should be ongoing for the participant until acceptance of the new plan has been received. In saying this the agency needs to ask are new plans required for all participants. Another option is to approve plans for the majority of participants for 3 to 5 years. This will strengthen the service provider market.

5. The NDIS participant experience –
Appealing a decision by the NDIA

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

Very little is known about how to appeal to the Administrative Appeals Tribunal. Legal assistance is required and there is not enough advocacy available to assist participants through this process.

The process is very demanding and emotionally draining experience, to the point of exhaustion. It is not uncommon to wait 3 months for information about a review.

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

Participants have been told that if they request an internal review their entire plan will be reviewed and they may be allocated less funding in other areas. Sometimes participants are waiting for a whole plan review when parts of their plan have been reviewed and could be activated.

24. How could the NDIA improve the decision review process?

The Agency needs to provide accessible information to explain the appeal process including the timeframe expected and the personal cost that a participant may experience when entering into an appeal in easy to understand language. Advocacy supports need to be provided and accessible for participants who can be vulnerable.

25. How long do you think reviews of decisions should take?

No comment

6. Removing red tape from the NDIS –
The legislative framework

26. 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?

Reasonable and necessary needs to have a human rights framework to allow flexibility for individual needs.

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

- a. Improve the way participants and providers interact with the Scheme?
- b. Improve the access request process?
- c. Improve the participant planning and assessment process?
- d. Better define 'reasonable and necessary' supports?
- e. Improve the plan review process?
- f. Improve the internal merit review process?
- g. Improve the way other government services interact with the Scheme?

A consistent approach towards participants and their service providers by NDIA planners and their LAC representatives is required.

Internal communications within the NDIA are inconsistent. There are inconsistencies between State and National NDIA staff responses.

7. Plan amendments

28. What are the significant challenges faced by NDIS participants in changing their plan?

Need to clarify when a plan amendment is needed, and when a plan review is required. The same process exists for amendment and review. This needs to be reviewed to assess whether they need to be differentiated.

Participants are at risk of funds running out and being in debt to Service providers for essential services that are necessary for quality of life.

29. 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?

No further comment

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

No comment

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

No comment

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

When a plan is up for review an urgency (including emergency) rating should be carried out initially in a timely manner so plans that require a very quick response are addressed to safe guard participants' safety.