



**Submission to the Department of Social
Services Discussion Paper on the *NDIS*
*Experience: Establishing a Participant Service
Guarantee and removing legislative red tape***

25 October 2019

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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INTRODUCTORY COMMENTS

Carers Australia welcomes the opportunity to provide input to the Discussion Paper on *Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape*.

Surveys undertaken by the National Disability Insurance Agency (NDIA) and direct feedback to Carers Australia and to state and territory Carers Associations suggest that the majority of carers affirm that the supports received through the NDIA have made a positive contribution to the wellbeing and prospects of participants and, by extension, to those who care for them.

However, many have found the path to receiving that support difficult to navigate, very slow and exhausting.

It is NDIA communications and processes which have attracted the most criticism. In particular, three themes emerge across the board when dealing with the NDIA. These are a lack of transparency, a lack of consistency and heavy-handed administrative requirements.

Lack of transparency goes to the excessive use of specialised, jargonistic language in NDIS communications which impedes the ability of participants to engage in the Scheme and certainly hinders their ability to exercise choice and control. It also goes to insufficiently clear communications on deliberations in relation to both planning and reviews.

Inconsistency includes contradictory and unreliable advice provided by NDIA staff and contractors and the perception of arbitrariness in planning deliberation. With respect to the latter, there is a perception that outcomes will be dictated by who you get as a Local Area Coordinator (LAC) and a planner rather than on the merits of the case.

Heavy-handed administrative requirements and processes impact on the efficiency of the NDIA and on the time and effort required by participants.

Together these features of the NDIS experience contribute to frustrations, inefficiency and delays.

Unless these problems can also be resolved, identifying timeframes for actions under a Participant Service Guarantee will be of limited value. After all, some timeframes for the completion of reviews are already identified in the Act, but process delays have occurred anyway.

Similarly, restructuring processes will not be sufficient to address pain points if workforce capacity to meet timelines and turnover is not addressed at the same time.

We do want to note that the NDIA has recently invested considerable effort into finding ways to address identified pain points associated with the finalisation of plans and plan reviews. It is difficult from outside the NDIA to find out about the scale and scope of these improvements. We have only been able to do so in a consolidated way through a submission that the NDIA made to the current Australian Government Joint Parliamentary Inquiry into NDIS Planning. If we don't know, then it is unlikely that many participants and their representatives will know about these process changes. Nevertheless, the changes identified appear to be heading in the right direction. However, many of these process reforms have been only partially implemented or are yet to be implemented. The extent to which they will overcome some of the key problems identified by participants and carers has yet to be established. We discuss some of these changes below.

We have also raised some issues at the end of this submission on what the Participant Service Guarantee actually entails from the consumer perspective and we have suggested some wording changes in the Act in relation to reasonable and necessary supports.

PLANS AND REVIEWS

Communication breakdowns in the planning process

“Many carers have reported that the information or assurances provided by LACs that supports would be included in the plan have not been reflected in the plans they have received from the NDIA, resulting in significant distress on receiving plans that do not fund many of the agreed supports. The lack of direct contact with NDIS planners in many cases limits communication between the planner and the participant and their carer, creating confusion and frustration for participants and carers as they do not understand why some decisions have been made or been able to discuss alternatives or providing further evidence.”

Carers NSW¹

The consequences of delegating the initial phase of planning to LACs who must then pass the draft plan to NDIA planners for consideration and authorisation has been identified as problematic by many carers.

¹ Carers NSW submission to the Joint Standing Committee on the NDIS Inquiry into Planning, 2019

While the LACs will have face-to-face contact and direct communication about the circumstances of participants and, in some cases, their carers, the planners who determine the supports which will be authorised under the final plan generally do not have this connection. If the plan they receive does not reflect the conversations, and in some cases the expectations, created through the LAC engagement with participants and their carers they are likely to be frustrated and confused.

To add to the problem, participants are missing out on the opportunity to review and respond to their plan before it is finalised. This in turn is likely to lead to a request for a review which can also be time-consuming for both the NDIA and for participants and carers.

The NDIA response to the break-down in communications in the pre-planning and plan finalisation stages between participants, LACs and planners has been piloted and introduced via “soft launch” to test the value add of joint planning meetings between the participant, the LAC and the NDIA planner prior to plan finalisation.

This meeting gives the participant an opportunity to ask questions and to better understand their NDIS plan and to clarify their need for support before the plan is approved. According to the NDIA, “in most cases, the participant will leave the joint planning meeting with an approved plan and will be able to access their supports immediately”²

While it may take a little longer to finalise a plan under these arrangements, the outcome should be fewer requests for time and energy consuming reviews to the extent that participants have had better input into and understanding of their plans.

While we applaud this joint planning initiative, it is currently only being applied on a very small scale in South Adelaide. The NDIA says it will roll out the initiative more broadly following an evaluation of this soft launch and it is unclear the timeframe in which this will take place. A long delay is likely to have consequences for the effectiveness of the Participant Service Guarantee.

Recommendation:

- All participants should be able to see their plans before they are finalised.
- Expedite the national roll-out of joint planning meetings between assigned planners, LACs and participants prior to finalisation of plans.

² National Disability Insurance Agency (NDIA), Submission to the Joint Standing Committee on the NDIS Inquiry into Planning, 2019, page 6

INTERNAL REVIEWS

Scheduled Reviews

1. The number of scheduled reviews required

The NDIS Act does not allow a participant plan to be “rolled over”. Generally, participants’ plans must be fully reviewed annually.³

While there is likely to be some value in a mandatory requirement to revisit a participant’s plans after the first year of its operation when they have had time to reconsider their original goals and objectives and the appropriateness and availability of supports, why is it necessary to repeat this process every year if the current plan is achieving the desired outcomes from the viewpoint of participants and/or their carers?

We do note that the NDIA has said it will introduce options for 2 to 3 year plans or longer for participants who have more stable arrangements at the end of 2019.⁴ But it continues to be a requirement for a planner or a LAC to determine the plan duration upfront.

While there are some differences between Aged Care Home Care Packages and the NDIS (including that set amounts are allocated to different levels of support in Home Care Packages) recipients of Home Care Packages do not have to be re-evaluated every year by undertaking a new Aged Care Assessment Test (ACAT). They request an ACAT assessment when their circumstances change and they need adjustment to their level of support. It is part of exercising choice and control.

From what we hear from carers, requirements to participate in scheduled reviews can be confronting in terms of the preparation and levels of anxiety attached the review processes. It feels to them that they have to pass an examination and they are afraid that it will result in a loss of supports if they have not fully activated their plans or on the basis of other considerations they don’t understand.

“I am living on a 12-month cycle. Every year is a lottery in terms of how your plan will be assessed and new funding allocated. I have found it seems to be

³ <https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-setting-plan-review-date#12>

⁴ National Disability Insurance Agency (NDIA), Submission to the Joint Standing Committee on the NDIS Inquiry into Planning, 2019, page 8

unfairly dependent upon the planner you are assigned on the day. My 19-year-old's plan was halved for our second year and has been tripled for our 3rd year. It is hard to comprehend such huge changes in their assessed need."

Carers Australia Peer Support Network

Why impose the significant administrative burden on both the NDIA and participants arising from a compulsory annual scheduled review?

Recommendation: Participants and/or their carers to be given more choice and control over the duration of the plans

2. Failure to complete a scheduled review on time

"There is considerable anxiety around plan reviews, although these have generally gone well so far. I have had to chase the agency or LAC each year to make sure a meeting is held in time as they have not been on top of plan end dates. We have had times of not being able to find a provider or a worker to work with us, so delays in implementing the plan."

Carers Australia Peer Support Network

As mentioned above, NDIS plans are generally in force for a year (with shorter periods for young children) and the funding for the new year is subject to review which must be undertaken before the current plan expires. We have heard complaints from carers that the NDIA has failed to initiate these reviews within the required schedule or to contact participants and/or their family carers in relation to such reviews. Carers NSW reports that in some cases there have been delays of up to six weeks before a plan has been reviewed and a new plan established.⁵

We were pleased to find out from the NDIA submission to the Joint Standing Committee NDIS Planning that a new business enhancement has been introduced and that "providers will now be able to claim for all supports delivered in accordance with their plan while waiting for their plan review."

While this should address funding gaps, it is essential that planning reviews take place within their scheduled timeframe to reduce uncertainty and anxiety.

In its submission the NDIA noted that key service improvements progressively implemented between late 2018 to early 2019 require that "ninety days before a

⁵ Carers NSW Submission to the Joint Standing Committee on the NDIS Inquiry into Planning, 2019, p 14

participant's plan end date, the NDIA attempts to contact a participant or their nominee or child representative, to begin the scheduled plan review process."⁶

This sounds very reasonable and should be included in the Participant Service Guarantee.

However, it does not reflect the information on the NDIA website with respect to the operational guidelines governing planning:

"Generally speaking, the NDIA will ensure that plans have a minimum duration of 12 months and will specify a plan review date of 4 - 6 weeks before the end of the participant's plan"⁷.

The important thing is that it actually happens and that the scheduled review process not only begins but is completed in reasonable time for the new plan to be developed, considered and discussed with participants and/or their carers so that they can proceed with confidence and not be put through the time, effort and anxiety created by requesting an unscheduled review.

Unscheduled Reviews

"The review process is seriously flawed. After my son's funding was halved in 2018, I lodged a review with the help of a legal aid organisation. Despite multiple calls and lodging an official complaint, I never received any information about this review, the funding was not changed. I don't even know if my request for review was looked at. Some people I have talked to have had some success with going into the NDIS office with the person they care for and just waiting until someone will see them. Usually, this promotes action as the person with a disability gets disruptive."

Carers Australia Peer Support Network

The sad tale of the complications and long delays in processing requests for unscheduled reviews has been identified over and over again in inquiries into the performance of the NDIA, including by the Productivity Commission, the Commonwealth Ombudsman and parliamentary inquiries into the NDIS. While the CEO is required to respond to the request for such a review within 14 days and while an approved review must commence within 14 days, there is no required timeline in which the review must be completed. The upshot is that is that participants and/or their family carers may have to continue for a very long time with unsuitable or inadequate support options which in turn can contribute to unavoidable plan

⁶ National Disability Insurance Agency (NDIA), Submission to the Joint Standing Committee on the NDIS Inquiry into Planning, 2019, page 8

⁷ <https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-setting-plan-review-date#12>

underspends or overspends. This in turn can impact on the outcomes of their next scheduled plan reviews in perverse ways.

A number of factors contribute to these outcomes. One is the sheer number of unscheduled reviews requested which suggests flaws in the original planning process. The requirement for the whole plan to be reviewed as opposed to an amendment focussed on a particular element of that plan also adds unnecessary administrative effort and, for participants, extra angst. Many participants will not request reviews which would result in better outcomes for themselves and for the Scheme for fear that a full plan review may leave them even worse off.

In March the NDIA responded to these complaints in part by a workforce reorganisation to better coordinate and allocate reviews to appropriate staff.

In mid-2018 the NDIA introduced what they call “light touch” reviews, which they describe the creation of “new plans for participants requiring a simple change to the plan on the system that doesn’t require a plan build”⁸. If by this they simply mean an amendment to the existing plan, we are unsure why it is described as the creation of new a plan.

If these new initiatives make a major difference to the capacity of the NDIA to manage its review workload, we can’t see why the Participant Guarantee should not include a timeframe for completing unscheduled reviews.

We would also like to see online tracking of applications, approvals, reviews and complaints made available to participants to let them know how their case is progressing and, indeed, that it is progressing.

Recommendations:

- Carers Australia concurs with the proposal in the Discussion Paper that legislative changes to the planning process could be included in the NDIS Act through introducing the concept of a ‘plan amendment’. A ‘plan amendment’ would occur when the participant’s goals and outcomes do not need to be changed, but minor changes need to be made to ensure it remains fit for service.
- We also concur with the suggestion that “incomplete” plans should proceed while supporting materials are gathered for additions such as AT, home modifications or SDA to be added later.

⁸ National Disability Insurance Agency (NDIA), Submission to the Joint Standing Committee on the NDIS Inquiry into Planning, page 8

- The NDIS should introduce on-line tracking of their individual applications, reviews and complaints for participants.
- With planned improvements to the NDIA's business system, prescribed timeframes for the completion of unscheduled reviews should be considered.

What is the Participant Service Guarantee?

The Participant Service Guarantee will perform a useful purpose even if it does nothing more than to make it clear to participants and/or their carers what they can expect in terms of NDIA processing times – providing of course that this information is conveyed in clear, accessible language and through a medium which meets the communications requirements of different kinds of NDIA participants,

What we are unsure about is the extent to which it reflects the usual components of a service guarantee. Service guarantees usually contain remedies for situations where the guarantee has been breached, including with respect to agreed delivery times. What is the remedy for participants where they do not feel they have received the service promised through no fault of their own? If there are no remedies, in what sense is this new initiative a service guarantee?

Recommendation:

Clearly define the role of the Participant Service Guarantee including participant redress for breaches of the guarantee.

AMENDMENTS TO THE ACT

The Discussion Paper invites feedback on parts of the Act or the Rules that are not working or make things harder for people interacting with the NDIS, with a particular reference to the concept of “reasonable and necessary supports”. Part 2 Division 1, Section 34 (e) of the Act says that, in determining what constitutes reasonable and necessary supports in a plan, “what it is reasonable to expect families, carers, informal networks and the community to provide” should be considered.

Further interpretation of this requirement in the section of the Rules relating to Supports for Participants⁹ fleshes out this concept to some extent in relation to family carers.

For example:

“for a participant who is a **child**:

- (i) that it is normal for parents to provide substantial care and support for children; and

⁹ National Disability Insurance Scheme (Supports for Participants) Rules 2013, Part 3, Section 3.4

- (ii) whether, because of the child’s disability, the child’s care needs are substantially greater than those of other children of a similar age; and
- (iii) the extent of any risks to the wellbeing of the participant’s family members or carer or carers; and
- (iv) whether the funding or provision of the support for a family would improve the child’s capacity or future capacity, or would reduce any risk to the child’s wellbeing”

For **adults** the considerations are:

- “ii) the suitability of family members, carers, informal networks and the community to provide the supports that the participant requires, including such factors as:
 - (A) the age and capacity of the participant’s family members and carers, including the extent to which family and community supports are available to sustain them in their caring role; and
 - (B) the intensity and type of support that is required and whether it is age and gender appropriate for a particular family member or carer to be providing that care; and
 - (C) the extent of any risks to the long-term wellbeing of any of the family members or carers (for example, a child should not be expected to provide care for their parents, siblings or other relatives or be required to limit their educational opportunities); and
- (iii) the extent to which informal supports contribute to or reduce a participant’s level of independence and other outcomes”

Our problems are with the way in which the Act and the Rules have been interpreted in both the Operational Guidelines and in planning decisions and reviews.

We have already mentioned that one of the major difficulties with the NDIS is the apparently ad hoc way in which planners exercise their decision-making discretion. What it has been considered reasonable for families to continue to provide has been a particularly vexed issue.

For example, planners have worked on the premise that, since family members usually provide transport to other family members, the inclusion of special arrangements for transport in a plan is not required, even if the participant’s plan requires considerably more travel and, in the rural and remote context, to quite distant destinations. Similarly, requests for the provision of more paid care, including with activities of daily living, to enable family carers have some quality time with other members of their families (including children and partners) have also been rejected because they cannot be directly related to the participant’s individual goals and aspirations. And the need for replacement care to allow family members to take a decent clean break from very intensive and often unremitting

provision of care (not just a few hours) has also been problematic. In this context it is important to note that family carers of people with disability have often lost eligibility and access to subsidised respite services where the person they care for becomes an NDIS participant.”

Recommendation:

Carers Australia believes there would be value in adding further clarity to sub-section 34 of the Act. The reference to what is reasonable for the community to provide should be separated from what is reasonable for families, carers and informal networks to provide. The new subsection in relation to families, carers and informal supports should be amended to read:

“what it is reasonable to expect families, carers and informal networks to provide taking into account the complexity, intensity and duration of that support, its impact on family functioning and the sustainability of informal caring relationship.”