

# **Improving the NDIS Experience:** Establishing a Participant Service Guarantee and removing legislative red tape

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## Introduction

The review into the NDIS is an important moment for people with disabilities in this country.

The original aim of the NDIS was to enhance the lives of people with disabilities, to give them choice and control over what they need to live their lives to the fullest.

The NDIS has not always lived up to this aim.

This review is an opportunity for people who access, supply or encounter the NDIS to voice their views on how to improve this system which so substantially impacts their lives.

I have approached this submission as a representative of the people of Indi, where I am the Independent Federal Member. As at September 2019 there were 2,101 NDIS participants in the Ovens Murray NDIS district, which covers almost all of the electorate. This represents 1.6% of the population of Indi, which is higher than the national average (1.1%).

The NDIS is one of my most common constituent concerns and my office currently receives on average 8 calls per week. Many people contact my office to express frustration at issues they have been dealing with for months and sometimes years. These systemic problems require urgent remedy.

My goal in preparing this submission is to synthesise these views, and to put forward practical, sensible recommendations for reform that would improve the lives of people across Australia.

The NDIS is a fundamental commitment to the notion of a fair and compassionate Australia, and something we all may access at some point in our lives.

The way we deliver support to some of our most vulnerable Australians is therefore central to the type of country we want to be. We must get it right.

## Outline

I have prepared this submission in response to the *Discussion Paper: Improving the NDIS Experience* released by the Department of Social Services.

Based on common themes from feedback from my constituents, the submission focuses on 4 topics arising from the discussion paper questions:

1. Challenges faced by NDIS participants in the planning process (Q. 10)
2. Opportunities to improve the planning process (Q. 11)
3. Challenges faced by NDIS participants in using the supports in their plan (Q. 16)
4. Opportunities for NDIA to help participants use their plan and find supports (Q. 18)

Where relevant I make recommendations, outlined below.

My submission documents feedback I have received from constituents. These constituents are not just people accessing the NDIS, but also NDIS planners, allied health specialists, service providers and friends and family of people who access the NDIS.

Their views have been recorded from people speaking directly to my office, letters and emails, telephone calls, parliamentary sessions and public information sessions.

## Recommendations

This submission makes 8 recommendations, in response to 2 discussion paper questions:

*Opportunities to improve the process of **creating plans*** (Question 11)

1. Require all plans to be approved by the participant before being agreed
2. Improve training for NDIA planners
3. Ensure housing is considered in planning process
4. Lift the cap on NDIA staff to ensure an appropriately resourced workforce

*Opportunities to improve the process of **using plans*** (Question 18)

5. Expand available treatment options to enable access to effective services
6. Account for travel costs in NDIA plans, particularly in rural and regional Australia
7. Ensure providers are paid on time
8. Improve coordination between the NDIA and physical and mental health services

## 1. Challenges faced by NDIS participants in the planning process

*In response to question 10 of the Discussion Paper*

- **Lack of agency over developing the plan**

Currently, NDIA planners, and plan approvers, are ultimately responsible for determining which supports are 'reasonable and necessary' for an individual NDIS participant. The participant can put their requests forward, but has no say over the final decision about required supports.

Many participants feel that enabling the NDIA to make an exclusive determination of the supports they need, denies them the self-determination to make choices about how they can function to the best possible level. One constituent told me:

*My son is in a second-hand wheelchair that was suitable when he was 13. He is now 21 and the chair is having quite serious detrimental effect on his body. His request for a new chair was refused and he was offered a service instead. His request for a motorised chair was also refused. He cannot walk.*

- *Support person of male NDIS Participant, 21*

This story is emblematic of a failure of the planning process to identify and meet the basic needs of NDIS participants, particularly as they change over time. Individuals are best-placed to understand their needs and how to address them and they should be more meaningfully involved in the decisions made about them.

- **Long wait times and lack of responsiveness**

My constituents regularly contact me regarding lack of responsiveness from their NDIA planners and subsequent long lag times in receiving approvals. I frequently hear of constituents being forced to wait months for the initial pre-planning meeting, not getting calls back from the NDIA or their planners, waiting months for plans to be approved, and months more for revised plans to be approved.

*I sent my plan in for approval and it took six months to get back. When I did get it back it was incorrect and many of the things I had asked for were not on it. I had to then request an unplanned review to try and fix it. This took another four months to get approval for this to happen. I now have to do a new plan which I know will take another six months to be approved. All this time I am suffering and not getting the help I need.*

- *NDIS Participant, Male, 52*

- **Housing**

Many participants do not have housing, and associated costs, considered in their original plans. There is also a lack of accommodation options for people with a disability, including supported disability accommodation (SDA), supported independent living (SIL), and public housing. Some people on the NDIS are living in aged care facilities due to a lack of other options. In 2018, there were 72 people under the aged of 65 living in residential aged care in

the Aged Care Planning Region of Hume (which covers most of Indi). Access to quality housing is a key determinant of health, and this is particularly true of people with disabilities with specific housing requirements.

Respite accommodation for participants is a critical part of NDIS support. The transition to a new funding model has impacted services in the thin markets that characterise rural and regional communities. In October 2019 the only short-term respite facility in Benalla notified participants it would close in early November, advising it was no longer financially viable. While the provider has worked hard to identify suitable alternative providers, these are located approximately 50-100km away. The distance, time, additional transport costs and need to plan months in advance for these services creates real barriers to accessing support.

- **Creation of inaccurate plans**

Many people are forced to revise their plans due to errors made by their NDIA planners. This is not only debilitating to people on the NDIS but is highly inefficient on many levels. Inaccurate plans lead to long delays, unscheduled plan reviews, creation of new plans, collection of support evidence and quotes and approval of new plans. While this is occurring, people are going without crucial services or items such as wheelchairs, hoists, and assisted technologies.

Many constituents reported feeling desperate, helpless, and frustrated at not being listened to in the first place. Many occupational therapists have contacted my office stating the frustration they have in working with clients whose plans have not included the necessary services or supports they require, despite it be communicated at the time of planning.

- **Inadequate training of NDIA planners**

The level of staffing and staff qualifications is regularly raised with my office as an ongoing problem. Concerns have been raised about the ability of staff to deal with the complex and emotional nature of cases in a respectful, sensitive and compassionate way. Consider two accounts from constituents in Indi. The first, a mother said:

*I was asked if my son, who has Down Syndrome, would “grow out of it”.*

- *Support person of male NDIS Participant 25*

Another constituent, who is quadriplegic, noted that:

*I was told that if I needed technology to have contact with the outside world, I should get my community access funding increased to get out more.*

- *NDIS Participant, Male, 63*

These examples are not isolated cases. They evidence a clear lack of training among NDIA planners, as well as a failure to listen and understand the challenges people face.

*I am wheelchair bound and have complex physical needs. The planners have said they will not fund the cost of incontinence pads that I need to wear. They have also cut my carer support hours so I have no one to help me get to the toilet or change the incontinence pads.*

- *NDIS Participant, Female, 39*

## 2. Opportunities to improve the planning process

*In response to question 11 of the Discussion Paper*

- **Recommendation 1: Require all plans to be approved by the participant before being agreed**

Participants must have a greater say in determining what supports are ‘reasonable and necessary’ for them to achieve their goals. Requiring all plans to be signed off the NDIS participant themselves before being submitted for approval would be a simple way of ensuring that plans actually reflect participant needs. It would also allow both participants and planners to identify errors in the plan, and avoid lengthy unscheduled review processes.

Accurate pre-planning and the creation of an accurate proposed draft plan must be undertaken by the participant and their planner/support person together. Last year, a pilot joint planning meeting ‘side by side’ program undertaken in Victoria was to be progressively rolled out from mid-2018. A pilot joint planning approach is currently underway in South Australia. We should build on these pilots to develop a workable model.

- **Recommendation 2: Improve training for NDIA planners**

Planners need to be appropriately trained to ensure that they have sufficient understanding of the NDIS system to properly advise on planning and access, and an understanding of disability and the needs of people with various conditions.

Planners must be able to advise people about what their entitlements are, and in which funding category their supports sit to allow for flexibility of use. For instance, a planner must be sufficiently trained to advise a participant about the different levels of service provider costs and the different levels of transport, access, and mobility support funding.

Moreover, planners must be trained to work professionally and supportively with participants, listening and understanding the challenges they face, focusing on the participant’s present and long-term goals, and ensuring the participant, or their nominated support person, is empowered throughout the planning and usage process.

- **Recommendation 3: Ensure housing is considered in the planning process**

Greater attention must be paid to the housing needs of NDIS participants. Where appropriate accommodation is not available, Government has a clear role in ensuring sufficient supply of appropriate housing. More group housing facilities, for instance, are clearly needed. Planners must therefore ensure plans detail and meet participants’ short- and long-term accommodation needs, or enable them to achieve their goals in regards to housing. When housing needs change suddenly, unplanned reviews must be able to respond quickly to changing needs.

- **Recommendation 4: Lift the cap on NDIA staff to ensure an appropriately resourced workforce**

Many of the concerns raised by constituents stem from a lack of staffing resources. Removing the existing NDIA staffing cap to enable an increase in personnel numbers will be critical to ensuring the implementation of the Participant Service Guarantee.

### 3. Challenges faced by NDIS participants in using the supports in their plan

*In response to question 16 of the Discussion Paper*

- **Accessing services in rural and regional Australia**

As a rural and regional electorate, many people in Indi are forced to travel long distances in order to access healthcare and disability support services. The costs and other challenges that this presents are often not factored in to individual plans:

*The amount of money allocated for transport costs does not meet the needs of people living in rural and regional areas. We have to cover distances to get services. For me to get one of my really important services takes an hour to drive there and an hour back. Services are sometimes 100km away.*

- NDIS Participant, Male, 25

- **Long wait times for approved services to be delivered**

Even after plans are approved, many people are forced to wait long periods for services and care to actually be delivered, or for delivered equipment to be repaired:

*I have been waiting for my motorised wheelchair for a year and a half. It was in my original plan, all the quotes were sent in, and approved, and I'm still waiting. I can't move without it. I am stuck in my small unit by myself and can't take myself to the supermarket or to see other people.*

- NDIS Participant, Male, 65

- **Service providers not being paid**

Many NDIS registered service providers remain unpaid for long periods of time. For small and medium-sized businesses, such delays either result in providers encountering cash flow problems, providing care effectively unpaid for lengthy periods, or ceasing to provide an important service required by the participant.

- **Use of Temporary Transition Payments**

Many service providers have contacted my office about the use of Temporary Transition Payments. They are concerned the NDIA has encouraged them to charge these at a higher hourly rate but that participants' plans have not been changed to accommodate this. As the cost of a service is higher, participants end up being able to access fewer services.

- **Lack of coordination between disability, health and mental health services**

Many constituents have contacted my office raising concerns about the lack of coordination between disability services, and physical and mental health services. Some participants experience both disability and significant health issues, and a failure to coordinate services across these various needs leads to increased stress and often an inability to access the services they need.

## 4. Opportunities for NDIA to help participants use their plan and find supports

*In response to question 18 of the Discussion Paper*

- **Recommendation 5:** Expand available treatment options to enable access to appropriate services

NDIA participants should be empowered to access treatment options that have been demonstrated to be effective for addressing their particular needs. Criteria for determining which participants are able to access which services must be informed by a rigorous, evidence-based approach and applied by NDIA staff with sufficient training to determine whether an individual meets criteria for accessing a given service.

- **Recommendation 6:** Account for travel costs in NDIA plans, particularly in rural and regional Australia

NDIA participants must be able to access the care and services that the NDIA has determined they require. In rural and regional Australia, this must necessarily involve adjustments to travel allowances to ensure that people can travel often significant distances to access the support they need.

- **Recommendation 7:** Ensure providers are paid on time

The NDIA must improve its internal accounting performance to ensure that providers are paid promptly.

- **Recommendation 8:** Improve coordination between the NDIA and physical and mental health services

NDIS plans need to be coordinated with physical and mental health services to ensure that individuals have a joined-up support system. Participants' mental and healthcare needs must be recognised in their plans, and access to these services must be accounted for in developing their NDIS plans.



## Conclusion

In this submission I have shared the experiences of NDIS participants, their supporters and providers, all of whom are my constituents.

My hope is that their voices will shape the evolution of the NDIS so that it can live up to the hope and promise felt by so many when it was first created.

The development of a Participant Service Guarantee will give people who use the NDIS better certainty, security, and the ability to plan for the future. My expectation is that the Guarantee will drive change throughout the NDIS to make the process quicker and more straightforward, and provide meaningful channels for review if the Guarantee is not met.

Many of my recommendations relate to the adequate resourcing of the NDIA. This will reduce delays, allow training of staff and ensure prompt payment of providers. It is absolutely essential for everyone, not just participants, that the NDIS is properly resourced so that it can deliver what it sets out to achieve.

Rural and regional Australians face very different opportunities and challenges than people living in major metropolitan cities. Under-resourcing is acutely felt, providers are under pressure to remain afloat, and there are fewer available treatment options and subsequently fewer choices. My recommendations regarding transport, housing and prompt payment of providers reflect the reality of accessing the NDIS in regional areas. It is critical that the NDIA recognise and respond to these differences.

I recognise the constructive relationship my Office has with our NDIS representatives and area managers, and their commitment to making NDIS work for participants in Indi. I commend the Government for conducting this review. I look forward to positive improvements to the NDIS for all involved in its implementation and in particular for the people in our community for whom it helps to have a healthy, peaceful and dignified life.