



Physical Disability Council of NSW
Ordinary People Ordinary Lives

Submission to the Department of Social Services
Review of the NDIS Act and new NDIS Participant Service
Guarantee

5 November 2019

Alice Dixon-Wilmshurst
Policy Officer

Physical Disability Council of NSW
3/184 Glebe Point Road, Glebe NSW 2037

02 9552 1606
www.pdcnsw.org.au
alice.wilmshurst@pdcnsw.org.au

Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e.: self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability) so they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

Introduction:

The Physical Disability Council of NSW (PDCN) appreciates the opportunity to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) on its inquiry into NDIS Planning, as part of its role to inquire into the implementation, performance and governance of the NDIS.

The NDIS is one of the most important social reforms in Australian history and will provide individually funded support to an estimated 460,000 Australians with disability when roll out is completed in 2020. At its foundation the NDIS seeks to provide participants and their families greater choice and control over the disability supports they receive. Given the scale of the transition to the NDIS, the implementation of the scheme has not been without significant challenges.

PDCN acknowledges that, since the May Federal election, the Federal Government has been proactive in reviewing the NDIS and its implementation, for example by establishing the Joint Standing Committee on the NDIS and conducting this review of the NDIS Act. It also acknowledges that the NDIA is working to improve the participant experience, through programs such as the NDIS Participant Pathway reform. PDCN welcomes these commitments and while it is still too early to see what recommendations these reviews will make and what effects the changes may have, PDCN is optimistic they will be positive and lead to change for NDIS participants.

Since 2016 PDCN has run numerous capacity building programs to assist people in accessing the NDIS and implementing NDIS plans. This has included NDIS Ready workshops, NDIS Plans in Practice workshops and NDIS self-management workshops. Through these programs, PDCN has followed several NDIS participants from pre-planning to plan implementation and plan review and has observed numerous issues with the implementation of the NDIS and with the consistency of the planning process. These issues will be outlined within this submission.

The following submission will not answer all discussion questions, rather respond to the ones where we can make a contribution to the discussion.

What could a participant service guarantee look like?

Principles for NDIA service standards

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

PDCN believes all the principles are important for the NDIA to adhere to. These principles should form the basis of everything the NDIA does and how the NDIS interact with participants or potential participants. PDCN is however concerned by the term 'expert', as we do not believe NDIA staff should (or can) be 'experts' and that people with disability are in fact 'experts' in their own lives. Rather, PDCN believes NDIA staff should be experts in disability awareness and in knowing how to empathetically and effectively interact with people with disability and source the required information from a participant to ensure their NDIS plan is the best it can be. At present, feedback from participants is that the current approach in interacting with participants or potential participants can be quite clinical, and many of the planners and LACs lack empathy and understanding.

2. In your experience with the NDIA, do you think they fulfilled the above principles?

Feedback from our members suggests that the NDIA does not fulfil the principle 'valued'. Participants report a lack of empathy on behalf of their planner or LAC. Participants feel they constantly have to argue their case and prove their disability. Participants feel that even when they have put in the time and effort to prepare for their planning meeting, that preparation is ignored, and planners or LACs are more interested in getting answers to their own (set) questions. PDCN believes a more effective approach would be to focus on being approachable and empathetic. This would indicate to participants that the planners are respectful and interested in the person and their individual lives – rather than just trying to tick boxes.

This approach would also save time for the NDIA in the longer term as undertaking planning with a less clinical and 'ticking of boxes' approach and asking more incisive questions will mean richer and more accurate information will be obtained from the person with disability, ensure initial plans are accurate and in turn decrease the need for changes to a plan.

We would also suggest that 'timely' include consideration of urgency of need and interim plans, so that people at risk are able to access an interim plan to ensure they get the supports they need, when they need them. The NDIA needs to consider timeframes for emergency situations, and the flexibility to provide early interventions. There is also confusion around the timeframes for an access request and clarification needs to be provided as to whether the 21 days mentioned in the current timeframe for CEO and NDIA decisions is referring to 21 days in total or 21 business days. If the total time is 21 days, then PDCN considers that to be ample time to complete an access request. We would suggest 14 days be the expected timeframe for "standard" requests, and 21 days for more complex requests.

Our response to 'accessibility' is that the NDIS does not currently meet this standard, as it is difficult to access for both people with vision impairment and people who are isolated (e.g. do not have access to the internet or a computer). For example, people with vision impairment report difficulties with using the portal to self-manage their plan. Through its self-management workshops PDCN has had contact with a person who has vision impairment. This person finds self-managing difficult because there is a lack of plan management applications (for people with vision impairment) in the portal or on the market. For people who do not have access to a computer, accessing the portal is difficult as it is a web-based application. This excludes a large cohort of people who are disadvantaged and cannot access the internet. It also makes it difficult to find any information and they may have to rely on contacting the NDIA via phone, which PDCN members have reported is also difficult to do.

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

The NDIS is founded on the ideas of participant 'choice and control', which is on the back of United Nations Convention on the Rights of People with Disabilities (CRPD). As such, PDCN believes that the Participant Service Guarantee (and NDIA Act) should be approached from a rights-based perspective. We believe this is the most important principle to developing a Participant Service Guarantee, and all other principles will flow on from this. Staff from the NDIA need to realise that they are dealing with real people and real lives, and in all their interactions start from a position of 'do no harm'. Therefore, we suggest adding another principle, 'Empathy', to ensure that NDIA staff are valuing individual people and their lived experience and approaching each meeting from a strengths based perspective (focusing on a person's strengths and what they can do, and building from there).¹

¹ Victorian Government, *Strength-based approach: A guide to writing Transition Learning and Development Statements*, February 2012
<https://www.education.vic.gov.au/documents/childhood/professionals/learning/strengthbappr.pdf>

- 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 that you think should be included?**

PDCN agrees that these service standards are fitting, however makes the following recommendations for additions to the service standards:

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

If it is not already doing so, PDCN suggests the NDIA introduce a short participant survey that could be completed post-planning meeting to obtain an idea of how the interaction was experienced from the participants perspective. It is important that the survey be short – a few questions – with the concluding question asking whether the participant would be willing to participate in a follow up discussion, to assist with the NDIA’s ongoing improvement processes.

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?**

PDCN members report one of the biggest difficulties in accessing the NDIS is that it is a time consuming, costly and complex process. Contacting the NDIA to commence the access process and obtain an Access Request Form is an unnecessarily difficult process. There is also a great deal of complexity in knowing the right documentation to provide and people are often relying on GPs, whose inexperience or lack of understanding are often part of why the initial application fails. Another significant challenge faced by people accessing the NDIS is communication – or lack thereof. Members report a lack of communication in the early part of the process and believe that more open communication from the start would lead to better outcomes. Finally, accessing the NDIS can be costly, as the specialist reports required can be expensive.

- 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?**

Depending on the complexity of the access request, PDCN suggests it should take 14 days for straightforward decisions, and 21 days for more complex cases.

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

According to the current timeframes for CEO and NDIA decisions referenced in the discussion paper, the NDIA has 21 days to make an access request decision or request further information, and 14 days to make a decision following the receipt of additional information. One suggestion to make it quicker and easy to access the NDIS is to shorten the timeframes. For example, if further information is needed, the NDIA could contact the applicant within five days of receiving the access request and make a decision within 14 days of receiving the requested information.

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?

PDCN members have indicated that there isn't enough information provided, and the NDIA is hard to contact to get further information. A checklist of steps and documentation requirements may be useful for potential participants and NDIA staff.

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?

Good communication is essential.

Feedback and anecdotal evidence from PDCN members suggest that one major flaw with accessing the NDIS is poor communication. Responses to access requests are often indoctrinated, robotic responses that aren't responding to the individual. When the NDIA doesn't respond to a message in a humane or considered way, they do not appear to be transparent. More explanation is required as to why access is denied, as current reasons show there is no consideration of the actual person. In a recent survey of PDCN members, one respondent who has a physical disability, indicated that she was denied access to the NDIS because she "wasn't bedridden enough" (survey respondent no. 42).

Planning process 1: Creating your plan

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

There are too many layers – participants should have the opportunity to speak directly to a NDIA planner throughout the planning process. Feedback from PDCN members shows that participants are incredibly frustrated with the level of bureaucracy intrinsic to the scheme and believe they should get rid of the 'middle person' – in this case, LACs.

An improved process could involve an experienced planner making initial phone contact with the person with disability, to ask questions and gain a better understanding of the access requirements and who would be best suited to assist the participant in preparing for a planning meeting. This would also assist in determining whether a LAC or more experienced NDIA planner should conduct the planning meeting.

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

As mentioned in answer to the previous question, the planning process is significantly hampered by the attitude of planners or LACs, and the poor communication by NDIA staff. People often leave a planning meeting not knowing whether the questions asked or responses they have provided are adequate. There are generally no further communications of what to potentially expect in a plan and people are then often surprised when the plan they receive a plan with inadequate supports or funding, or funding for an area of need that different to their needs or goals.

In the case of one member, his plan came back with goals listed from an earlier plan (not identified as still necessary in the new planning process), and funding for equipment also provided in the previous plan, however the equipment requested in the new plan was not mentioned. When the member brought this to the attention of his LAC, he was hampered firstly as the LAC who had undertaken the planning was no longer on staff, secondly by receiving no response to numerous emails for MONTHS post them being sent, and lastly through bureaucratic 'bungling' inside the NDIA, where one area provided contradictory information regarding the progress of his review request to another. In all this simple error took over 9 months to be dealt with satisfactorily. In the meantime, he was called for a planning meeting for his NEXT plan, then when he explained the review request, was told he couldn't undertake a planning meeting whilst a review request was in place.

In another, the plan returned named someone completely unknown to the person whose plan it was!

In addition, PDCN members consistently report that the planning approval process takes far too long - with some people waiting months for a plan. This process could be improved by simple communication or progress tracking mechanism that could be available via MyGov.

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?

PDCN suggest the planning approval process should take no more than 21 days, once the planning session has been completed.

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?

PDCN members have indicated that there isn't enough information provided, and the NDIA is hard to contact to get further information. A checklist of steps, including reasonable documentation required, may be useful for potential participants and NDIA staff. The NDIA could also assign people with a contact from the NDIA to help them prepare for the planning meeting.

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

As has been previously mentioned, good communication is essential. Feedback and anecdotal evidence from PDCN members suggest that one major flaw with the planning process is poor communication. Responses from the NDIA are often brief and offer no explanation as to why a decision has been made. In addition, participants are neither contacted by the NDIA (after the planning meeting) or given a direct contact at the NDIA who they can contact if any issues arise. When the NDIA doesn't respond to a message in a humane or considered way, they do not appear to be transparent, honest or working in the participant's interest.

Planning processes 2: Using and reviewing your plans

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

PDCN has observed the choice and control of NDIS participants being compromised by insufficient support and information available to implement their NDIS plan. PDCN acknowledges that undertaking planning with an NDIS participant is a complex process that requires a high degree of skill and time to complete effectively, however feedback from members suggests that LACs do not have the resources to assist participants to understand and implement their plans. PDCN has observed many participants who were in possession of their NDIS plan for several months before utilising any of their funding. PDCN believes this is due to a lack of guidance from LACs combined with participants' limited understanding of the plan itself; specifically, the difference between core, capital and capacity building supports, and the flexibility allowed in terms of the use of funds within each of these areas; plan management options and how supports can be purchased through the NDIS portal.

PDCN members have consistently reported an absence of locally available services to a point where only one disability service provider is available outside of metropolitan areas. NDIS participants in rural and remote NSW have reported difficulty in sourcing suitable support services and skilled workers, restricting the effectiveness and flexibility of their NDIS plans.

17. 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?

The NDIA could provide all participants with support coordination, particularly in their first plan, to assist with implementing their plan and finding the right supports for them. The NDIA could also provide information (for example fact sheets) on where to find services, or who to contact, when a participant gets their first plan. It could also improve the service provider information on the NDIS website. Currently, this consists of a list of service providers, with no way to sort information. This could be improved by making it a search engine, so participants

can search by location, type of service etc, rather than scroll through a long list of service providers.

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

Responses to PDCN's recent survey indicated that participants and their families believe that LACs and NDIA planners are inconsistent in their approach to planning, and in their knowledge and skill level. LACs and NDIA planners are lacking in the knowledge and experience in asking questions that identify needs and gather the information required to develop the plan. For example, several participants report a lack of understanding of daily support needs – leading to a significant reduction in hours of care in their plan. This in turn leads to an increase in plan reviews. In each scenario, the original planning meeting was carried out by a LAC. It would have been of benefit to the participants had the planning meeting carried out by a skilled NDIA Planner, and they had the opportunity to see a draft plan.

PDCN members who are NDIS participants have also reported facing challenges including losing funded items out of a plan review (for a unrelated issue or item to what is being reviewed), delays with getting a review, and often being left without services while a review is in progress – unless they can re-allocate funds.

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

PDCN is consistently told by members that the ability to see a draft plan would considerably improve the planning process. This would allow for a more consultative process with greater liaison between participants and planners and would enable support gaps to be raised and comprehensively addressed during the construction of plans, making the planning process more efficient and reducing the overall number of plan reviews requested.

20. How long do you think plan reviews should take?

This is a grey area, and dependant on the person and their plan. If the plan is working and there has been no major changes, PDCN suggests there should be a mechanism in the Act, or Operational Guidelines, to roll over plans. Plan reviews should not take more than 14 days, unless there are significant changes, in which case 21 days should be the maximum amount of time required.

Appealing a decision by the NDIA

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

Anecdotal evidence from PDCN members, and responses to a recent survey, suggest the main challenge is obtaining an appropriate report for evidence of disability. This can be a costly and timely exercise, often futile because the NDIA doesn't always interpret support

needs correctly and are often looking for ways to pass the support need to another government department, such as health. Numerous members feel the NDIA shows little interest in their personal situation and the feeling is that the NDIA are “passing the buck” to mainstream services where in fact specific disability support is required.

PDCN members also note challenges in finding the required supporting documentation. For example, General Practitioner (GP) reports are not considered specialised or enough to support an application for a review, so reports are then required from specialist at further cost to the participants.

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

As mentioned in the previous question, participants face challenges in obtaining the required documentation to support their review application, as it is a costly and time consuming process. There are also times when a potential participant has been asked to obtain an assessment only to find out it may not have been necessary, but there is no way of recovering the cost of such assessments. If funding was available to assist with the relevant assessment at the onset, then plans may be built in a more precise manner, therefore avoid costly internal review.

As an insurance scheme, the NDIA approach to reviews often works towards finding ways to minimise costs to and liabilities of the agency. This may then be to the detriment of the participant who has reasonable and significant needs. Improvements could be made, time and possibly money saved if rather than operating in an insurance scheme mentality, staff were to consult with participants to discuss any issues they may have, or assist in identifying needs, ensuring they do this in a way that is cognisant of the lived experience of the participant.

Plan amendments

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

The complexity of the process and the length of the process can lead to a significant amount of work, for what is often a simple change. Even minor amendments currently trigger the development of a whole new plan and can then leave people without essential supports or in having changes made to a plan that worsen their support situation.

30. 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?

PDCN supports the inclusion of a ‘plan amendment’ and believes that it could improve the experience for people who only seek to make minor changes, such as who manages the plan. It is also likely to save the NDIA significant time, money and effort.

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

This should be variable based on the evidence required, but we suggest anywhere between 7 and 14 days would be reasonable and ensure that a plan amendment happens in a timely manner.

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

The NDIA could have a direct phone line to a dedicated team that could triage plan amendments that could be dealt with quickly and easily, (and do so), or advise where there would be a need to complete a full plan review – and the process and requirements needed to make the review run as smoothly as possible.

Changes to NDIS Act and the Rules:

PDCN suggest that the NDIS Act and Rules be changed to accept anyone with a disability that meets the criteria of access, including those OVER the age of 65.

Currently a huge inequity arises for anyone with a disability over the age of 65, whom are, for reasons unclear no longer considered a person with a disability, but elderly, and forced to seek services under Aged Care legislation. My Aged Care is completely incapable of managing the needs of people with significant disability (particularly those whom would be eligible for the NDIS under all other access criteria) even with a Level 4 package (should one even be able to be obtained – there are currently huge wait lists for these packages)

Under the UNCRPD all people with a disability are entitled to equal rights, and the current refusal of the NDIS to allow access to a person over the age of 65 at roll out completely denies those rights.

Recommendations

Recommendation 1: Changes to service standards:

Timely

- 'Participants receive a call within 5 days to acknowledge access request or plan amendment.

Expert

- NDIA staff have a high level of disability awareness training and understand what questions to ask to get the most relevant information from a person.
- NDIA staff are trained in emotional intelligence.
- NDIA undergo regular workforce training to ensure skills stay up to date and they remain responsive to client needs.

Valued

- NDIA staff recognise that people with disability are experts in their own lives and are respectful in all communications with them – including ensuring timely and efficient communications on the progress of access requests or plan reviews/amendments.

Accessible

- The NDIA provides information that is accessible for all, including people with vision impairment, people who are homeless or people who have low levels of computer literacy.
- The NDIA provides diversity training to all staff to ensure they are inclusive in all communications.
- The NDIA ensure the workforce is as diverse as the community it serves.

Recommendation 2:

Introduce a short participant satisfaction survey to be completed at the end of each planning meeting.

Recommendation 3:

Add a clause to the current timeframes for CEO and NDIA decisions that stipulates the CEO has five days to request further information, and 14 days to make the decision upon receiving the information.

Recommendation 4:

Establish a checklist of steps and documentation requirements for potential participants and NDIA staff to utilise.

Recommendations 5:

Have an experienced NDIA planner make initial telephone contact with potential participants.

Recommendation 6:

Introduce a plan progress tracking mechanism via My Gov.

Recommendation 7:

Create an online provider database and search engine that can be accessed via the NDIS website.

Recommendation 8:

Introduce draft plans and a more personalised and empathetic consultation process.

Recommendation 9:

Introduce a direct phone line to a dedicated ‘triage’ team to address plan amendments quickly.

Recommendation 10:

Change the NDIS Act to accept anyone over the age of 65 years on to the scheme.