



people with disability

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People with Disability Australia (PWDA)

Are people with disability in control? Markets, service provision and the NDIS

Submission

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About People with Disability Australia

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is also a founding member of Disabled People's Organisations Australia ([DPO Australia](#)) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. DPO's are organisations that are led by, and constituted of, people with disability.

The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability In Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities. DPO Australia has been funded by the Australian Government to represent the views of all people with disability and provide advice to Government/s and other stakeholders.

Introduction

For people with disability, the services they can access and receive make a huge difference to whether they are able to go about their daily lives. PWDA supports market provision of disability services as an essential way to provide choice and control to people with disability. Rather than seeing markets in isolation, however, we see them as parts of an enabling system of supports that includes the Australian government, the National Disability Insurance Agency (NDIA) and other regulatory bodies. These other parts of the system must put measures in place for instances when markets fail to meet our needs. We encourage the members of the Joint Standing Committee to consider the role of government in providing safeguards to the market basis of the National Disability Insurance Scheme (NDIS).

People with Disability Australia's submission represents the interests and views of our members and supporters. In responding to the Joint Standing Committee on this matter, PWDA has communicated the issues covered in the inquiry in plain English, and listened to the views of 50 members and supporters in a variety of accessible formats, including survey, phone conversation, email and in person.¹ The survey consisted of eight questions related to the inquiry terms, using a variety of answer formats including open ended questions, yes/no and multiple choice. It was distributed using PWDA's mailing list and social channels. A copy is attached as an appendix at the end of this submission.

People with Disability Australia supported 2370 advocacy clients last year, and 49 per cent of those cases were directly regarding the NDIS. This submission has been written in consultation with individual advocates. The people accessing our individual advocacy support are often experiencing multiple forms of vulnerability regarding the NDIS, service provision, and other issues such as housing, education, child protection, abuse and neglect, or health. This collective knowledge of the lived experience of people with disability has been built up over many years, and PWDA can provide more information as a witness if required.

This Inquiry covers issues that are of great importance to people with disability, and for this reason, PWDA is concerned about the accessibility of the Inquiry. The Inquiry Terms of Reference contained specialised language that would not be understood by people without expertise in the fields of economics and policy. Despite PWDA's request for Easy and plain English versions, this was not provided.

PWDA recommends that all Australian Parliamentary inquiries, but particularly those with obvious relevance to people with disability, be made available in accessible formats.

¹ Unless otherwise noted, where quotes and case studies are used, names and other identifying details have been changed to protect the privacy of our members and supporters.

Summary of recommendations

1. *PWDA recommends that all Australian Parliamentary inquiries, but particularly those with obvious relevance to people with disability, be made available in accessible formats.*
2. *PWDA recommends that the NDIA urgently establish robust procedures to respond to urgent and crisis situations, particularly those that constitute risks of abuse, neglect and exploitation. This would mean that the market based system could protect people's rights and interests from both NDIS and market failure.*
3. *PWDA recommends:*
 - a. *That processes to encourage self-management and plan management by people with disability and their supporters be urgently reviewed and strengthened by the NDIA, in consultation with people with disability*
 - b. *That support co-ordination is funded ongoing for people with complex needs, including lack of negotiation skills, or who have a complex network of support providers*
 - c. *That the NDIA recognise that some people will always require support co-ordination*
 - d. *That the Joint Standing Committee on the NDIS call on the NSW and QLD governments to continue funding advocacy services.*
4. *PWDA recommends:*
 - a. *That the Joint Standing Committee review and make recommendations on the underfunding of needed supports and whether there is a pattern of reduced funding for core supports and at plan review.*
 - b. *That the NDIA urgently review and release findings on the patterns of funding for core supports from the start of trial to the present and patterns of change to funding at plan review.*
5. *PWDA recommends that independent price setting and monitoring take place outside of the NDIA, and that the Joint Standing Committee inquire into and report on options for this measure as part of this inquiry.*
6. *PWDA recommends that the NDIA urgently investigate and report on options to provide services itself when private providers are not available or appropriate, using a combination of direct service provision with appropriate oversight and incentivising private provision.*
7. *PWDA recommends that the NDIA release a draft of the 'Maintaining Critical Supports' policy and undertake thorough consultation with people with disability as soon as possible. This policy should include government provision of services where needed.*

A. Transition to a market based system

While the transition to the NDIS has been positive for many people, others have struggled with the shift and its unforeseen consequences. When a participant is in a crisis or emergency situation, the new system does not currently have the capacity to respond to protect their rights and wellbeing. For those who have a sudden change in circumstances, had an inadequate plan to begin with, or have their supports cut upon review, this can lead to serious harm including neglect, severely compromised health, inability to leave bed or perform daily tasks such as going to the toilet, showering, attending work, school, or university.

Lee lives in Western Sydney and is 48 years old. She has multiple disabilities and needs support to leave her bed. Lee does not have enough hours of support in her package and the NDIS will not pay in circumstances where the client has exceeded their allocated funding. However, the participant's needs outstrip her hours of support, and while services originally met this need, because they are not receiving payment from the NDIA, two of Lee's four services have threatened to withdraw. While the participant's Service Coordinator applied for a review in time to deal with this situation and has flagged it as urgent, it has not been dealt with in time. Despite the NDIA complaint guidelines saying that any complaints with risk of abuse neglect and exploitation will be dealt with in two days, this is not happening. Lee is at risk of hospitalisation or being admitted to a nursing home.

PWDA recommends that the NDIA urgently establish robust procedures to respond to urgent and crisis situations, particularly those that constitute risks of abuse, neglect and exploitation. This would mean that the market based system could protect people's rights and interests from both NDIS and market failure.

B. Finding the right service and the right service provider

Most people with disability in Australia have usually not had to navigate markets of disability service providers before the NDIS, unless they were one of the small numbers of people self-managing under state systems. While there are people with disability who are confident with this task, a number of factors can make it very challenging for particular groups, including their type of NDIS plan management, the nature of disability, quality of support and capacity building to deal with service providers, and how accessible service providers are themselves. In PWDA's survey, 54 per cent of respondents said they found it difficult to find the right service provider.²

Under the National Disability Insurance Scheme (NDIS) there are three kinds of plan management, meaning three ways that the financial transactions of service payment are managed:

- Agency managed
- Plan managed
- Self-managed.

Agency managed plans mean that the NDIS pays providers directly and the service has to be registered with the NDIS. In practice, agency managed plans can also mean that there may be little opportunity for participants to actively negotiate provider markets, as services might be decided in the planning process, and planners, or more likely Local Area Coordinators (LACs), may do the negotiation of providers.

Being plan managed means a financial intermediary does the payments for the participant, taking away the account management issues but leaving the participant to negotiate the arrangements with service providers.

Self-managed means the participant does their own financial transactions and negotiation with service providers.

The type of plan management in place will impact the type of negotiations people are engaged in with the service providers who make up a market, with people who are self-managing typically most engaged, and those who are agency managed being least active in negotiations. One person with disability noted the benefits of plan management:

there are still not many options to choose from. For example, we tried to find a garden and only 1 of the providers listed on myplace who list that they do gardening services actually offer them. They say they are going in the future and are trying to gauge interest. but this is just acting as a barrier to us accessing services. We spent days calling and waiting to hear back from people - a total waste of time. We're lucky enough to have chosen plan management so we were able to get a local, non NDIS registered provider, to do our gardening.

² 'Difficult' was defined as limited choice, few appropriate services, difficult to book, negotiate or access service providers.

As of late 2017, over 70 per cent of participants in the NDIS were agency managed.³ Just over 10 per cent were plan managed, and the remaining participants were fully or partly self-managing. This means that there are many participants who may not be taking an active role in the negotiation of new markets. Thus, the majority of participants could have quite a limited negotiation role with service providers, if they are not encouraged to do so. One survey respondent said: “[t]he service we want cannot be used because the provider forced on us has the contract for 2 years.”

The role of consumer of disability services, as opposed to recipient, is relatively new for many people with disability, and some will have weak negotiating skills and positions, if at all. For people who have lived their lives in institutions, or closed settings like group homes, it could take years of support to develop these skills and fulfil the role of active consumer. Some people may always require support in this area due to the nature of their disability. People with greater support needs have to perform a lot of additional work to overcome any barriers they may experience, such as inaccessibility of common communication methods. For some people with vision impairment or intellectual disability, for example, accessing online contact or complaint forms will be extremely difficult and often this is the only form of contact readily available.

Access problems are exacerbated when support co-ordination, a crucial part of holistic disability support, is denied or under-funded. Support co-ordination assists people with disability to negotiate complex markets and support needs, allowing greater choice than would otherwise be possible. When it is not funded for people who struggle with market negotiation, this reduces their choice and control, which can lead to limited life outcomes. PWDA and other representative and advocacy organisations have seen this happening at greater rates as the NDIS has rolled out across beyond the trial sites. Advocacy organisations, which are under threat of defunding in NSW and QLD, often fill this gap.

PWDA recommends:

- *That processes to encourage self-management and plan management by people with disability and their supporters be urgently reviewed and strengthened by the NDIA, in consultation with people with disability*
- *That support co-ordination is funded ongoing for people with complex needs, including lack of negotiation skills, or who have a complex network of support providers*
- *That the NDIA recognise that some people will always require support co-ordination*
- *That the Joint Standing Committee on the NDIS calls on the NSW and QLD governments to continue funding advocacy services.*

³ Productivity Commission, 2017, *National Disability Insurance Scheme (NDIS) Costs: Productivity Commission Study Report*, p.360.

D. The right price for supports? The impact of pricing on the development of the market

For participants in the NDIS, the issue of pricing is tied up with the issue of funding. Of the 45 respondents to our survey, an equal number felt pricing was adequate and inadequate. However, some respondents said that while line item pricing was appropriate, they were not receiving adequate funding to cover all needed supports or therapies. For example:

We get enough per session to pay providers but don't get enough to fund the recommended number of sessions for therapy. I can't work out how our social skills funding was supposed to work. Planner said we should get 20 sessions but the \$ only covered six.

Another participant simply stated: “[f]ully covers individual sessions. Not enough to cover all needed sessions.”

PWDA advocates have noted a pattern of inadequate funding of core supports and therapy sessions being funded in NSW and QLD. In addition, plan funding is being cut in review without explanation or after inadvertent non-use of funds when a person does not know how to use their budget to get needed supports, and is not being supported to do so.

Patrick is 11 and has autism. He attends the regular class at school and is doing very well in maths. His social skills and other subjects, as well as daily living skills, are improving and being maintained with supports. With these supports he is able to maintain a normal life and his parents can maintain work. His mum Jenna was shocked to see his core supports cut from \$31 000 in 2017 to just over \$11 000 in 2018, with no evidence that his needs had reduced or functioning had changed.

An area where low pricing is of particular concern includes supports for people with psychosocial disability. As one person responding to PWDA's survey stated: “The basic hourly rate of \$43.58 does not adequately cover psychosocial disability supports. It has been estimated by some providers that it would be closer to \$55-\$60.”

PWDA recommends:

- *That the Joint Standing Committee review and make recommendations on the underfunding of needed supports and whether there is a pattern of reduced funding for core supports and at plan review.*
- *That the NDIA urgently review and release findings on the patterns of funding for core supports from the start of trial to the present and patterns of change to funding at plan review.*

E. Setting prices for supports: the NDIA or independence

People with disability are concerned about pricing of supports, and of those PWDA surveyed and interviewed, around half strongly supported independent price setting and monitoring. Another 20 per cent felt the NDIS should continue to set pricing; the rest were unsure. Independent price setting provides is in line with the Productivity Commission's October 2017 recommendations:

NDIS price caps should be set by a body that has relevant capability and necessary resources, and in a manner that is transparent, evidence-based, supported by clear and limited legislative authority, independent and timely.

To better reflect these pricing principles and ensure that market development receives the necessary attention over the longer term, the Commission recommends that NDIS price caps be deregulated in three stages by:

- mandating that the NDIS Quality and Safeguards Commission (QSC), when it commences in July 2018, act as an independent price monitor. This will be a 'check and balance' on the NDIA's pricing decisions over the transition period, and should assist with the transparency of pricing — a problem that the NDIA has only partially addressed to date
- transferring the NDIA's pricing power to the QSC by no later than July 2020. The QSC would also be responsible for determining when supports would no longer be subject to price caps
- continuing independent price monitoring by the QSC following price deregulation.⁴

PWDA is pleased to see the NDIA accept recommendations⁵ from McKinsey and Company's *Independent Pricing Review*⁶ but remains concerned that these recommendations do not extend to independent expertise and price setting.

A selection of comments from people with disability and their supporters regarding pricing were as follows:

- "This is difficult. A lot of services charge the highest rate allowed under NDIS when they would normally charge a lot less. Therefore taking advantage of the system and I don't think it's right."
- "There seems to be patchy knowledge within NDIA of the real costs of supporting people with profound disabilities."
- "NDIA should set a reasonable/market value amount they will pay for specific supports. This will encourage providers to charge prices close to theirs."
- "NDIS with some independent body consultation, so it is fair and realistic with the actual costs."

⁴ Productivity Commission, 2017, *National Disability Insurance Scheme (NDIS) Costs: Productivity Commission Study Report*, p.291.

⁵ NDIA, 2018, *NDIA accepts Independent Pricing Review recommendations*, available at: <https://www.ndis.gov.au/news/ipr-report.html>

⁶ McKinsey and Company, 2018, *Independent Pricing Review: National Disability Insurance Agency*, available at: <https://www.ndis.gov.au/medias/documents/ipr-final-report-mckinsey/20180213-IPR-FinalReport.pdf>

Another person responding to PWDA described her experience trying to get Auslan classes for her foster daughter, telling us that when she originally inquired it cost \$120, but when she called back with an NDIS plan, she was quoted \$360. The experiences of people with disability show that independence monitoring of both NDIA price setting and market prices is needed, at least while the market is still in its early stages.

PWDA recommends that independent price setting and monitoring take place outside of the NDIA, and that the Joint Standing Committee inquire into and report on options for this measure as part of this inquiry.

F. When we cannot get appropriate providers: market intervention options to address thin markets

People are at risk when services are not available in a market-based disability support system. Risks include inability to complete daily tasks such as showering, toileting and dressing, attending work and school, or having inappropriate service provision. People with disability are concerned about this, and the majority who responded to our survey said the government should supply services themselves when there are not enough providers, particularly in rural and remote areas. A further 20 per cent believed the government should increase prices to incentivise more services in this scenario. People shared the following insights into what should happen when there is a lack of providers:

Allow greater flexibility in who can provider services and for these services allow for them to be charging a bit more- should be more of a case by case basis. They should also investigate supplying the services themselves but that will only give the person with disability the choice of one provider - not exactly what the NDIS stands for

there needs to be agreement reached by all governments on a definitive model of provider of last resort and continuity of support. Both need to clearly articulate in practical terms what each would look like in practice. there can't be the situation where there is market failure or at the very least limited services available, and no agreement reached on who will then provide services. This will lead to people being left without support.

advertise to the general public. There are so many ways and options to help and be employed by PWD with an NDIS plan that most people are not aware of.

Members of PWDA from the LGBTIQ+ community expressed concern that they either currently have, or may in future have to have a religious service provider, which would potentially have discriminatory values about their sexuality. Some members felt they had little choice when there were only a few large, religious service providers in the area.

PWDA recommends that the NDIA urgently investigate and report on options to provide services itself when private providers are not available or appropriate, using a combination of direct service provision with appropriate oversight and incentivising private provision.

I. When there is no appropriate provider to meet the needs of participants

When there is no appropriate provider, people with disability want the government to provide support, including crisis accommodation when needed. Eighty six per cent of people responding to our survey said they wanted a government emergency provider. Members of PWDA expressed their concerns that people with needs that providers find difficult are being pushed out of the market by providers in favour of clients providers consider easier.

There needs to be access to emergency care. Emergency care is not ask the hospital and taxi. I cannot push my manual chair. I need to know when to book emergency care or when workers are going to call in sick. How do I predict next tues at 1 am I need a worker to pick me up from the ED. Totally ridiculous and these are basic support needs not support choices. There is still no guaranteed flexible or emergency support assistance for self-cares.

Another simply said: "We all have the right to live safely allow us to get a motel room or do we have to sleep on the street", thus indicating that in some cases private provision of last resort accommodation would be acceptable.

The NDIA has not released a policy on maintaining supports in situations where there is not an appropriate provider, despite stating in November 2016 that this was being negotiated in each jurisdiction.⁷ Recently Rob De Luca, Chief Executive Officer of the NDIA, stated that:

We also have a project underway to make sure our approach to 'Maintaining Critical Supports' (historically referred to as 'Provider of Last Resort') is participant-centric, supports choice-based principles and operates within our legislation. When this project is completed, we will report back to the COAG Disability Reform Council.⁸

PWDA calls for a consultation draft to be released as soon as possible.

PWDA recommends that the NDIA release a draft of the 'Maintaining Critical Supports' policy and undertake thorough consultation with people with disability as soon as possible. This policy should include government provision of services where needed.

⁷ NDIA, November 2016, *NDIA Market Approach: Statement of Opportunity and Intent*, available at: <https://ndis.gov.au/medias/zip/documents/h8a/h09/8799129960478/NDIS-Market-Approach-FINAL-002-.docx>

⁸ NDIA, 2018, *CEO Opening Statement – Senate Estimates*, available at: <https://www.ndis.gov.au/news/senate-estimates-statement-mar18.html>

Appendix

PWDA survey questions

1. The NDIS has changed the way disability services are funded and provided. Instead of state governments providing disability services or funding NGOs to provide services without users having a choice, the NDIS provides funding to you and you should be able to choose the provider and way your supports are delivered. Has this been a positive change for you? Why or why not?

2. How easy is it for you/ other people with disability to find the right disability service provider?

- Very Easy (lots of choice of appropriate services, easy to book, negotiate, or access)
- OK (some choice, some appropriate services, possible to book, negotiate or access)
- Difficult (limited choice, few appropriate services, difficult to book, negotiate or access)
- Impossible (no choice, no appropriate services, difficult to book, negotiate or access those that are available, if any)

3. If you find it difficult or impossible to find the right service providers, can you tell us the reason for this?

- Not enough providers to choose from in my area
- Don't know how to approach or compare providers
- Need more support to decide what I am looking for
- Other (please specify)

4. If you find it easy to find the right service provider, can you tell us what made this work for you?

- Many providers in my area
- I am experienced and skilled at dealing with service providers, or my family member, friend or ally has these skills
- Service providers have been responsive to my needs
- Other (please specify)

5. Do the NDIS prices for your supports cover what you need to pay your providers?

- Yes
- No
- Other (please specify)

6. Should the NDIA set prices for supports, or should this be done independently from the NDIA?

- NDIS should continue to set prices for supports
- This should be done by an independent body
- Any comments?

7. What should the government do when there is no service provider that meets the needs of the person with disability, particularly in rural or remote places? w

- Supply services themselves
- Increase prices to encourage private providers
- Other (please specify)

8. What should happen when there is no appropriate provider, for example there is a crisis and urgent need for accommodation?

- The government should provide 'last resort' services and support, meaning when no other service is available that the government is the provider.
- Other (please specify)