



Women
With
Disabilities
Australia
(WWDA)

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ADVOCACY FOR INCLUSION NDIS REVIEW CONSULTATION

Volume 1: Appreciative Inquiry Report

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With assistance from Max Hardy Consulting.

About Advocacy for Inclusion

Advocacy for Inclusion incorporating People with Disabilities ACT¹ is a leading independent organisation delivering reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

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¹ On March 24, 2021, Advocacy for Inclusion (AFI) officially merged with People with Disabilities ACT (PWDACT), a systemic advocacy organisation based in the ACT. Herein, reference to 'AFI' also acknowledges the values and philosophies of PWDACT.

Acknowledgment

Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work. We respect and celebrate the diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

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Acronyms

NDIS – National Disability Insurance Scheme

NDIA – National Disability Insurance Agency

Background

As part of the NDIS Review consultation process, AFI was contracted by Women with Disabilities Australia, who were funded by the Australian Government, to hear feedback from people with disability about the NDIS, focusing on listening to ways in which the NDIS can improve.

We selected a group of people with lived experience of using the NDIS and different feedback methodologies to gather this information. To help us look at the issue of participant interactions with the NDIS we chose a method of discussion called an Appreciative Inquiry.

Appreciative Inquiry is a way of looking at change which focuses on identifying and doing more of what is *already* working, rather than looking for problems and trying to fix them.

We chose this format to look at 'customer service' and participant interactions with NDIS staff because we know that people with disability are having many interactions with the NDIS. As people with disability report both good and bad NDIS interactions, we saw this as an opportunity to build on what works for people, as well as imagining what excellent experiences could look like and feel like.

What follows are the views of participants – these are not necessarily the views of AFI.

How to read this report: This report combines both narrative text and analysis of the Appreciative Inquiry process, with many quotes directly from participants. Wherever we quote from participants, this is presented *as a block of text in italics*.

Appreciative Inquiry Methodology

The Appreciative Inquiry objectives were to explore peoples' experiences of NDIS customer service interactions, gather their insights and imagine what good NDIS customer service could look like.

To prepare for this discussion, participants completed a set of pre-reading. This covered:

- **Participant Journey** – A visual summary of the different times people may have contact with the NDIS.
- **NDIS Participant Service Charter** – A summary of what people can expect when they contact the NDIA.
- **What Does Good Customer Service Look Like?** – An outline of features of what good customer service might look like.
- **Reflections** – This was a space to write some thoughts on what good NDIS customer service might look like, with questions to prompt thinking.

To gain the most of people's time, the Appreciative Inquiry session was divided into the following sections:

Participant Journey

1. Naming the high points and low points of first contact with the NDIS.
2. Discussing scheduled and unscheduled contact with the NDIA.

Participant Charter

3. Sharing stories of better, if not exceptional, customer service – based on the participant journey.

Dream

4. Dream – if those experiences were the norm, and not the exception, what would that be like?
5. Suggestions for improving customer experience according to the Participant Charter.

Our facilitator, Max Hardy, guided participants through each of these sections to gather peoples' views.

Session Outcomes – What we heard

Following is a collation of what we heard during the Appreciative Inquiry. These are ideas from participants and we present them without prejudice. AFI does not endorse all of these ideas.

Participant Journey

1. Naming the high points and low points of first contact with the NDIS

In summary participants high points included:

- Successful application process when receiving assistance from either a support worker or advocate.
- Positive feelings about planning meetings.

In summary, participants low points included:

- When lodging applications in person, at a NDIS office, applications were lost or misplaced with participants not hearing anything for months or years.
- Lack of transparency during the planning process.
- Lengthy wait times (over 12 months) to hear about acceptance/rejection of application.
- The application process is really difficult. While people complete the form to the best of their knowledge, they often hear they are rejected due to a lack of information. The application form needs to be clearer in stating what is required, i.e., a functional assessment.
- Rejection letters are too technical, quoting various parts of the legislation but no real reasons why a person is rejected or what actual evidence they need to provide.

Following are some recounts of participants' high and low points of their first contact with the NDIS.

First contact

I had two initial experiences; one negative and one positive. My first experience was, I handed in my initial application in person. I didn't receive any confirmation that it had been handed in. I had no contact whatsoever and after two years there was just absolutely nothing. I was then hospitalised for my mental health and when that happened I was appointed a support worker and they helped me create a new application. They contacted the NDIS on my behalf who said it seemed as though they've lost my application. There was no record of it or anything, but I had handed it in, in person, in the office. The second application was lodged and approved within a week. So a positive and negative experience.

My first contact was ringing the NDIS to make [an] access request and that was back in early 2019. I knew NDIS was around, but I didn't know much about it. I wasn't familiar with the language that they use, which I found really hard. The actual phone call, which was my first one to ask for the form to be emailed, went quite smoothly. I thought the process was fine but it was weird that you have to call someone to get the form. You can't just go and download the form and do the application. In terms of first contact it was a neutral / high point.

Application process

What followed after I got the application form is probably the low point. The application form was fairly short. It didn't tell me what kind of things that they were looking for. I didn't have any access to an advocacy organisation or haven't asked for anything, so that was brand new for me and I found it harder than doing my PhD.

There was a tremendous barrier in terms of what kind of information the NDIA were looking for and what I needed to provide. The first time I did it I went with what's on the form and what they asked and then of course I got rejected because the form doesn't tell you anything about all the things that you actually need to provide to get through.

Planning

Planning meetings are always very positive and feel really good. They sound like they really listen and they were really wanting to help you to access all the sorts of supports that you might be eligible for, but then the actual decision would always be a very negative experience. You'll often get things turned down without any explanation really as to why decisions were made in particular ways. And then we'd get turned down and we'd have to go through the whole decision review process.

2. Scheduled and unscheduled contact with the NDIA – what was that like?

Participants outlined their high and low points of scheduled and unscheduled contact with the NDIA.

Scheduled contacts

High points

- For some participants, it was good for them to hear from the NDIA well before their plan is due to expire and be given the option to rollover their plan which worked for them.

Low points

- The NDIA did not contact the participant for their scheduled contact but said they had. So, the participant felt unprepared for their review and it went poorly.

Plan rollovers

Long before my plans are due to run out, about three months beforehand, they [the NDIA] write to me and say we're going to give you the same amount of funding as we did the year before. If that's fine with you, then that's fine with us. And I like that. That's gives me plenty of notice and it's straightforward, so the scheduled contact has been good.

Unscheduled contacts

High points

After contacting the NDIA, a staff member gave a participant a direct phone number to call if they needed to follow up on anything. This alleviated stress and anxiety even if they did not need to use the number.

My biggest challenge with the NDIA is that you ring the 1800 number and you may or may not talk to someone. Someone may or may not ring you back. Then if you need to follow up on that specific concern, you end up talking to a new person, and there's often no paper trail in the office about what was discussed before. So the benefits of having someone's name and their number – you don't necessarily want to ring them back [but] it's nice to know that if you do – you know who to contact. That alleviates so much anxiety and stress with all of those interactions.

Low points

The NDIA call on an undisclosed number so participants do not want to answer. If the agency sends a text, the message reads 'please click on this number'. Participants do not want to do this as many of them are told 'don't answer undisclosed numbers, don't click on links in text messages'. Therefore, communication between the NDIA and participants can be poor.

I have had to contact the NDIA quite a lot because of enforced plan reviews and needing to speak to delegates and unfortunately they ring you back with an unidentified number. On principle I don't pick up unidentified numbers. I actually ended up getting a text message from one of the delegates saying, 'hi, my name is so and so I'm from the NDIA and I've been trying to contact you. Could you please click on this number?' And I'm thinking, no, I'm not going to do that. That is an issue because so many of us are told not to pick up undisclosed numbers and don't click links.

I struggle a little bit with communication and so I need things written down and the NDIA ignore that. There have been planners who have pressured me when they've called and they've said, 'look, it'll just take a few minutes, we need to do it on the phone now. We're going to reject your home modifications application if you don't speak to me now.' And threatened me if I don't talk on the phone to them and that is an issue.

Participant Charter

3. Sharing stories of better, if not exceptional, customer service – based on participant journey

Good experiences of customer service with the NDIA centred around unscheduled contact with the agency. When participants have the opportunity to speak directly with NDIA staff, who understand their needs and can respond in a timely and positive way, it creates an interaction which is both responsive in practical terms and empowering.

I have had a couple of times when my plan needed amending and the NDIA listened and then the issues I had been experiencing were resolved quickly. I think it's an ability to speak to someone who can make decisions, ability to talk to someone who actually listens and understand what you are saying. That makes a huge difference.

I rang the NDIA and I spoke to a wonderful young man and he picked up on my problem immediately. I think that is what will make everyone happy is when someone fixes up the problem straight away. So getting it solved by the first contact is the best.

I wanted to say how good the web chat is. I don't have to ring up and be on hold or wait for somebody to respond to an email. The conversation is there in writing for me so that I can cut and paste it and read it again later if I need to. They're patient with me, with typing slowly or having to rephrase the question a couple of times so that it's clear what they mean and they've got good resources at

their fingertips or good knowledge personally, which means they can answer the questions straight away. It's good to have the option to use the webchat rather than call. I struggle with phone calls. I struggle with processing information and so being able to have it in written form to be able to look at a later time is really important to me.

Dream

4. Dream - if those experiences were the norm, and not the exception, what would that be like?

Review of decisions

We need to really simplify the review process and have everybody at the table, or at the end of a phone, that you need to be there to make that decision. The delegate needs to be present, even if it's only briefly to understand the situation and get the full picture, to be able to make the decision with having some contact with the participant. Otherwise you've got some faceless person at a desk somewhere in the middle of the bureaucracy making life changing decisions about you without any understanding of how their negative response will impact your life.

Dream: To be able to talk to delegates before review decisions are finalised.

Phone call identification

The NDIA need a better way of contacting people, even if they have a general screen that comes up saying NDIS, or something with a generic number so you know that somebody from the NDIA is calling rather just saying caller ID unknown.

Dream: To have some form of caller identification on phone calls, for example NDIS, so participants know the NDIA are calling.

Supporting documentation

I think the NDIA could give people guidance on the supporting documentation they want. Maybe not quite a template, but something approaching it, and that this should be available on the NDIS website for everyone to see. It's burdening for the individual and there should be a template that could be used if people want to. That template should be very structured with two paragraphs of the most important information right up top so it is easy to see.

Dream: Clear guidance and a simpler way to present supporting documentation to the NDIA.

Report Language

I think that it's important for the NDIA to remember that although there's people that act on behalf of participants, that the participants have disabilities and so a lot of the language that is used in reports isn't necessarily easily understandable. And so, for example, while I do have my support coordinator, if I'm provided with information, I'm the one that's going to be reading that. And I think it's important that I am able to actually understand what they're saying as well.

Dream: The language used in reports should be written in a way that participants understand so that it is an empowering process.

Reports

There is a heavy reliance on specialists' reports that are burdening for the system. The reports are deficit focussed. They are not empowering. They need to improve the report template that these specialists have to fill in, so it's really clear what the NDIS is asking for and why. Then have all of the functionality information as a separate piece of work that stays there on your file. So you don't have to go through it every time, because for many of us our functionality probably remains fairly similar and if not, you can ask them to modify it.

Dream: Clearer reasons why specialists' reports are needed. Developing a template for specialists to complete, which states what information the NDIS is seeking and why.

Feros care

Stop outsourcing that extra layer of Feros care as LACs and give that staffing back to the NDIS to get things done more quickly.

Dream: Return the local area coordination role to the NDIS.

Central shared participant file

I would like to see a central resource of a shared file, so that if delegates at the NDIA leave, everything's on file. So when somebody leaves their job, I want something to hand over and having the participant involved in the handover process, if they want to participate, so that there is a continuity of understanding and care.

Dream: If delegates at the NDIA change, allow participants to be involved in the handover process together with a central shared participant file.

Funding – Short term investment for long-term benefit

It would be good for the NDIS to be flexible in their funding approach. Maybe if there are two buckets of funding. A bucket of funding to help get over a particular hurdle, and once I'm over that, to be able to live a much better life. And then there's another group of funding to help every day for these tasks.

Dream: Flexible funding approach.

Funding – Reasonable and necessary

I think they need to look at requests for funding individually, as in case by case. For example, it could be empowering for someone to have the NDIA pay for six months storage. That may not be reasonable for everybody that comes with that request but would be transforming for participant's with that particular need, therefore it's reasonable and necessary. But how do you ensure that that's considered, compassionately, by someone who understands what that would mean?

What is going to work? What do they need to make their life the best life that they can have?

That might be outside their own ability to pay for now on the on that argument. To me, the funding I'm asking for is reasonable and necessary, but how do you get that across to your planner? Reasonable and necessary seems to be a one-way street where it's got to be reasonable and necessary for the NDIA. But how do you explain what's got to be also reasonable and necessary for the participant?

Dream: To have reasonable and necessary funding which meets participants needs.

Goals

I find it really hard because I feel like every time I look at my goals, I'm not meeting them because due to my condition, I am constantly declining. The NDIA seem to frame conversations around goals in the context of "improving" or "maintaining my health". And yet, because my condition is really rare I don't know how far I will decline I can't set realistic goals. I feel like goals are not tailored to be framed around things like improving the quality of my life.

Dream: Goals could be framed around improving participants quality of life.

Suggestions

5. Suggestions for improving customer experience according to the Participant Charter

The *Participant Service Charter* outlines what the NDIS is committed to doing for participants. It is based on five principles for their engagement with participants. During the Appreciative Inquiry, participants were invited to share their thoughts against the Charter principles.

Listed below are responses relating to general comments about the charter principles:

Transparent

We will make it easy to access and understand our information and decisions.

- *It would be good if the NDIA could provide support to help people fill out their applications because they know what they want but we don't.*
- *Consistency of definitions of who does what in the NDIA would be helpful.*
- *Transparency – we need to see what the LAC submits to the agency regarding our plan.*

Responsive

We will respond to your individual needs and circumstances.

- *If they're not sure about something, rather than saying no and then having to go through all these sets of hoops, why don't we have an intermediate step where they make contact with you and discuss it with you to see if they can clarify it before they make their final decision? It would save them so much time and money.*

Respectful

We will recognise your individual experience and acknowledge you are an expert in your own life.

- *It seems a real shame that an agency that's been built to help individuals improve the quality of their life actually can't tick any of these boxes consistently.*

Empowering

We will make it easy to access and use information and be supported by the NDIS to lead your life.

- *I wanted to touch on a combination of empowering and connected. When I was very first approved, there was no real information provided to me in regard to what supports I was entitled to and what supports I could have put in place. There's no central place that gives you information as far as recommendations on what kind of supports are ideal for you in your plan.*
- *The way it's set up at the moment in order to get the funding, you've got to give them what your worst day looks like in order to beg for the funding and support you need. That is so disempowering. We should be telling them what our best day looks like and why we want funding so that all our days can be best days.*

Connected

We will support you to access the services and supports you need.

- *My support coordinator has helped in some ways, but more so when I've come to them with suggestions of what I might like put in place. When I was first approved, I had no idea what kind of supports I was entitled to and where I could get those supports. The NDIS have got their list of support providers but I didn't know what supports I could actually have.*
- *The NDIS says we will support you to access services and supports you need, but there was absolutely no support from the NDIS to access those supports in the first place.*

Conclusion

Through the Appreciative Inquiry participants highlighted a number of areas where communication was working well and where it needed improvement.

Participants provided ideas and markers for an improved customer contact ecosystem for the NDIS which could be developed and mapped to compliance with the NDIS Participant charter. These might include:

- Call identification on phone calls
- A strength-based approach maximising those communication features which were seen as working well such as the web chat
- Clearer guidance and a simpler way to present supporting documentation to the NDIA
- Improvements to the language and reports so that participants can understand it
- Clearer reasons why specialist reports are needed including better information and templates for specialists
- Reform of the local area coordinator role and arrangements in the ACT
- Improved centralised information and corporate memory on clients especially during handovers including a central shared participant file
- Improved capacity to be flexible and nimble with funding during a package period
- Ensuring goals related to improving participants quality of life

Overall the participant charter provides a good frame for assessing performance and this should be used by the NDIA.

A participant summed it up by saying:

In the disability community we have the saying 'nothing about us, without us' but that becomes lost in translation when you're working with the NDIS. If you're talking to someone who's got access to a different set of information that you can't see, you've got no confidence that they're reflecting your stuff, your issues, your request, your plan, your aspirations.

Please note these are the views of participants and not necessarily the views of AFI or our funding partners. However they do align to many of the themes raised in our submission to the NDIS review as well as themes in the companion report on the NDIS Review depth interviews.

AFI thanks our funding partners at Women with Disabilities Australia for enabling this project through funding provided by the Australian Government. We also acknowledge contributions from Max Hardy our session facilitator. We thank AFI staff but above all thank those who were part of the Appreciative Inquiry.