Media Release: NDIS Review Consultations – What We Heard

30 November 2023

As part of the UN International Day of People with Disability, Advocacy for Inclusion are releasing three reports from their *AFI NDIS Review Conversations Project – What We Heard* and holding a webinar which will share real life stories from NDIS participants.

Ahead of the expected release of the NDIS Review next week, the reports reveal the difference the NDIS is making and the magnitude of the changes that participants want to see to the way the NDIS communicates with clients and manages the services market, information and workforce.

The reports include a report on communications with the NDIS, a report on client experiences with the NDIS market, planning and other issues and a professionally produced set of real life stories from participants.

The Stories publication is the focus of a **webinar event** being held from 12 noon tomorrow Friday 1 December, featuring participants and PWDA President Nicole Lee. Representatives from the NDIA will also be present to receive the report. You can join the webinar [here](https://events.teams.microsoft.com/event/f2189951-74ad-469c-a1a7-f5438700c356@82be5bff-88dc-4ad8-b79f-f1291fce535e).

Over several months AFI conducted a panel-style Appreciative Inquiry and Depth Interviews with a small but informed and representative group of Canberra NDIS participants to gather insights on their experiences. The consultation was supported by the Australian Government through Women with Disabilities Australia.

AFI’s Head of Policy Craig Wallace said “these reports reflect honest, and at times raw, truth-telling. The NDIS is a great reform but we can do better. We are releasing these detailed accounts to focus attention on the need for action in front of the coming NDIS review, expected to be released next week.

“Participants spoke to some dire and direct consequences of poor decision making and delays in obtaining services in areas like home modifications. These included a person reporting they had to sleep in their armchair for 12 months due to an inaccessible bed and being unable to shower or having repeat incidents of incontinence due to not being able to navigate a bathroom step. A person was told they might be better off moving house rather than making their home accessible.

“Communications were a key theme and participants also described confused and often mishandled communications with the NDIS, including impenetrable reports and a lack of basic templates to assist with reports. They also pointed to gaps including a corporate knowledge and staff handover. Communications around appeals and denials of funding were also seen as poor.

“People were particularly concerned about the scope and quality of local area coordination. Issues included: the quality of information from coordinators, staff turnover and referral runarounds.

“We also clearly heard a case for quality information and referral services including reform of the Australian Government funded Disability Gateway with a more useful, interactive and continuously updated resource with quality information on goods, services, spaces, places, equipment and services plus room for consumers to review and comment on services. This should include a central directory of allied workers and accessible vendors, including builders, handymen, therapists and specialists.

“Participants also highlighted some burning issues in the NDIS workforce such as the need for better hygiene and health and safety practices by support workers.

“In addition the need for better supports to people outside the NDIS was highlighted. AFI is concerned that some of the long term flexible supports previously available to people with disabilities are falling away following the end of the Community Assistance and Support Program (CASP) here in the ACT. There is a need for better coordinated case management services in the ACT and we will be highlighting this in our Budget advocacy.

“In the lead up to the NDIS review report these compelling accounts from participants are a pointer to the need for early action to improve market stewardship, local area coordination, information and communication”, Mr Wallace concluded.

The *AFI NDIS Review What We Heard Report* is available in three volumes.

[Volume One](advocacyforinclusion.org/wp-content/uploads/2023/11/FINAL-Appreciative-Inquiry-Report-1-1.pdf) (Appreciative Inquiry) building better communications with the NDIS.

[Volume Two](advocacyforinclusion.org/wp-content/uploads/2023/11/FINAL-NDIS-Review-report-What-People-Told-Us-.pdf) (Depth Interviews) Markets and Planning.

[Volume Three](advocacyforinclusion.org/wp-content/uploads/2023/11/FINAL-Looking-Forward-Looking-Back.pdf) Looking Forward, Looking Back, highlights participant stories and aspirations for the future of the scheme.

A set of representative quotes is at Attachment A.

The reports should be read in conjunction with AFI’s own submission to the review which can be found [here](https://www.advocacyforinclusion.org/submission-to-the-ndis-review/).

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Attachment A

**Highlights from the What We Heard Reports: Participants tell it like it is**

*Funding:*

“The kind of plan you get feels solely dependent on your rapport with staff and whether they’re maybe having a good day or a bad day at the time.”

*Lack of guidance and confusing language:*

“The disability advocate that I met in 2019 was the first person who explained things to me. [They] explained the kind of language I needed to use and that I needed to have a functional OT assessment, which I didn’t have initially.”

“There's some information available on the NDIS website, but it wasn't clear what I need to do before I had my first planning meeting.”

“I turned up to the first planning meeting and I had no idea that you had to prepare.”

“It was very stressful. The form itself wasn’t telling me anything.”

“The NDIS basically has its own language and vocabulary, and different terms and nuances that you wouldn’t know unless you had done a lot of work with it or [were] on it.”

“It took me a couple of years to feel like I knew how to navigate the system and who to ask questions to.”

*Reporting and documentation:*

“It took several months to get everything sorted and then I was rejected the first time around, so I had to [provide] more documentation for a review of the decision.”

“I don’t think anyone reads the pages and pages of reports that people provide for reviews. I can tell that [the staff I speak to] haven’t read anything. There’s no effort to understand the situation and what I need.”

“The amount of paperwork, energy and time that you need to do a review or [submit] a change of circumstances is a lot. It takes a lot out of you and for months you are stressed.”

*Local Area Coordination*

“I don’t really understand the role of the local area coordinators. All they seem to do is forward emails higher up the chain to NDIA. They don’t offer any advice. They take weeks and weeks to even acknowledge an email before they forward it on.”

“I think in the original model, the delegates were actually supposed to be [involved in] the planning process directly with the client and I think somehow, they got lost along the way. The role has [almost] been given to the local area coordinators, who are an intermediary between the participant and the delegate.”

“I don’t think I’ve had the same [local area coordinator] for more than six months.”

“The only time I hear from my local area coordinator is around a plan review and I don’t have their email address. If I really need to ask them a question, I have to call someone higher up and I’m not even provided with their last name – only the first letter of their last name.”

“It’s like they just have too much on. They don't have the time or capacity or resources to contact people.”

“I wish there was someone who you could contact and ask questions, and who could spend enough time to get to know you.”

*Wait times*

“I'd been told prior to [my application] that the wait time for approval could be a couple of years.”

“It took a really long time [to get accepted]. I think it took 7 months for them to get back to me to say ‘yes, you’re accepted’.”

“It turns into a long winded very slow process where you have your planning meeting [and then your request] goes into the void, until 3, 4, 5 or six months later you get a verdict and it's maybe not the verdict you were hoping for.”

*Mistakes and mishandling*

“They actually gave me a huge chunk of money in my plan, but it was in the wrong bucket. Then they kept saying, ‘no, you can't spend that because it's in the wrong bucket’.”

“We had to let that plan expire.”

“The portal couldn't cope with me having permission to control my own home renovations and it took [the NDIS] eight weeks to reprogram the portal. I couldn’t actually access the funding that was sitting in there ready for me to do my own home modifications.”

“Considering the fact that I’d taken in it person, I just couldn’t comprehend how they possibly could have lost it.”

*Unsatisfactory and limiting recommendations*

“We went through the process [of requesting home modification funding] again and they came back and said, ‘what about if you looked at actually moving to somewhere that was accessible rather than trying to make your house accessible?’”

“They will approve certain things for certain people and not for other people because a request has to be part of your goals and whatnot.”

"In my most recent plan, I applied for an adjustable bed to help me better work through my symptoms of swelling in my legs and acid reflux. I can’t lie down flat anymore, so for the last 12 months I’ve been sleeping in my armchair.

*Limited help finding good services*

“In the beginning I found it really hard, at least in the first year, to figure out what I need help with and where to get it and how to go about it.”

“One of my colleagues said, ‘did you know that there are Facebook groups where you [can] learn a lot more stuff or ask questions?’”

“I felt really lost in terms of figuring out like what I need, what's possible and how to get it.”

“She said ‘here's a list of providers, I can't actually recommend any of them to you because I'm not allowed to’.”

*Excessive treatment and service costs*

“They jack up the prices when you’re an NDIS participant.”

“[Providers] charge a lot more when they find out you’re an NDIS participant. I complained and said, ‘I’m self-managed, why am I having to pay $40 more than the average person?’”

“Once you mention the NDIS, people’s eyes have those dollar signs in them.”

*Excessive modification and equipment costs*

“I don’t want to risk getting fresh quotes and going back for fresh approvals, because that triggers a whole review process.”

“I felt really uncomfortable about the fact that they thought they could just make up however much they were going to charge me and send it off to someone else.”

*Limited services in the ACT*

“I think there’s just the one [brain training clinic in Canberra]. That’s a single point of failure right there.”

“When I was first getting my hand controls fitted, we actually ended up going to Sydney to get them done by ParaQuad (now Forward Ability Support).”

“I’ve been relying on Mable and Hireup. I wouldn’t even know where to start if I wanted to use a registered provider for support work.”

*Service delivery constraints*

“I’ve had builders want to put up lots of handrails and stuff that’s just not useful to me as a wheelchair user because it just makes extra barriers [and I don’t] use rails.”

*Inadequate quality and training of support workers*

“I’ve asked for assistance cooking and been sent a 20-year-old who didn’t know how to cook.”

“I feel like I’m constantly having to find new people.”

“I've got some really lovely ladies who look after me but [need reminding about] really basic things about using soap when they're washing their hands instead of just rinsing with water and [not emptying mop water in the kitchen after] mopping the bathroom and the toilet.”

“[Support workers] have left open bladed scissors and knives in the bottom of the sink, which is dangerous for the next support worker who might reach into the sink and not know they’re there.”

*Reduced availability of non-NDIS services*

“I rang up a lot of community service and everyone asked, ‘are you on NDIS?’ All of the services were only for NDIS participants.”

“I do miss having a group environment for support.”