Media Release: NDIS changes must not turn back the clock

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Canberra advocacy groups have said NDIS changes being introduced by the Federal Government and discussed with the States and Territories must not turn back the clock to capped and rationed supports characterised by arguments between governments. The call comes on the day that the Federal Minister for Disability, Bill Shorten MP, introduced an NDIS Amendment Act into Parliament

The [NDIS Amendment Act](https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r7181&fbclid=IwAR0xzxCUyMeiQuk-L-0HvFnGUxNyI4NQksd3llB2qqa4CWxLPa2Id5r4SDs_aem_Ac_Spv92jCsFV2geCcJ2JP_F7wXIBonfgBQlubuOXYJZmapccEDC7WIGKGtQ6aM0d8-V2_4rP5gwB5wCUqykeUl7), introduced into Parliament earlier today, flags a number of important changes to the scheme which include new assessments to determine what supports people receive under their plans, new rules about items which can and cannot be funded, longer plan periods while funding will be allocated on the basis of impairments that meet disability requirements, not by having a listed medical condition that guarantees entry to the scheme.

In our [response](https://www.advocacyforinclusion.org/media-release-ndis-review-threatens-choice-and-control/) to the NDIS Review last year Advocacy for Inclusion, along with other ACT Disabled Peoples Organisations, set out some strong views on the mooted changes. We remain concerned about proposals to require people to only use registered providers and also to change funding for participants requiring 24/7 living supports to be on the basis of those supports being shared with two other people. We also expressed our concerns about NDIS funding being made available on the basis of point in time functional assessments.

In addition we flagged concerns about the proposed new system of foundational supports and how these would be provided. Some of these concerns have been reinforced by news that the States, Territories and the Commonwealth are already at loggerheads over the funding and provision of foundational supports especially supports to young children with autism.

We are also concerned about the speed of the many changes to the NDIS and the lack of consultation and codesign with our community.

Craig Wallace, AFI Head of Policy said, “The changes to the Act and the unwelcome revival of the old funding arguments over disability are one reason why this week AFI joined by other Disabled Peoples Organisations has issued a shared statement which sets out our expectations in the scope, design and implementation of the planned new systems of foundational supports.

“The statement says any new system of foundational supports needs to avoid crude carveouts of entire support systems and populations, like young children, people with autism or people with psychosocial disability, from the NDIS.

“It also says foundational supports should not be capped and rationed. They must be bedrock, consistent and entitlement based and must address known gaps, not reduce the quantity, variety and quality of supports. A good start would be vastly improved information and referral services managed by people with disability.

“We also need to stop the services and supports that are already available in the community from disappearing. One example is some of the supports at the allied health interface lost in the transition from CASP to CATS and another is the closure of the Y Health and Wellness Gym. There are also many providers leaving the NDIS including in local area coordination. This tide needs to be stemmed and service changes managed in a respectful and caring manner by services and govts alike.

“We’ve warned against sliding back to the old capped and rationed system with a lottery dependent on your diagnosis and we’ve also reflected on the lessons from the NDIS introduction years ago which saw some good services lost.

“We’re also concerned that the changes recommended by the NDIS review late last year seem to be being introduced at warp speed by Government bypassing the usual process of an independent review, a government response and then time taken with the community to co-design changes.

Going forward the Government needs to enable genuine resourced co-design including funding people with disabilities and their organizations to properly engage with clear success measures and expectations at the outset. We will continue to put these views to Government”, Mr Wallace concluded.

Attached – Statement on Foundational Supports

Media contact: Craig Wallace, Head of Policy on 0477 200 755

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.”