



Association for
Children with a
Disability

Association for Children with Disability

Snapshot: Making the NDIS better for children and families

May 2023

Background

Association for Children with Disability (ACD) is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability.

ACD held six online consultations with families of children with disability between August 2022 and March 2023 to understand their experiences of the National Disability Insurance Scheme (NDIS). These consultations focused on access, planning, and making the NDIS better for children 0-8.

This snapshot highlights feedback from families of children with disability on what worked in making the NDIS work for their families and highlights areas in need of improvement.

For more information contact

Karen Dimmock CEO

karend@acd.org.au

0448 912 786

A better NDIS for children and families

1. More support for families and carers

Children with disability rely on their families and carers to access the NDIS and suitable supports, but the system doesn't always support families. Gaps include:

- Insufficient support to navigate the system, including understanding the process and completing forms
- Support finding professionals who can complete diagnoses and reports
- Limited knowledge, information and support around goal setting
- Support finding appropriate service providers in their area once their child's plan was in place. For example, families shared experiences of being given an outdated list of providers in their local area with hundreds of organisations to sort through
- Lack of emotional support for parents before, during and after the access and planning process
- The significant time required to complete paperwork, request and collate documents, and research and prepare for meetings
- Limited knowledge about advocacy support and where to get help.

Family-led organisations are well-placed to provide advocacy support and information and resources. However, family-led organisations face funding shortfalls and funding uncertainty.

"I literally had a panic attack when [the planner] called me, because it was just such a stressful [time]."

"We asked for support coordination to help with building a team because the skills we needed were so rare and were refused every year."

"It shouldn't be about the best equipped, the best researched, the most articulate person gets the things and if you don't know how to ask for it you don't get it."

"We need more funded support groups for parents. It's a lonely road."

"I took 6 weeks off work and devoted all my time when the children were at school to collate all the information and letters of support and evidence to lodge my claim."

"I struggled. I had no idea really... [The planner] said, 'You can only have this many goals', and I was like, 'Well I don't know'. And she asked, 'Well, what's most important?' and I said, 'I don't know!' I feel like there's a lot of onus on parents to tell them what's wrong but at that point I didn't have any therapists so I didn't know."

2. A stress-free NDIS

Navigating the complexity of the NDIS caused considerable stress for families. When families didn't have prior knowledge of the system or support from family, friends or professionals they were already engaged with, the NDIS was often overwhelming.

Concerns raised by families about the access and planning process included:

- Lack of information about the general process
- Long waiting times for access and planning meetings, and their outcomes
- Lack of clarity around outcomes and decisions made by planners
- Additional difficulty navigating the system for children with multiple disabilities, rare conditions or when multiple in one family had a disability
- The deficit approach, and feeling pressured to describe their child as a burden to access supports
- Being incorrectly referred to community health by GPs and maternal and child health nurses instead of the NDIS
- Lack of information about the need for a formal diagnosis once their child turned seven
- Lack of consistency in outcomes based on the family's writing and advocacy skills. Families advocated for the removal of NDIS jargon.

"Not knowing anything about this very unfriendly and complicated system [made accessing it harder]."

"[There was an] emotional cost of reading reports and having to focus on all the negatives."

"I think a good understanding of terminology is needed too, which isn't really fair."

"I've got four plans (three kids, one adult) and five kids with issues. The NDIS need to look at the whole family not just individual."

Families need the NDIS to be easier to understand and easier to navigate to ensure their child can have the best start to life.

"Only have one LAC coordinating all care for the client and/or family as a whole if there are multiple plans in one household."

"End to end with ONE planner."

"Someone with knowledge on the NDIS should support families to fill in forms."

"Create an IT system that tracks your progress."

3. Address NDIA workforce gaps

Families spoke about knowing their child best, but were clear they were not disability or NDIS experts. Families felt Local Area Coordinators (LACs) and planners often had limited understanding of disability, the NDIS and family's needs.

Gaps in the NDIA's workforce knowledge and expertise meant families experienced:

- Inconsistency in getting a good plan outcome
- Lack of guidance and support during the planning and goal setting phase, particularly where children had recently received a diagnosis
- Feeling overwhelmed, guilty and alone for not getting the best outcome for their child
- Stress around the application of parental responsibility. Families felt there was a lack of understanding about the additional care and responsibility provided by families of children with disability
- Being treated poorly by staff, including feeling interrogated
- Frustration with the burden of compiling reports and feeling they weren't given due consideration in planning recommendations and final decisions
- Poor communication between NDIA staff and families, including when staff went on extended leave or resigned.

"Don't rely on the luck of having a good coordinator. Train them better so assistance is consistent."

"My child has Down syndrome. When I submitted her diagnosis, we were kept on hold, and then we call them back only to be told they were waiting on something like, 'How long with your child have this disability.'"

"Apparently if you don't request certain assistance, you miss out. But how am I meant to know?"

"Need a degree to get my child the help they need."

"Because our child was so young they said, 'Oh, well, that's just parental responsibilities. That's what's expected.' ... There was no way... that's not a normal workload that would be expected."

"They did not consider the report at all."

"My LAC went on 3 months' leave and didn't hand our plan over to anyone, so it sat there waiting till they came back."

"My planner resigned [3 months ago] and I didn't even know until I was going through planning with another child."

"I had four planners in nine months."

When the access and planning process went well, families spoke about consistency in the workforce and having access to knowledgeable and supportive LACs.

"The one planner I had that was amazing actually called me to go over the plan and why we got what we did."

"The same LAC throughout applying for the NDIS and managing the next plans made it easier."

"Having a really good LAC that explained a lot about what my child could have in their plan."

4. Diagnoses and reports

The time and cost of getting a diagnosis was a big challenge for families. Families shared experiences of long wait times to access public services for diagnoses or having to pay thousands of dollars out of pocket to go privately.

"A family shouldn't have extra financial burden because they have a disabled child ... There should be a principle of either the waitlist is reasonable for public or there's funding to go private."

Families shared experiences of GPs, paediatricians and allied health professionals not understanding the diagnosis and report writing process. This put additional pressure on families to have in-depth knowledge of the system and advocate for their child's needs.

"I had to educate the paediatrician on the diagnosis process. I had to ask for mine to be rewritten because it didn't say things like 'lifelong'."

Families were also concerned about the need for lengthy and onerous reports. This was particularly frustrating when their child's situation or condition had not changed or only changed minimally, but they were still required to spend the time and funds to provide the NDIS with new reports.

"If nothing has changed, why do we need to pay for more reports? Can't it be a shorter report?"

When families had access to a diagnosis from an early age, they spoke about how this set them up for success when navigating the NDIS. Many families also spoke about the importance of knowledgeable and supportive professionals – from maternal and child health nurses identifying early signs of disability or delay, to GPs, paediatricians and allied health supporting them with knowledge of the NDIS and preparing accurate reports.

5. Accessing best practice, family centred supports

Families noted there was a lack of choice and control due to difficulties finding and accessing services. Families experienced lack of support navigating the system, long wait lists, and lack of service provision particularly in rural and regional areas.

Additional barriers included travel not being funded which ate into accessing other much needed services, and lack of knowledge by families and practitioners about best practice and family centred approaches. Families also noted that not every therapist was a good fit for their child, and that it could take years to find the right one due to waiting lists.

"You google therapists and you're overwhelmed."

"I think there should be an element of support coordination that's given to everyone the first year to facilitate this initial set-up, where someone who knows the local region and knows what's there can really help connect you with the right people the first time ..."

"I just rang around and whoever took me and got to me first was who I went with. There wasn't really a choice... I live in a regional city."

"I'm rural and with our wait times ... it's taken me too many years to find some suitability and get in there ... If it doesn't work you have to wait another 18 months to find a service that might work."

"We're rural and my child has a [Behaviour Support Plan] with restrictive practice that they have to implement ... there's simply not enough [registered providers] in the rural areas for us to have choice let alone choice and control."

"Travel costs also take a lot of our funding being rural."

"In our rural area, best practice isn't really being implemented. We have therapists come in, spend one hour with the child, but no time with the family, even though we want to learn tips on how to support our child too."

6. Improve early learning experiences

Families had mixed experiences in early learning. For some, playgroups, kindergartens and long day care centres were welcoming. Their staff had the right attitude and approach to working with their child and were willing to collaborate with allied health staff.

"Our daughter's childcare centre was fantastic. They organised additional funding for additional support through federal government."

For others, their child was excluded from early learning settings, they were unable to access the needed support and there were significant gaps in workforce knowledge and expertise.

"We have been asked to leave three playgroups."

"Being rural there are limited daycare places at the best of times. Had a lot of issues first getting daycare and then issues with older educators with no current training about kids with differences."

"Our experience was that there were a lot of kinders and childcares who said yes we can accommodate your child, and then after a week or two they said hmm, maybe we can't."

Families said strong connections between early learning settings and the NDIS was vital. This included supporting children to access allied health services onsite, and a collaborative approach between all professionals and the family. Intentionally increasing collaboration between the NDIS and early learning services would boost best practice in supporting children with disability, while increasing the knowledge and capability of all professionals supporting the child.

"We couldn't access childcare as my child had too many medical appointments and therapy."

"Our kindergarten teacher decided not to write autism on my child's transitional statement because she felt it might expire as my child outgrew it."

"It really depends on the educators you get, and then there is high turnover. We have had some great educators who really take on the advice of the therapist."

7. Improve school transitions

Transitions from early learning to school went well when the kindergarten/long day care, therapists, and schools worked together with families. Transitions also worked well when families were well equipped to advocate for their child, for example, through capability building activities delivered by advocacy services.

Families raised two messages about the NDIS and their child's transition to school:

- Children needed access to funded therapists in school. This was not always allowed and, in these instances, had a negative impact on their child's transition.
- The NDIS could do more to support the transition to school. Families raised concerns that funding was often reduced on the cusp of the transition.

"Not being able to have therapists go into the school has been terrible... I miss kinder and daycare because the therapists can go in there. I'm now the mediator with like 20 people."

Families spoke empathetically about the pressures many teachers are under. Families wanted teachers to have additional training and support so students with disability could successfully transition to school.

"It is 100% not the teacher's fault, there is so much already being asked of them and [they're] very unsupported."

"Speciality training needs to be given, teachers or education support staff aren't trained fully in special needs."

Too many families spoke about unsuccessful school experiences, which led to school exclusion and families considering home schooling as their only option.

"The teacher's melted and reached out to the paediatrician to setup a meeting with me to discuss [my child] being removed from school to be home schooled, as the school couldn't cater [for my child]."

Informed by families

This submission was informed by the experiences of 85 participants who attended ACD consultations on the NDIS. Of those, approximately 6 per cent were men and 94 per cent were women. Three per cent of attendees identified as Aboriginal and/or Torres Strait Islander. Nineteen per cent identified as culturally and linguistically diverse. Almost 30 per cent live in regional Victoria. At the time of the consultations, their children were aged 0 to 17 years.

This submission was also informed by an additional 17 participants who attended consultations in March 2023 that focused on kindergarten.