



## **Introduction to Association for Children with a Disability**

Our vision is that children with a disability and their families have the same rights and opportunities as all children and families.

ACD is the leading advocacy service for families of children with disability in Victoria. We are a not-for-profit organisation led by and for families of children with a disability.

For almost 40 years we have supported families across Victoria and advocated for children with all types of disabilities.

## **NDIS Planning for children and families**

The NDIS planning process is complex and demanding on families with children with disability. As a result there are children and families waiting too long for essential supports.

ACD has supported more than 4,000 Victorian families to access the NDIS for their child with a disability. We have invited families to share their experiences of the planning process and many have contribute their ideas for improvements.

These are the recommendations:

### **1. Planners to have greater understanding of disability and child development**

Overall planners need to have a greater understanding of disability and child development.

While Early Childhood planners are required to have child development qualifications this should be required for all planners working with children up to the age of 14. Planners working with young people aged 14 to 25 should have qualifications in youth work.

Planners' lack of disability knowledge is made worse by them not reading or taking into account information provided by specialists, medical practitioners and therapists. This is a very consistent complaint about the planning process.

The NDIS requires families to collect extensive information and reports about their child. These reports provide significant information about the child's disability and their needs and these reports must be read and taken into account.

*Every year we go through hours and hours of appointments and collecting information and verification of our child's disability. My daughter is 19 years old and has a severe brain malformation, I have so much documentation. These appointments cost a lot of time, money and were exhausting.*

## **2. Planners to understand and address complexity of family as a whole**

While the planning process does look at the capacity of families to provide "informal supports" it does not look at the family as a whole and address complex situations.

By taking such an individual approach centred on the participant the planning process can miss the complex needs which exist for the child and family.

The planning process needs to be structured to incorporate the needs of families including:

- Multiple children with disability
- Parents with mental health issues or a disability themselves
- Parents caring for children and other families members such as aging parents
- Grandparents or kinship carers raising children
- Relationship breakdown or family violence

*The NDIS will not look at us as a whole family and consider my needs as a disabled parent with disabled children - they will only look at us individually. Due to my son's age I've been told that some of the care we've asked for is not allowed as it's expected that the parent will do this anyway. But when you physically can't because of your own disability, it's a whole other situation.*

## **3. More planners and more training and professional development**

The need for additional planners is clearly demonstrated by the time it takes for the approval of assistive technology and reviews to occur, as well as how long it takes for administrative errors to be rectified.

The need for more training and professional development is dearly demonstrated by the lack of consistency - we regularly hear from families that they get a different answer every time they ask a question of the planner or call the NDIS contact centre.

*My NDIS planner has become uncontactable for months, I continue to wait for answers relating to services and time ticks on. I'm having to re-organise use of funds because I won't have time left to use those funds where they were originally intended to go.*

#### 4. Planning process to be face-to-face and families to see a draft plan

A child's planning meeting is emotional and exhausting for families. For families it feels like you have one chance to get your child the support they need. A number of practical steps can improved the planning process for families:

- It is essential that families are offered face-to-face planning meetings (not encouraged to take over the phone meetings).
- Planning meetings often go for more than 2 hours, some planners encourage families to bring their children but most children would struggle to sit through such a long meeting. Whether children attend should be at the discretion of the family.
- As part of the planning process families are required to complete the Paediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT). This can be long and distressing as it focuses on everything your child cannot do. Families would like the option to complete the PEDI-CAT online before the meeting.
- Families should see a draft plan before it goes to a delegate for approval. So many plans contain mistakes and omissions. A draft plan allows families to check they haven't left something out at the planning meeting and check what the planner has documented.

*There needs to be a lot more transparency about what goes into the plan before it is sent for approval. I've had two plans put through that didn't cover everything we'd discussed in the planning meeting. I really welcome receiving a draft version to make sure it covers everything. In our situation we had to ask for a review, then a change of circumstances to get the extra funds our child needed*

#### 5. Make sure plans don't create gaps for children and families, especially in relation to assistive technology, respite and positive behaviour support for children

Gaps in a child's plan are a major cause of stress for families. The most common gaps relate to assistive technology, respite and behaviour support:

- Major assistive technology and home and vehicle modifications, would be best covered in a separate supplementary plan. Too often when decisions are made regarding assistive technology and home and vehicle modifications the rest of the plan is reviewed and adjusted without consultation with the family. In addition, through the lengthy decision making process regarding major AT and modifications families don't have the confidence that their child's ongoing supports are approved.
- Children do best when their families are supported. Families with children with disability have much higher caring responsibilities. Respite should be an upfront part of the planning conversation and it should take into account the need for regular breaks and the particular pressures on families during school holidays.
- For families providing a much higher level of care for their child with a disability sometimes the best support will be assistance with home cleaning or care for their other children to enable them to meet the needs of their child with disability.

- Parental responsibility is unfairly applied and does not accurately assess the level of care being provided by families with children with disability compared with children of the same age without disability.
- Addressing behaviour issues early is in the best interests of the child and family, but often positive behaviour support is only available once there are significant behavioural issues.
- Families are often very stressed by what will happen if their capacity to care for their child changes due to their own health or family circumstance. Families have no confidence that the change in circumstance process will address their needs quickly enough.

*Our son is a wheelchair user and dependent on us for all activities of daily living. He frequently experiences pain at night and requires us to get up and reposition him 3 times a night. At our first planning meeting we were allocated less than 3 hours of respite a week. We were told it was up to us how we allotted the hours. We don't have the ability to do that when many of the hours go to supporting our son so we can stay employed!*

## **6. Simplify language, quickly address system and administration errors and let families know how long the process will take**

The NDIS needs to use accessible language that people can understand. Language that needs simplifying includes:

- Referring to families as “informal supports”
- Referring to respite as “sustaining capacity to care”
- Dividing the plan into core, capacity building and capital supports
- Having both reviews of reviewable decisions as well as (annual) reviews
- Early Childhood Early Intervention and the ECEI acronym

When administrative errors occur or mistakes are made on the portal these need to be corrected within one business day. Unnecessary delays create an additional administrative burden on families and greatly add to stress experienced by families.

When a correction is made to a plan this should not create a whole new plan – simply a new version. Otherwise every correction generates a new plan which means families have to go through the process of re-signing service agreements with all their providers.

Not knowing how long a process will take is also very stressful for families. The assistive technology and review process can take months with no communication to let families know where the process is up to.

*I am beside myself as I can only access one of my grandchildren's accounts and I need to arrange allied health for my grandson and thanks to someone not uploading relevant documentation I am not listed as his representative despite being his legal guardian.*

## **7. Reviews are triggered by mistakes, gaps and inconsistency – addressing these issues will reduce the number of reviews**

No family wants to go through the review process, it is long, complicated and draining on the family. Implementing the recommendations made in this submission will go towards reducing the number of reviews.

*I am currently waiting since February 2019 for a review and up to now there hasn't been any progress. There been no communication, no phone calls from NDIS I'm not sure when it will ever be review by the NDIS.*

## **8. Provide families with certainty. If plans are going well give families the option of a 12 month roll over rather than an annual review**

The annual review process is a source of stress for families, once again needed to collate reports and assessments. Families are concerned support will be reduced for their child.

If a family is happy with their child's plan there should be the option of a 12-month roll over without the need for a review.

*If you have a plan you are happy with, an easier plan review option would be great. The stress and time required for these meetings is too much!*

## **9. Support for families through planning process**

Getting ready for a planning meeting and waiting for the outcome is stressful and time consuming for families.

Families need child and family focused assistance with navigating the process. Once transitions is complete children will be the largest cohort entering the NDIS each year.

Families also need access to independent advocacy. The Australian Government National Disability Advocacy Program only funds one child and family service (Family Advocacy NSW). Funding for child and family focused advocacy needs to be expanded to all states and territories.

*Our lives are complicated and finding a way to navigate through it all with the help of ACD has been a lifesaver.*

## **10. Ensure plans create opportunities for children**

Finally it is the goal of the NDIS to support people with disability to enjoy an ordinary life. At times the planning process does not seem to create these opportunities for children.

Given how few children and young people with disability participate in mainstream community activities not actively supporting their participation is detrimental to long-term social participation.

We regularly hear stories such as:

*We could get Support Workers to assist my son attend a disability specific camp but not to attend his scout camp.*

*My son is learning wheelchair tennis alongside Dylan Alcott and Heath Davidson, he is about to grow out of his borrowed sports chair, it would be wonderful if a sports chair could be part of his plan.*

This is the opportunity for the NDIS to make a difference in the lives of children with disability.