



## Submission to the Review of the NDIS Act and Participant Service Guarantee

### Introduction to Association for Children with a Disability

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 disability.

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

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

### NDIS for children and families

The NDIS processes are complex and demanding on families of children with disability. As a result, there are children and families missing out or 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 NDIS and many have contributed their ideas for improvements.

These are our recommendations:

#### 1. Timely

There have been excessive delays for children in getting a planning meeting. We, and many families, have welcomed the Interim Plans as a measure to reduce the waiting times.

However, considerable delays continue at many other steps of the process, including: the time between a planning meeting and getting a plan, approval for Assistive Technology (AT) and consideration of reviewable decisions or changes in circumstances.

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

### **Our recommendations:**

- Each step of the process to have a maximum 4-week response time.
- Emergency situations such as urgent repairs or replacements of AT or a critical change in circumstances to have a 48-hour response time.
- The NDIA to report on timeliness results against guarantee as part of the quarterly reporting. Reports to be segmented by state and age of the participant.
- Any penalty for not meeting time-frames must not require participants or families to apply for compensation, it needs to be an automatic payment.

## **2. Quality measures**

In addition to timeliness, quality measures and positive outcomes for children are essential. Key areas of concern include:

- **Accessing ECEI as early as possible**  
Since the roll-out of the NDIS, there has been a significant reduction in the number of children under the age of 2 accessing early intervention in Victoria. Children with disabilities such as Down syndrome and cerebral palsy, which can be diagnosed at birth or in the first six months, are missing out on intervention at the earliest possible opportunity.
- **Family-centred ECEI**  
The NDIS recognises a family-centred approach as best practice for children and the NDIS Price Guide includes the option for Key Workers. However many families are not aware of best practice, and their desire to do the best for their child means they will often prioritise therapy above Key Workers.
- **Children whose families relinquished their care**  
Since the roll-out of the NDIS, there has been a small increase in the number of children who have been relinquished and a significant number who are at risk of being relinquished. This is devastating for child and family.
- **Transition to school**  
Starting school is a major transition for all children. For children with disability, there are considerable additional processes to ensure they are prepared, and that the school has additional funding in place right from the first day of school. In Victoria, as early intervention sat within the Department of Education and Training, there was considerable attention and support provided to ensure the best start to school. There has been a reduction in this support.

### **Our recommendations:**

- These four areas to be measured and publicly reported as part of the quarterly reports on a state by state basis.
- Increased training for child health practitioners about the ECEI referral pathway.

- ECEI plans to separate 'capacity building and therapy for the child' from 'capacity building and support for the family', so that families don't feel they are "taking" from their child's plan.
- Risks of relinquishment to be a discussion at planning meetings, especially when the known at-risk factors are present. Any change in circumstance which leads to a consideration of relinquishment to be responded to within 48 hours.
- Plans to include specific funding to support the transition to school.

### **3. Expert**

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

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 NDIS.

#### **Our recommendations:**

- 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 or other relevant qualifications.

### **4. Accessibility**

The accessibility of the NDIS is affected by the complexity of the process and the cost and time it takes to get reports from therapists documenting developmental delays or diagnosis. The administrative demands of applying and implementing an NDIS plan can impact on families' capacity to access the NDIS. Every measure must be taken to simplify the process.

Post the full roll-out, children will be the largest cohort entering the NDIS each year. Families need access to advocacy and pre-planning support to assist them to "navigate the maze".

While we know overall there is lower participation by families from Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) communities, to address this issue we need to know where the major gaps are.

#### **Our recommendations:**

- Cover the cost of assessments and reports for children with developmental delay and disability.
- Provide families of children with pre-planning and advocacy support as their children enter the NDIS.

- Gather data and include in the quarterly report the time it takes for participants and families to apply for and administer their NDIS plan. Use this data and consultation with participants and families to reduce red tape.
- Quarterly reports to include NDIS participation by age, CALD or ATSI community and state.

*'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.'*

## **5. Transparency and decision making**

Currently, families don't have any contact with the people who actually make the decisions about plans. Families receive very limited information about the reasons for decisions, often just references to the NDIS Act.

Parental responsibility is used as a reason not to fund supports even when a family is doing considerably more than a parent of a child without disability

*'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'd 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.'*

### **Our recommendations:**

- Planners, Local Area Coordinators and ECEI Coordinators to have delegation to make decisions about plans so that families and participants can meet directly with decision makers.
- Families to see a draft plan before it is approved.
- Families to be given detailed reasons for decisions.
- Publicly available guidelines and definition of parental responsibility.

This is the opportunity for the NDIS to make a difference in the lives of children with disability, we thank you for the opportunity to make a contribution.

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