



# Our hopes for our children and the NDIS



Association for  
Children with a  
Disability

# Summary of recommendations

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## 1. Help children and families to thrive

- Focus on inclusion, provide all children with core support so they can participate in ordinary childhood activities.
- Provide core support so families can have short breaks.
- Remove primary disability and take a holistic perspective.

## 2. Cut the red tape

- Stop the plan cuts.
- Explain what evidence is needed and give families extra time after the planning meeting to get necessary evidence.
- Offer all families support coordination.
- End the gap for Medicare funded mental health support.
- Provide greater clarity on parental responsibility.
- Coordinate multiple plans in one family by offering the same Planner or scheduling plan reviews at the same time.
- Include Companion Cards with an NDIS plan if needed.
- Make it much easier for NDIS participants to access the Disability Support Pension when they turn 16.

## 3. Make it safe and accessible for all

- More funding for child and family focused advocacy and peer support to navigate the NDIS.
- Improve quality and safety by requiring all early years capacity building providers to be registered.
- Train health care professionals and allied health therapists in writing reports and what the NDIS can and can't do.
- Structure plans and the price guide so they reflect best practice, including Key Worker model and capacity building for the family.
- Ensure Aboriginal and Torres Strait Islander and culturally diverse families can access NDIS support for their children.

## 4. Guarantee the future of the NDIS

- Greater representation of people with disability on the Board and in senior management.

# Introduction

As families with children with disability we have a huge vested interest in the success of the NDIS.

And even though we often feel confused by the NDIS, we are also experts with an incredible amount of knowledge and insight.

This document brings together the experiences and recommendations of thousands of Victorian families.

Over the past seven years the Association for Children with a Disability (ACD) has assisted families across Victoria to understand and navigate the NDIS and speak up for their children.

We have delivered more than **300** workshops helping thousands of families to understand this new system.

We have helped train more than **2,100** child and family workers in how the NDIS works.

We provide self-advocacy support to hundreds of families every year and we have asked families what will make the NDIS better for children.

We also bring our own lived experience — **80%** of our Board and **60%** of our staff are NDIS participants or parents of children and young people who are NDIS participants.

When we ask families what will make the NDIS better for children, the answers always fall into four key areas:

- 1. Support our children and families to thrive**
- 2. Cut the red tape**
- 3. Make it safe and accessible for all**
- 4. Guarantee the future of the NDIS**

In this document we share the experiences and wisdom of families with you, in the hope that the NDIS can change and be better for our children and those that come after us.

# The voices of families

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## 1. Support our children and families to thrive

Help our children to **thrive** not just become less disabled.

There is too much focus on capacity building and not enough on supporting the **rights of children to inclusion**.

Give our children an ordinary childhood, the chance to hang out with friends, have fun, dance, play footy and go to Scouts. Don't just focus on disability-specific groups but provide Support Workers to help them join **mainstream activities**.

Get rid of primary disability. My child is autistic, low vision and hard of hearing. Just focusing on his autism does not look at him as a **whole person** and all his support needs.

My child doesn't sleep. I know all children can have disrupted sleep but this is way beyond that. I am up 4 – 5 hours a night. I need help. But they say this is **parental responsibility**.

We are desperate for more core support. The subjective use of parental responsibility and **lack of respite is devastating**.

My child has autism, ADHD and anxiety. It is impossible to judge where each diagnosis starts and finishes. My child needs a psychologist to support their anxiety, their behaviour, their peer relationships. This relates to their disability and needs to be covered by the **NDIS not Medicare**.

Every plan, including early childhood, needs **core support**.

A Key Worker does not replace **Support Workers**.

*Encourage teens to be able to use a Support Worker to support friendship groups on social outings – not everything has to be with an organisation.*

*Provide **transport funding** before they turn 18! Most teenagers do not rely exclusively on Mum and Dad to get them places.*

*Support Workers are needed to help teenagers get **real work** and real volunteering opportunities.*

*My child is funded for social skills. It would make sense to use this **funding at school**. I know the NDIS and schools are separate, but it would be better for them to learn and practice social skills alongside their classmates.*

***Support Workers are gold** and we need more. They give our children the support to play and have fun and build independence, they help implement therapy goals, they enable us as families to continue to care.*



## 2. Cut the red tape

Every review I'm terrified key support is **going to be cut**.

I'm left wondering what support will my child get as they get older. It is hard to know **what the future holds**.

The appeal process is awful. You have to fight. If you go to the AAT they send you long legal letters and have lawyers in the room. It is **so intimidating**.

The time it takes to get reports is crazy. If you miss something and don't get the right evidence, your child's plan can be slashed. The process of **appealing is exhausting** and emotional.

The **burden of proof** sits with us. We have to prove our child's needs year after year.

You are **always on a knife edge**. Either a therapy is working too well and the NDIS says that's enough, no more. Or your child isn't making gains quickly enough and so the NDIS says that's not working and stops funding it.

The amount of work for families is enormous. I spend at least a day a week on **NDIS admin**.

Give all families **support coordination** with their first plan.

The NDIA Partners can be great or awful. They are both the gatekeeper and a source of information. While they can be supportive they cannot replace **Support Coordinators**.

When you speak with a Local Area Coordinator they say one thing, then a Delegate comes in and **changes** it all.

There is **no accountability** for Local Area Coordinators. If they do the wrong thing there is no one you can complain to.

Mistakes are made all the time. I have to repeatedly ring the NDIA just to **get things fixed**.

I have **multiple children with NDIS plans**, that means I'm always preparing for a plan review. It is exhausting.

In families where parents and children have NDIS plans the **family as a whole** is not considered. You can't look at everyone separately.

Why does the speech therapist **charge my daughter more** because she is on the NDIS? It doesn't seem fair.

**Include Companion Cards** with an NDIS plan. One less thing for us to do.

When my daughter with very high support needs turned 16 the process of applying for the Disability Support Pension was a **bureaucratic rollercoaster**. The NDIS had all the information about her disability, why couldn't that prove she was eligible for the DSP.



### 3. Make it safe and accessible for all

When trying to find **early intervention services** for your child you are left on your own. You don't know what is a good service and what is not.

I don't know if I made the **right therapy choices** for my child.

Where I am in regional Victoria I had **no choice**.

When you have just found out your child has a developmental delay or disability you are **very vulnerable** to people claiming they can fix your child.

**Waitlists** for therapists are such a problem.

There are so many waiting lists for therapists I just took **whatever I could get**.

Don't expect families to suddenly understand **best practice**. Make sure that is what providers are offering.

Only **registered providers** in the early years.

The NDIS has a lot to learn from mainstream services for young children. If you're choosing child care, family day care or kinder you can choose between local services that are all accredited or working towards accreditation. You can search for services and find out about their **quality standards** on the government's Starting Blocks website.

Spend time and money training Maternal and Child Health nurses, paediatricians, GPs and therapists on what the NDIS can do and what it can't. Teach them **how to write reports**. Don't expect families to do this.



*I learnt so much from other families and from ACD. More families **need this support.***

*As an early childhood educator, I work under the Early Years Learning and Development Framework. This embeds family-centred practice. It acknowledges families as their child's first teacher. It promotes **cultural safety** and indigenous ways of thinking. It focuses on the children feeling like they belong. The NDIS early childhood approach and service providers need to do the same.*



#### 4. Guarantee the future of the NDIS

*I want the NDIS to support my children **as they grow up** and become adults.*

*I want to see adults with disability involved in the governance and **leadership of the NDIA.***

*The Board and management need to **hear more from families.** A child and family advisory group should be established.*

# We are not alone in raising these issues

As families we are not alone in raising these concerns and recommendations.

In 2019 the Tune Review recommended that the NDIS Rules be amended to reinforce that reasonable and necessary supports for children with disability recognise the additional informal supports provided by their families and carers.

The Tune Review also recommended providing access to supports in the home, other forms of respite and building capacity for families and carers to support children with disability in natural settings and the community.

In the recent report Support for Families and Carers (November 2020), the Independent Advisory Council to the NDIS provides compelling evidence of the importance and impact of caring.

The report outlines the importance of short breaks, supports in order to participate in paid work and a 'whatever it takes' approach to supports to facilitate a healthy well-functioning family.

In the report on Supporting Best Practice in Early Childhood Intervention (March 2020) the Independent Advisory Council highlighted the importance of a family-centred approach, dedicated goals and resources in plans to build family capacity, and support to help the family to thrive.

While the ECEI reset and subsequent changes to the Early Childhood Approach have addressed some of these issues, particularly around building capacity in natural settings, there is a long way to go to ensure young children receive high quality, family-centred support.

There has been no consultation or guidance around reasonable and necessary supports for families or respite. There is no clarity around parental responsibility.

The NDIA's own report Young People and the NDIS (June 2020) reveals the low level of participation by children from culturally diverse backgrounds. This indicates much more needs to be done to build the cultural safety of the NDIS.

The report also breaks down the very high utilisation rates of the small core support budgets in children's plans. This demonstrates how important core support is to children and families.

## About ACD

### **Empowering families for over 40 years**

ACD is Victoria's leading information, support and advocacy organisation for families of children with disability.

We are a trusted source of information and support for more than 10,000 families and for many professionals working with children with disability.

We are a statewide service providing families living in Victoria with up-to-date information and resources, self-advocacy support, capacity building and peer support. We support families with children aged 0–18 who have any development delay or disability.

We empower parents to speak up for the rights of their children, help them navigate 'the system', including the NDIS. We work to ensure schools, children's services and recreation opportunities are inclusive of children with disability. Our work is informed by the social model of disability.

Our vision is for children with disability and their families to have the same rights and opportunities as other children and families.



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**The NDIS is confusing and stressful,  
but it also opens up opportunities  
for our children.**

For more information and an opportunity to meet with families with children with disability to discuss these recommendations, contact:

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