Child+Family Disability Alliance

Submission: NDIS Review

August 2023

The Child+Family Disability Alliance is a national alliance between Kindred (NSW), Kiind (WA) and ACD (VIC). We are family-led, not-for-profit organisations that advocate for and support children with disability and their families.

Together we assist more than 30,000 families raising children with disability each year. These families reflect the diversity of disability and the diversity of the Australian community.

Over the past 10 years our organisations supported thousands of families to transition to and access the NDIS. We have a unique understanding of the specific issues faced by families with children from birth to 18 who are NDIS participants.

21 recommendations to make the NDIS better for children and families

Better outcomes for children:

1. Increase funding for family-led capacity building that help families navigate the journey.

2. More core support to promote the inclusion of children in their community and provide support to families.

3. Partnership with education. From policy settings to promoting a partnership approach between NDIS funded therapists and educators, teachers and schools.

4. Pilot models such as early childhood education and care settings being early childhood intervention providers.

NDIS that works for children and families

5. Acknowledge the fundamental roles families have in children's lives. Introduce the concept of family plans.

6. NDIS partners in the community to refer families to local registered early childhood intervention providers that offer a lead therapist model and family-centred practice.

7. NDIS partners to refer families to family-led capacity building organisations.

8. Update information on the Raising Children Network to provide families with a clear explanation of allied health therapists, and what good therapy looks like.

9. Clear transparent criteria for which families will be offered support coordination with their first plan.

10. All plans to come with a plain English explanation that depicts the plan as "building blocks" that will help the family support their child's development.

11. Incentivise the provision of family-centred practice.

12. Introduce market levers to prioritise young children's access to early intervention.

13. Fund travel for therapists separately.

14. Clear transparent definition of parental responsibility.

NDIS that is fair and easy to use

15. Capacity building for trusted early childhood professionals to understand the pathway to accessing the NDIS early childhood approach.

16. Address waiting lists and costs in getting a diagnosis.

17. Get rid of primary diagnosis – it rarely tells the full picture.

18. Much greater transparency around planning. What is the role of Typical Support Packages? If families need to get reports provide therapists with training and easy-to-use templates.

19. Goals in early childhood approach plans to be “practice goals”.

20. Families can request a plan roll-over if their child’s plan is working.

21. Families see draft plan before it is finalised.

1. Better outcomes for children and families

Strengthen family-led capacity building

Family-led organisations play a pivotal role in helping families navigate and understand the disability journey and create a good life for their children.

As family-led organisations, ACD, Kiind and Kindred reach more than 30,000 families a year. We offer hope, help families connect with others, encourage families to be part of the community and enjoy every-day activities with their children.

Importantly we not only help families navigate the NDIS, we connect families to support outside of the NDIS. Helping children and families to access education, sport, recreation and other family activities.

Families speak highly of the role we, and other peer support and disability advocacy organisations, provide in building their knowledge, skills and confidence.

Effective family-led support stretches across the ages and stages, all disability and offers multiple touchpoints with varying intensity, from tailored information through to group support and one-on-one assistance.

Family-led organisations help families navigate the maze of support, that is funded by both state and Commonwealth governments.

Family-led organisations help families move from distress to hope, we showcase a good childhood and seek to change attitudes towards children with disability.

> *"The patience, understanding and wealth of knowledge that you have. Your support has been invaluable and I didn't feel like I was drowning.*
>
> *I loved the honesty you both shared with respect to the learning curves we all experience. Everything was helpful and great it was fellow parents who had been there done that.*

It is vital family-led organisations continue building the capacity and self-advocacy of parents and carers, so they can continue to care for their children.

Current investment in family-led capacity building is piecemeal and grant based. There are great outcomes from ILC investment that need to be sustained.

> *"Thank you for your continued advocacy. Your website and workshops are fantastic.*
>
> *Thanks for everything guys – it's nice chatting with others who understand our 'language' and our 'situation' ☺."*

CASE STUDY – Teens and Beyond

Teens and Beyond is an ILC funded activity delivered by ACD. It builds the capacity of families to support the growing independence of their teenagers with disability.

An evaluation by the Parenting Research Centre found there were significant and sustained improvements six months post-program in parenting self-efficacy, parent confidence to support their adolescent's independence, and parental sense of empowerment.

The funding for Teens and Beyond current ends in June 2024.

> *"You can feel as though you're drowning, because there are so many things you're trying to do and so much you need to know in order to stand up for your child.*
>
> *Your support is like a life ring that helps you rise to the surface."*

Core support to promote inclusion

Children with disability and their families need more core support from the NDIS to enable a "good life" for them all.

Core support has a double benefit. It enables children to enjoy ordinary childhood activities and helps families juggle all their commitments, including caring, parenting, paid work and looking after their own health and wellbeing.

> *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.*

Support Workers help build "other boats in the ocean" by engaging children in their local community. Support Workers can mean children can participate in regular childhood activities rather than always attending "disability" activities.

Support Workers are incredibly important in the transition from childhood to adolescence to adulthood. They enable teenagers to spend time away from their parents, something that is critical for all teenagers.

"Support workers to help my child join activities like scouts."

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

Access to core support is often denied because of "parental responsibility". The reliance on parental responsibility by decision makers causes significant distress for families. Families say the use of parental responsibility demonstrates a gross lack of understanding about what it meant to care for a child with disability.

There are no publicly available guidelines on parental responsibility which raises significant concerns about consistency and transparency.

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

The health of families of children with disability worsen the longer their children are NDIS participants. For families caring for children from birth to 14 years, those who rated their health as good, very good or excellent deteriorated from 75.3 per cent to 62 per cent over four years.

Families want more support for carers including peer networks, access to advocacy support, more mental health services and access to respite.

"More support for carers and realisation that not all care for a child with disability falls within the normal remit of parental responsibility."

Partnership with education

Families welcome a strong connection and collaboration between early learning, schools and NDIS funded support.

Child development does not occur in isolation. Skills develop at home, in long day care centres, kindergarten and school.

Children receive the best support when NDIS funded therapists work with early childhood service or school and educators and teachers. However, this is not systematised and too many families feel their children aren't viewed holistically because of the divide between the NDIS and education systems.

"Not being able to have my child's therapists go into the school has been terrible. The school hasn't set up a meeting, my child's goals are completely different. The transition has been absolutely horrendous, I can't sugar-coat it."

The lack of joined up systems of support around children results in an incredibly complex and time-consuming workload for families. In the first five years of parenting a child with disability families:

- Navigate a diagnostic journey
- Access the NDIS and all that is involved in putting a plan into action
- Work with child care to apply for inclusion support
- Separately apply for kindergarten inclusion support
- Work with school to apply for school-based individual funding.

Each of these steps requires forms, reports, evidence, meetings, planning and more.

When children aren't viewed holistically and don't access the right level of support in education, it often results in poor outcomes for children including increased risk of exclusion in early learning and reduced hours of attendance at school.

Families want the interface issues to be addressed so they can focus on supporting their child and family to thrive.

"The disconnect between NDIS funding and education is confusing and hasn't worked for us."

"Make kinder/school work in a more functional way with the NDIS."

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

"At kinder we were lucky to have one educator who has a child with an autism diagnosis and really understood and helped my child immensely.

School has been good so far, and happy to work with our therapists.

After-school and holidays have been more difficult mainly due to educators that just don't get it and the outside school hours care company hasn't sought any further info… I've reduced as much as possible the need to have my child in outside school hours care, including reducing my working hours."

Pilot new approaches

With the roll-out of up to 30 hours a week of 4-year-old kindergarten and pre-school in NSW and Victoria it is essential that new ways of working together between the NDIS and early childhood education and care are developed.

Pilot options such as NDIS funded services being provided by early childhood education and care providers or having a preferred provider relationship.

2. An NDIS that works for children and families

Recognise the fundamental role of families

The NDIS currently ignores the fundamental role families of children play and the importance of supporting families to care for their children. It is contrary to the approach taken by universal children's services, such as schools and health care, which see families as the primary support for a child and seek to work in partnership with them.

The information for families and carers on the NDIS website makes the opening statement: "The role of families and carers is often essential in supporting people with disability to realise their goals, so it is important to include them in discussions about supports." This tone continues in the NDIS language that refers to families as "informal supports".

Supporting families goes beyond promoting family-centred practice and starts with "family plans" that see their child's primary support as their family. Children do best when families are supported.

Guide families to best practice service providers

Many families are cobbling together information about the best way forward. They seek advice from other families, therapists or service providers, online communities and peer support organisations, to understand how to utilise their child's plan.

> *"In our first year of NDIS we spent almost nothing. I was overwhelmed and unsupported and didn't know where to locate therapists or support workers."*

Out of necessity, families spend much time searching for services because there is no one source of truth or known place where families can go for support and advice. Families search for services by googling and looked to friends, family, Facebook groups and other parents for advice.

Some families report that their Early Childhood partners and LAC provided lists of potential service providers, others report they had been told that NDIS partners couldn't provide any advice on where to find therapists.

Many families say that they had never heard of an OT and weren't sure what therapy to prioritise.

> *"I had no idea what I was doing, what I needed and what they (therapists) were meant to do. I feel like our first physio knew this, and took us for a ride."*
>
> *"I had no idea who to trust."*

Unfortunately if families go to the Australian Government funded parenting website the Raising Children Network Parent Guide: Therapies for autistic children there is a strong emphasis on intensive therapy, and no explanation of how family-centred speech therapy and occupational therapy can work with their child and family.

"You google therapists and you're overwhelmed."

Lack of transparency and consistency around what services families can access and what their child's funding can be spent on increases stress.

"LACs and Early Childhood Partners regularly give conflicting or incorrect advice and often try to gatekeep what funds can be used for."

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

Leaving families confused and overwhelmed does not help children.

Early Childhood partners should refer families to several local, registered capacity building providers that offer the best practice "lead therapist" model. This does not remove choice and control, because families can go elsewhere, but it will guide families to best practice support that will assist their children.

NDIS partners should also refer families to family-led capacity building organisations.

Offer Support Coordination

Families suggest support coordination be part of every child's first plan to reduce pressure on families. When families apply for support coordination, many are refused, including families with multiple children with disability, or whose child had very particular needs that make sourcing supports even more difficult.

Clear transparent guidance is needed on who is eligible for and proactively offer support coordination. This should include: families with more than one child with disability, newly arrived families to Australia, families with limited English or digital access, children in out-of-home care and families engaging with housing, family violence or child and family services.

In addition to caring for their child families say accessing the NDIS and putting a plan into action is an unreasonable workload.

"There's so much learning curve, so much research put on parents instead of having experts in the area do it, which would really, really help."

NDIS plans as building blocks

Families need more guidance on how best to use their child's NDIS plan.

$20,000 is a large amount of money in any family's household budget. Many families expect an NDIS plan of $20,000 to provide more support than it does. Families are shocked that allied health providers consistently charge higher hourly rates for NDIS participants.

> *"Why does the speech therapist charge my child more because they are on the NDIS? It doesn't seem fair."*

Early in their child's journey families will almost always prioritise therapy for their child over any other form of support.

This can mean families don't see the benefit of a lead therapist, parent coaching sessions or involving therapists in meetings with early childhood educators.

Plans should come with a plain English information sheet that is structured to help families understand what the plan will provide, and outline what the plan can and cannot be used for, not just as a dollar amount.

The information sheet could present the plan as "building blocks" that reflects best practice. For example, information sheets could show the plan includes a "lead therapist", fortnightly therapy, a meeting once a term between the child's educators and the lead therapist, a meeting once a term between the family and child's lead therapist. This will help families understand what the plan will provide for their child.

> *"Information on what we can get. I feel like it's a secret you have to find out what you can get from others. Consistency!"*

Incentivise the provision of family-centred practice

Families want to feel confident that the services they are accessing deliver the best for their child. But they feel unclear what best practice looked like.

> *"I hear a lot of those terms [best practice and family centred practice] and found very little difference in the practice of people who used them."*

There is some concern about therapists providing one on one supports to a child without building the knowledge and capacity of the family so they can continue to support their child.

> *"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."*

Families say how it is importance to get support on how to use their child's plan and find the right services.

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

Prioritise young children in waiting lists

The importance of the early years in child development is well established. Early childhood intervention builds on this critical developmental phase.

However, the NDIS has not undertaken market stewardship to ensure that young children can access early intervention as quickly as possible.

Long waiting lists for services is a barrier for families and in a significant number of instances leads to plans being underspent.

> *"We had to call lots [of therapists] and was told waitlists closed for a lot of them, or had one year or more wait lists."*

Families with young children report having to contact dozens of therapy providers only to be put on waiting lists. This is administratively burdensome as it requires filling in an online waitlist form and emailing a copy of the plan. It is particularly challenging for families with limited English or low digital access.

Families living in regional and rural areas report additional hurdles in accessing the right support for their child due to limited offerings.

While the early childhood approach means that young children can access an NDIS plan relatively quickly (there has been significant improvement in this area) children can then spend months on waiting lists for services.

This issue is reflected in NDIS data that shows plan utilization for children aged 0 to 6 is lower than any other age group. Many service providers that previously focused on children aged 0 to 6 now offer services to participants of all ages.

There is nothing in the structure of NDIS plans or market stewardship that prioritises young children's access to therapy services despite the importance of early intervention. Market levers need to be implemented to incentivise service providers to prioritise young children's access to early intervention.

Almost 50 per cent of families said they didn't spend all of the funds from their child's last plan.

Of these families, they said they couldn't find a find a therapist or service with availability, they couldn't find a regular time that worked for their child and family, couldn't find a replacement therapist when theirs changed, there were no therapists in their area, or they didn't know what types of services or supports to purchase.

Fund travel for therapists separately

Including therapist travel as a separate line item in children's plans is a practical strategy that will mean children get therapy where it will have the biggest impact.

Providing early intervention in every day settings is best practice and gives children the best opportunity to practice skills every day. For young children this means therapists seeing them at home or in their early childhood education setting.

Most plans do not include travel time for therapists. This can result in children only accessing therapy in clinical settings. Some families feel they have to reduce the number of therapy sessions their child receives to use some of the therapy time for travel time.

3. NDIS that is fair and easy to use

Improve understanding of access in early childhood professionals

Many families first heard about the NDIS from friends and family or from other services such as maternal child health nurses. For families and communities who may be less likely to have friends and families already in the NDIS such as some culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander families, this raises concerns about their pathways into the NDIS.

More than 57 per cent of families said applying for the NDIS was difficult or challenging in some way.

The knowledge of professionals of the referral pathway into the NDIS is identified as another gap by families.

Trusted early childhood professionals need to know about the Early Childhood Approach, including that a diagnosis is not needed between birth and 6 years of age. This is particularly important for professionals working with Aboriginal children and families, new arrivals and families receiving support from housing, family violence or child and family services.

Address waiting lists and costs in getting a diagnosis

Not requiring a diagnosis to access the Early Childhood Approach between birth and 6 years old is as an important feature of the scheme.

But getting a diagnosis by the time a child turns 6 can be expensive and there are currently lengthy delays.

Waiting times to access public services for diagnoses and reports is another issue. When families can't access public services within a reasonable timeframe, they seek support from private professionals at significant personal cost. Families unable to afford this missed out on months or years of support while they wait.

> *"It took over two years to get a diagnosis. During this time the distress to mother, child and family was debilitating and impacted all our lives emotionally, mentally, financially."*

Families found the emphasis on primary diagnosis is restrictive in building a full picture of their child's needs.

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.

Greater transparency around planning

Families report the enormous emotional toll of the current planning process.

Families say it often feels like a full-time job to go through planning, and there is a lack of transparency and consistency in outcomes. Experiences are often dependent on whether families were allocated knowledgeable and supportive Early Childhood Partners, Local Area Coordinators (LACs) or planners.

Families say it feel like the system skewed outcomes towards those with the best knowledge of the system including how to use the right jargon, those who are lucky enough to be linked in with the right support, and those with the right skills to research the intricacies themselves.

There needs to be much greater transparency around planning. If Typical Support Packages are the basis for plans why do families to spend so much time and resources on getting reports from therapists?

If reports are required then the NDIS should training therapists on the types of reports they need. The current early childhood report template is long and unwieldly.

More than 75 per cent of families said the NDIS planning process was difficult or challenging in some way.

Families often feel overwhelmed or like they've failed their child by not getting the right level of support. Families report significant concerns about recommendations and advice from professionals being disregarded in the planning process.

> *"We had a million reports and requested a review when the new plan time was coming up. NDIS just rolled it over and didn't care about all the new reports and changes and needs.*

Thinking and talking about it is soul draining."

Too many families aren't supported to understand what is available to support their child, aren't given explanations about the outcome of their child's plan or how to use their child's plan.

More than 70 per cent of families said the planner's decisions were not clearly explained to them. A further 15 per cent of families said someone tried to explain the planner's decisions, but not well.

Practice goals

Families see goals as a secret language that if you know what to do, this result in better NDIS plans. Families are concerned their children missed out on funding because their goals weren't formulated in a particular way. Some goals reflect an initial issue the parents had noticed, such as toe walking, but didn't reflect emerging priorities like toilet training and communication.

Goals should be used differently in the early childhood approach and reflect the broad common goals to children having a good childhood: sleeping well, eating well, developing toileting skills, learning to communicate, playing and developing motor skills. Any discussion of goals as part of the planning process for the early childhood approach should simply be practicing how goals work as part of an NDIS plan for children aged 9 and older and not greatly influence the plan.

> *"My child's first plan was made easier due to having a fantastic Early childhood coordinator who suggested and helped me figure out goals. It was difficult as a first-time user to know what I should be asking for and how to word the goals."*

Able to request a plan roll-over

Many families spend hours preparing for an NDIS reassessment meeting only to be offered a plan roll-over in the week before the meeting. This means the child gets the same level of funding for the following year. If a plan is working families should be able to request a roll-over and avoid the stress and workload of a reassessment.

Get a copy of the draft plan

Families are often asked question like would you like this to be a one- or two-year plan without seeing the plan. It's like a stab in the dark. There have been many recommendations that families get to see a draft plan as part of the planning process. This needs to happen immediately and must be included as part of the PACE roll-out, with families getting a copy of the draft plan before having the plan explained to them by an NDIA planner.

Families want to work with one person from beginning to end. They want that person to have emotional intelligence, disability and NDIS knowledge and expertise, and someone who will provide them with proactive support to get the best outcome for their child.

> *"Having no frame of reference and being completely unaware of options."*

> *"Requesting too much support paperwork, too bureaucratic."*

Self-Management

Most families with young children have self-managed plans. Families with self-managed NDIS plan must work out budgets, service agreements, contracts, invoices and payments. These are complicated tasks.

Many families report self-managing their child's plan can feel like a part-time (unpaid) job. Managing funding to make their child's plan last is onerous and unreasonable, particularly for families of young children and adds unnecessary stress and pressure.

Some families who are struggling to organise to pay invoices are told their child can no longer attend therapy services.

Remove the stress and explain the differences between the types of plan management and offer families plan management in their child's first plan.

> *"Self-management is not as easy as online banking."*

Informed by families

The Child+Family Disability Alliance is a national alliance between Kindred (NSW), Kiind (WA) and ACD (VIC). We are family-led, not-for-profit organisations that advocate for and support children with disability and their families.

Together we assist more than 30,000 families raising children with disability each year. These families reflect the diversity of disability and the diversity of the Australian community.

Over the past 10 years our organisations supported thousands of families to transition to and access the NDIS. We have a unique understanding of the specific issues faced by families with children from birth to 18 who are NDIS participants.

Kindred is by families, for families raising children with disability and developmental delay in New South Wales. We empower parents and caregivers to grow their skills, knowledge and confidence to support their children and family to thrive. We are a not-for-profit organisation, and our peer groups and programs, trusted resources, and supportive community are online and free.

Kiind is a family-led, independent peer support organisation with 36 years of operation. Kiind supports families raising children living with disability and developmental delay. We provide practical assistance, emotional support, connection to other families and help to find the most appropriate services and supports for children and their families. We support 6,000 families in Western Australia and all services are provided free-of-charge.

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. We provide information, capacity building and advocacy support to families raining children from birth to 18. We support 15,000 Victorian families a year.

For this submission consultations were undertaken with 278 families of children with disability. Of those families:

- 40% were from New South Wales, 43% from Victoria, 9% from WA, 8% from Qld and 8% from ACT, SA and Tasmania. No families were from the Northern Territory.
- 75 per cent of families lived in a metropolitan area, 21 per cent lived in a regional area and four per cent lived in a rural area. No families lived in a remote area.
- Two per cent identified as First Nations and 15 per cent identified as culturally and linguistically diverse.

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