



Association for
Children with a
Disability

Association for Children with Disability

Snapshot: Foundational Supports – what works for families

July 2024

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. Our vision is an inclusive community where children with disability and their families thrive.

In 2023, the NDIS Review report recommended investment in two streams of foundational supports – general and targeted – to create a better ecosystem of support for people with disability, their families and carers. For children with disability, the report recommended these foundational supports be closely linked to and integrated with education services.

In May 2024, ACD held two online sessions with families of children with disability to understand what a strong foundational support layer could look like. We asked families about their experiences with peer support and parent education. We asked families what boosted collaboration between early learning and school, and early childhood intervention lead practitioner would mean for their family.

These sessions gave families the opportunity to share their experiences, connect with other families and have their voices heard on issues that affect them.

This snapshot highlights families' experiences of what's working well, where there are gaps, and opportunities for Victoria to ensure children with disability and their families can get access to the support they need outside of the NDIS.

For more information contact

Karen Dimmock CEO

karend@acd.org.au

0448 912 786

Strong Foundational Supports

When families are connected with their peers and empowered with information and resources, children with disability and their families thrive.

Families tell us when they have these supports it can increase resilience and wellbeing – however, outcomes for families in the NDIS aren't as good as they should be with challenges in accessing supports and services that meet the needs of their children and family, and declining rates of health and life satisfaction.¹

Foundational Supports are an opportunity to strengthen existing offerings and address identified gaps across peer support, family capacity building and best practice early childhood intervention to improve outcomes for the whole family.

This snapshot builds on a range of approaches and programs that families told us work that we highlighted in our snapshot on exploring strong foundational supports for Victorian children and families.²

Next steps

Children with disability and their families have unique needs that will require a dedicated response to ensure Foundational Supports are designed with these unique needs and circumstances front of mind.

The Victorian Government should create a child and family specific taskforce to inform Victoria's Foundational Supports to ensure it is fit-for-purpose.

1. Targeted Foundational Supports

Most families with young children with developmental delay and disability have only known the NDIS. To explore other options of their child getting support we asked them to put the NDIS to one side and to imagine what it could mean for their child and family if their child could access a lead practitioner in the context of early education or school. Families consistently identified three key benefits: better outcomes for children, reduced pressure on families and boosted collaboration and workforce capability.

How Foundational Supports could be embedded in early learning and school

Embedding access to a lead practitioner in early learning and school would enable the practitioner to deliver a best-practice approach by working with the child, the child's educators and teachers, and the child's family. The lead practitioner model could include observing children, providing some one-on-one assistance to support their engagement in learning, small group sessions to develop and refine a key skill, and working with the educator/teacher and child's family to ensure everyone is on the same page. Identified periods for reflection and assessment to understand whether strategies have been effective would also be included.

¹ National Disability Insurance Agency 2022, *Family and carer outcomes to 30 June 2022*.

² https://www.acd.org.au/wp-content/uploads/2024/04/ACD_Snapshot_Exploring_Foundational_Supports-April_2024.pdf

1.1 Better outcomes for children

Families spoke about children missing out on early intervention due to long wait lists for services, challenges finding appointments at times that worked around education and parent's work commitments, challenges accessing a diagnosis and difficulties accessing supports for children with more complex needs. This meant issues that could have been addressed early weren't and contributed to challenges down the line.

Families spoke with optimism about better learning outcomes for their children through embedding access to a lead practitioner in early learning and schools including:

- More support for emotional regulation leading to reduced meltdowns.
- Less exclusion and increased time spent learning.
- Children less likely to be playing catch-up.
- Improved connection with peers.

However, some families were cautious that there may not be equitable access to supports due to location.

'Levels the playing field for children so they can access support regardless of where they are on their learning journey.'

'I think that would have been amazing in primary schools. So if you have the allied health people on site from the moment that the teacher or the parent or anyone picked up something they could observe the child, they could fill out the report, make suggestions.'

'If children / educators could access allied health children would be able to access learning and have a positive experience of education and community.'

'When teachers are inclusive, other children will be too.'

'So I would like to see modelling and supporting peer interactions, children engaging with each other. I'd like to see allied health talk to educators about how to support children's learning in routines that are based on what their daily routines are in their long daycare or kinder or school environments. I would like to see them also be part of a relationship where educators can ring them and say, "Hey, what do you think about this?" or they could be part of sitting in on team meetings or planning so that it's not just then and there what's happening as well.'

1.2 Reduced pressure on families

Juggling travel time to and from appointments contributed to career disruption for many families, in some cases leading to financial hardship. Some families spoke about having to pick and choose which person in their household needed support most urgently due to financial constraints, particularly for families where multiple children had disability and support needs.

By embedding access to lead practitioners where children already learn, families highlighted the opportunity for greater understanding among parents in the school

community about the needs of children with disability. They also noted the additional expertise of allied health professionals would reduce the burden on families to give schools and teachers information and reports to justify supports for their child.

'It will be great as right now we need to ... drive to and from multiple appointments and it is disruptive on my kid's school life and I need to give up my career to manage this.'

'Reduce stress load of getting to appointments.'

'Potential for better understanding among other parents about why a child with disability behaves in a certain way.'

1.3 Boosted collaboration and workforce capability

Families have long advocated for better collaboration between their child's allied health therapists and education to get everyone on the same page, create more consistency for children, develop shared strategies and coordinate goals. Families spoke about benefits to staff, including:

- More insight and understanding of child's needs and behaviours.
- Real-time support for teachers to get advice from professionals who understand the classroom context and the child.
- Tailored strategies to support children, including identifying and implementing reasonable adjustments, room set-up, and ways of addressing challenges before they escalate.
- Increased understanding between teachers, education support staff and allied health.

These benefits could reduce stress and pressure on educators and teachers by giving them the resources they need to increase their knowledge and skills to better support children with disability. Families said when their children are supported, they are less likely to have outbursts and meltdowns.

Families also highlighted the benefits to staff-family relationships by removing the need for families to take on the primary role of providing information and education to staff about disability and their child's support needs.

'Better supported kids = easier classroom to teach.'

'Better relationship between families and school as allied health can take on role of educating teachers.'

'Reduce burden on families to provide schools/teachers with information and reports to access funding.'

'Teachers would feel more supported.'

2. General foundational supports for families

The NDIS Review report highlighted the importance of peer support and family capacity building. The report recommended investing in universally available family programs for families of children with development concerns and disability that includes information and resources, and peer support.

We asked families about their experiences of peer support and parent education, including what they valued and opportunities for programs to better meet their needs.

When peer support and parent education worked well, families talked about benefits including:

- Sharing knowledge
- Gaining practical advice
- Building skills and learning new strategies with guidance from professionals and peers
- Feeling connected, validated by shared experience and feeling understood
- Benefiting the whole family, including parents/carers, grandparents and siblings.

Key elements that made programs a success included being:

- Led by parents of children with disability
- All disability and diagnostic specific
- Specific to the needs of families raising children with disability rather than general information about children
- Short, sharp parent education sessions that focus on one or two points that families could implement.

2.1 Enabling participation

To access the right services, families need to know they exist, where to find them, and have the right support to participate. Families identified opportunities to overcome barriers to participating in peer support and parent education sessions, including:

- Leveraging GPs, maternal child health nurses, early learning services and schools to boost awareness and promote services
- Providing financial or practical support to look after children for families who need it while they attend peer support and parent education sessions
- Increasing scheduling flexibility with more offerings across times, days, duration, and locations in face-to-face and online options
- More support in places where families already connect such as early learning services and schools.

'To have information about supports from maternal nurse would have helped me know where to go back when my kids were young.'

'Make peer support easier to find.'

'Support for my child so I can attend [is a gap].'

'Region specific so the other people understand your challenges in terms of your local area and can possibly refer you to services that work well for their children with similar issues.'

2.2 Providing additional support

Peer support and parent education needs to be designed with backbone funding to provide sustainable and safe spaces for families at different points in their parenting journey.

Families wanted models to include:

- Backbone funding for peer support groups, both face-to-face and online. Moderated online groups encouraged safe spaces where all families could connect where families held different views about challenging topics. For others, ongoing funding meant supporting groups to be sustainable and move through transition phases as children got older.
- Built in follow-ups after workshops and sessions. Families spoke about the value of having a facilitator checking in a month or two after a workshop. This would provide a point of connection to refer families to additional courses or individualised support if they were struggling.
- Peer support training for families to help them develop skills to support other families.

'Sometimes I'm blown away by how amazing some people are at supporting other families ... I would personally love to have training in how to be a really good peer supporter.'

'The best peer support groups I have found very helpful is a Facebook peer support group ... once I joined it, it changed my life because so many resources, so many supports anytime, even if you post the same question everyone has posted 5 days ago, doesn't matter. Everyone is willing to jump on, help you.'

2.3 Tailoring programs and services

Families identified additional topics for parent education, including:

- Supporting children's independence, diverse communication needs, diagnosis support, toileting, and disability specific information.
- Understanding and managing their own expectations of their children and what they can help their children achieve.
- Looking after the whole family, including regulating emotions, self-care, sibling education, and how to care for multiple children while juggling the supports needs of a child with disability.
- Focusing on dads, regional areas, culturally diverse families, and reflecting different ages and stages not just the early years.
- Boosting self-advocacy skills for parents to navigate different service systems on behalf of their child.
- Navigating peer connections. This included relationships with family, friends and parents of children without disability. Families often felt judged and that there was limited understanding of their circumstances by families without children with disability.

Families noted that parent education needed to be targeted, practical and specific. Mainstream advice that wasn't targeted to families of children with disability wasn't always useful.

'[I want] more diversity training - parents can say cruel things about other kids.'

'Practical advice information is most valuable.'

'Being able to use the information to back me when I have had to fiercely advocate. Knowledge is power.'

'Was good to learn some new strategies to try.'

'Short sharp sessions that teach you one or two points with strategies you can go away and try. A week to two between sessions is a good timeline.'

'Resources and education, but most importantly the importance of self-care and parent/carer support.'

'I would love to see online education or webinars about specific disabilities and what to expect at different ages, progression of symptoms, what supports will probably work, etc. Community organisations might be well placed to do this as they already have specialist knowledge about the condition/disability/syndrome they represent.'

'We lived in the UK when my son was diagnosed as being autistic and as a result of the diagnosis [my husband and I] were then put into a parent education group. And so we had like a 6 to 8 week parent education program where every week we talked about something different and then we also did problem solving each week ... It was just fabulous because you came together with people with children that were you were at a similar diagnostic stage and ... share how you are managing things ... It was a really fabulous way of combining peer support and parent education and not feeling so lonely sort of through that early phase when you're trying to get a grip on everything. So ... that was fabulous.'

Families who participated

This snapshot was informed by the experiences 37 families, which included 33 parents who attended ACD's consultations and four who provided email responses. Their children were aged between four and 18 years old. Autism was the most represented primary diagnosis (65%). Most participants lived in metropolitan Melbourne (75%) compared with regional Victoria (25%). Almost 20% of attendees identified as culturally or linguistically diverse, and one attendee identified as Aboriginal and/or Torres Strait Islander.