

A new connected system of support and new early intervention NDIS pathway

The panel's vision

There should be a new connected system of support for children with developmental concerns, delay or disability and their families to ensure they are well supported and have what they need to thrive.

This new system of support should include more support outside the NDIS in mainstream and foundational supports as well as a new early intervention pathway in the NDIS. There should be better screening to pick up issues early, so early intervention can be provided when it is most effective.

Mainstream services must become more accessible and inclusive and there should be more foundational supports available specifically for children and families. Identifying developmental concerns and disability early to give timely support will improve outcomes for all children and their families.



What is the problem?

One-in-five children in Australia has a disability or developmental concerns. This means supports for children with learning difficulties and disability are mainstream issues. Yet we have heard that children with disability and developmental concerns are not always identified early in life, when early intervention can make a big difference. And once identified, many children and families struggle to get the support they need, when they need it.

Children with disability and developmental concerns are less likely to attend childcare or early education (kindergarten or pre-school), can experience difficult transitions to school and often face barriers to staying at school with their siblings and peers.

With no or limited support it is understandable that families turn to the NDIS. But we also heard that access to the NDIS is inconsistent, it is often delayed, based on diagnosis, and is not based on the child's needs. It can be hard for families to know how or where to find good quality support that will meet their child's needs.

Families of young children, allied health and early childhood professionals all told us how important best practice early intervention is to ensure good outcomes for children. They also told us that good support for families is critical to making sure children have what they need to thrive.

What is the solution?

A new connected system of support

We want children with disability or developmental concerns to get support matched to their needs early in their lives. We recommend creating a connected system of support including accessible and inclusive mainstream services, more foundational supports and individual funding available through the NDIS.

This should include:

- Better screening to pick up developmental concerns as early as possible in maternal, family and child health centres, pre-schools and kindergartens.
- Investment in foundational supports for children under the age of 9 and their families outside the NDIS. Foundational supports specifically for children and families should include information, advice, peer support and family support. In some cases it should include access to a Lead Practitioner.
- Action so mainstream services like pre-schools and schools are genuinely inclusive.

A new early intervention NDIS pathway for children with higher levels of need

- For children with higher support needs, access to the NDIS would be fairer, clearer and more consistent. Access to the NDIS would be based on a child's support needs, not their diagnosis.
- Once a budget has been set, families should get more help to find and use supports. Support should be based on evidence about what works best for children to give them the best start in life.
- Existing NDIS Access Lists would be replaced. Evidence to make access decisions would be clear, streamlined and based on development relative to peers. If more evidence is needed to make a decision the NDIA would arrange and pay for reports. Children who have clear lifelong support needs would continue to be eligible for the NDIS beyond the age of 9.
- Just like for adults, there would be a new, fair process to gather information about the child and family to set an NDIS budget, based on the child's support needs. This would include a needs assessment to identify what support a child needs to do everyday activities. It would include information from families as well as any treating professionals.

Support for families

- There should be two kinds of help for families. First, a navigator should help all families find mainstream services and foundational supports that will best suit their child. This would replace help some families currently get from support coordinators.
- Families with children with a higher level of need should also be connected to a Lead Practitioner (also known as a key worker), an allied health professional who would provide early intervention to support children and families in their homes, early childhood settings and schools. This will help children to learn and practice skills in their everyday environment. The Lead Practitioner should also help coordinate with other services so there is a supportive team built around the child and family.
- There should be regular check-ins with the Lead Practitioner and Navigator to make sure supports are working and help to change them if they are not.

Children with lifelong support needs would be eligible for NDIS

- Children who have evidence of lifelong support needs due to their permanent and significant disability would continue to be eligible for the NDIS beyond the age of 9. Families should be advised well before their child reaches the age of 9.

What is the solution? (continued)

Children who do not have a permanent and significant disability

- Children whose support needs will be better met within the connected system of mainstream services and foundational supports will be supported by a navigator to gradually move out of the NDIS and to access other supports.
- Children under the age of 7 in the NDIS current early childhood approach should have a long transition period until they turn 9 years.
- Families should have at least two years before they are asked to participate in any access, support needs assessment or budget process. We know you might be worried about what the changes will mean for you. We want to give everyone lots of time to adjust to the changes. We recommend:
- Children under the age of 7 should have an extended transition period until they turn 9 years, when they will move from the current NDIS early childhood approach.
- Children who have clear lifelong support needs would continue to be eligible for the NDIS beyond the age of 9.
- Families should have at least two years before they are asked to participate in any access, needs assessment or budget process.

Who will this benefit?

Families and children will benefit from improved mainstream services and foundational supports so that children are included with their peers. Families will be better supported with advice, peer support and guidance to understand what will work best for their child and their family.

Children with higher support needs will be able to access the NDIS. Access to the NDIS will be clear and fair. Individual budgets will be based on support needs. Families will have more help to find supports and services that will get the best outcomes for their child.

What happens next?

We know you might be worried about what this will mean for you and your child. To make sure everyone has time to understand and get ready, we recommend that changes should be introduced in stages. We strongly recommend that people with disability, their families and organisations should be closely involved in designing and testing new processes to make sure the changes work well.



HOW THE FUTURE NDIS PARTICIPANT EXPERIENCE COULD WORK

Case Study:

Malik is the first child of young parents Amira and Kareem. Malik loves stories and going to the zoo. His childcare educators have met with Amira and Kareem to talk about Malik's development.

They've noticed Malik doesn't always make eye contact, and he doesn't settle and join activities as well as his peers. Amira and Kareem are worried about Malik at home as he is not eating, sleeping or communicating well. The educator thinks Malik might benefit from early intervention.

Malik's parents find their local Navigator, Clancy, by looking online. They tell Clancy about their conversation with the educators and their concerns about Malik's development. Clancy suggests an online peer support program where they can speak in Arabic to other families of children with developmental concerns.

Clancy helps Amira and Kareem to make an NDIS access request for Malik using information from Malik's early childhood educator. The next step is a developmental and behavioural evaluation assessment for children who might have developmental delay. Malik's regular doctor (George) is trained and approved to complete an assessment.

During a long appointment, Dr George completes a child-focused developmental assessment with Malik and his parents. Dr George also discusses Malik's development with his early childhood educator.

The results of the assessment are uploaded to the NDIS, and show that Malik has a moderate delay in language and mild delay in social-emotional development. The NDIS confirms that Malik is eligible for a support needs assessment. Clancy explains that the needs assessment will confirm the type and level of support Malik needs. If that can't be met by foundational supports, he'll receive funding in his NDIS budget for additional services.

Malik is matched to Lucy, an experienced NDIA Needs Assessor who is a speech therapist. Lucy reads the developmental and behavioural evaluation assessment and Dr George's notes. Amira agrees for Malik's support needs assessment to be done at their home. Lucy reads all the information on Malik's file to prepare for the needs assessment.

Malik likes animals so Lucy packs a game and books about animals. Malik is shy at first, so Lucy observes Malik through play and during lunch. She asks Amira and Kareem about how they are feeling and how they support Malik to manage his emotions.



Lucy returns to Malik's home for a second assessment. She shows Amira and Kareem how she has assessed Malik's needs so far across each area and gives them a copy of her notes.

The early needs assessment shows Malik has a much higher level of support needs compared with his peers. Lucy thinks that Malik is likely to benefit from two years of early intervention to improve his social, communication and self-care skills.

After six months of early intervention, Malik's followup needs assessment shows strong improvement. His parents tell Lucy that he is sleeping better and he is enjoying lots of different food. They are happy that Malik is more comfortable within the broader family and his childcare educator reports that he is settling better and joining activities. As his development does not align with his peers, Malik continues with another 18 months of early intervention before his next reassessment.

HOW THE FUTURE NDIS PARTICIPANT EXPERIENCE COULD WORK

Case Study:

Ella is a funny and charming 8 year old child who loves to sing and dance with her school friends. Ella is the first child of James and Gill.

When she was six months old Ella was diagnosed with cerebral palsy with a score of Level 3 Gross Motor Functional Capacity Score. When Gill and James received Ella's diagnosis, the hospital social worker advised them to contact the NDIS.

When Ella was 10 months old, her GP advises her parents to visit the local navigator. Gill is matched with Navigator Leonie who explains the early childhood approach. Leonie helps Gill complete a NDIS access request online and sends a link to Ella's paediatrician to add information directly to the access portal.

Leonie encourages Gill to join an inclusive parents and bubs playgroup in her suburb. Gill joins the playgroup when Ella is one year old. A physiotherapist drops in each month and reviews Ella's development. When Ella is 18 months old Leonie helps Gill join a workshop run by the cerebral palsy association for families of children with cerebral palsy.

Ella is accepted into the NDIS early intervention pathway. Gill receives a phone call from Shane, an NDIA Needs Assessor who is a physiotherapist. He makes a time to meet Gill and Ella in their home. Gill wants to do one longer assessment.

Shane reads the information in Ella's application and seeks advice from the cerebral palsy expert in the NDIA assessor team to help him prepare for Ella's needs assessment.

During the assessment, Shane spends several hours talking with Gill and James and plays with Ella. Gill and James agree for him to contact Ella's paediatrician for more information.

Based on all the information from Ella's family, her treating professionals and the NDIA cerebral palsy expert, Shane recommends that Ella would benefit from at least four years early intervention to support her physical and communication skills development. Shane knows that Ella's needs will evolve so her needs assessment accounts for expected growth and development, as well as equipment costs. Regular informal catch-ups and more formal case conferencing sessions are included. Ella's needs can be reassessed if needed.

As Ella will need significant support with her physical development, Ella's navigator Leonie suggests working with a Lead Practitioner with a physiotherapy background. Ella and her family are matched with Kristine, who coordinates a team of therapists around the family and supports them to build activities into Ella's daily routines. Kristine ensures Ella has the right equipment and level of support to move, play and learn in pre-school and then school.

Gill and James feel well supported. They ensure that Ella joins in childhood experiences like Little Athletics where she sets a new personal best in her wheelchair.

At age 5 after four years of early intervention, Ella repeats the Gross Motor Functional Capacity Score test and again scores a Level 3. Ella's paediatrician explains this means Ella is likely to always need a walking aid indoors and a wheelchair outside. Kristine advises Gill that Ella will likely need disability support from the NDIS for the rest of her life.

Six months before Ella turns 9, the NDIA advises Gill and James that they don't need any more information about Ella and she can transition to section 24 (NDIS disability requirements) based on her previous needs assessments. Ella's support will continue as she gets older.



Want more information? Read the final NDIS Review report and recommendations, NDIS Review Guide, NDIS Review fact sheets and FAQ at www.ndisreview.gov.au