12 September 2025

Quote from an attendee: 'I would think this should be a given — better data sharing between governments and the ability for individuals to update their own information.'

What we talked about

The Group talked about the Thriving Kids initiative - a new government program commencing from 1 July 2026 to support children with developmental delay and autism. Parents and carers were encouraged to contribute to a parliamentary inquiry and survey , open until early October.

The Group revisited the scope of its work, clarifying areas it can influence - such as NDIA staff training, how and where parents and carers interact with staff, pathway information, and improvements to systems like the NDIS website and forms. Parents and carers appreciated this clarity and found it helpful in understanding the parameters of the co-design process.

NDIA gave a summary of what the group has shared so far. Feedback from parents and carers is being used across the agency to help shape ideas, while also considering things like laws, timeframes and budgets. Some of the suggestions are already being worked on.

NDIA provided an update on issues in the co-design process and what’s coming next. Previously, the Group focused on sharing stories to help NDIA understand real experiences with the current system. Now, the focus is shifting to shaping and refining ideas for a new pathway.

The Group reviewed and prioritised a range of concepts previously shared by parents and carers to improve the NDIS experience for children under 9. Feedback focused on what could work well, key concerns, and what changes are needed to better support parent and carers.

What we heard

Thriving Kids

- Parents and carers felt the program lacks clarity and detail and called for meaningful co-design with the disability community before rollout. Uncertainty around future NDIS eligibility is contributing to distress and anxiety among families.
- Language like “mild to moderate” developmental delay and autism raised fears of future exclusion and inequity.
- Parents and carers welcomed stronger collaboration between Thriving Kids and mainstream services, with neurodiversity-affirming and culturally appropriate support. They also raised concerns about workforce shortages, especially in regional areas, which risk fragmented care and increased pressure on schools.

- Parents and carers emphasised the importance of a seamless experience between Thriving Kids and the NDIS, especially to avoid retelling their stories and to ensure continuity of care.

Prioritising key concepts

- Parents and carers prioritised concepts that reduce complexity, save time, and improve continuity of care. There was strong support for having a single point of contact throughout the NDIS journey - someone well-trained, consistent, and able to build trust. This role was seen as essential for guiding parent and carers through application, planning, and transitions.
- Parents and carers valued collaborative planning, where they could meaningfully contribute to their child’s plans and avoid rigid processes. They called for flexible, practitioner-informed goals that reflect children’s changing needs without triggering unnecessary reassessments.
- There was clear interest in tools that improve visibility and reduce repetition, such as interaction history logs, tracking tools, and portals to view and manage child-related information. Different accessible format options and real-time updates were also suggested to support accessibility and reduce administrative burden.
- Ideas such as coordinating professions to work together to assess children’s needs and assigning support staff at the right levels to guide families, were seen as good ways to make sure children get the help that suits them. Parents and carers also supported government systems sharing information — as long as it’s done with their consent and is clear about how the data is used.
- Some concepts, such as child-facing materials and budget dashboards, received mixed feedback due to concerns about relevance, accuracy, and potential confusion.
- Overall, parents and carers want a system that is clear, responsive, and inclusive, with practical tools and well-trained staff who understand their child’s needs.

Next steps in co-design

- Parents and carers appreciated the shift in the co-design process. This change allowed them to move from reflecting on past experiences to contributing practical solutions.
- They expressed strong interest in continuing to collaborate on improvements that would make the NDIS journey clearer, more supportive, and better tailored to the needs of parents and carers and their children.

What we agreed on

- The NDIA will keep improving these ideas based on feedback from parents and carers and will share updates with the teams working on the new NDIS pathway for children under 9.
- Future meetings will include a session to explore the Lead Practitioner role, along with activities where parents and carers can help further design the new NDIS pathway through journey

mapping and other activities.

Next meeting

The next Children’s Pathway Parent and Carer Engagement Group meeting is on 3 October 2025

Who we met with

Fifteen parents and carers with a child in the scheme under the age of 9.

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