28 May 2025

What the Group talked about?

Jane, the NDIA Co-Chair from the Children’s Taskforce shared some background on the new NDIS early intervention pathway for children younger than 9 (the new pathway), including what is in scope and out of scope of the design of the new pathway.

Jane also explained the role of this group, which is to share advice and input from a lived experience perspective on how to design the new pathway.

The group discussed what should be included in a group agreement to ensure meetings are safe and inclusive, allowing all parents and carers to share their experiences comfortably.

There was information shared on different ways the group can participate and interact in meetings and how group members can suggest topics for future meetings.

Design Principles

Jane provided the group with an overview of the design principles that will guide the creation of the new pathway. These principles will be used by Agency staff who are designing the new pathway

The group was asked to share their thoughts on the words that will form the basis of these design principles to understand what matters most to parents and carers.

Key themes shared by the group

Empathy and understanding for parents and carers throughout the NDIS pathway.

Better connections to the right contacts, ensuring that people are warmly directed to each other.

Trust in the system. Families need to trust the system rather than being stressed about phone calls and potential interruptions to assessments.

The pathway needs to be flexible, as a linear approach does not work for all children. There are often unusual gaps that need to be addressed.

Improved communication and consistency. The NDIS needs to be more communicative and consistent.

Making Connections, and Applying to the NDIS: Participant Experiences

As part of designing the new pathway, research is being conducted to understand the current experiences of parents and carers at different stages of the NDIS participant journey. The group was given a summary of the themes heard so far, focusing on the initial stages: making connections and applying to the NDIS.

The group was then asked to share their own experiences with these stages, including what worked well and what didn't.

Key themes shared by the group

Many people are unaware of the NDIS and its services. There is a need for better publicity and information dissemination through various channels like GPs, schools, and developmental checks.

The process of accessing the NDIS involves waiting and advocating, which can be exhausting for families.

Accessing support in rural and remote locations is difficult due to fewer available services and specialists.

There is a shortage of therapists and experienced medical professionals who can accurately identify and diagnose disabilities, leading to delays in accessing necessary support.

The cost of obtaining necessary reports and accessing specialists is a significant barrier for many families.

Parents and carers may not always recognise if there is an challenge with their child, which can delay seeking support.

What were the key actions

Send out a draft group agreement for feedback from the group

Send out the Meet the Group Booklet

Related articles

Children’s Pathway Parent and Carer Engagement Group Friday 28 March 2025

Date
28 May 2025

Children’s Pathway Parent and Carer Engagement Group 9 May 2025

Date
9 May 2025

Children’s Pathway Parent and Carer Engagement Group – Meeting #8

Date
1 August 2025
Read more news