

Independent Advisory Council Children, Young People and Families Reference Group Meeting Bulletin 14 May 2021

The National Disability Insurance Scheme (NDIS) has an Independent Advisory Council (Council). Council gives independent advice to the National Disability Insurance Agency (NDIA) Board. This is a part of the NDIS Act 2013.

Council brings the participant's voice to the heart of the NDIS. It does this by using its four reference groups, to inform and improve its advice. Reference groups include members with expertise and experience in specific areas of disability.

The Children, Young People and Families Reference Group (Reference Group) gives advice about ways to support children and young people with disability to be:

- able to do things for themselves
- included in the community.

This Bulletin summarises the 14 May 2021 Reference Group meeting, led by:

- Ms Sylvana Mahmic, Council Member and Reference Group Co-Chair
- Ms Liz Reid AM, Council Member and Reference Group Acting Co-Chair
- NDIA Representatives and Council Secretariat.

From the Reference Group Co-Chairs

Ms Mahmic said the Reference Group is the voice for children, young people and their families in the NDIS. The Reference Group gives:

- Members the opportunity to influence NDIA policy and practice in this area
- NDIA staff access to people with disability and expertise in this area.

Ms Mahmic spoke about:

- children and young people, who depend on their families and carers for supports
- children who are aged 0-6 with approved NDIS plans. At 31 March 2021, 16 per cent of NDIS participants with approved plans were children aged 0-6. That is 70,745 children.

Ms Reid added that the Reference Group will help Council make its advice better.

Reference Group member reports

Reference Group members reported on concerns they've heard from people with disability in their communities.

They said they've heard about:

- Concerns that funding packages appear to be given out randomly. This goes against the principles of ‘reasonable and necessary’ and ‘choice and control’.
- Concerns that the [Autism Early Intervention paper](#):
 - does not represent Autism the right way
 - puts participants into fixed groups, because of how it gives funding packages.
- Challenges faced by families of children aged 7+ to access and move through the NDIS. These challenges are harder for people from culturally and linguistically diverse (CALD) backgrounds.
- Concerns that families are losing trust in, and are feeling cut off from, the NDIS. This is a problem because early intervention supports are vital for childhood development.
- Access issues for people with lesser known disabilities, who don’t always get NDIS supports.
- Issues with the idea of ‘parental responsibility’. Including:
 - what it means
 - what are reasonable supports to expect from parents, while still promoting children’s independence
- Issues beyond Independent Assessments (IAs) that the NDIA still needs to solve for children and young people with disability. This is reported in the [‘Avoiding simple solutions to complex problems’ report](#) from CYDA.
- Anxiety on IAs, and the need to balance general operational guidelines with personalised supports for young people with disability.
- Challenges between the NDIS and the education system, with gaps in childhood school transition. Many children lack education supports or are excluded from capacity building supports in schools.
- Issues with culturally appropriate and safe services for CALD communities in the NDIS. With concerns about the end of the [National Community Connectors Program](#).
- Challenges with NDIS services in rural and remote areas:
 - for Early Childhood Early Intervention (ECEI)
 - with growing waitlists for services for children
 - with concerns that poor internet connectivity will affect IAs.
- Challenges for people who are deaf and hard of hearing to:
 - access the NDIS.
 - be included in NDIA consultation processes.
- NDIS operational issues, with:
 - simple requests for assistive technology or home modifications requiring plan reviews. This adds stress and costs to the system.
 - repeatedly needing to explain your support needs.

Update of NDIA work for children and young people

Mr Peter de Natris is a Strategic Adviser at the NDIA. His work focuses on Autism and ECEI. He gave updates on the NDIA’s work for children and young people.

Mr de Natris said that the NDIA is focused on:

- Communicating the importance of outcomes in early childhood intervention (ECI), rather than plan sizes, through its work with ECEI partners.
- Getting a nationally consistent approach on developmental delays, especially on the definition and interpretation of 'developmental delays'.
- Ensuring that planners and ECEI partners have the right skills and training, especially for access decisions under the NDIS Act 2013, Section 25.
- Building capacity for young people and families. This is to reduce the need for long-term supports and assist participants to transition out of the NDIS.
- Autism Early Intervention consultation.

Reference Group members raised matters including:

- The need for whole-of-government work to integrate the NDIS into children's lives.
- Challenges with the education system, which harm the social and economic outcomes for children.
- NDIS and interface issues. These issues keep participants away from mainstream activities. Lack of inclusion leads to poor outcomes for people with disability.
- The need for the NDIS to work according to the basic principles of the Scheme, and UN Convention on the Rights of Persons with Disability.

Ms Belinda Epstein-Frisch AM is an Independent Consultant for Council. She gave a summary of Council's work for children and young people, including Council's advice on:

- [Promoting best practice in ECI](#); and
- [NDIS support for families and carers](#).

Reference Group priorities

Ms Mahmic led discussions on priorities for the Reference Group. This includes advisory work it will complete in its three-year term, until June 2023. The priorities aim to provide solutions to issues faced by children, young people and their families in the NDIS.

The Reference Group will finalise its priorities out of session. The priorities will align with Council's Work Plan and advice, and the NDIA Corporate Plan.

More information on the Reference Group

The Reference Group will next meet in the second half of 2021. You can find out more about Council meetings at the [Council's website meeting page \(external\)](#). You can access advice from the [Council's website advice page \(external\)](#).

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