

Independent Advisory Council Children, Young People and Families Reference Group Meeting Bulletin 11 October 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 11 October 2021 Reference Group meeting, led by:

- Ms Robyn Kruk AO, Council Principal Member & Reference Group Co-Chair
- Ms Sylvana Mahmic, Council Member and Reference Group Co-Chair.

The meeting included NDIA Representatives and Council Secretariat.

From the Principal Member

Ms Kruk acknowledged the major changes to the NDIS, and work done by the NDIA and Council, since the [Reference Group's last meeting on 14 May 2021](#).

She thanked members who added to the Reference Group work plan. The plan outlines priority work the Reference Group will do over three years, and links to [Council's 2021-22 work plan](#). The plan aims to find solutions to issues that affect children, young people and families in the NDIS, and to inform Council's advice.

Ms Kruk acknowledged Reference Group members' involvement in co-design workshops with the NDIA, Council and the disability community. The workshops held in September 2021, fulfil outcomes from [July's Disability Reform Ministers' Meeting](#). The workshops aimed to:

- strengthen relationships between identified stakeholders.
- identify projects that can be progressed through co-design.

Ms Kruk stressed the need to embed the voice of children and young people in the NDIA's work and processes. She asked members to recommend young people they know, to be a part of Council's Reference Groups.

She also acknowledged members' earlier work:

- to develop Council's formal advice, '[Strengthening Scheme Reforms to Access and Planning](#)'.

- during the Scheme improvement forums, held throughout Q4 2020/21.

From the Reference Group Co-Chair & Council's Independent Consultant

The Reference Group Co-Chair, Ms Mahmic, acknowledged that Reference Group priorities will progress at different speeds and encouraged members to be flexible about the work.

Ms Mahmic said that some Reference Group members met with the NDIA about its work on [early intervention for children with autism spectrum disorder \(ASD\)](#). She advised that there would be further engagement with the NDIA's Early Childhood Services (ECS) Branch about this as part of their work on the Early Childhood Early Intervention (ECEI) Reset. The ECS Branch is responsible for delivering the [ECEI approach for the NDIS](#).

Council's Independent Consultant, Ms Belinda Epstein-Frisch AM, noted that Council met with the Department of Social Services (DSS) on the [NDIS legislation review and public consultation](#). Council made a submission to the consultation.

Ms Epstein-Frisch said the NDIA has paused work on the indicative funding levels that were included in the [Interventions for children on the autism spectrum \(DOCX 1MB\)](#) consultation. The NDIA will do further research based on feedback received during the consultation. She noted that some Council and Reference Group members have met with the NDIA about:

- progress in its early childhood approach, as part of the [Early Childhood Early Intervention \(ECEI\) reset](#)
- [designing an adaptable approach to early childhood assistive technology](#).

Reference Group Members said:

- The NDIA needs to do more work on autism funding, particularly the intensity of supports and how it defines 'intensity'.
- There is a need to further explore the delivery, marketing and outcomes of purely medical approaches to treating autism.
- The NDIA and [ECEI partners in the community](#) should consider family circumstances, particularly family violence impacts, in order to tailor supports.

Reference Group member reports

Reference Group members reported on matters for the Council's and Agency's attention, on behalf of people with disability in their communities. Members said:

- Children, young people and their families have difficulty accessing and navigating the NDIS and multiple government agencies to get support they need. Especially those from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse (CALD) backgrounds.
- There is a lack of connection and communication between early childhood intervention registered providers, the NDIA and ECEI partners.
- The sector and service providers should create meaningful relationships with the children, young people and families they aim to support. Families can feel that they are only consumers for commercial providers.
- There are ongoing concerns around the delivery of early childhood supports, and the need for education to empower families to have choice and control.
- Some health practitioners lack understanding about the early childhood interventions and pathways available to help children and their families access supports.
- There are issues with thin markets or lack of service availability.

- Some NDIS participants are having their funded supports reduced without explanation. Participants are lodging reviews with the [Administrative Appeals Tribunal](#) because of this.
- Coronavirus vaccine access, information and accessible vaccination practice for children and young people needs improvement. Especially for those with guardianship arrangements and sensory issues.
- As some states exit lockdowns, the NDIA should think about its coronavirus recovery planning and communications. For example, how to support children and young people with disability transition to school-based learning and find employment, while minimising risk.
- Given that most children rely on their parents and peak bodies to represent them, the NDIS needs to strengthen the voice of young participants in all its work.
- There is a need to support 'parental agency' and educate parents on ways to make choices and decisions that support their children's development and independence. There are issues around the idea of 'parental responsibility', including what it means and what reasonable supports to expect from parents.
- The quality of support coordination for children and their families in the NDIS differs from person to person.

Strengthening the voice of children and young people in the NDIS

Ms Mahmic invited Reference Group Member Mary Sayers, to present initiatives that [Children and Young People with Disability Australia \(CYDA\)](#) has delivered to support and mentor children and young people with disability.

Reference Group members then participated in workshop discussions about ways to strengthen the voice of children and young people in the NDIS.

Members said:

- The NDIA needs to include the voice of children and young people in its co-design projects.
- Children and young people need their own autonomous voice, not a voice alongside adults. [A child's voice is critically important](#), so is the [student voice in education planning](#).
- The NDIA should think about children in all its communications, ensuring that information is accessible and available in alternative formats. This includes, plain language/English, Easy English/Read, Auslan and others.
- There is a need for technology and games-based interventions to support the development and engagement of children and young people, particularly those with communications and access challenges.
- Parents and families should be empowered to use and communicate a skills-based approach, in order to empower children with disability to build independence skills.
- The NDIA should educate families and children from CALD backgrounds about choice and control in early childhood supports.
- The need to carefully consider the support needs of children and young people who use augmentative and alternative communication (AAC).
- Children and young people with disability should be involved in making their own decisions, and get the supports they need to do so.

- There is a need for more youth leaders, meaningful engagement and peer networks/support groups. Children and young people with disability need to see and connect with role models and mentors they can relate to.
- The [Information Linkages and Capacity Building program](#) is important for children and young people. For example, one grant is focussed on developing user controlled self-advocacy tools or mobile applications.
- NDIS partners in the community are a critical enabler for children and young people.
- NDIS planners should have specialist skills or focus on child and adolescent issues.

More information on the Reference Group

The Reference Group will keep working out of session to progress its work, before it formally meets again in 2022. 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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