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Reference Group meeting bulletin – 2 August 2023

Children, Young People and Families Reference Group

The [Children, Young People and Families Reference Group](#) (Reference Group) met recently. This bulletin summarises the videoconference meeting which took place on 2 August 2023.

The Reference Group know a lot about children and young people with disability. They advise the Independent Advisory Council (IAC) on issues which affect them. This informs the IAC's advice on how to improve the National Disability Insurance Scheme (NDIS) for children and young people.

[Ms Leah van Poppel](#), IAC Principal Member, led the meeting.

From the Reference Group Co-chair

Ms van Poppel opened the meeting by welcoming new and returning Reference Group Members. Members will work with the Reference Group from 1 July 2023 to 31 December 2024. Ms van Poppel will appoint a Reference Group Co-chair once the Minister for the NDIS' announces IAC membership.

Ms van Poppel highlighted work the IAC and IAC Reference Group has done since their last meeting on [11 May 2023 \(DOCX 87KB\)](#). This includes the IAC advice *'Improving the NDIS for children and young people: the importance of being guided by their voice'*. The IAC have endorsed this advice and the National Disability Insurance Agency (NDIA) is currently developing its response to the advice. Ms van Poppel acknowledged the work of the Reference Group in creating this advice.

What Members have heard in their community

Reference Group Members told us things the NDIA need to know, including:

NDIS access and planning

- Some parents worry their child's plan will change in a planning meeting. The NDIS should let parents know before the meeting that they have the option to roll the plan over if there are no changes in the child's support needs. This could avoid spending on professional assessments.



- Reports that NDIS planning meetings can be traumatic for some families.

NDIS service and supports

- For some families, most funding in 2-year plans is spent on assessments in the first year. This is to get proof of the child's disability to secure long term NDIS support. This can mean:
 - Children might not get the right amount of support they need as early as they should.
 - Families focus on what their child can't do instead of their strengths and potential.
 - Allied health services may be too busy with assessments to give as much therapy as they could.
- Calls for the NDIS to look at the benefits of preschools' connecting families to Early Childhood Partners. Preschools can provide a supportive and nurturing environment for children to receive NDIS services.
- The NDIS needs to better support participants' transition from childhood to adulthood. This includes:
 - Providing greater access to support workers who are not their parents.
 - Supporting them to do more for themselves on their own, or capacity building.
 - Funding supports that get young people with disability involved in social activities. We should focus support on young culturally and linguistically diverse (CALD) people in particular.
- Reports that some young people with disability are being told not to work until they have left secondary school.
- Reports that a reduction in funding when a young person leaves secondary school creates added challenges. Participants need support to transition into adulthood.
- Some young people don't have a lot of choice in what supports they can get. This is especially true for young adults with complex needs who want to live independently of their parents.
- Some young people with disability who are frustrated about the lack of choice or agency in their lives may not use their supports. When this happens, the supports may be removed due to lack of use. It can be difficult to get these supports back later.
- Finding an occupational therapist in some states is sometimes difficult. In some instances, therapy could be delayed for up to a year. Therapy is also being delivered less effectively via videoconference.

Community and other government services

- Calls for NDIS supports to be delivered to children at school to promote inclusion. Therapy is also more effective when delivered in the child's natural environment.
- Many children in foster care and the justice system have diagnosed and undiagnosed disability. The NDIS should work more closely with these services to find these children and get them the support they need early on.



- In some places there are few opportunities for young people with disability to socialise with others their own age. This is common in rural areas.
- Early intervention is often led by medical professionals. There should be more community-focused pathways that:
 - Make parents aware of their important role.
 - Empower parents to speak up for their child.

Developing the Reference Group Work Plan

Members discussed the areas of work and advice the Reference Group should focus on over the next 18 months. These priorities will form a Work Plan, which will guide the Reference Group's advice to the IAC. The Reference Group noted that it will apply intersectionality to its work. The Reference Group agreed on the priorities put forward, including the need for a NDIA Youth Advisory Council. They will also look to focus on:

- Support and education for parents of children with disability. This will help them understand their important role as a parent and how to advocate for their child.
- Better support for children and families as they move through life stages. For example, from childhood to young adulthood to adulthood.
- Early access to the NDIS, as well as consistent and fair NDIS support for all children who need it.
- The use of best practice models for children's supports. This means children should get supporting services in natural and everyday environments. Parents should also get supports to understand what best practice means.
- Ways to support independence for young people with disability, especially those who are approaching 18 years. There should be a transition period for young people to learn how to use their NDIS plan before they come of age. This may help young adults when they take control of their plans.
- Improving the NDIS planning process so that young people have a voice in their plan.
- Understanding how to engage young children so they can contribute their views and experience to our work. For example, by using online game-based platforms.
- Key areas within community and other government supports/services. For example, justice and education.

Update on the NDIS Review

Professor Bruce Bonyhady AM, Co-Chair of the Independent Review Panel updated the Reference Group on the work of the NDIS Review. Professor Bonyhady discussed the Review's ['What we have heard' report](#) and invited Member feedback. Reference Group Members noted:

- The NDIA should improve community awareness of the goals and the intentions of the NDIS. This should highlight the NDIS as creating better outcomes for people, not just delivering services.

- The Government needs to think more about what young people with disability need. Especially those struggling with accessing housing and public housing. There were calls for planning for children's housing and out of home care needs.
- The need to increase state/territory and local government community supports and programs. These are important for filling the social needs of people with disability.
- That the NDIS and education system are not well connected. There were calls for NDIS supports to be delivered in schools so that children with disability can be included.
- The NDIS early childhood pathway should extend to young adulthood. This would help the NDIS consider the unique needs of young people/adults.
- Early access to support services provides the best outcomes for children. This may be part of why there is a focus on early diagnosis and access to the NDIS, resulting in more children than expected in the Scheme. This should not be framed negatively by the NDIA, especially as some participants feel blamed for the NDIS cost blow out.
- The NDIS often uses reasonable and necessary justifications when removing supports. This decision making is not always consistent across the NDIS.

Update on the Early Years Strategy

The Department of Social Services (DSS) gave the Reference Group an update on the [Early Years Strategy](#). The Strategy aims to shape the Government's vision for the future of Australia's children and their families. The Reference Group noted that the disability community should have a further say on the Strategy, once the consultation report is released.

More information on the Reference Group

The Reference Group will next meet on 12 October 2023. Find out more about Reference Group meetings and bulletins at [the IAC's website](#). You can also access [the IAC's advice here](#).

The IAC publishes an Easy Read version Bulletin. This is part of its commitment to accessibility.