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Reference Group meeting bulletin – 12 October 2023

Children, Young People and Families Reference Group

The [Children, Young People and Families Reference Group](#) (Reference Group), met via videoconference on 12 October 2023. This bulletin provides a summary of the meeting.

The Reference Group focus is on how to support children and young people with disability in the NDIS. They share their knowledge on issues affecting children, young people and their families with the Independent Advisory Council (IAC). The IAC uses this information to advise the National Disability Insurance Agency (NDIA) Board on the National Disability Insurance Scheme (NDIS).

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

From the Reference Group Co-chair

Ms van Poppel opened the meeting and thanked members for attendance. She noted that IAC membership was in the final stages of being finalised and that once membership of the IAC has been confirmed, Ms van Poppel will appoint a Co-chairs this Reference Group.

Ms van Poppel acknowledged the period of significant change that is facing the disability community, particularly with the release of the [Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability \(Royal Commission\) report](#), and with the NDIS Review soon to complete.

Ms van Poppel also acknowledged the work of the Reference Group in creating their Work Plan for the next 18 months. The Work Plan will soon go to the IAC for review. This is to ensure alignment across IAC and Reference Group work.

What members have heard in their community

Reference Group members shared insights from their communities that the IAC should be aware of, including:

NDIS access and planning

- Concerns that high assessment costs and long wait times for a diagnosis will result in some children missing out on disability support, especially for families with multiple children with disability or developmental delay.
- Calls for NDIS planners to use a trauma informed approach, especially when working with parents and families with experience of the child protection system.
- Concern some [Early Childhood Partners](#) (Partners) and NDIS planners are not connecting families to peer supports.
- Reports of the NDIS reviewing supports in a child's plan that families thought were confirmed, and that this can cause families a lot of stress.
- Concerns that some families will not complain about their experience with a planner because they are concerned that their child will be disadvantaged in the planning process if they do so.

NDIS service and supports

- Concern families do not know how to find safe service providers for their children. Members suggested that Partners give parents resources on this.
- Continued concern that some NDIS funded therapies are discouraging parents from playing an active role in their child's development. Members were also troubled by the number of parents asking for these therapies instead of safer and better family-focused approaches.
- Members said that some participants are afraid to make complaints which will identify them and highlighted the need for both anonymous complaint making options and culturally safe ways to raise issues.
- Members highlighted the difficulties of being a carer of a NDIS participant and also a NDIS participant themselves, including a lack of understanding by the NDIA planners of how their carer role can impact their disability.
- Members reported that support workers do not always understand how to engage with young children or give older children the mentorship they need. They observed the need for better regulation for the support work industry and for the status of disability support work to be increased.
- Members highlighted that behaviour support plans are often difficult for parents to understand and are therefore not always used correctly at home and school.

Community and other government services

- Reports children with disability are sometimes excluded in schools even when they have lots of NDIS support. Members suggested state and territory education departments send disability experts into schools to help them understand how to include students with disability.
- Members explained that a student's disability can mean they have less time for learning and socialising. The way some schools work can reduce this time even more.



- Members highlighted how the rules for using accessible services can sometimes create new barriers for people with disability.
- Members asked for more information about how the NDIS and child protection systems work together. Particularly to avoid any risk of homelessness when a child in out of home care turns 18 years old.
- Members are optimistic the current increase in public awareness of disability rights will lead to a greater effort to understand and include people with disability in other government and community services.

Update on the NDIA's Children's Taskforce

Ms Samantha Taylor and Ms Loretta Kingston-Brown from the NDIA's Children's Taskforce gave an update on their work. The Reference Group gave the following feedback:

- Long wait times to see Partners can lead families to seek advice elsewhere.
- Members are concerned by the number of families wanting NDIS funding rather than the other supports outside the NDIS that might be better suited to the needs of their child, and asked what Partners were doing to recommend those supports.
- Members highlighted how medical advice currently guides many early decisions on a child's disability or developmental delay. Programs like the [NDIS' Early Supports](#), which build the parent's capacity, are important for taking families out of the medical model of understanding disability.
- Members discussed how NDIS participants need help to self-manage and that families don't always realise self-management is a big responsibility.
- Members recommended using co-design to understand how information should be shared with families.
- Members congratulated the Children's Taskforce on co-designing [resources for early childhood educators](#). These aim to support early childhood educators to accept and include children with disability and developmental delay in early learning centres.

Reflections on the Royal Commission

The [Royal Commission report](#) was released 29 September 2023. The Reference Group reflected that:

- Members identified transport, early childhood education and post-school pathways for people with disability as possible gaps in the Royal Commission's report.
- Members highlighted how some of the language used in the report, especially in [Volume 8, Criminal Justice and People with Disability](#), could promote negative attitudes about disability.
- Members discussed the Royal Commission's work on inclusive employment including how volunteering could be an option to prepare for paid work.
- Members reflected that achieving the recommendations will involve a lot of complex work which will likely take a long time to complete.



Update on Reforms for Outcomes

Ms Sylvana Mahmic and Ms Skye Kakoschke-Moore of the Reference Group gave updates on their involvement in co-design to assist the NDIA's [Reform for Outcomes](#).

Members gave the following feedback on the workforce capability Reform for Outcomes co-design work:

- Members advocated for specialist planners who understand children and families.
- Members suggested collecting data on all the skills planners currently have, to find knowledge gaps to target with training.
- The Reference Group recommended this co-design work also focus on how to keep good staff.
- Members suggested hiring disability-led training organisations and giving NDIA staff a safe space to ask questions and learn from people with disability.

Members gave the following feedback on the plan flexibility Reform for Outcomes co-design work:

- Flexible plans could include the ability to move funding from [different categories beyond your core supports](#) or choose a section of your plan to review.
- Members highlighted the importance of flexible plans in times of crisis like natural disasters and family or sexual violence.
- Members recommended plans are flexible for common changes, like starting or leaving school. For other life events like starting a family or moving house, a participant would apply for a [change in circumstance plan reassessment](#).

More information on the Reference Group

The Children, Young People and Families Reference Group will next meet in 2024. 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.