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Reference Group meeting bulletin – 13 September 2022

Children, Young People and Families Reference Group

This Bulletin summarises the recent meeting of the [Children, Young People and Families Reference Group](#) (Reference Group). The Reference Group met on 13 September 2022. [Leah Van Poppel, Council Principal Member and Reference Group Co-chair](#), led the meeting.

The Reference Group gives advice to the Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS). Its advice aims to support children and young people with disability to do things for themselves and have inclusion.

From Council's Principal Member

Ms Van Poppel acknowledged the work the Reference Group has achieved since [their last meeting in May 2022](#). She noted this meeting will help Council develop advice for the National Disability Insurance Agency (NDIA). The advice aims to promote the voice of children and young people in the NDIS. It has the working title 'Welcoming the voice of children in the NDIS'.

Developing advice about the voice of children and young people

The Principal Member asked for feedback about the scope and approach needed for the advice development. Members suggested their ideas for the advice, including:

- The need to reflect on a child's human rights and the Convention on the Rights of the Child.
- The importance of enabling a child or young person to have their own authentic voice. While supporting families to develop their child's agency.
- The need to include children and young people in the development of the advice. Especially activating unique voices across different age groups, disabilities, and accessibility needs. This includes those who are nonverbal.
- Engaging with children and young people requires using a relationship-building approach.



- The importance of including children and young people as members of Council, its Reference Groups, and the NDIA's Participant Reference Group. It was acknowledged this would need peer support and mentoring.
- There is merit in using game-based technology to engage with young children in ways they enjoy.
- Children and young people should be engaged in NDIA policy and guidance development. They should also be engaged in NDIA co-design projects.
- The NDIA should consider a policy or framework for how they engage with and hear the voice of children and young people with disability.
- The NDIA's executive leadership team and organisational structure should support younger participants. Acknowledgement the NDIA has an early childhood strategic advisor.
- NDIS marketing and communications materials should feature children and young people representing themselves. The NDIA should not use adults who speak for children.
- The [Disability Gateway website](#) can include information about supports for children, young people, and their families.
- Exploring the NDIS Quality and Safeguards Commission's role. Especially with ensuring quality services for children and young people.

Work the NDIA and disability community are doing for children and young people

The Reference Group learned about the NDIA's work to promote the voice of children and young people in the NDIS, and the NDIA's work on co-design. Members noted:

- The NDIA engages children and young people in varying ways across co-design. The NDIA's co-design projects should meaningfully involve younger people across all co-design work.
- The work on participant safety must consider the risks faced by children and young people. Especially those transitioning from out of home care and guardianship arrangements.
- The NDIA should give regular progress updates about its co-design projects. Especially updates between Co-design Steering Committee and Advisory Group meetings.
- The NDIA may consider the [Victoria's Youth Strategy 2022-2027](#) to guide its co-design approach.
- The NDIA should use engagement methods informed by best-practice in the sector and research in early childhood. An example of this related to youth advisory councils.

The Reference Group learned about disability community's work to promote the voice of children and young people. This included work by the [Autism CRC](#) to develop a [National Guideline for supporting autistic children in Australia](#). Members noted:

- The Autism CRC's faithfulness to process and the importance of having guidelines around a child's assent and how that differs from informed consent.
- The need to better understand supports available for autistic people, especially for employment. This may happen via a showcase of best practice and nationally consistent support programs.



- The important role that social inclusion and community participation has on childhood development. Especially the inclusion of children with disability at school.

The Reference Group learned about ways [Children and Young People with Disability Australia's](#) (CYDA) work to include the voice of children and young people. This included ways to authentically co-design projects with children and young people to ensure inclusion and safety. Members noted:

- Given the age and developmental range across children and young people, there is a need to create safe spaces for each age category to provide feedback and participate.
- There is a need to consider strategies that include children and young people who are nonverbal.
- Because there is not 'a one size fits all' approach for engagement with children and young people, it is important to use a range of methods. For example, photovoice, images, and other visual material to get children's views and promote participation.
- Organisations should pay young people (who meet working age) involved in co-design and engagement projects.

Reference Group Members' community reports

Reference Group Members reported on matters about children and young people for the NDIA's attention. Members provide these reports on behalf of people with disability in their communities, to engage with NDIA staff. The community reports include:

- Young people with disability need support to find employment. They want supports to transition from education/training to employment. Some youth peer groups report that their members want supports to find employment that is fair and pays them. Especially those young people from diverse communities and people with intellectual disability.
- Some people in the deaf community who travel a lot have lower plan utilisation and have issues accessing their supports.
- The need for coordinated work between the NDIS, providers, education systems, and families. This will support development, collaboration, and inclusion for children and young people.
- NDIS can improve some support gaps through better representation and engagement with children, young people, and their families.
- The NDIA should release information that uses children to let people know about changes to the NDIS early childhood approach.
- Reports from some families that NDIS plan approval processes have improved markedly over the past quarter. Especially around assistive technology supports.
- Concerns that some businesses and providers are appearing to use sharp practices. This includes charging a higher fee once they become aware people are NDIS participants.
- Challenges and concerns around plan reviews with reports of plan reductions or removal of supports. Increased reports that parents who support their child through plan reviews find the process, combined with parental duties, impacts on their mental health.
- Concerns that some professional evidence reports are allegedly not considered by the NDIA.



- There are concerns that plans reduce in value when the NDIA applies a plan variation. This is due to prorating. This can impact participants who have banked their plan funding for periods of high support needs, such as school holidays.
- Concern about the [recent termination of the Partners in the Community \(PITC\) program Request for Tender](#) to provide early childhood and local area coordination services. This appears to be impacting the workforce, especially around finding staff and employment security.
- Reports that some people with disability do not test NDIS access eligibility after advice and guidance from local area coordinators (LAC) and early childhood partners.
- Reports that NDIS plans for children under 7 years have little or no support coordination. Concern that LAC do not provide enough support for children and their families.
- CYDA will soon release a report that addresses issues around gatekeeping and exclusion in early childhood.

NDIS review discussion

The Principal Member noted the terms of reference for the planned review of the NDIS have not been finalised. [Disability Ministers have agreed the review should focus on the design, operation, and sustainability of the NDIS](#), and on building a more responsive and supportive market and workforce.

Members noted that terms of reference should include children and young people. This is based on people aged 18 years and less making up almost half (48 per cent) of all NDIS participants. Members expressed the need for those undertaking the NDIS review to have the knowledge, understanding and the skill set to address nuances of the younger age group.

More information about the Reference Group

The Reference Group will next meet in 2023. They will keep developing their advice between meetings. Find out more about Reference Group meetings and bulletins at [Council's website](#). You can also access [Council's advice here](#).

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