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# Reference Group meeting bulletin – 27 February 2023

## 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 27 February 2023. [Leah van Poppel, Council Principal Member and the 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 September 2022](#).

### 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:

#### NDIS access

- The disability community wants more information about NDIS eligibility/access for people with fetal alcohol spectrum disorder (FASD). They also want data on the number of NDIS participants who have FASD as a primary disability.
- Lengthy wait times (up to 3 years) for families referred for an autism spectrum disorder assessment via the public health system. Private assessments also have long wait times too.
- Concerns that delays for NDIS assessments impact children's development/capacity building. Sometimes delays mean that other government departments (like child services and justice) become involved as families reach crisis point.



- Reports that some organisations are taking advantage of wait times by increasing fees.
- Some parents worry that their child will not be able to access the NDIS without clinical diagnoses of disability.

## NDIS plans

- Reports of plan reductions, with little explanation about why or use of a step-down approach.
- Concerned parents think their child's plan will reduce if they report on improvement or regression.
- Concern that plans will reduce if funding is not used. This is often due to lengthy wait lists or thin markets, not through lack of trying by families to access supports.
- Concern about the term 'parental responsibility' and how it is being applied by the NDIA.
- Familial challenges and concerns around removal of NDIS supports for children. This combined with 'parental responsibility' impacts on mental health.
- Some parents from culturally and linguistically diverse (CALD) communities want clear information about the NDIS, especially ways to use their child's funding and plan reviews.
- A need for families to have better information on self-management. Some felt families should get support coordination for their first plan to help them adjust and learn about the NDIS.
- A need for a pathway to help participants use their supports, especially for families with school aged children.
- Concern that informal and long-standing kinship relationships are not recognised by the NDIA and need extensive evidence, resulting in funding delays for supports.
- There is conflict between government funded and NDIS funded activities/supports.

## Providers

- Concern that providers are not held accountable for the quality and outcomes of school leaver supports. Sometimes they are used as core support rather than providing a proper pathway to employment.
- Reports some support workers are refusing to wear N95 masks around participants who have high risk health needs.
- Reports the NDIS Quality and Safeguards Commission does not acknowledge some complaints.

## Disability community

- The NDIS Review should include/represent the voice of children and the voice of parents in the NDIS.
- Concern that parents of young children with developmental delay or disability face mental health issues and need support as they guide their child through the NDIS early childhood pathway.
- Autism CRC released [Australia's first national guideline for supporting the learning, participation, and wellbeing of autistic children and their families.](#)

## Reference Group engagement with the NDIS Review

The Reference Group discussed ways the Council engages with the NDIS Review and priority NDIS improvement areas they want to highlight through Council's engagement. Reference Group Members said:

- The Reference Group would like the NDIS Review to engage with them about complex matters that affect children and young people.
- Clear and transparent progress reports/updates are needed from the NDIS Review.
- They want to know if the NDIS Review panel has engaged in consultation with children, young people and their families.
- That it is encouraging that the NDIS Review will implement recommendations throughout the review process.
- The NDIS Review should consider trends from Council and Reference Group Member's community reports.

## Discussion about advice, voice of children and young people

Reference Group Members gave their feedback about Council's drafted advice, which aims to promote the voice of children and young people in the NDIS. The advice has the working title *'Improving the NDIS for children and young people: the importance of being guided by their voice'*. Members gave the following feedback:

- The advice needs to clearly outline the importance of co-design and what is meant by parental agency.
- The advice should activate the voice and experience of children and young people who are nonverbal.
- The advice will be a great guide for the Agency and help children and young people feel empowered. But the NDIA should carefully implement advice recommendations.
- The need to understand the work of the NDIA's newly established Children's Taskforce and how they will engage with this new group.

## Update on NDIA early childhood approach

Reference Group Members got an update on the NDIA's work to improve the early childhood approach in the NDIS. Members noted:

- An appreciation of the NDIA's openness and transparency in discussing their work on the early childhood approach.
- A need to look at the early childhood approach in remote and very remote areas where there are no early childhood partners.



- A need for the NDIA to carefully consider Autism CRC's 'National Guidelines for supporting the learning, participation and wellbeing of autistic children and their families' for current and future work practices.
- The opportunity to strengthen early childhood partners based on research, best practice and collaboration.
- Concern about the lack of mainstream and community supports for those children transitioning from the NDIS.

## More information about the Reference Group

The Reference Group will next meet on 11 May 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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