

Independent Advisory Council Children, Young People and Families Reference Group Meeting Bulletin 9 May 2022

This Bulletin summarises the recent meeting of the Children, Young People and Families Reference Group (Reference Group), held 9 May 2022.

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 be included in the community.

Ms Leah Van Poppel, Council Principal Member, and Ms Sylvana Mahmic, Council Member and Reference Group Co-Chair, led this meeting. The meeting included NDIA Representatives and the Council Secretariat.

Updates from Council's Principal Member & Reference Group Co-Chair

Ms Van Poppel acknowledged the traditional owners of the various land people were meeting on and the extensive knowledge that members bring to the Reference Group. She also noted significant NDIS changes that have occurred [since the last Reference Group meeting in October 2021](#).

Ms Mahmic noted the work the Reference Group has achieved so far, including work outside of formal meetings to progress priorities. She stressed the need to include and advocate for the voices of the children and young people in [the NDIA's work on co-design](#).

Reference Group members' community reports

Reference Group members reported on matters for the NDIA's and Council's attention, on behalf of people with disability in their communities, including:

- Continued challenges with funding and plan reviews for children and young people. Increased reports about:
 - the NDIA reducing larger plans without warning and/or a step-down approach.
 - inconsistencies with NDIS funding and decisions made by planners.
 - families needing to complete too many functional capacity assessments as part of the review process and getting little or no funding to action recommendations.
 - families being at crisis point and fearful about how reductions will affect their child's development and wellbeing.
 - children and parents feeling exhausted by the planning process, navigating the NDIS and other government agencies for supports.
 - the funding needed to access positive behaviour supports and improved relationships supports for NDIS participants under eight years. Some support coordinators are not aware that these supports are suitable for children.
- Challenges with the education interface for parents of children or young people with disability. Increased reports:

- about reduced supports for children at school and breakdowns in parent-school relationships.
- that children with disability in schools do not have their voices heard. Therapists could use a child's NDIS funds to ensure their voice is amplified at school. For example, by developing visuals to assist children in communicating and learning.
- that some children and young people with disability are finding it hard to transition to school-based learning after the coronavirus pandemic.
- There is a need for more education around the social model of disability and community supports that promote understanding about early intervention best-practice and inclusion for children and young people, and their families. Increased reports that:
 - people do not know about the benefits of and/or ways to spend core funding on group/community services.
 - families do not understand the difference and benefits of one-on-one therapy, support, and practice through informal support in naturalistic environments
- Growing mental health issues for parents of children or young people with disability.
- Families who do not have strong informal supports feel they are being assessed as having the same level of supports as other families when they do not. The need for more supports for:
 - single parent families who do not have or have limited informal supports.
 - parents to learn the skills and strategies needed to support their child's positive behaviour.
- The NDIA should be more transparent around:
 - data on plan reductions beyond what is currently in [Quarterly Reports](#)
 - how planners make decisions about plans and support packages.
- Growing waiting lists for early childhood supports and services, is at odds with the benefits of early intervention.
- Some young adults with disability, particularly those with intellectual disability, find it hard to use their own voice to communicate freely when a parent is present. Given their parents manage their NDIS supports, it is hard for them to use choice and control about supports to gain independence in everyday life.
- Favourable changes in the [Private Health Insurance Legislation Amendment \(Age of Dependants\) Bill 2021](#) for NDIS participants, who are now covered under a family private health insurance policy, as a dependant, regardless of age.
- Positive response to recent government funding announcements for people with intellectual disability, with emphasis on children and young people.
- Young people with disability want to vote in the upcoming federal election. But they do not have access to information that helps them understand the election or supports that help them vote.
 - Reports there has been a lot of advocacy relating to the election, including community events.
- Some specialist services do not understand or know how to best assist NDIS participants. For example, specialist's formal training and qualification do not include NDIS training, and their lack of understanding about how to provide reports and evidence to align with NDIS review process disadvantages some participants.
- There is a growing misunderstanding in the community about the early childhood support services that are provided under the [NDIS Act 2013](#). This is the legislation

that governs the NDIS. This misunderstanding is creating a disconnection between the NDIS and family expectations of the NDIS.

Update on the NDIA's early childhood approach

Peter De Natris, Strategic Advisor, Early Childhood and Autism, NDIA, gave an update on the NDIA's work for the Autism Advisory Group and early childhood. Mr De Natris discussed ways the NDIA is improving the effectiveness of the early childhood approach in the NDIS through:

- improved Scheme design for children and families
- vision and leadership in the NDIA and NDIS
- market commissioning and stewardship,
- reasonable and necessary policy development in early childhood intervention, through revised access frameworks, plan development processes and implementation support.

Mr De Natris noted the current work of the Autism Advisory Group (AAG). This included that the AAG will be providing input into the NDIA's Information Gathering for Access and Planning project.

Mr De Natris invited the Reference Group to engage with the NDIA out of session and invited them to share their views on the NDIA's work in early childhood. Members noted:

- The NDIA's early childhood approach and early childhood intervention requires leadership, astute decision-making and co-design with the disability community.
- The principles of choice and control, trust, empowerment and inclusion, feel removed from how the NDIA manages the NDIS today.
- It is hard for families to have the time and energy to understand evidence-based and best-practice early intervention.
- Families are feeling traumatised by NDIS processes.
- There appears to be a significant decline in information and capacity building funding for young children and their families. This affects how families make informed choices about using NDIS supports to increase community participation.
- Systematic oversight of standards and accreditation for providers requires collaboration between the NDIA and other governments.
- That a market driven approach may not be the best fit for early childhood and human services.
- The need for market stewardship to move its focus to quality outcomes rather than thin markets.
- Capacity building for families may work better if the NDIA facilitated this rather than NDIS partners who, because of their tendered contracts, feel restricted from giving useful advice.
- We need early intervention supports for parents, to help them learn about the best ways to support their child with disability.

Update & discussion on co-design

Ms Van Poppel noted productive meetings held as part of [the NDIA's work on co-design](#). She noted that Co-design Steering Committees provide strategic advice, governance and oversight for the co-design and development of four key policies:

- Information Gathering for Access and Planning
- Home and Living

- Support for Decision Making
- Participant Safety.

Members noted:

- There needs to be national collaboration and deep listening to children, young people and families as part of co-design, especially around the challenges they face and their hopes for the future. This is in line with the United Nations Convention on the Rights of the Child, Article 12.
- The voice of children, young people and their families, and their safeguards, should be a part co-design and the development of all four key NDIA policies.
- Children need to tell the NDIA, through children and youth engagement approaches, about what an ideal childhood looks like for them, not just the outcomes they want to achieve.
- The NDIA needs to access the voice of children who are non-verbal and have very high needs and gain their advice without adding to their family's stress.
- There is a need for health and education systems to be involved in co-design and to listen to the voice of children and young people.
- The NDIA should think about children in all its communications, and they should develop resources with both children and parents in mind. This is on top of resources being made available in accessible and alternative formats, like plain language/English, Easy English/Read, Auslan and others.
- There is an opportunity to use photo voice, technologies and games-based interventions to support the development and engagement of children and young people, particularly those with communications and access challenges.
- Children and young people need to be empowered to take ownership of their lives. We need to support young people to become future leaders by involving them earlier in informing the services that apply to them.
- We achieve disability access when inclusion is a part of a child's whole life. The same concept is for youth engagement. Include young people in all situations.
- We need to have the right support in place for young people coming into reference groups.
- Children and young people need their own autonomous voice, not a voice alongside adults.

More information on the Reference Group

The Reference Group will next meet in late 2022 and will keep progressing its work 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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