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# Reference Group meeting bulletin – 11 May 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 gives advice to the Independent Advisory Council (Council) to the National Disability Insurance Scheme (NDIS). Its advice focuses on best practice for children, young people, and families and ways to maximise their independence and inclusion.

The Reference Group met on 11 May 2023 in Melbourne and via videoconference. [Ms Leah van Poppel](#), Council Principal Member and Reference Group Co-chair led the meeting. [Ms Sylvana Mahmic, Council Member and Reference Group Co-chair](#) supported Ms van Poppel at the meeting.

### From the Reference Group Co-chair

Ms van Poppel noted the work the Council and Reference Group Members have done since their last meeting on [27 February 2023 \(DOCX 87KB\)](#).

### What Members have heard in their community

Reference Group Members reported on matters for the NDIA's attention, relating to:

#### NDIS access and planning

- Concerns about the disparity of plan values and supports given to children with similar disability, with questions around consistent decision making by the NDIA.
- A need for more information and promotion of the key worker model, which works well when understood.
- Lack of funding for young adults with disability, especially those with intellectual disability to build their capacity to get involved in their community.
- The NDIA should engage responsibly with children and young people by ensuring they have the right supports. This includes considering strengths-based and family-centred practices.

## NDIS service and supports

- Reports from stakeholders and the disability community that the NDIA complex support team are making a concerted effort to educate about the justice liaison officers' service offering.
- Overwhelming concern for the desperate plight of single parents of children and young people with disability whose caring duties have severely strained their mental health and ability to support their children.
- Calls for the NDIA to better support and guide parents and families, especially families where children have complex needs, those from culturally and linguistically diverse (CALD) backgrounds, and male parents.
- The NDIA should encourage peer supports for children and young people with disability and their families.
- Calls for the NDIA Pricing Arrangements and Price Limits to include training for family and community, to involve the broader community that supports the child not only carers/parents.
- Reports that the high turnover of therapists affects the quality of supports for children and their families and impacts other areas in a child's life, their development and choice and control.
- People should be paid for their time and effort to build the capacity of young people and their skills.

## NDIS providers, community and other government services

- Reports of a general lack of accountability in those models of care provided through online disability support platforms. For example, Hire Up and Mable.
- Concerns around support quality and safeguards, especially related to young people with disability and those with complex needs who use support workers from both registered and unregistered providers.
- Some people with disability say there are workforce challenges in relation to inconsistent quality of planners and support coordinators. Additionally, some participants say unregistered support workers do complex tasks without the right training, which is a safety issue.
- Calls for better state and territory supports for parents and children engaging with the education system. Language in education reports should emphasise a strengths-based view.

## Disability community

- Concern in some networks that high autism representation in the NDIS impacts supports and funding for people with other disabilities.
- Calls for the NDIA Board to better represent people who are carers for people with disability.
- There are some people in the disability community who are anxious about the recent Commonwealth Government budget announcement around NDIS expenditure.

## NDIA Children's Taskforce

The NDIA updated the Reference Group on its work to establish a Children's Taskforce to elevate the focus on children aged 0-14 years within the NDIS, consistent with a life stages approach. Members welcomed the scope and focus of the Children's Taskforce and gave the following feedback:

- The need to learn from First Nations communities that are achieving strong outcomes for children and young people.
- The need to look at practical ways to link with other community and/or government systems of support outside the NDIS. Particularly capacity building and learning via early childhood partners and education providers.
- Most parents with children with disability say they learn the most about how to support their child from other parents, not a professional, which highlights the need for peer supports.
- Questioned how the Children's Taskforce may work with states and territories to improve supports and outcomes for children and young people.
- The Children's Taskforce should emphasise the role of parents and carers in participant plans.
- NDIA language used around 'incentivising providers' should change to 'expectations for providers', and 'early childhood intervention' should change to 'early childhood supports'.
- There is opportunity to adopt a family-centred approach to support parents in their important role, which is central to supporting their child's development.
- There is a need to have a similar way for the NDIA to consider young people aged 14-25 years.

## Reflecting on our work

Members reflected on the work they've done this year, including the Reference Group's achievements and ways to improve future work and priorities. Members were pleased with work done to date but noted:

- The importance of progressing and inputting to the Council's advice '*Improving the NDIS for children and young people: the importance of being guided by their voice*'.
- There is a need to support families and children with disability, especially those with complex needs, through family-centred practice.
- The Reference Group would benefit from having more youth representation, noting there are challenges with payments for youth engagement.
- While the Reference Group membership may change in the future, it is vital to continue and carry the Group's current priorities and work.
- There needs cohesive connections with other systems that interact with the NDIS. For example, Information Linkages and Capacity Building (ILC) program and education.
- The NDIA should support youth with disability to find meaningful employment and live independently, when they wish.
- Plans for children with disability should be longer in duration, and planner capability is vital for delivering the best possible participant plans and outcomes for children and young people.



## Shaping Council's priorities for the NDIS Review

The NDIS Review panel, led by Professor Bruce Bonyhady AM, discussed the work of the NDIS Review. Professor Bonyhady welcomed feedback from Members about solutions to NDIS issues for children, young people, and their families. Reference Group members told the NDIS Review panel:

- There is a need for the NDIS Review to include recommendations that address the disparity of supports given to children with similar disabilities, considering some parents and families are at breaking point without supports.
- There is an opportunity to adopt a functional and family-centred approach for children with disability, recognising their strengths, belonging to family, and community. This approach calls for the strengthening of ILC and plans for young people as they navigate various life stages, especially the transition from school to employment.
- There is the opportunity to help parents of children with disability with supported decision making and capacity building, which will in turn support their child's development and capacity.
- Enhancing collaboration and connections between the NDIS and education providers is vital to deliver positive outcomes for children and families, including childhood development and familial supports.

## More information on the Reference Group

The Children, Young People and Families Reference Group will next meet on Thursday 20 July 2023. 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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