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Reference Group meeting bulletin – 22 June 2023

Equity and Inclusion Reference Group

This Bulletin summarises the recent meeting of the Equity and Inclusion Reference Group (Reference Group). The Reference Group gives advice to the Independent Advisory Council (IAC) to the National Disability Insurance Scheme (NDIS). Its advice aims to promote diversity, inclusion, equal opportunity, and fairness in the NDIS.

The Reference Group met on 22 June 2023 via videoconference. Ms Leah van Poppel, IAC Principal Member and Reference Group Co-chair, and Adjunct Associate Professor Jennifer Cullen, IAC Member and Reference Group Co-Chair, led the meeting.

From the Reference Group Co-chair

Ms van Poppel noted the work the IAC and Reference Group Members have done since their last meeting on 23 March 2023 (DOCX 86KB). She acknowledged members' work and noted that this would be the last meeting for the Reference Group in its current state, given that its membership will be refreshed from 1 July 2023.

Ms van Poppel noted the progression of the advice 'Improving Equity in the NDIS' to the Minister for the NDIS and the <u>Disability Reform Ministerial Council</u>. Adjunct Associate Professor Cullen highlighted the meeting's focus on supported decision making and complex support needs and guided an update on the progress of the National Disability Insurance Agency's (NDIA) First Nations Advisory Group.

What Members have heard in their community

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

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NDIS access and planning

- Systemic issues with home and living supports and plans. This includes supported independent living (SIL) plan inflexibility, specialised disability accommodation (SDA) provider malpractice and lack of housing availability.
- Continuous NDIS accessibility administrative issues. For example, the NDIS asks for a nominee
 to sign NDIS access forms for people with significant physical disability who could for example
 potentially use a signature stamp or sign with a recognised symbol.
- Some people with psychosocial disability, who are at risk of homelessness, say they find it almost impossible to access the NDIS.
- Some plan managers say that they are seeing increased funding reductions for participants since
 <u>National Cabinet's announcement of an 8% annual growth target for the NDIS</u>. There are also
 calls from some plan managers for the review of their service costs to account for consumer price
 index (CPI) increases.

NDIS service and supports

- Inconsistent and confusing messaging from local area coordinators and planners, who sometimes shift responsibility to plan managers. This relates to charging high intensity rate for participant supports.
- Calls for the NDIA to explicitly clarify the purpose of 'check ins' with NDIS participants. For example, NDIS phones some participants for 'check in' and then extends plans without a participant's knowledge.
- Reports that some people with disability (in particular those with psychosocial disability) find it
 hard to find suitable and safe supports workers, which is not only disempowering but puts them at
 risk. Also, lack of support worker options causes those people who want individualised living
 option (ILO) supports to be funnelled towards SDA options, given that is the only pathway to
 reliable support workers.

NDIS Providers and disability community

- Reports of an alleged system of incentivised referral and payment practices among registered providers.
- Calls for the expansion of lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, (LGBTIQA+) focused NDIS providers. This would be seen as providing options for culturally safe supports to LGBTIQA+ people with disability.
- Calls for the NDIA to ensure NDIS participants who identify as LGBTIQA+ are safe and receive trauma informed supports, especially in relation to the recent anti-transgender narrative in the community.
- There is a need to look at the quality of all interactions between participants and NDIS providers to ensure they are considering and supporting intersectionality.



NDIS Review

- Calls for the NDIS Review to conduct more in-depth engagement with the LGBTIQA+ community, to ensure their voices are heard and represented in the review.
- Networks have highlighted the importance of work being done by the NDIS Review, NDIS Quality
 and Safeguards Commission, and the Independent Mental Health Advocacy's (IMHA) NDIS
 mental health toolkit on equity issues related to those people with psychosocial disability.
- The importance of newly established advocacy organisations for LGBTIAQ+ people with disability, like <u>Inclusive Rainbow Voices</u>.

Update on NDIA's supported decision making work

The NDIA gave the Reference Group an update about its work to implement the <u>Supported decision</u> <u>making policy (PDF 200KB)</u>. The NDIA started implementing the Policy this year, and will continue over a number of years in line with its <u>Implementation plan (PDF 156MB)</u>. Members gave the following feedback:

- General agreement that the policy is high-quality, which is a credit to the time taken to properly co-design.
- The implementation work should clearly communicate short-term and long-term goals.
- The need to address NDIS structural issues that create barriers for people to be actively involved in supported decision making.
- Supported decision making should start with intersectionality and allow for dignity of risk.
- Future work should aim for all people with disability to have autonomy in the context of community, not only as individuals, and focus on cross-cultural co-design.
- The need to focus on allowing people who live in group settings to take part in capacity building so that they can make their own decisions and have a voice.
- When a decision is being made for an individual, that person should completely understand the impact that decision has on their plan and their daily life.
- The importance of having different peer groups available so that people with disability can have options on who they with on engage on different issues.
- Wondered if the NDIS has a role to support people whose rights are challenged under guardianship mechanisms, like nominees and state trustees.

Update on NDIA's Complex Support Needs Pathway

The NDIA gave the Reference Group an update about its work on the Complex Support Needs Pathway. The Pathway, which was rolled out in 2018, provides specialised support for participants living with a disability who have many different challenges impacting on their lives. Members gave the following feedback:

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- General agreement that the Pathway provides ease in NDIS access, coordinated supports, and an improved participant experience. Also, that the Pathway's clinical advisory team provide strong oversight on behaviour support plans and restrictive practice.
- There is a need to investigate data around First Nations and culturally and linguistically diverse (CALD) people's representation in the Pathway and engage with these people using a traumainformed approach over time to build trust.
- Wanted further information about the way and/or extent in which the Pathway liaises with other Government supports and/or programs outside the NDIS, like justice, mental health, and guardianship.
- Challenge for participants across Australian who are in this Pathway but are subject to different legislations and government supports for each state and/or territory.
- The importance of ensuring the safety of children, especially transgender children, in the Pathway. With reference to those children who live in out of home settings and appear to be subject to unauthorised restrictive practice.
- The need to consider displays of inappropriate behaviour as an expression of self, especially with young people with intellectual disability and autism.
- The importance of lifestyle planning and creating meaningful relationships via circles of support, especially for people with guardians.

More information on the Reference Group

The Reference Group will next meet on Thursday 24 August 2023. Find out more about Reference Group meetings and bulletins at the IAC website. You can also access IAC advice here.

The IAC publishes an Easy Read version Bulletin. This is part of its commitment to accessibility.