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Meeting bulletin – 18 May 2023

This bulletin summarises the Independent Advisory Council's (IAC) recent meeting. The IAC gives advice to the National Disability Insurance Agency (NDIA) Board. The IAC's advice aims to improve the National Disability Insurance Scheme (NDIS). Ms Leah van Poppel, who is <u>the IAC Principal Member</u>, chaired the meeting, held via videoconference on 18 May 2023.

Update from the IAC's Principal Member

Ms van Poppel gave an update on the IAC's advice and other recent work done with the NDIA. This work includes a forum with NDIA and Disability Representative and Carer Organisations (DRCO), which the <u>Minister of the NDIS</u> also attended. The IAC gave their feedback on <u>recent budget announcements</u> relating to the NDIS. Additionally, Ms van Poppel acknowledged the valued contribution of Dr Ben Gauntlett, who is stepping down from his IAC role as <u>Expert Adviser at the end of June 2023</u>.

Update from the NDIA

<u>Mr Kurt Fearnley AO</u>, NDIA Board Chair, thanked the IAC for their commitment to working with the NDIA and the <u>Minister of the NDIS</u> on budget announcements and NDIA's priorities. Mr Fearnley acknowledged the important work done to date by the IAC on its advice about children and young people.

What Members have heard in their community

<u>Council Members</u> and the <u>Expert Adviser</u> reported on matters for the NDIA's attention, related to:

NDIS access and planning

- Concerns that NDIA systems do not carry over plan variations, particularly around assistive technology, that are added to a plan before a 'plan continuation'.
- The report <u>'Comparison of NDIS plans for those living with Machado-Joseph Disease (MJD) in</u> <u>the NT and QLD</u>' says that plan values overall increase in line with MJD disease progression. But average plan values have fallen for people who are in the moderate or severe-ambulant stages of the disease. There has been a reduction in support coordination and therapy funding in plans, across cohorts, for those with MJD.

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NDIS service and supports

- Ongoing reporting that the NDIS call centre does not give consistent information to participants and/or continuity in service, which causes participant's unnecessary distress.
- Calls for more information, planning, and family engagement to help older people with disability with access to palliative care.
- Reports of NDIA communications and systems breakdowns related to internal review of decision that are not looked when/if a new plan is being developed.
- Calls for more information and support to be provided to participants who self-manage, including proactive distribution of the <u>Self-Management Guide</u>.
- Reports of instances where reasonable and necessary supports are reduced at plan review (due to changed circumstances), despite the provision of extensive evidence. This particularly relates to younger participants with complex disability who seek <u>school leaver employment supports</u> (<u>SLES</u>).
- Delays with early childhood partners connecting children in foster care with NDIS plans and supports. this highlights inadequate care arrangements and other interface challenges.
- Agreement that childhood development benefits from parental education. Concerns families don't
 value this education it as much as therapy and that early childhood planners often reject the
 support in plans.
- Reports that there is a need for more information and education on participants being able to use their supports when in hospital. This is particularly important for NDIS participants with severe behavioural and/or complex communications needs. Additionally, there is inconsistent advice being provided by some hospital liaison officers.
- Reports from some families, plan managers and support coordinators in Tasmania that the NDIA's PACE trial has some implementation issues, including payments being delayed.
- While there are mixed views on the effectiveness of support coordinators, they are considered important supports for some people with intellectual disability.
- Concern about people with public guardians in Victoria not allowed to speak for themselves. They instead need to go to the Victorian Civil and Administrative Tribunal (VCAT) to get permission for this. Suggestion that this may be a national issue.
- Positive meetings with the NDIS Quality and Safeguards Commission on regulatory enforcement models and human rights issues within the NDIS Act 2013.
- Mixed views on the role of the NDIS Pricing Arrangements and Price Limits, with calls for the NDIA to control some areas more strictly than others.
- Praise for the NDIA's work in the Northern Territory to support participants evacuated from floodeffected remote communities. Particularly NDIA Planner teams who met with participants regarding their change of circumstances and supports and services linkages.

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Home and living

- Concerns the <u>Specialist Disability Accommodation (SDA) Pricing Review</u> might make overly optimistic assumptions. This will have the effect of significantly underestimating the cost of SDA developments. This will have a disproportionately large impact on SDA developers who are building bespoke solutions that are designed alongside individual participants.
- The need for the NDIA to ensure the NDIS Pricing Arrangements and Price Limits drives positive behaviour in providers, with many currently making risk-free profits at the expense of participants.
- Positive reports related to the NDIA better understanding the technical ways SDA supports work and incorporating this learning into the <u>SDA Pricing Review</u>.
- Challenges for some participants with severe and complex disability relating to continuous nursing care given by providers that operate SDA dwellings. This is particularly effecting those living in <u>existing and legacy stock</u> homes when others leave the accommodation and supports reduce.
- Reports that some SDA requests are delayed for up to two years. Calls for an automated escalation process to assist with timely plan and request completion.
- Concerns around inconsistent planning decisions, specifically around SDA. Some participants
 with intellectual and/or complex disability get an unrequested plan increase when they are denied
 supports for SDA. For example, they are denied SDA due to not meeting the extreme functional
 impairment criteria, but their overall plan has almost doubled in value.

Disability community

- Some of the disability community, including early childhood and not for profit sector, are feeling hopeful after the government clarified its <u>recent budget announcement</u>, which referenced an annual growth target.
- Anticipation in the disability community around upcoming information sessions by the NDIA to raise awareness and educate key stakeholders in the Northern Territory about <u>justice liaison</u> <u>services</u>.
- Reports by advocates about inaccurate and/or out of date participant information held by the NDIA, as well as delays with the <u>Independent Expert Review Program</u>.
- Calls from the disability community for the <u>NDIS Review</u> to release more information about the work they are doing so that the community can stay informed and up to date.

Update about the IAC's advice to the NDIA Board

The IAC discussed the latest version of its advice, 'Improving the NDIS for children and young people'. The IAC endorsed the advice, noting the need to expedite the work to the Board to ensure the NDIA better understands the unique needs of children and young people and to improve outcomes for younger people in the NDIS.



Update about the Administrative Appeals Tribunal's work

The IAC got an update of the work of the Administrative Appeals Tribunal (AAT), specifically the NDIA's trialling an Independent Expert Review (IER) Program. Members commended the results of the IER Program, and gave the following feedback:

- Any future dispute resolution pathways should be trauma-informed and inquisitorial rather than adversarial.
- The importance of reaching out to participants from First Nations or culturally and linguistically diverse (CALD) backgrounds who seem to be underrepresented in the trial. Also, to ensure participants with intellectual disability understand the aim of the IER trial.
- A similar approach to the trial, where participants are given the option of earlier dispute resolution before an AAT hearing, should be used as standard practice by the NDIA.
- The IAC look forward to hearing more about the IER Program evaluation and hope it includes measures of participant experience and costs.

Developing IAC's future Work Plan

The IAC discussed the priorities for its future Work Plan. The Work Plan is an annual accountability statement that the IAC make. The IAC discussed the current changeable landscape and that some of their continuing priorities should include:

- Workforce and employment, including the quality of services provided to people with disability and intellectual disability.
- Recommendations from the NDIS Review and <u>Royal Commission</u>.
- Advice on participants who are ageing, as well as ensuring the implementation of IAC's advice on equity and inclusion in the NDIS.

More information on the IAC

The IAC's next meeting will be held in Melbourne on 6 July 2023. Find out more about IAC meetings and bulletins at the <u>IAC website</u>. You can also access advice from the <u>IAC website</u>.

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