RVA Education

National Disability Insurance Agency Consultation

The National Disability Insurance Agency (NDIA) is currently consulting about a range of changes to the NDIS that have implications for people with rare conditions who access or wish to access NDIS funding. Rare Voices Australia (RVA) will be lodging a submission to address issues that are relevant to the rare disease community who already are, or are looking to become, NDIS participants. The consultation closes on 10am ADST Tuesday February 23, 2021.

Information from the NDIA about the consultation

What we are consulting on

> *In our Participant Service Charter, we committed to including people with disability and the community to help us develop and test our processes.*
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> *That is why we have released three consultation papers and one project consultation report. We're also sharing our project report on the Early Childhood Early Intervention (ECEI) Implementation. This report is for sector stakeholders, governments and mainstream supports like education and health, and outlines the research, recommendations and background behind the third paper; Supporting young children and their families early, to reach their full potential.*
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> *The three consultation papers explain proposed changes to NDIS including what these changes will mean for participants.*
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> 1. *Consultation paper: access and eligibility policy for independent assessments*
> 2. *Consultation paper: planning policy for personalised budgets and plan flexibility*
> 3. *Consultation paper: supporting young children and their families early, to reach their full potential*
> 4. *The Early Childhood Early Intervention Reset Project consultation report.*
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> *Papers 3 and 4 cover the ECEI Implementation Reset project, which includes background to the project for context, areas for improvement and further detail on how best practice is intended to work.*
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> *We need your feedback about how these changes will work.*
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> *By providing your feedback, you'll be helping us deliver a better and fairer experience for all people with disability accessing the NDIS and participants already in the Scheme.*
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> *At the end of each paper, there are some questions. We welcome your responses to these questions. You can answer some or all of them, you can also make a submission to some or all of the papers.*

You can provide a written, audio or video submission.

You can access more details and each of the consultation papers here.

Considerations for the rare disease community

RVA developed a Position Statement in response to the Tune Review that addresses some of the aspects of this consultation, in particular the independent assessment process and changes that make the NDIS more person-centred. In addition, you may wish to comment on:

- The removal of lists consisting of particular conditions that were used as part of the assessment process. This indicates a further shift away from a diagnosis being prioritised as part of the assessment process to a focus on a person's capacity and capability.
- How independent assessment processes for those impacted by rare conditions will ensure that they have access to rare disease expertise to understand the complexity of how the condition impacts on functional capacity.
- What additions the NDIA might consider to ensure there is better integration between support systems for people with a rare condition including the interface between health and disability support.
- How the new processes will account for the episodic and/or progressive nature of many rare conditions that cause functional incapacity.
- The recognition of people with rare conditions as a priority population for NDIS purposes.

The above is not intended to be a complete list and represents some possible areas of focus for your submission. There may be other aspects of the proposed changes that you either welcome or have concerns about. This consultation is your opportunity to raise these concerns with the NDIA for consideration.

Resources to assist you in developing your submission

- You can respond to any, or all, of the consultation papers.
- The papers provide a list of questions that you may choose to respond to, you can respond to some, none, or all of the suggested questions.
- The report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases,* has research and information that may be helpful to include in your submission.
- RVA has released a Position Statement on the Tune Review addressing areas to highlight around the use of independent assessments and the need for better integration between health and disability supports.
- The National Strategic Action Plan for Rare Diseases (the Action Plan) is also an important resource for making suggestions as part of your submission. The next section covers the Action Plan in relation to the NDIS.

RVA is also able to provide mentoring and support to RVA Partners developing a submission. Please contact our Stakeholder Engagement and Education Officer, Louise Healy, at education@rarevoices.org.au for assistance.

The National Strategic Action Plan for Rare Diseases and the NDIS

The Action Plan has several recommendations that are applicable to disability and the NDIS. In your submission, it is useful to reference these recommendations as they have the support of the Parliament already. Specific items include:

Action 1.2.2 Improve consultation and communication between policy-makers and the rare disease community.

Implementation

1.2.2.1. Rare disease organisations strengthen their connections with policy-makers. This would build on current coordination by existing national and state-based collaborations.

1.2.2.2. Further articulate the consumer voice through the facilitation of an advisory group to improve consultation and communication on a range of issues including disability, health, housing, education and employment.

Priority 2.1 Provide rare disease care and support that is integrated and appropriate for all Australians living with a rare disease, while being both person and family-centred.

Action 2.1.1 Provide rare disease care and support that is integrated, incorporating clear pathways throughout health, disability and other systems.

Implementation

2.1.1.1. Establish standards for care and support that are integrated and incorporate clear pathways throughout all systems. Ensure these are informed by clinical and consumer rare disease experts and that such consultation informs policy development.

2.1.1.2. To reduce fragmented care, ensure policy meets people's full range of needs, including health, disability and education. Support this work with a cross-jurisdictional, cross-sectoral working party.

2.1.1.4. Ensure care and support is responsive to the specific needs of rural and remote communities and health services, Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations.

Action 2.1.2 Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.

Implementation

2.1.2.2. Strengthen the National Disability Insurance Agency's response to the nature of disability caused by rare disease that can manifest as chronic, intermittent and often progressive. Initial implementation should prioritise:

- fast tracking access to the NDIS; and
- ensuring NDIS participants can access an appropriate range of respite to meet the needs of families.

Action 2.1.5 Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases.

Implementation

2.1.5.1. Capture and promote the voice of people living with a rare disease and their families and carers by:

- involving people living with a rare disease at every level of decision-making;
- ensuring ongoing engagement to capture broader input from people living with a rare disease through surveys, focus groups, newsletters and representation on boards; and
- calling for key structures and systems to routinely and effectively capture broader input from consumers, as done currently in some research settings and HTA (consumer hearings).

2.1.5.2. Enhance culturally safe and appropriate approaches for Aboriginal and Torres Strait Islander people, including aligning with existing initiatives to develop and implement ways to integrate Indigenous Australian languages to equitably enhance care and support.