

RARE VOICES AUSTRALIA POSITION STATEMENT

SEPTEMBER 2020

GOVERNMENT RESPONSE TO THE TUNE REVIEW OF THE NATIONAL DISABILITY INSURANCE SCHEME ACT 2013

BACKGROUND

In May 2019, the Federal Government announced a review to look at the *National Disability Insurance Scheme Act 2013* to identify opportunities to streamline National Disability Insurance Scheme (NDIS) processes and remove legislative barriers to positive participant and provider experiences. This review was conducted by former senior public servant David Tune who delivered the report to the Government in December 2019. [The report](#) was publicly released in January 2020 and made 29 recommendations to improve the way the NDIS operates.

In October 2019, Rare Voices Australia (RVA) launched the report [Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases](#) (*Disability & Rare Disease* report). The report highlighted significant unmet need and the need for the health and disability sectors to collaborate to provide person centred care. RVA presented the report to the Minister for the NDIS, Hon Stuart Robert MP, and the Shadow Minister for the NDIS, Hon Bill Shorten MP.

On 28 August 2020, the [Federal Government announced](#) that it supports, or supports in principle, all of the recommendations of the Tune Review. Over the next six months, the Government said it will work in close collaboration with people with disability and the disability sector to implement these reforms, including consultation on any legislative changes required.

The Government has also released the:

[Participant Service Charter](#) - outlines what participants can expect from the National Disability Insurance Agency (NDIA) and its partners. Within the Charter, sits the Participant Service Guarantee which includes clear timeframes for key NDIS processes.

[Participant Service Improvement Plan 2020-21](#) - details improvements the NDIS will make over the next two years.

Additionally, from next year, the NDIA will fund [independent assessments](#) for people applying for the NDIS.

RVA'S INITIAL RESPONSE TO THE GOVERNMENT'S ANNOUNCEMENT

RVA welcomed the announcement by the Government and its commitment to consult with people living with disability and the disability sector. We remain cautiously optimistic that the announcement will begin to address the concerns of people living with a rare disease who are NDIS participants that were presented in the *Disability & Rare Disease* report.



RECOMMENDATIONS AND GOVERNMENT RESPONSES THAT ARE RELEVANT TO PEOPLE LIVING WITH A RARE DISEASE

RVA has reviewed the information the Government released on 28 August 2020, including its formal response. Below, we have highlighted aspects of the Tune Review recommendations and Government responses that are relevant to Australians living with a rare disease and their families and carers.

Please note: this is not intended to be an exhaustive list.

We encourage you to download a copy of the Government's formal response [here](#) when referring to the below information. All direct quotes listed have been taken from the Government's formal response.

THE ACKNOWLEDGMENT OF THE INTERFACE BETWEEN DISABILITY AND HEALTH (SEE RECOMMENDATION 1)

Recommendation 1 outlines the Disability Reform Council (DRC) adding the resolution of four outstanding policy matters to its forward work program including "the treatment of chronic health conditions under the NDIS." RVA welcomes the Government's support of Recommendation 1 and acknowledges the work underway that is flagged in the Government's formal response (see below excerpt):

"Considerable work is underway to prioritise and resolve boundary and interfaces between the NDIS and other service systems. All governments are working together to progress, as a priority, the roles and responsibilities of all service systems and consistency of application of the Principles to determine the responsibilities of the NDIS and other service systems..."

CONCERNS AROUND THE USE OF INDEPENDENT ASSESSMENTS (SEE RECOMMENDATIONS 2 AND 7)

Whilst the NDIA's movement towards "a more collaborative and transparent planning experience" is a positive step forward, RVA remains concerned about the Government's commitment to utilising independent assessments. Lack of awareness of rare diseases often contributes to missed opportunities for improved outcomes. Rare diseases typically display a high level of complexity and there is variation within each specific rare disease. Independent assessors must have a solid understanding of rare diseases and the individual participant in order for this reform to meet its objectives for people living with a rare disease. With over 7,000 different rare diseases, it is impossible for any individual (including qualified health care professionals) to be aware of every rare disease. The [independent assessments are intended to create a complete picture](#) of how people manage tasks and activities in their day-to-day life. We know that people's circumstances can change rapidly when living with a rare disease. Where changes do occur quickly, people need resources to be approved quickly to meet their needs. Likewise, we know that significant life-stage transitions (e.g. transitioning from child to adult hospitals) are crucial for people living with a rare disease and that support services must be made available as needed. RVA believes the collection of documents and assessments from familiar doctors, specialists and other experts — people who know the individual and understand the impact of their rare disease — is essential for NDIS participants living with a rare disease.

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SUPPORTING PEOPLE WITH DISABILITY TO NAVIGATE THEIR WAY THROUGH THE NDIS (SEE RECOMMENDATION 3)

The Government's recognition "that there are people with disability in Australia who are harder to reach and engage with than others and may be in need of assistance" is important for the rare disease community. The National Strategic Action Plan for Rare Diseases identifies a number of Priority Populations including Aboriginal and Torres Strait Islander people and those from Culturally and Linguistically Diverse (CALD) backgrounds. Such populations, where English is not necessarily people's first language, can find navigating the NDIS difficult. RVA supports the NDIA's intent to "increase its communication to help people with disability navigate the NDIS." We acknowledge the Government's "\$20 million commitment to expand the NDIS Community Connectors Program to assist hard to reach communities to navigate the NDIS..."

THE PARTICIPANT SERVICE GUARANTEE (SEE RECOMMENDATIONS 11, 24 AND 25)

The *Disability & Rare Disease* report details individuals waiting 18 months for approved wheelchairs. Such delays can have a lasting impact, especially for children who require equipment to meet specific developmental requirements such as the ability to stand or walk.

The Government's commitment to implementing the Participant Service Guarantee is encouraging for NDIS participants living with a rare disease. RVA welcomes the amendment of the NDIS Act to reflect that a plan must be facilitated and approved in accordance with the timeframes outlined in the Participant Service Guarantee, which increases both transparency and accountability. Service standards mean people will know how long key processes such as access decisions and plan reviews will take. Uncertainty can be incredibly disempowering for people living with a rare disease and increased transparency will help to reduce anxiety. RVA supports collaboration between state and territories "to consider and implement amendments to the NDIS Act and Rules," in addition to the review of the Participant Service Guarantee two years after it is enacted.

FOCUS ON A PERSON-CENTRED APPROACH (SEE RECOMMENDATION 15)

Amending NDIS Rules "to clarify that supports in a participant's plan should be used flexibly," facilitates person-centred care. This is particularly important for people living with a rare disease who typically display a high level of symptom complexity and frequently have complex and multi-system needs. RVA welcomes the Government's support of Recommendation 15 and acknowledges the steps already in motion as outlined in their formal response:

"The Government recently announced its intention to provide participants with greater flexibility in using their NDIS funding, in parallel with the national rollout of independent functional capacity assessments. This will provide participants with more choice and enable them to maximise the benefits of their NDIS funding in ways that support them to pursue their goals and aspirations.

"The Government supports amending the NDIS Rules to enshrine flexibility as a key principle underpinning the delivery of NDIS supports. This is in keeping with the Government's commitment to improve the participant experience."



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UNDERTAKING UNSCHEDULED PLAN REVIEWS

(SEE RECOMMENDATION 20)

RVA welcomes the Government's support and recognition that plan review processes must be simplified, red tape reduced and that more transparency is needed around how the NDIA makes its decisions. The new "Category D rule-making power that sets out the matters the NDIA must consider when deciding whether to undertake an unscheduled plan review," is key to this increased transparency. The removal of jargon wherever possible paves the way for more effective communication.

DEVELOPMENT OF A NEW INDEPENDENT PARTICIPANT SATISFACTION SURVEY

(SEE RECOMMENDATION 24)

The Government's consideration of opportunities to "strengthen existing survey metrics" will further contribute towards better, person-centred care. Measuring participant satisfaction is crucial to participants, particularly those living with a rare disease. As part of research conducted to compile the *Disability & Rare Disease* report, 398 people living with a rare disease and 373 carers were surveyed — when asked about their satisfaction with services received under the NDIS, one in three people reported being dissatisfied or very dissatisfied. The highest level of dissatisfaction is in outer metro regions, where 40 per cent of people are either dissatisfied or very dissatisfied.

NEXT STEPS

The Federal Government stated it will consult with people living with disability and the disability sector. RVA believes this consultation process, which must be inclusive of people with disability and key representative organisations/peak bodies, is critical. Embedding the voice of people living with a rare disease and their carers and families, is crucial to achieving positive outcomes for the rare disease community.

Draft legislation is scheduled to be released in October 2020 for consultation, with the view to introduce reforms to Parliament for consideration in 2021.

ABOUT RARE VOICES AUSTRALIA (RVA)

RVA is Australia's peak body for rare diseases, advocating for the best outcomes for Australians living with a rare disease. RVA provides a strong, unified voice to campaign for policy as well as health, disability and other systems that work for people living with a rare disease. Our person-centred focus sees us working with all key stakeholders including governments, key peak bodies, researchers, clinicians, and industry.

