Rare Voices Australia submission to the Joint Standing Committee on NDIS Capability and Culture of the NDIA

Introduction

Rare Voices Australia (RVA) welcomes the opportunity to provide a submission to the Joint Standing Committee on NDIS on matters relating to Capability and Culture of the NDIA. RVA is the national peak body for the estimated two million Australians living with a rare disease. Our submission is closely aligned with the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan). [i]RVA led the collaborative development of the Action Plan, which was informed by multistakeholder collaboration, and launched in February 2020 with bipartisan support.

Our submission is also informed by the McKell Institute 2019 report *Disability and Rare Disease: Towards Person-centred care for Australians with Rare Diseases*[ii], which was commissioned by RVA in recognition of lack of data and research on this important issue. This report also includes results from a National Rare Disease survey completed by 398 people with a rare disease and 373 carers of people with a rare disease (total 771). Survey results revealed that:

- 7/10 respondents with disability responded that their disability needs were not being met or only partly being met. The problem is worse in rural Australia where over 8/10 reported not being met or only partly met, including 1/4 people reporting that their disability needs were not met at all.
- 1/3 people reported being dissatisfied or very dissatisfied with the NDIS
- 85% of respondents indicated the NDIS would not be able to meet their changing needs in a timely manner

The McKell Report informed the National Strategic Action Plan for Rare Diseases, in particular,

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
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
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.
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*

Since the McKell Report, and development of the Action Plan; RVA has continued to focus on these important issues. As such, our submission is also informed by:

- RVA Partner NDIA working group discussions
- Monthly Peak Body Stakeholder Engagement Meetings with NDIA
- Informal consultation with RVA and the RD sector

Current situation
It is important to acknowledge that the NDIS has been a profound game-changer for a number of people living with a rare disease, but it is also important to acknowledge that significant barriers remain for many, and much work needs to be done to strengthen the NDIA capability and culture to respond more effectively and consistently to Australians living with a rare disease.

In December 2021 RVA established a small but diverse working group of RVA partner organisations (specific disease consumer-led groups) through a Expression of Interest process. Selection criteria include people who were able to advocate on rare diseases more broadly and not just their own individual disease community. A virtual roundtable workshop was convened with senior executives from NDIA. This was the first meeting of its kind to be held and provided a much-needed forum for the NDIA to hear directly from the rare disease community on the extensive and systemic policy issues that currently exist within the NDIS and impact on many people living with a rare disease such as the unique challenges around eligibility access and planning for those who are part of the Scheme, and those that have yet to be accepted.

This was followed by a number of ongoing meetings with the Consumer Engagement and Communications team. After a period of time, there was mutual agreement that it was more appropriate for the Codesign and Engagement team to engage with RVA as a peak body. These meetings have occurred monthly since September 2022. While RVA feels that engagement is now at the right level and is more likely to achieve systemic change, it is frustrating that it took such a long time for the NDIA and an experienced peak such as RVA to begin to engage effectively. This suggests there are issues related to NDIA capability and culture.

The key issue relating to NDIA capability and culture for the rare disease community
Through our monthly meetings with the NDIA, it was confirmed that there is no defined role or position within the NDIA dedicated to advising on participants with a rare disease. Although in many ways RVA is not surprised by this, it is quite shocking when you consider 2 million Australians live with a rare disease.

Initial key recommendation:
RVA sees the establishment of a 'rare disease' role/ position within the NDIA as vital to lift the profile of rare diseases within the NDIA and also provide leadership to progress other important recommendations.

Other key recommendations:
2. Establish ongoing consultation and framework to codesign what a technical advisory panel/ group/ expertise should look like. The McKell Report had a similar recommendation of,

> *Working with the Technical Advisory Team, which is set up to assess the more complex eligibility applications, with a view to meeting the accessibility needs of people with rare diseases; or*

developing disability profiles for rare disease. This will ensure rare disease applicants with complex care needs don't miss out…

There is a need for RVA and the rare disease sector to partner with the NDIA to develop dedicated principles and practice guidelines for participants living with a rare disease. There is an opportunity to leverage the existing expertise of the rare disease sector to upskill NDIA staff. Out of necessity, many individual rare disease groups have already developed awareness and education material such as snapshots. Our understanding is that the NDIA do utilise snapshots however will only use snapshots that have been formalised by the NDIA. The rare disease sector would welcome the opportunity to work with the NDIA more collaboratively in the development of education material. To streamline such work, RVA believes there would be value in collaboration between similar disease group when developing education material.

There would be many opportunities for the NDIA to implement staff professional development on the disability needs of Australians with a rare disease. Participation in the RVA National Rare Disease Summit and other events would be a valuable way for the NDIA to connect and engage with the community they are serving. There is definitely a need for the NDIA to prioritise rare diseases. Noticeably, at the recent National Rare Disease Summit delegates included multiple Department of Health personnel but no one from the NDIA.

3. Establish a specialised pathway for people with rare diseases in recognition of their complexity. The McKell Report recommended the establishment of a "specialised pathway" for people with rare diseases in recognition of their "complex needs". There is an existing complex pathway intensive stream in the NDIS that provides a high level of support for a finite period of time. However, this is only used for participants where there is intersection with judicial, child safety or homelessness systems. There needs to be the similar intensive process available for participants with rare diseases, in response to the integration between health and disability inherent in rare disease. There is this false line that exists between health and disability that is just simply not person-centred. The McKell report states;

> *The separation of funders which has occurred under the NDIS between the disability and health sectors has created gaps in service provision, which in contested spaces, can impact individuals with rare disease that have an underlying medical cause of their disability.*

4. The NDIA to start measuring and reporting on data around participants and applicants who have a rare disease. In Australia we do not know how many NDIS participants have a rare disease. It is not directly coded. This is vital to assist with service planning.

5. Fix the disconnect between the language of the NDIA and the experience of the rare disease community. The current system is geared around language. It feels that you need to say the right words and tick the right boxes to open up the right level of funding. The language of the NDIA needs to be more nuanced. Indeed, from the perspective of the rare disease community, some NDIA

language is at best, inappropriate and at worst, offensive. The emphasis on capacity building for people with often lifelong and life-limiting nature of many rare diseases. The whole premise of requiring individuals to plan for future needs is problematic for people living with a rare disease for which there is limited data, often uncertain prognosis (especially in the case of undiagnosed rare disease), and in regards to the fluctuating and progressive nature of rare diseases

We encourage the NDIA to interpret the legislation in the broadest most inclusive and be wary of cherry-picking parts of it. For example, consider capacity building in relation to the whole family not just the individual. The focus should be focus on mitigating and alleviating impact, preventing impact on functional capacity

6. Develop a more fit for purpose for rare diseases; and flexible approach to funding much needed support coordination. Some rare disease organisations provide support coordination to respond to their community's need for specialist knowledge and service that generalist providers are unable to meet. This strengthens the NDIA workforce capability but is potentially unsustainable as the NDIA funding model is geared for service providers to service their local areas. The majority of rare disease organisations have members all across the country or all across the state. Due to the rarity of each disease, members are typically geographically dispersed, adding extra travel and time costs.

Thank you for the opportunity to provide input. RVA would welcome an opportunity to participate in a public hearing in the future. Please do not hesitate to reach out to RVA for any further information and/ or clarification. RVA is feeling positive about the Government's commitment to codesign and the effective dialogue that is now occurring between RVA and the NDIA. The recommendations that RVA has put forward would help drive the necessary systemic change to effectively and consistently meet the needs of participants living with a rare disease.

[i] Australian Government, Department of Health (2020) National Strategic Action Plan for Rare Diseases
[ii] McKell Institute (2019) Disability & Rare Disease: towards person-centred care for Australians with rare diseases