

## Rare Voices Australia Submission

### Joint Standing Committee on the National Disability Insurance Scheme Parliamentary Inquiry into Independent Assessments

#### Background

Rare Voices Australia (RVA) is the peak body for Australians living with a rare disease. RVA led the collaborative development of the [National Strategic Action Plan for Rare Diseases<sup>1</sup>](#) (the Action Plan), the first nationally coordinated effort to address rare diseases in Australia. In keeping with the cross over between many rare diseases and disability, aspects of the Action Plan specifically address the National Disability Insurance Scheme (NDIS) and the arbitrary and unhelpful line that is often drawn between medical issues and disability. In particular, the Action Plan highlights the need for coordinated and integrated care (see Appendix 1).

Since its inception in 2012, RVA has consistently highlighted the impact of disability on the lives of people living with a rare disease. In 2019, RVA commissioned the McKell Institute to deliver a white paper, [Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases \(Disability & Rare Disease report\)<sup>2</sup>](#), which informed the Action Plan. Additionally, in September 2020, RVA published a [Position Statement<sup>3</sup>](#) in response to the Tune Review to specifically address aspects of the Review that are most relevant to the estimated two million Australians impacted by rare disease and their families. RVA formally partners with more than 80 rare disease support groups and has consulted with 25 representatives of these groups in the development of this Submission.

#### Terms of Reference (TOR)

TOR A: The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS.

RVA supports processes and systems that will create more consistent and equitable access to NDIS support for Australians living with a rare disease. We welcome the focus on person-centred processes and systems. RVA is also supportive of ensuring that evaluation processes do not disadvantage any particular group. We support changes that focus on a person's functional capacity rather than on a specific diagnosis.

RVA does not support changes that use a "one size fits all" approach and are not person centric. We do not support changes that make the process less transparent, and that cannot be reviewed or challenged by individuals and their families. We therefore do not support the use of independent assessments for rare disease candidates.

Based on the lived experiences of families impacted by rare diseases, RVA believes that independent assessments will further embed the inequity and inconsistency that many people living with a rare disease and their families have encountered in previous dealings with the NDIS. Without significant alteration and additional resourcing, independent assessments will result in incomplete and inadequate information being considered by the National Disability Insurance Agency (NDIA) in the development of NDIS Plans. Rare diseases are often complex, progressive, multi-system disorders with highly variable presentations from person-to-person. They can also be characterised by extreme fluctuations in symptoms. They cannot be adequately responded to with time limited, standardised assessment by anyone without specialised knowledge of both the disease and the individual.

### *RVA Recommendations*

- Targeted approaches for assessing NDIS access requirements for rare disease applicants should be utilised. A “case management” approach, such as the one outlined for Australians living with mental illness in a 2006 Department of Health monograph<sup>4</sup>, would be much more appropriate and would provide a mechanism for more integrated and coordinated care for rare disease applicants. It would also help to address the ongoing issues faced by people living with a rare disease who fall through the gaps between healthcare and disability support.
- Any assessment of a rare disease applicant is required to be informed by expert input from an individual or group with specialised knowledge of the particular rare disease.
- Input is sought from clinicians and carers with knowledge of the individual being assessed to ensure that a complete picture of the complexity of the condition and its impact on the individual is considered in budget and planning decisions.
- Fast-track reviews be incorporated into any changes to assessments to ensure that necessary and reasonable supports for sudden disease progression and incapacity can be accessed in an appropriate timeframe.

TOR B: The impact of similar policies in other jurisdictions and in the provision of other government services.

RVA is concerned that the privatisation and standardisation of NDIS eligibility and access processes will result in services and responses that are less person-centred, less flexible and less capable of responding to the breadth and complexity of the needs of individuals whose rare disease has resulted in disability. Evidence presented during the Royal Commission into Aged Care Quality and Safety demonstrated that privatisation and standardisation resulted in reduced services, reduced flexibility for ageing Australians and an increased focus on cost containment and reduction. People living with a rare disease and disability are extremely vulnerable and the *Disability & Rare Disease* report<sup>2</sup> identified that the extremely high burden of care, coupled with the high degree of uncertainty faced by many rare disease families, left individuals and carers with few resources to navigate complex systems. Assessments need to be responsive to these issues.

Changes that remove the person-centred and individualised nature of the NDIS, or that reward for-profit organisations for cost reductions and/or containment, should not be considered. In addition, assessment processes need to account for the vulnerability of candidates and the pressures already faced by their carers.

#### *RVA Recommendations*

Other models of achieving increased equity and consistency need to be considered. These models could include:

- Increasing the skills and knowledge of NDIA staff to complete individualised assessments that are informed by input from treating health professionals who have direct knowledge of the individual being assessed.
- Continuing to use treatment reports as a key part of the assessment process, while including a cap on the number of reports required and providing funding for independent assessments for applicants to get these reports. This would address inequities by creating an equitable and standard yet personalised process for collecting data and evidence for assessment purposes.
- Implementing quality control measures by comparing data on plans for similar disabilities to build increased consistency into the NDIS.
- Providing specialist support for rare disease candidates who do not have support networks that can assist them in completing eligibility or assessment processes.

TOR D: The independence, qualifications, training, expertise and quality assurance of assessors.

Whilst RVA supports systems and processes that enable a more equitable and consistent NDIS, we have grave concerns regarding the capacity of a three-hour independent assessment, conducted by an assessor with general knowledge of disability, to understand and address the complexity of rare diseases. The complex nature of rare diseases presents a significant challenge for an independent assessor without specialist knowledge of a person's disease, the individual and the family living with the disease. These challenges include:

- There are more than 7000 different rare diseases.
- Rare diseases can be difficult to diagnose and often lead to delayed diagnosis. In the past, a lack of diagnosis has been a barrier to rare disease candidates gaining access to the NDIS.
- The presentation of the same rare disease can be vastly different in individuals.
- Rare diseases are complex and often multi-system.
- The impact of the disease can change very quickly.
- Many are episodic or intermittent in nature.
- Due to their rarity, the presentation and progression of the condition can be uncertain.
- Many rare diseases are progressive in nature.

### *RVA Recommendations*

Given these challenges, RVA believes that a standardised assessment carried out by an independent assessor would be unable to provide a complete picture of the nature of an individual's disability. Consequently, it would be difficult for an assessor to understand the necessary supports required for that individual regardless of their qualifications, skills and experience.

The [Disability & Rare Disease](#)<sup>2</sup> report made a series of recommendations to address the gaps experienced by Australians living with a rare disease in the current system. The implementation of recommendations 3, 5 and 7 from the report (detailed below) to the independent assessment and review process could address current concerns about the limitations of independent assessments of rare disease patients with a disability.

- **Recommendation 3:** *Australia introduce personal care plans to cover an individual's health, education, and disability care needs. These overarching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.*

*For those applicants with complex rare disease needs, we suggest a case management approach could assist to ensure that support is both integrated but not duplicated and is provided by the most appropriate system. While the proposed changes address the different responsibilities of different systems, there is no suggestion in the consultation paper about how to ensure these systems are integrated to provide integrated care for people with complex needs. A case management or system navigation approach could address this issue and streamline the process for people living with a rare disease and disability. It could also reduce duplication by ensuring that supports are received in the appropriate systems. The early childhood model, which fosters collaboration across government agencies to ensure care and support is less fragmented and more integrated, could be considered.*

- **Recommendation 5:** *Introduce mandatory training of relevant health and disability care professionals on the nature of rare diseases, effective management strategies, how to locate information and referral pathways to support and advocacy groups.*

*Some disabilities, including rare disease related disability, can be intermittent, complex and multi-system. Understanding that the difference between what a 'good day' and 'bad day' looks like can be significant. Mandatory rare disease training for assessors and specified NDIA staff will assist in accounting for the complexity of rare disease when completing assessments and making access decisions.*

- **Recommendation 7:** *The NDIA to incorporate a 'fast tracking review' category for people with rare diseases who have been identified as having permanent and significant disability. This would allow for quicker access to additional supports when required through consultation with clinicians.*

Additionally, RVA recommends that:

- It is a requirement for any assessment to include specific rare disease expertise and knowledge as part of the assessment process. This can be clinical expertise but where there is a lack of clinical expertise, rare disease patient groups should be consulted. In cases of ultra-rare diseases, the patient and their family may be the only source of expertise about their condition. This information should then be incorporated into the assessment and recommendations for budgeting and planning purposes.
- The assessment process acknowledges that the contact person for the application is often caring for someone who is very unwell and has a life limiting condition. Many current rare disease NDIS recipients report that the process was stressful, time consuming and characterised by repeated rejections of funding requests. Changes should focus on addressing these concerns.
- Requests for reviews from those with progressive conditions be fast tracked so that emerging needs can be addressed in a timely manner. Feedback from rare disease RVA Partner organisations indicate that at times, a response is required within days. Noting either the episodic or progressive nature of the condition during the assessment process and building capacity into the budget for progression of sudden, severe episodes could address the needs of rare disease candidates in a timely manner.
- The needs of the family and primary carers are considered in the development of plans. Evidence collected in the development of the [Disability & Rare Disease](#) report showed that the immediate carers and family of those with disability, faced high levels of social isolation, mental distress and physical exhaustion. Many families have a family member with an extremely complex multi-system disorder that is either undiagnosed or so rare that it is poorly understood, even by clinicians. In these cases, care needs are complex and demanding, medical appointments are time consuming and without a diagnosis, there is little social, emotional, or practical support available. Assessments and subsequent budgets/plans must consider these impacts on families.

TOR F and G: The implications of independent assessments for access to and eligibility for the NDIS and for NDIS planning, including decisions to fund reasonable and necessary supports.

The proposed changes to the NDIS address issues of access **once eligibility has been determined**. For the rare disease community, demonstrating eligibility has been consistently problematic. As part of the development of the [Disability & Rare Disease](#)<sup>2</sup> report, the McKell Institute surveyed 771 people living with a rare disease and found that 7 in 10 are not having their health and disability needs met and that almost 1 in 3 have experienced a deterioration in the support they receive under the NDIS. This data reflects the anecdotal reports from many members of the rare disease community, that lead to a perception that there is a lack of understanding about the complex, episodic and progressive nature of rare diseases within the NDIA. This has meant that having a rare disease is often a barrier to accessing the NDIS as the lines between disability and disease are blurred. Sadly, RVA also hears stories about people's

condition progressing while they are waiting to access the NDIS where earlier access could have prevented deterioration in functional capacity.

Additionally, the following requirement may be a difficult initial hurdle for some rare disease patients to achieve: “A person who applies for the NDIS will provide information on their age, residency and evidence of their disability, including if their impairment is, or is likely to be, permanent. If these criteria are met, we will then request an independent assessment.” Limited data is a common feature of rare diseases and often, little is known about a rare condition or its likely progression, making it difficult to demonstrate likely permanency. It is therefore important that decisions about eligibility for an independent assessment are informed by rare disease expertise and that NDIA staff are better informed about rare diseases and disability.

#### *RVA Recommendations*

- Formation of a Rare Reference Group within the NDIA similar to the current Autism Advisory Group and NDIA Mental Health Sector Reference Group. This group could ensure that systems, processes and communications within the NDIS are adapted to meet the specific needs of rare disease candidates and could provide essential linkages and expertise in eligibility, assessment and planning processes within the NDIS.
- Flag eligibility applications from rare disease candidates as complex applications requiring specialist rare disease knowledge to be sought and included in eligibility decisions.
- As per Recommendation 6 of the [Disability & Rare Disease](#)<sup>2</sup> report (“Urgent review of delays in access to equipment to ensure that NDIS participants receive approved equipment in a timely manner”), fast track applications, especially for equipment, where evidence suggests a condition is likely to progress and fast tracking can help to prevent further deterioration.
- Access rare disease expertise during the decision-making process regarding eligibility to ensure that there is a comprehensive understanding of the implications of the condition for the individual and their families/carers.
- Equip NDIA staff with rare disease knowledge and have eligibility applications assessed by someone with specialised knowledge of rare disease and disability. This could be a health professional but where there is a lack of local clinical expertise (as is often the case in rare disease), rare disease support groups should be consulted. In ultra-rare conditions where there may be fewer than 10 families in Australia with a condition, the family and individual often have the deepest expertise about their conditions.
- Collect and evaluate data on NDIS support for Australians living with a rare disease to ensure that the NDIS is meeting people’s functional capacity needs.

TOR I: Opportunities to review or challenge the outcomes of independent assessments.

RVA does not support the introduction of any type of assessment that does include a transparent and equitable process for reviewing and/or challenging outcomes. Mechanisms for challenging outcomes of any type of assessment processes, independent or otherwise, should be implemented. For most rare disease RVA Partner organisations, the current proposal that the outcome of the assessment cannot be challenged is of grave concern. Most have experienced repeated rejections of requests for necessary supports and have been required to make repeated submissions and provide additional evidence in order to access necessary support. RVA does not support any assessment process and/or reporting that is not fully transparent and subject to due process and natural justice.

#### *RVA Recommendations*

Any changes to eligibility and access processes to the NDIS for people living with a rare disease must build the opportunity to review and challenge assessments into the process.

TOR J: The appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds.

RVA suggests that for the identified cohorts, and any other relevant cohorts, including people living with a rare disease and people from lower socio-economic backgrounds that face systemic inequity in health and social support systems, any form of standardised assessment is likely to further exacerbate existing inequity. RVA believes that independent assessments are not appropriate for assessing the requirements of people living with a rare disease who have a disability.

#### *RVA Recommendations*

- Provide additional support to these cohorts in navigating the system and gathering the additional evidence required to demonstrate reasonable and necessary supports. This may include funding reports from specialists and health care providers who have an individualised knowledge of the person and their needs. It may also include incorporating a case management approach for complex applications into the system, ensuring that care across government disability, health, education, employment and social support systems is integrated but not duplicated.
- Ensure that any assessment process is person-centred and focuses on the individual's capacity and their needs, with the flexibility to fast track those with progressive conditions so that emerging needs can be addressed in a timely manner.
- Consult with leaders and peak bodies in these cohorts to develop a deeper understanding and knowledge of the needs and barriers to care in these cohorts.

- Provide those undertaking assessments and using assessments for budgeting and planning purposes with training to understand the additional challenges of these cohorts. This could include developing units with expertise in the identified cohorts.

## Summary

RVA supports changes to eligibility and assessment processes that will make the NDIS more equitable and transparent. RVA does not support the introduction of independent assessments for rare disease candidates due to concerns that:

- Standardised assessment processes are not fit for purpose in assessing the needs of rare disease patients.
- The independent assessment approach is not person-centred and cannot address the complexity of rare disease candidates.
- Applicants will not be able to review and challenge the results of the independent assessment as this does not meet the need for transparency and due process.
- Privatisation of this process will lead to a reduction in services, support and flexibility for candidates and will become focussed on cost containment.

RVA is grateful for the opportunity to respond to this Inquiry.



## APPENDIX 1

National Strategic Action Plan for Rare Diseases<sup>1</sup>– relevant excerpts:

***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.

***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.

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 culturally and linguistically diverse (CALD) backgrounds, and other priority populations.

***Action 2.5.1: Ensure people living with a rare disease, including their families and carers, receive the community, clinical and digital mental health supports and services they need.***

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## References

1. **National Strategic Action Plan for Rare Disease** (2020) Commonwealth of Australia as represented by the Department of Health 2020 <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases>
2. **Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases (2019)** McKell Institute [https://mckellinstitute.org.au/app/uploads/Disability-Rare-Diseases\\_2019.pdf](https://mckellinstitute.org.au/app/uploads/Disability-Rare-Diseases_2019.pdf)
3. **RVA Position Statement: Government Response to the Tune Review of the NDIS Act 2013 (2020)** <https://rarevoices.org.au/rva-position-statement-government-response-to-the-tune-review-of-the-ndis-act-2013/>
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