

## RVA Submission: NDIS Consultation - Access and Eligibility

### Background

Rare Voices Australia (RVA) is the peak national body for Australians living with a rare disease. RVA led the collaborative development of the [National Strategic Action Plan for Rare Diseases](#) (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 (Appendix 1). In particular, the Action Plan highlights the need for coordinated and integrated care.

RVA has consistently provided leadership in raising issues related to the disability and rare disease and in 2019 commissioned a white paper - the McKell Institute report [Disability and Rare Disease: Towards Person Centred Care for Australians with Rare Diseases](#). In addition, RVA have published a [position statement](#) in response to the Tune report to specifically address aspects of the Tune report most relevant Australian's impacted by rare disease and their families. RVA partners more than 80 individual rare disease consumer groups and consulted with 25 representatives of these groups in the development of this submission.

### Response to access and eligibility consultation

RVA supports processes and systems that will create more consistent and equitable access to NDIS support, and the focus on person-centred processes and systems. RVA is also supportive of ensuring that evaluation processes do not disadvantage any particular group. However, based on the experiences of many families impacted by rare diseases, there are several aspects of the proposed changes to access and eligibility that must be addressed in order for the NDIS to fully meet the needs of Australians living with a rare disease.

### Eligibility requirements

In 2019, RVA commissioned the report, [Disability and Rare Disease: Towards Person Centred Care for Australians with Rare Diseases](#) (*Disability and Rare Disease report*), which was timed to inform the development of the Action Plan. 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, leading to a perception that there is a lack of understanding about the complex, episodic and progressive nature of rare diseases within the National Disability Insurance Agency (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.

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." 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 disease and disability.

### RVA Recommendations:

1. Flag eligibility applications from rare disease candidates as complex applications requiring specialist knowledge to be sought and included in eligibility decisions.
2. As per recommendation 6 of the *Disability and Rare Disease* report, fast track applications, especially for equipment, where evidence suggests a condition is likely to progress and fast tracking can help prevent further deterioration.
3. Access rare disease expertise during the decision-making process regarding eligibility for independent assessment to ensure that there is a comprehensive understanding of the implications of the condition for the individual and their carers.
4. 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 consumer groups should be consulted.
5. Collect and evaluate data on NDIS support for Australians living with a rare disease to ensure that the NDIS is meeting their functional capacity needs.

### Use of Independent Assessments

Whilst supporting systems and processes that enable a more equitable and consistent NDIS, RVA has a range of concerns about the capacity of a 3-hour independent assessment, conducted by someone with general knowledge of disability, to understand and address the complexity of rare disease. The complex nature of rare diseases presents a significant challenge for an independent assessor without specialist knowledge of both the disease and the individual and family living with the disease. These challenges include:

- there are more than 7000 rare diseases;
- the presentation of the same rare disease can be vastly different in individuals;
- rare diseases are complex and often multi-systemic;

- 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; and
- many are progressive in nature.

## RVA Recommendations

The *Disability and Rare Disease* 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 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 make the experience of people rare disease and disability more seamless. It could also reduce duplication by ensuring that supports are received in the appropriate systems. The early childhood model that 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.

The consultation paper acknowledges that some disabilities, in particular psychiatric disabilities, can be intermittent and proposes strategies for acknowledging this in the recommendations. In particular, 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 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.

In addition, RVA recommends that:

- It is a requirement for independent assessors to access 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. This information should then be incorporated into the assessment and recommendations for access.
- 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 our rare disease partner organisations indicate that sometimes 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 or sudden, severe episodes could address the needs of rare disease candidates in a timelier way.
- The needs of the family and primary carers are considered in the development of plans. Evidence collected in the development of the [Disability and 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 multisystem 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 diagnosis, there is little social, emotional, or practical support available. Assessments and subsequent budgets/plans must consider these impacts.
- Assessment information is provided in a variety of formats to respond to the diverse needs of the rare disease community and priority populations (as identified in the Action Plan). Rare disease related functional impairments range from intellectual impairment (sometimes in both carers and NDIS candidates due to the genetic nature of many rare diseases), mobility impairments, vision, and hearing impairment. Information relating to both eligibility applications and preparing for an assessment needs to be provided in formats accessible to all impairment types including visual, auditory, and simplified version as well as versions that are culturally and linguistically appropriate for priority populations.
- Qualities and skills an assessor should possess (based on feedback from RVA partner rare disease organisations):
  - Empathy – rare disease families regularly share stories of lack of care and empathy in all parts of the care systems they have engaged with. This is particularly true where there is no diagnosis or for rare conditions that are poorly understood by most people. It is

- important to the rare disease community that the starting point of any assessment process is empathy.
- Training in the specific challenges of rare diseases including the impact of lack of knowledge about the condition, the impact on families, the high levels of uncertainty around progression of the condition, the loneliness and isolation experienced by people with rare conditions and their families, the episodic nature of rare conditions, the fragmentation in care received by most rare disease families.
  - An assessor who understands 'invisible' nature of some disabilities.
  - A person who is able to recognise the immense complexity of rare diseases that cause functional incapacity and is therefore able to take on expert input that should be provided by either a clinician with specialist knowledge of the rare disease being assessed or, in the absence of local expert clinical knowledge that is common for rare diseases, the rare disease patient group.
- Mechanism for challenging assessment outcomes be added to the process. For most 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 the need to make repeated submissions and provide additional evidence in order to access necessary support. The system must address the reality that a single 3-hour assessment is unlikely to capture the full picture for people with complex rare diseases and build the opportunity for review of assessments into the process.

## APPENDIX 1

National Strategic Action Plan for Rare Diseases – 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 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.***