Rare Voices Australia Interim Submission

Joint Standing Committee on the National Disability Insurance Scheme

Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme

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[1] (the Action Plan), the first nationally coordinated effort to address rare diseases in Australia. The Action Plan was informed by extensive multi-stakeholder consultation and was launched by the Minister for Health in 2020, with bipartisan support. 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)[2], which informed the Action Plan. Additionally, in September 2020, RVA published a Position Statement[3] 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 90 rare disease support groups. This is an interim Submission. RVA plans to provide a more detailed Submission after consulting broadly with our partner organisations whose members have lived experience with the NDIS.

Terms of Reference
In this interim Submission, RVA's intention is to solely address the two Terms of Reference (TOR) listed below and to highlight areas of concern in the rare disease community in relation to these TOR. All other TOR are outside of our scope as the national peak body for Australians living with a rare disease.

b) The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education, and justice services;

Evidence collected in the development of the *Disability & Rare Disease Report*[2] , in addition to input received in consultations conducted in 2020-2021 with RVA's community regarding NDIS matters, demonstrates that interfaces between NDIS services and other government services, in particular health, aged care and education, present significant challenges and frustrations for Australians living with

disability caused by a rare disease. *The Disability & Rare Disease Report*[2] found that "seven in 10 people with a rare disease report not having their health and disability care needs met." (p10). This report highlighted the fact that the NDIS is explicitly designed to exclude mainstream health care but found that, in practice, this meant there were often grey areas between health and disability and these grey areas caused delay and confusion and often left participants without adequate or appropriate support. The lack of integration between providers of different types of support services means that support for Australians with a disability cause by a rare disease and their families and carers leads to the provision of fragmented care with significant gaps.

Additionally, many of our rare disease partners (support groups) report significant gaps between support provided as part of the NDIS when compared to support provided under aged care frameworks. Senior Australians with a disability caused by rare disease experience significant inequity in accessing reasonable and necessary supports under the auspices of aged care plans. It is essential that regardless of the support mechanism, Australians with a disability caused by a rare disease are able to access reasonable and necessary supports in a straightforward, timely and equitable manner.

The complex and unique nature of many rare diseases can present a range of challenges to accessing appropriate supports. 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 rare 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

The *Action Plan*[1] included the following recommendations to address these gaps:

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.*

2.1.2.2. *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.*

Based on this, RVA recommends that Recommendation 3 of the *Disability and Rare Disease Report* [2] be implemented to ensure greater integration between services provided to people with disabilities.

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 NDIS applicants with complex rare disease needs, a personal care plan, similar to a case management approach, could ensure that support is both integrated but not duplicated and is provided by the most appropriate system. This could increase sustainability by ensuring that supports are received in the appropriate systems without redundancy. The early childhood model[4], which fosters collaboration across government agencies to ensure care and support is less fragmented and more integrated, is a good example of a care plan approach.

c) The reasons for variations in plan funding between NDIS participants with similar needs, including:

i. the drivers of inequity between NDIS participants living in different parts of Australia,
ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and
iii. measures that could address any inequitable variation in plan funding;

Inconsistency between plans for people with similar levels of functional capacity continues to be a cause of great frustration and concern for those in the rare disease community who access NDIS supports. People who are reliant on health professionals in the public health system to provide evidence and documentation in support of an NDIS application, report feeling disadvantaged compared to those who are in a position to self-fund multiple specialist and allied health professional assessments and reports in support of NDIS applications. Those living with a rare disease in regional, rural, and remote Australia report barriers to accessing adequate support when compared to counterparts in major metropolitan locations. People from priority populations, including Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse backgrounds and those experiencing socio-economic hardship, regularly report feeling overwhelmed by the bureaucracy surrounding applying for and accessing NDIS supports. Future planning must consider steps to address inequities arising from the above issues.

RVA Recommendations

Models of achieving increased equity and consistency must be considered. These models could include:

- Increasing the skills and knowledge of National Disability Insurance Agency (NDIA) staff to complete individualised assessments that are informed by input from treating health professionals who have direct knowledge of the individual being assessed and rare disease expertise.

- Standardising the use of reports from treating specialists in the assessment process, while including a cap on the number of reports required and providing funding for applicants to get these reports (for example, access to bulk billed reports as suggested by the recently tabled report on Independent Assessments). This would address inequities by creating an equitable and standardised 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.
- Formation of a Rare Disease 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[2] 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.
- Quicker access to additional supports when required through consultation with clinicians.

APPENDIX 1

National Strategic Action Plan for Rare Diseases[1] – 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.

References

1. ***National Strategic Action Plan for Rare Diseases*** **(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

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**/**

4. ***The Role of Case Management*** **(updated 2006)** https://www1.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-p-mono-toc~mental-pubs-p-mono-bas~mental-pubs-p-mono-bas-acc~mental-pubs-p-mono-bas-acc-cas