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National Disability Insurance Scheme Review

Rare Voices Australia Submission | June 2023

The National Disability Insurance Scheme and Rare Diseases

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease. We welcome the opportunity to provide a Submission to the Federal Government commissioned National Disability Insurance Scheme (NDIS) Review, conducted by the NDIS Review Independent Panel.

RVA provides a strong, unified voice to advocate for policy as well as health, disability and other systems that work for people living with a rare disease. RVA's work is non-disease specific and is based on the commonalities of the approximately 7,000 different rare diseases. Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, over 100 RVA Partners (rare disease groups/organisations), governments, key peak bodies, researchers, clinicians and industry. RVA advocates for the best outcomes for Australians living with a rare disease.

National Strategic Action Plan for Rare Diseases

RVA led the collaborative development of the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan).[1] The Action Plan is the first nationally coordinated effort to address rare diseases in Australia. It 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 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.

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.

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[1]

RVA's Submission references The McKell Institute's 2019 report, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases (Disability & Rare Disease Report)*,[2] which informed the Action Plan.

Rare Voices Australia's National Disability Insurance Scheme Submission

RVA has been actively seeking improvement within the NDIS for people living with a rare disease since its inception. The organisation has lodged several submissions to the Joint Standing Committee on the NDIS addressing a range of matters, including Scheme Implementation and Forecasting, the Inquiry into Independent Assessments, and the review of the Capability and Culture of the National Disability Insurance Agency (NDIA).

In 2019, RVA collaborated with the rare disease sector to develop the *Disability & Rare Disease Report*. This paper collated evidence about the unmet needs of Australians living with a rare disease that cause disability. The report also informed recommendations related to rare disease, disability and the NDIS in the Action Plan.

In 2021 and 2022, representatives from rare disease groups/organisations, including RVA Partners: Angelman Syndrome Association Australia; Batten Disease Support and Research Association Australia; Fragile X Association of Australia; Huntington's NSW ACT; Mito Foundation; Muscular Dystrophy Queensland; and SCN2A Australia met with representatives of the NDIA alongside RVA. The purpose of these consultations was to highlight how the complex, changing and multi-faceted needs of people living with a rare disease could be better addressed. Selected comments from these discussions are included in this Submission.

RVA has since engaged in multiple discussions at various levels within the NDIA. In 2022, the NDIA recognised the value of this ongoing conversation and formally identified RVA as a key peak body stakeholder. This Submission includes and builds on the key issues raised in these discussions with feedback, input and insights gathered from the rare disease sector over several years.

RVA's Submission provides guidance and direction around key goals and priorities for Australians living with a rare disease who have significant, permanent and severe disability impacts. It offers recommendations to improve their experience with the NDIS and their subsequent quality of life outcomes. The recommendations are presented under five themes, with each theme outlining priorities, actions and implementation areas. The themes are:

1. **Engagement and Collaboration:** Building ongoing sustainable engagement and collaboration arrangements between the NDIA and RVA.

2. **Knowledge and Capability:** Embedding rare disease knowledge and capability within the NDIA through defined roles.

3. **Policy, Procedures and Practice:** Improving NDIS policies, procedures, and practices.

4. **Data Management:** Improving NDIS rare disease data management to better inform decision-making and policy development.

5. **Other Sector Interfaces:** Improving the interface between the NDIS and health, housing, early childhood and education, recognising the specific needs of people with disability and participants with rare diseases.

What Is a Rare Disease?

A disease is rare if it affects fewer than five in every 10,000 people. There are approximately 7,000 different diseases and an estimated two million Australians live with a rare disease. Around 80% of rare diseases have a genetic origin and due to the hereditary nature of some rare diseases, multiple people within the same family could be impacted.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges. While not all people with a rare disease have an associated disability, those who do experience substantial and permanent disability impacts. These individuals often require support from the NDIS.

Many rare diseases are neurological disorders with predictable, fluctuating, or unknown disease progression. Some conditions may emerge late (late onset) or be secondary (co-morbid) to the primary health condition. For others, a diagnosis explaining all symptoms may be unattainable (termed 'undiagnosed rare diseases').

There is no cure for many rare diseases. Thus, enhancing the quality of life and extending the life expectancy of those with a rare disease depends on an integrated, person-centred approach that provides the right health, disability, care services and social support. The *Disability & Rare Disease Report* indicated that 70% of people with a rare disease feel that their health and disability needs are partially met or are not met at all.[2]

Rare Diseases and the National Disability Insurance Scheme

NDIS participants living with a rare disease require a dynamic and responsive scheme to cater to their varying disability support needs. Instead of requiring less support over time, their needs may actually increase to maintain their functioning or prevent a decline. They are likely to have frequent interactions with the healthcare sector, require high levels of disability-related health support, use assistive technology extensively, and need specialised disability accommodation and/or supported independent living funding. A well-trained workforce is essential to meet these significant needs. Moreover, the socio-economic disadvantages faced by many with a rare disease can compound the psychological, emotional, and financial impacts experienced by them and their caregivers. This necessitates additional considerations for this group.

Outcome Measures

RVA and the rare disease community acknowledge the transformative role the NDIS has played in funding and supporting disability in Australia. However, we believe the NDIS hasn't fully actualised its life-changing and life-sustaining potential.

Additionally, in part, we believe this is because of the outcome measures used to gauge scheme effectiveness. These measures often focus on capacity building with the intent to reduce funded support over time, which might not be possible for people living with a rare disease. RVA proposes a shift towards human rights and a quality of life lens in measuring outcomes, focusing on enhanced dignity, increased participation in activities, greater independence, and improvements in caregiver/family employment and quality of life indexes. This is consistent with research that shows people with a disability value quality of life dimensions (e.g. safety, self-care, dignity) over health status dimensions (e.g. vision, hearing, physical mobility).[3]

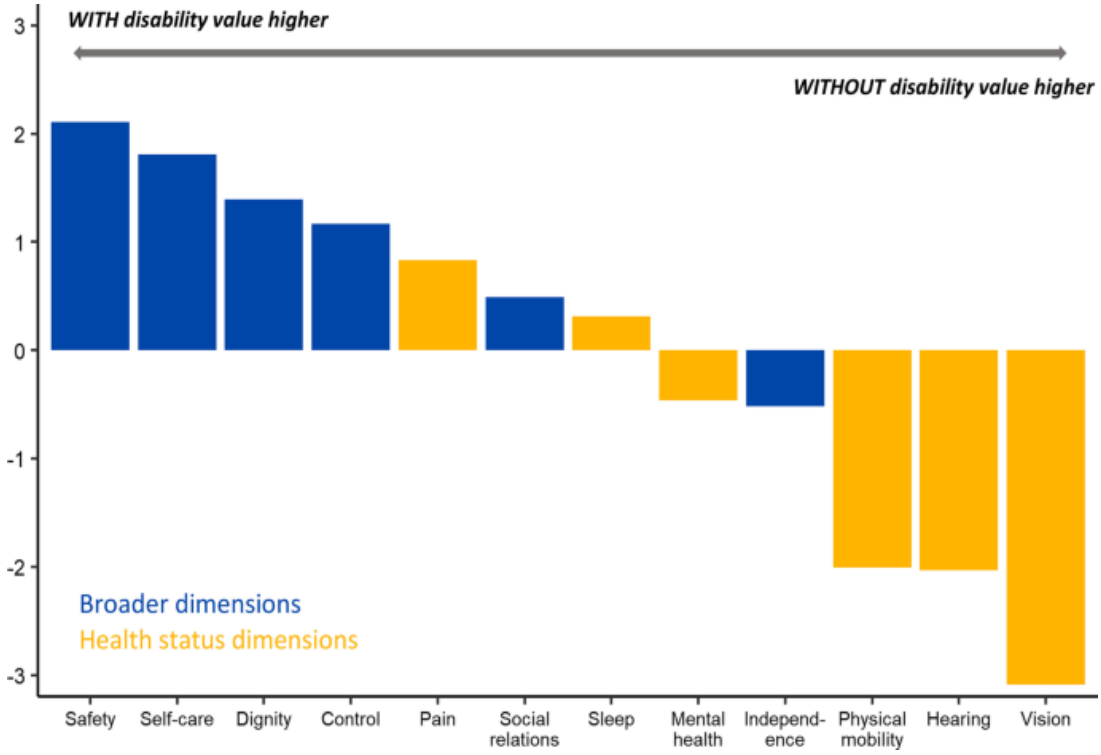

Figure 1: Relative importance of key quality of life dimensions for people with and without a disability.

The Role of Families and Carers

Families and carers play a crucial role in supporting people living with a rare disease, providing vital life-sustaining support. They often face significant strain, burnout, and financial impacts due to the high support needs of family members, out-of-pocket costs associated with care and support, or due to loss of income associated with taking on a carer role. Families and carers also face social isolation, mental distress, and physical exhaustion due to complex care needs, frequent time-consuming medical appointments, and lack of support. These issues are exacerbated for people with undiagnosed rare diseases.

RVA strongly endorses initiatives that consider family and primary carers' needs in the development and implementation of NDIS plans.

> "A key issue for rare disease participants and families who are dealing with very complex medical conditions and associated disabilities, is the enduring emotional burden and anxiety they face around ensuring ongoing NDIS access – each time they have to go through a process to prove their level of access." **– Rare Voices Australia**, Rare Disease Working Group Discussions

Theme 1: Engagement and Collaboration

"Embed the voice of people living with a rare disease and their families and carers throughout structures and systems that impact rare diseases."[1] – National Strategic Action Plan for Rare Diseases

The NDIA prioritises collaboration and co-design with the disability community to ensure the unique perspectives of participants and their families form the foundation of NDIS policy design and implementation. Currently, several national disability representative organisations receive funding through the Disability Representative Organisations (DRO) program, to provide systemic advocacy and to champion the interests of Australians living with disabilities. This current funding allocation, amounting to over $5.2 million per annum, will continue until 30 June 2024. At the time of writing, there are no rare disease organisations in the DRO program.

As the national peak body for Australians living with a rare disease, RVA is in a unique position to collaborate and engage with all key stakeholders in the rare disease sector. Stakeholders include people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry. Additionally, RVA formally partners with over 100 rare disease groups/organisations (RVA Partners); individuals living with a rare disease (including family and carers); researchers; clinicians; and other care professionals. RVA's work ranges from raising awareness about rare diseases to education through our Education Program, engaging and promoting evidence-based research and supplying crucial information to help those navigating the NDIS.

RVA asserts that the NDIA could greatly benefit from the pooled knowledge and insights of RVA Partners, as well as the first-hand experiences of their members and families. This could be achieved through an established and sustainable mode of engagement, offering the NDIA timely access to extensive resources about specific rare diseases and participants' lived experiences. This would provide the NDIA with clearly identified channels for engagement.

Proposed Actions

1.1. Disability Representative Organisation (DRO): As the national peak body for Australians living with a rare disease, RVA will apply for DRO grant funding to ensure disability policies reflect the needs of this significant cohort.

1.2. Stakeholder Matrix: The NDIA should establish a comprehensive centralised matrix of key stakeholders, fostering active engagement with all relevant groups, including those living with a rare disease.

1.3. Rare Disease Liaison: The NDIA should institute a high-level liaison role in the Leadership & Policy branch to cater specifically for rare diseases. This would serve as a dedicated link between the NDIA and the rare disease sector, fostering ongoing, formalised engagement, and presenting opportunities for co-design and effective systemic advocacy.

1.4. Research Collaboration: The NDIS Research Branch should engage with RVA and relevant rare disease groups/organisations to:

1.4.1. Identify evidence-based therapeutic and support interventions that deliver meaningful and measurable outcomes for NDIS participants with a rare disease.

1.4.2. Develop a mutually agreed NDIS Research Strategy for Rare Diseases, identifying research opportunities that could better inform the NDIS' approach to funding early intervention and responses to progressive and fluctuating/episodic rare diseases.

1.4.3. Conduct a rare disease sector stakeholder consultation process to pinpoint appropriate research that can guide evidence-based disability support decision-making.

1.4.4. Encourage a research approach driven by lived experience by promoting collaboration between researchers and people living with a rare disease (both NDIS participants and non-participants) through workshops, conferences and rare disease groups/organisations.

Input From Rare Disease Working Group Discussions

"Individuals with Myotonic Dystrophy often have unsuccessful eligibility applications. Organisations such as Muscular Dystrophy Foundation Australia (MDFA) have had to support these individuals repeatedly in their eligibility application, until the NDIS assessor understands their complex profile of disability. This is concerning for those who may not have the support of organisations like MDFA to make their eligibility application. If this initial application is unsuccessful, many may fall through the cracks and are not able to access an NDIS plan they are entitled to, losing a lifetime of funding and support." – RVA Partner, **Muscular Dystrophy Foundation Australia**

"The rare disease sector has a wealth of information and expertise about each of their conditions, which they would be happy to share with the NDIA to help with building the capacity of NDIS assessors and decision-makers, and shaping policy." – **Huntington's Australia**

"People with the same rare disease may have similar levels of disability, and similar goals and needs – but based on who they interact with within the NDIS, they get vastly different outcomes (e.g. streaming, access to LACs or ECEIs vs. planners, etc.)." – RVA Partner, **Angelman Syndrome Association Australia**

Theme 2: Knowledge and Capability

In their *Capability and Culture of the NDIA Interim Report (March 2023),*[4] the Australian Government's Joint Standing Committee on the NDIS (the Committee) stated decision-makers within the NDIA do not seem to have adequate training, experience or understanding of disability, and that this continues to be an area requiring improvement. Additionally, RVA Partner groups/organisations reported a pressing need for focused education aimed at enhancing the competency of NDIA staff, equipping them to better assist individuals living with a rare disease.

Regarding the role of NDIS Planning, the Committee proposed that the NDIA establish a system to motivate planners to specialise in specific disabilities or participant groups. However, the government response indicated a preference for NDIA staff and partners involved in the planning process to possess knowledge of a wide range of disabilities rather than focusing on particular types or cohorts. Furthermore, in their response, the NDIA stated that participants requiring specialised planning expertise receive support in various

ways, including through the early childhood approaches and assistance from Technical Advisory Officers.

Currently, the NDIA offers its staff and partner members training through obligatory eLearning modules. The modules include 'disability snapshots' crafted in collaboration with peak disability organisations. Snapshots exist for conditions such as Parkinson's disease, Huntington's disease, and motor neuron disease (MND).

RVA appreciates the opportunity to standardise and broaden the approach, format and content of these resources, thus widening the NDIA's access to rare disease-related content, and significantly enhancing rare disease expertise within the NDIA.

Proposed Actions

2.1. NDIS Rare Disease Capability:

2.1.1. Technical Advisory Branch: The NDIA should establish rare disease expertise within the Technical Advisory Branch (or an equivalent body) that will provide guidance for NDIS participants with rare diseases.

2.1.2. Hospital Liaison Branch: A dedicated rare disease capacity should be built within the Hospital Liaison Branch to cater for frequent hospitalisations and the need for plan variations or reassessments due to fluctuating, emergent, or progressive functional impacts.

2.2. Rare Disease Training: RVA and the NDIA should collaborate to develop mandatory training on rare disease awareness for NDIA Planners. The training should cover the nature of rare diseases, effective management strategies, evidence-based practice for disability support, and how to seek specific guidance from rare disease groups/organisations.

2.3. Disability Snapshots and Standards of Support: The NDIA should work with rare disease groups/organisations to develop Disability Snapshots and Standards of Support for rare diseases, informed by clinical and participant experts. These snapshots and standards should include:

- identifying the necessary supports for people living with a rare disease during significant life-stage transitions;
- reaching the age cut-off point for paediatric services (e.g. transitioning from child to adult hospitals);
- relocating; and
- when needs change significantly (such as at end-of-life).

2.4. Rare Disease Participant Information: RVA and the NDIA should collaborate to develop and maintain a digital repository of information about specific considerations for NDIS participants living with a rare disease. This repository should cover NDIS access; process and evidence requirements; funding; types of support; and intersections with other community sectors such as health, education, employment and housing.

RVA should promote this repository to rare disease groups/organisations for distribution to people living with a rare disease, their families and carers, and assist in identifying gaps and opportunities for improvement.

Theme 3: Policy, Procedures and Practice

There is considerable diversity among rare diseases. However, people living with these diseases often encounter similar challenges, particularly concerning their disability impacts. We acknowledge it would be impractical to tailor NDIS policy to cater to the unique needs of over 7,000 different rare diseases. Instead, we advocate for the development of *General Practice Guidance for Rare Diseases* for NDIS decision-makers, which would address crucial considerations relating to NDIS access, streaming, planning, and responsiveness to changes in disability support needs. It would be valuable to develop additional guidance for rare diseases which can be categorised broadly into the following groups:

- neurological (with or without intellectual disability);
- progressive/degenerative;
- fluctuating/episodic;
- emergent/secondary; and
- undiagnosed.

Despite the inherent challenges in categorising rare diseases, this method may help to identify commonalities, allowing for improved targeting, while also informing NDIS policy, procedures and practice guidance. Lack of diagnosis has been identified as a barrier to obtaining eligibility or adequate funding from the NDIS, which further underscores the need for this initiative.

Additionally, guidance materials must respect the diversity within these cohorts, incorporating considerations for Aboriginal and Torres Strait Islander people, individuals residing in regional, rural, and remote areas, those from culturally and linguistically diverse backgrounds, and people facing socio-economic disadvantages.

Proposed Actions

3.1. NDIS Policy and Procedure Development: Consider and incorporate complex rare disease case studies in NDIS Policy and Procedure Development to ensure relevance to the rare disease cohort.

3.2. Practice Standards:

3.2.1. The NDIA and RVA to co-design *General Practice Standards for Rare Diseases*.
3.2.2. The NDIA and RVA to co-design additional guidance for broad groups of rare diseases, including neurological, progressive/degenerative, fluctuating/episodic, emergent/secondary and undiagnosed.

3.3. Access to Rare Disease Information: Ensure all NDIA decision-makers and partners have access to specific rare disease information through the Rare Awareness Rare Education (RARE) Portal for rare diseases and to disability support needs through Rare Disease Disability Snap Shots, developed by rare disease groups/organisations.

3.4. Trauma-Informed Approach: Utilise a trauma-informed approach during plan discussions, including sensitive language that acknowledges functional maintenance and prevention of decline versus capacity building.

3.5. Streaming: Stream participants with rare disease to Intensive or Super Intensive Streams.

3.6. Support Coordination:

3.6.1. Automatically allocate support coordination for people with a rare disease to assist with the implementation and management of their NDIS Plan.

3.6.2. Provide guidance on what is considered when increasing or decreasing support coordination funding. This should not be a time-limited support for people living with a rare disease.

3.7. Meetings:

3.7.1. Recognise the need for some form of supported decision-making from informal and formal supports due to the cognitive, emotional and physical impacts of a rare condition.

3.7.2. Reasonable adjustment in meetings, including to the length of meetings, are made (longer or spaced over several sessions) for people who cannot complete planning discussions in one meeting.

3.7.3. Recognition that telephone meetings can be a barrier to a person with complex communication needs and ensure in-person meetings are provided where appropriate.

3.8. Service Guarantee Timeframes: Improve participant service guarantee timeframes for rare diseases, including a defined and transparent escalation mechanism for time-sensitive critical support for progressive and episodic conditions.

3.9. NDIS Access:

3.9.1. Provide clear information for NDIS access, including for emergent/secondary (co-morbid) disability impacts and undiagnosed conditions.

3.9.2. Grouping of conditions: Facilitate grouping of multiple conditions for NDIS access given primary disability may be hard to define for some participants.

3.10. Security and Predictability:

3.10.1. Provide security and predictability of future plans and support funding to enable whole-of-life decisions, such as where to live, whether to commence study or employment etc., rather than adopting a short-term horizon.

3.10.2. Participants with a rare disease are only required to have a plan reassessment or plan variation on an as-needs basis (i.e. when their needs increase or their circumstances change).

3.11. Disability-Related Health Support: Actively consider disability-related health support requirements and direct participants to this support if appropriate.

3.12. High Intensive Support: Actively consider high intensive/high support requirements and direct participants to this support if appropriate.

3.13. Assistive Technology

3.13.1. Conduct Assistive Technology (AT) needs assessments over a 6-12 month period, noting progressive and fluctuating needs.

3.13.2. Address the current concern around wastage of AT equipment as it becomes obsolete, or when people pass away, by considering the reuse of quality AT to achieve economies of scale and environmental and scheme sustainability.

3.13.3. Improve the timeliness of access to essential equipment, including through a dedicated AT hire pool.

3.14. Functional Capacity Assessments:

3.14.1. Offer guidance on the validity and currency of Functional Capacity Assessments and reports, including when both need to be revisited, recognising stable or declining functional capacity.

3.14.2. Remove the requirement to repeatedly revisit and re-prosecute the disability impacts of someone with an established severe rare disease, especially if support ratios have been established as minimum 1:1 support.

3.15. Templates and Guidance: Provide best practice examples of Access Request Forms, Supporting Evidence, Functional Capacity Assessments and annual provider reports.

3.16. Carer Support:

3.16.1. Acknowledge the whole-of-person and whole-of-family impacts of rare diseases and consider respite and support funding even for families with children living with a rare disease.

3.16.2. Acknowledge high carer strain/burnout for informal supports and the need to sustain these supports through overnight support and increased short-term accommodation/respite.

Input From Rare Disease Working Group Discussions

"Ensuring the language used in planning discussions is appropriate for participants, and acknowledge the progressive nature and trajectory for a large number of these rare diseases. Speaking about improvements and better outcomes when the participant or their families/carers know that's not the pathway for them can have a significant emotional toll." – Rare disease group/organisation leader

"A person with cystic fibrosis and associated significant disability impacts was declined NDIS Access on the grounds that she hadn't exhausted all of her available treatment options – because she hadn't tried a lung transplant!" – RVA Partner, **Cystic Fibrosis Queensland**

"People with mitochondrial disease ('mito') can often live with chronic or disabling fatigue, leaving only 2-3 hours in the day where they feel they can properly function. Having someone to do the legwork involved in getting the supports they need is critical in being able to manage their disease; and when support coordination is not available, it makes a big difference to people's experiences." – RVA Partner, **Mito Foundation**

"Many rare diseases are fluctuating, meaning the functional impact of the condition can change significantly, and quickly. Yet, the ability to get an urgent change of circumstances through the system seems to be exceeding 90-100 days. It's not sustainable for people to have to go through that process for such an extended period of time." – Rare disease group/organisation leader

"Parents are typically the primary carers for individuals affected by complex, progressive rare conditions like Batten disease. They're time poor, exhausted and often overwhelmed. Add to this, the burden of having to be their child's NDIS advocate and disease-expert to ensure assessors truly understand their child's condition, and the weight of responsibility on parents is enormous. It's traumatic having to re-live the diagnosis and explain the hardships over and over, and at the same time, to be projecting into the future, trying our best to provide 'sufficient' evidence so we can plan for the inevitably grim reality ahead." – RVA Partner, **Batten Disease Support and Research Association Australia**

Theme 4: Data Management

"If we are not counting rare diseases, people living with rare diseases do not count."[1] – National Strategic Action Plan for Rare Diseases

In Australia, there is a significant gap in our health and disability information systems regarding the data on most rare diseases. Currently, there is no unified strategy to collect, analyse and utilise existing data. There's an evident need for a national, coordinated, and systematic strategy to gather and apply rare disease data, including the use of registries. This strategy would allow for continuous monitoring and the accumulation of knowledge about rare diseases, consequently informing clinical practice, research, and health and disability service planning. Greater knowledge of rare diseases can empower key decision-makers at all levels, enabling them to provide more responsive and appropriate services for those living with a rare disease, as well as their families and carers.

At present, it's unclear how many individuals with a rare disease are NDIS participants, how many have applied unsuccessfully for NDIS access, or how many have chosen not to apply due to concerns about losing access to their essential health supports.

We acknowledge the challenges faced by the NDIS in tracking and measuring rare diseases are not unique. Both Commonwealth and state approaches remain disjointed, and no single approach can serve as a universal template. Nevertheless, we welcome the opportunity to work with the NDIA to improve data coding for rare diseases within the NDIS. Detailed data reports can then inform strategic policy, decision-making processes, research efforts, and workforce initiatives across the disability sector. It can assist in driving innovation and translate research into evidence-based disability support and care.

RVA is encouraged by the government's commitment to the National Disability Data Asset (NDDA). This platform will provide a single source of information combining Commonwealth, state, and territory data on people with disabilities, significantly enhancing research, policy development and service delivery. RVA eagerly anticipates participating in the design and implementation of the NDDA to ensure the needs of people with disabilities who also have a rare disease are recognised as an important cohort.

The World Health Organization has released its 11th revision of the International Classification of Diseases (ICD) and Related Health Problems. The Australian Institute of Health and Welfare (AIHW) is conducting a review of ICD-11 to inform and assist decision-makers about ICD-11 and its potential adoption in Australia. NDIS systems currently capture participants' diseases and related health issues in a participant's profile using ICD 10th revision (ICD-10-AM).

The NDIS should adopt a coordinated and collaborative data collection framework for the coding of rare diseases, including undiagnosed rare diseases, that is consistent across disability and health.

Proposed Actions

4.1. Update NDIS systems to include the ICD-11 classification for better data collection and monitoring.

4.2. Include rare disease codes in NDIS participant records that are compatible with Orphacodes, ICD-11, and other relevant classifications, and include a generic code (e.g. '999') to identify undiagnosed rare disease conditions.

4.3. Develop these codes to raise alerts for NDIS Planners when accessing participant records, aiding in appropriate conversation and funding considerations.

4.4. Ensure rare disease and undiagnosed disease codes link with a person's Aboriginal and Torres Strait Islander status for culturally appropriate care.

Theme 5: The National Disability Insurance Scheme and Other Sector Interfaces

"Provide rare disease care and support that is integrated, incorporating clear pathways throughout health, disability and other systems.

"Rare disease care and support that is integrated streamlines participants' journeys through often fragmented and complex disability framework, health care and social systems. It ensures optimal, continuous and effective whole-of-life care."[1] – National Strategic Action Plan for Rare Diseases

People living with a rare disease often need extensive, interdisciplinary teams of medical professionals across various settings to manage their multiple medical problems and disabilities. Their health needs can fluctuate drastically over their lifetime, sometimes requiring immediate and critical adjustments in care. Additionally, they frequently have complex support needs extending beyond health and disability services to encompass social/welfare, mental health, education, employment and housing. Support for families and caregivers, who also face high and significant needs, is vital.

The complex nature of rare diseases requires the integration of numerous public domains that extend beyond disability to health, social/welfare, education, employment, housing and many other areas. At a national level, policy leadership is required to enable the effective and efficient delivery of integrated whole-of-life care that supports and responds to people's needs.

The introduction of the NDIS has inadvertently separated the funding and service provision between the disability and health sectors. This divide has resulted in gaps in service provision, negatively impacting individuals with a rare disease, whose disabilities often have an underlying medical cause.

This issue was reflected in the *Disability & Rare Disease Report*, which indicated that a high number of respondents reported that the NDIS has worsened their situation. Many people have been denied access to the NDIS or experienced delayed access as their conditions have been misclassified as solely medical, rather than disabilities.[2]

"The NDIS has revolutionised the way in which disability support is delivered in Australia, aiming to meet individual needs and aspirations. However, the NDIS has also broken down many of the existing linkages between the health and social care sectors relied on by people with rare diseases. The NDIS is explicitly not designed to replace mainstream health services for people with a disability and consequently, only covers supports for activities of daily living and not medical expenses. For individuals who have a disability with an underlying and ongoing medical cause, such as people with rare diseases, there can often be grey areas in coverage creating delays and confusion. In addition, this delineation between health and

disability services does not promote care integration that can best support the complex needs of people with rare diseases."[2] – ***Disability & Rare Disease Report***

An estimated two million Australians currently live with a rare disease and only a fraction of these people are eligible for the NDIS. As a result, the overwhelming majority of people living with a rare disease and disability are reliant on services and supports outside of the NDIS. There is a significant need for all state and territory governments to re-invest in disability programs, inclusion support in schools, universal obligations and reasonable adjustments in healthcare and education, and accessible and affordable housing.

Proposed Actions

5.1. Address Fragmented Care: Implement policies that cater to individuals' full range of needs, including health, disability and education. This objective can be achieved by establishing a cross-jurisdictional, cross-sectoral working party.

5.2. Palliative Care: Promote the specific needs of people living with a life-limiting rare disease to the NDIS, including delivering disability-specific services to participants receiving palliative care. This is particularly important for people with a rare disease and severe intellectual disability and/or complex communication needs.

5.3. Develop a Workforce Strategy:

5.3.1. Build and invest in the NDIS workforce for participants with rare diseases ensuring additional training and clinical supervision and support.

5.3.2. Identify existing gaps in the workforce that support people living with a rare disease, including provision of disability-related health supports and palliative care support for people with a rare disease and intellectual disability.

5.4. Address Health Versus Disability Issue:

5.4.1. Clarify the delineation between health and disability services to avoid confusion and improve service delivery for people with a rare disease.

5.4.2. NDIS to provide greater clarity and guidance on what is considered a health or medical issue versus a disability, including where co-morbidities have a disabling impact on the person.

5.4.3. NDIS to ensure all participants have access to their Chronic Disease Management Plan.

5.5. **In Hospital Support:** Ensure people with a rare disease have access to necessary disability support while in hospital. This may be essential for some participants (e.g. people with severe intellectual disability, for dysphagia and mealtime management, complex bowel care, communication support (non-verbal AAC users) and behaviour support).

5.6. **Formalise Care Delegation Process**: Establish a formal, transparent process to identify the delegation of care for high-support participants in hospital between health and the NDIS. This process should consider both health supports and emotional support needs. This includes recognising that assistants in nursing and nurses may not be qualified to provide specific disability-related health supports, and that family members may not always be available for support.

5.7. **Develop a Comprehensive Assessment Report Template:** The NDIS should create a comprehensive assessment report template for participant access. General practitioners should be able to complete these reports, with a specific Medicare Benefits Schedule (MBS) item for these assessments. This approach would reduce inequities resulting from the high cost of comprehensive occupational therapy reports and benefit people with unknown rare diseases and/or multiple conditions.

5.8. **National Assistive Technology Program:** Creation of a single, national program for assistive technology for people who do not have access to or are not eligible for the NDIS.

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Appendix 1

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Rare Voices Australia/National Disability Insurance Scheme Working Group Members

- Rare Voices Australia
- Angelman Syndrome Association Australia
- Batten Disease Support and Research Association Australia
- Fragile X Association of Australia
- Huntington's NSW ACT
- Mito Foundation
- Muscular Dystrophy Queensland
- SCN2A Australia