Rare Voices Australia

Second Submission for Final Report

Joint Standing Committee on the National Disability Insurance Scheme

Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme

28 February 2022

Overview

Rare Voices Australia (RVA), the national peak body for Australians living with a rare disease, welcomes the opportunity to lodge a Second Submission for consideration by the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) (Committee) in drafting its Final Report on the *Current Scheme Implementation and Forecasting for the NDIS*. This Submission builds on the information, evidence and key recommendations provided in RVA's Interim Submission[1], and is supplemented with examples of lived experience with the NDIS from members of our rare disease partner organisations.

Although individual diseases may be rare, the total number of Australians living with a rare disease are not. Collectively, around 2 million Australians (8% of the population)[2] live with a rare disease – making this community larger than those Australians living with diabetes (1.8 million).[3] While not every person with a rare disease will have an associated disability, those who do will often require support and assistance in their daily activities.[4] Yet, unlike many other conditions that cause disability, rare diseases are typically progressive and complex – meaning an individual's needs continue to change over time.[4] To ensure these needs can be appropriately met, systems such as the NDIS, must be responsive, flexible and provide person-centred care.[4]

Since lodging our Interim Submission, RVA has been encouraged by the interest and support the rare disease sector has received from the Minister for the NDIS, Senator the Hon Linda Reynolds CSC, and the Community Engagement and Communications Team at the National Disability Insurance Agency (NDIA), who have sought to understand the impact on people living with a rare disease when engaging with the NDIS. This Submission seeks to address some of the systemic and policy issues and explore possible opportunities for reform, with a specific focus on the four Terms of Reference (ToR) listed below.

To this end, and with an impending Federal Election that is yet to be announced, RVA also acknowledges and fully supports Recommendation 2 outlined in the Committee's General Issues 2021 Report, to reinstate this Inquiry in the next term of Parliament: *"the Joint Standing Committee on the National Disability Insurance Scheme of the 47th Parliament of Australia reinitiate this committee's inquiry into Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme and continue to consider evidence received by the committee in the 46th Parliament"*.[5]

Background

RVA formally partners with 100 rare disease support groups and our membership continues to grow. Since its inception in 2012, RVA has continued to actively advocate for the needs of Australians living with a rare disease, while consistently highlighting the unique challenges faced by those within the rare disease community living with a disability.

Commencing in 2018, RVA led the collaborative development of the *National Strategic Action Plan for Rare Diseases*[6] (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, the Hon Greg Hunt MP, in 2020, with bipartisan support.

To inform the Action Plan, RVA commissioned the McKell Institute to deliver a white paper in 2019, *Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases* (Disability & Rare Disease report); which highlighted the significant levels of unmet need for health and disability care services, and the considerable gaps that exist for people with rare diseases to access the supports they need.[4]

Current implementation of the NDIS: Implications for Australians living with a rare disease

ToR (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.

As reinforced in the Action Plan (pg. 20)[6], and highlighted by the Committee in its Interim Report (sections 5.15 and 5.16)[5], there is a real need for rare disease care and support to be less fragmented and more integrated, in order to improve the interface between the NDIS and other mainstream services. People living with a rare disease often have complex and multi-system care and support needs, which intersect across numerous government services provided by different jurisdictions, including health, disability, social services/welfare, education, employment, aged care, and housing, among others.[4,6] Yet, for many people living with a rare disease, a lack of clear referral pathways makes it difficult to navigate their way through these services.[6]

This is particularly apparent when moving through the health and disability systems, as there appears to be a blurred line between what the NDIS considers a health or medical issue, versus a disability. The consequences of this are far-reaching, often resulting in individuals not being able to access a certain level of support as their issue is considered to be a medical one. This is especially problematic for people living with a rare disease, as many of these medical issues can also result in disability. According to the *Accessing Support for People with Rare Disease survey* (Rare Disease survey), almost **one in three people have experienced deterioration in the support they receive through the NDIS** – this is despite the NDIS increasing its funding for disability services threefold.[4]

Examples of lived experience from the rare disease community:

- What applicants enter as their 'primary disability' appears to be a big determinant of how successful their application for access to the NDIS is, and the level of access they may be granted. This leads to inequity when some applicants have up to 20 different clinical diagnoses, meaning they have to be strategic about what they classify as a disability.
- Within the rare disease space, a number of conditions can be linked to epilepsy (e.g. SCN2A, Angelman syndrome, etc). Once NDIS planners encounter epilepsy, they automatically class it as a general medical issue; rather than assess the individual's specific disability support needs.

Whereas, these are rare conditions that have multiple disabilities, with epilepsy being only one part of that condition.

Regional, rural and remote population[4]

For Australians living with a rare disease living in rural and regional areas, this issue is further compounded, as there are often no medical specialists available in their area, or very limited treatment options. In order to receive the treatment they need, they must be able to readily access disability services and support. However, the lack of coordination between these services can create unnecessary burden on individuals who already have complex support needs. As more Aboriginal and Torres Strait Islander people live in regional, rural and remote areas, this disparity in access becomes even greater for this group.

Undiagnosed rare disease

Misdiagnosis and diagnostic delay are common in rare diseases and can lead to ongoing physical, psychological, emotional and financial costs for individuals and families.[6] A third (30%) of Australian adults living with a rare disease experience a diagnostic delay of more than 5 years (known as a 'diagnostic odyssey'), while almost half have received at least one misdiagnosis.[6,7] However, some people may never receive a diagnosis, representing one of the most vulnerable groups in the rare disease community – those with an 'undiagnosed rare disease'. This can negatively impact the level of care and support individuals receive, and is a significant roadblock to accessing plan funding and services through the NDIS.[6]

ToR (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.

> *"Several submitters indicated that the **inconsistent decision making** by the NDIA and partners **is contributing to inequitable outcomes for NDIS participants and people seeking to become NDIS participants**. Some submitters saw this inequity as being correlated with a person being in a regional or remote as compared to metropolitan area, while others noted the importance of having access to support through the NDIS access and planning processes… **planners and local area coordinators need to have a better understanding of different disability types, especially psychosocial disabilities, rare and genetic conditions, and communication disabilities.**"*
>
> - General Issues 2021 Report, Chapter 5, November 2021
> Joint Standing Committee on the National Disability Insurance Scheme
> (Sections 5.17 and 5.18; *'Decision making by the NDIA and its partners'*)

The ongoing inconsistencies experienced by the rare disease community when engaging with the NDIS has led to a range of unintended consequences that negatively impact participants, carers and families; diminishing trust and confidence in the NDIS, and its administrators.

There are significant variations in the way each rare disease can impact an individual. While people with the same rare disease may have similar levels of disability, and similar goals and needs – they can often get vastly different outcomes in terms of access to plan funding and support, based on who they interact with within the NDIS. This disparity can be extremely frustrating and burdensome for participants.

Examples of lived experience from the rare disease community:

- When families have requested to be restreamed onto the complex pathway (e.g. due to milestone transitions, such as leaving school), they haven't been permitted to.
- While most rare disease participants are dealing with a Local Area Coordinator (LAC), those living in rural and regional areas typically have access to a planner.
- Some participants with complex disability profiles have not been streamed at a high enough level; such as, a participant with spinal muscular atrophy (SMA) who had their planning meeting conducted by an LAC, rather than a senior planner, and wasn't given access to support coordination.
- An initial application that went through the system without Fragile X syndrome being identified as a primary diagnosis meant the participant did not receive the full support they were entitled to. So, although their needs had not changed from Year 1 to Year 2 on the NDIS, the level of funding and support they received did change once Fragile X syndrome was included on the application.

Proposed legislative amendments for plan variations

For RVA and the rare disease community, proposed legislative amendments to the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021*, introduced in the Australian Parliament in October 2021, are cause for concern. The existing NDIS Act currently requires a new plan to be completed for each variation (i.e. existing plans cannot be varied). Yet, the legislation being considered by the Australian Parliament gives the NDIA and its delegates the ability to vary a participant's plan at any time. While the NDIA's rationale for seeking this amendment is to provide greater flexibility and reduce the administrative burden on the NDIA, RVA and our rare disease partner organisations are seeking assurances that this will not inadvertently disadvantage rare disease participants, with variation decisions made by planners or LACs reducing the level of support they receive.

Timeliness/lack of agility

Feedback from the rare disease community has emphasised a need to significantly improve response times on decisions by NDIS planners and LACs; as well as build in greater agility and responsiveness to address issues as they arise. This has a direct flow-on effect on the ability of rare disease participants to access the care they need, when they need it. The Rare Disease survey found that although a high proportion of respondents were satisfied with the services they were receiving under the NDIS, **4 in 5 (80%) indicated they had experienced delays in receiving supports**.[4]

Examples of lived experience from the rare disease community:

- There is typically a 3-4 month wait on decisions to secure specialist disability accommodation (SDA) property, or a 'Silver' housing plan, for someone with very complex care needs. By the time the decision comes through from the NDIS, the provider who was prepared to take that person with complex care needs, may have moved on and given somebody else that placement who wasn't waiting on a decision from the NDIS – meaning the rare disease applicant has missed out on securing the accommodation they need.
- 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 is not feasible, or sustainable, for people to have to go through that process for such an extended period of time.
- The hospital and health systems need to have more accountability over the discharge and transitional care planning of their patients, e.g.
    - Different types of mitochondrial disease can lead to acute episodes, which see a major change in function. Hospitals are keen to discharge patients quickly if they are on the NDIS. However, if that person needs 'Hospital in the Home' support in order to manage their condition once they've been discharged, their plans are not responsive enough to provide that additional support after an acute episode or setback.
    - A family with mitochondrial disease – where one parent and two of the children were diagnosed with the rare disease – made a purposeful decision for one of the children not to become an NDIS participant, despite having many disability support needs. This was based on the previous experience they had with their other child, who had lost access to the hospital employed allied health team (who were experienced in mitochondrial disease), as the hospital felt the NDIA should be funding allied health services.
- There needs to be greater agility and nimbleness in planning for rare disease participants, including planning for future functional impacts, such as wheelchairs or behavioural issues, e.g.
    - SCN2A families are frequently in and out of hospital. Often, they might come out of hospital with much higher support needs than they went in with. One family could not go home from hospital, as they were unable to get the adaptations at home to support the participant – resulting in them spending a significant amount of time in hospital, without being able to get home.

ToR (g): The ongoing measures to reform the scheme including:

i. The new early childhood approach, including whether or how early intervention and other supports intended to improve a participant's functional capacity could reduce their need for NDIS funding; and
ii. Planning policy for personalised budgets and plan flexibility.

Early intervention

70 per cent of rare genetic diseases start in childhood[8], with diagnosis and management occurring early in life. While some people will have complex needs early on due to the progressive and life-limiting nature of rare diseases, others may develop these later in life. Putting an early intervention mechanism or pathway in place for rare diseases will ensure participants get the complex supports they need and reduce the issues that may come later on, as the disease worsens and things become more difficult. For example:

- In Batten disease, some children are put into Early Childhood Early Intervention (ECEI) or LAC, which then prevent pathways to the complex care teams or specialised planners – when their needs usually are complex to begin with. The nature of the disease means all people with Batten disease will develop these complex care needs at some point in their lives, so an early intervention pathway would be beneficial in managing the ongoing support services and care needs required.

Limited rare disease capacity within the NDIS

One of the key concerns raised by members of the community is the lack of understanding of rare diseases among many administrators and decision-makers within the NDIS, who may not have the expertise to be able to properly assess an eligibility application. This can have an extensive emotional impact on rare disease participants and their advocates, who are dealing with very complex medical conditions and associated disabilities. This can include:

- The anxiety they face around ensuring ongoing NDIS access, each time they have to go through the process to prove their level of plan funding.
- Having to repeatedly explain their condition and advocate for their individual situation, which can be unsettling.
- Feeling traumatised by having to continuously relive the diagnosis and hardships they've faced.
- The language used can be perceived as dismissive or diminishing the participant's lived experience.

Examples of lived experience from the rare disease community:

- A rare disease participant with mitochondrial disease was speaking with someone within the NDIS who continuously said the NDIS doesn't cover fatigue and remained quite dismissive of the symptom – without taking the time to understand the impact of this on the person's life.
- Parents are typically the main carers in rare disease (e.g. Batten disease, etc.), and often feel the weight of responsibility is on them. They're time poor and may be struggling – it is often traumatic to relive the diagnosis, or every hardship they've been through, as well as the current reality they're facing everyday with caring for their child or young adult. As a result, many struggle to know what kind of evidence to provide in their planning meetings.
- A family with mitochondrial disease required two adults to be awake (on duty) at all times to stop their child from asphyxiating through the night, but were told this was standard parental responsibility for a 4-year-old. These types of issues are hugely challenging for families when they are told their needs are insignificant.
- According to the Rare Disease survey, participants reported that **NDIS planners and support coordinators lack the necessary clinical expertise, resulting in a failure to incorporate key support recommendations in plans**.[4]
- 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.

ToR (h): Any other related matters.

Assistive technology

As there is currently no cure for many rare diseases, improving quality of life and extending life expectancy of people living with a rare disease is critical – and is reliant on providing them with appropriate treatment and care. Access to assistive technology (AT) is fundamental to this, and ensures rare disease participants are able to live their lives as fully as possible. However, while the benefits of early intervention have been established, ongoing delays to accessing AT have reinforced the inequities and inconsistencies that exist for rare disease participants within the NDIS.

Examples of lived experience from the rare disease community:

- Some rare disease families require a particular type of equipment to keep their child standing, which helps to reduce the burden on carers. Yet, the equipment came too late; and by that stage, better, more advanced equipment was available. Missing that window of opportunity to provide the support needed impacts on carers, demonstrating the need for balance between the level of information required to access AT, and not letting these people fall through the gaps.
- A number of RVA rare disease partner organisations support people with severe physical disabilities, who require bespoke equipment. This in itself is a challenge, as the more expensive the item of equipment, the more information and clarification that is required to secure approval from the NDIS. Once the equipment is finally approved, it can still take 3-6 months for the equipment to be assembled. For more advanced equipment, such as a new power chair or standing wheelchair, participants can sometimes be waiting up to 12 months to receive their AT.
- RVA rare disease partner organisations are also having to establish equipment loan pools to accommodate the delays while their members are waiting to access AT from the NDIS, which can often be a strain on these under resourced and underfunded organisations.
- Not all applicants are able to access private specialists to complete the required paperwork for AT, putting them at a disadvantage in getting the AT they need.
- The eligibility requirements don't appear to be consistent within the same rare disease cohort. There have been inconsistencies experienced by some participants (e.g. with Fragile X syndrome) who have the same AT support needs, where some will be given access to the equipment, and others won't.
- There appear to be a lot of mechanisms in place that make it difficult to access AT products and support services, which can be a real disadvantage for participants and families with complex care needs.
- Some participants (e.g. with SCN2A) use iPhones to communicate, but due to their disability, can often drop or lose them. Yet, they are unable to access iPhones as AT through the NDIS.
- This lack of agility in the NDIS has led to a decline in trust in the NDIS among some participants, families and carers.

Recommendations

To address the systemic and policy issues with the NDIS outlined in this Submission, RVA wishes to put forward the following recommendations for consideration. These recommendations are in addition to the recommendations included in RVA's Interim Submission and align with those outlined in the Action Plan[6] (**Implementation step 2.1.2.2**) and the Disability & Rare Disease report[4] (**Recommendations 3**, **6** and **7**), which prioritise the need to fast track access to the NDIS and ensure participants are able to secure the appropriate support and services to meet the evolving needs of people living with a rare disease and their families.

Recommendation 1: Adopt a model of integrated care to facilitate greater coordination between disability and mainstream services across Commonwealth, State and Territory Governments.

To ensure people living with a rare disease are able to successfully navigate disability and health systems at all levels, it is important that this care and support is both person and family-centred.[6] This will require national policy leadership to address the current system challenges, and facilitate care that responds to people's changing needs.[6] One potential model that could be considered by the Australian Government, is the Care Integration Model deployed in Sweden. Tailored to an individual's disability and healthcare needs, this approach allocates responsibility for the various care required to the relevant level of government or agency.[4]

Recommendation 2: Develop dedicated practice guidance for rare diseases and build capacity within the NDIS.

There is a clear need for rare disease expertise to inform how the NDIS operates, and minimise the emotional impact on participants and their carers. To support this, RVA proposes the development of dedicated practice guidance on rare diseases. This will not only help to build the capacity of NDIS administrators, but may also assist in shaping future policy to ensure greater participation by Australians living with a rare disease. This could be modelled on the existing practice guidance framework used for motor neurone disease (MND), which is considered a rare disease.

A key focus of this practice guidance will be to highlight the level of uncertainty many within the rare disease community face, and how the NDIS can respond to this uncertainty. For example:

- 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; and
- Understanding that 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.

Recommendation 3: Create a fit-for-purpose system/specialised access pathway, for rare diseases.

As the majority of rare diseases are complex and progressive, with varying levels of disability; an appropriate fit-for-purpose system – based on models or mechanisms used by the NDIA for other disability cohorts that are progressive and complex – would help to monitor, address and adequately meet the needs of people living with a rare disease. Creating a specialised access pathway for people with rare diseases who don't 'fit the mould' for the mainstream approach would be extremely welcome – providing a new way to get into the system, that is more sympathetic and better able to understand the special and complex needs they have. This fit-for-purpose system extends to establishing a mechanism for

ongoing dialogue between the rare disease sector and the NDIA, to improve participants' experience with the NDIS.

Recommendation 4: Undertake forward planning to assess rare disease progression and establish a baseline for AT support needs.

By forward planning and assessing the progression of rare diseases, the NDIS can be more nimble and agile in responding to participants' AT needs. This will not only improve the experience for participants and their carers, but may also improve administration of AT for the NDIA. A baseline threshold of evidence would not need to be revisited each time, meaning access to the right support and services can be maintained, without participants risking losing funding they are entitled to. For example:

- Being aware that a child with certain rare diseases will eventually require a wheelchair and/or other aids along their journey, can pre-empt their support needs and reduce delays in accessing AT when these needs arise.
- This can be particularly useful when there is a sudden change in circumstance, allowing more rapid access to AT.

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