rare voices

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NDIS Provider and Worker Registration Taskforce

Rare Voices Australia Submission
May 2024

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease. RVA provides a strong, unified voice to advocate for policy as well as disability, health 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. RVA advocates for the best outcomes for Australians living with a rare disease, including those impacted by disability.

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.

RVA welcomes the opportunity to provide a Submission to the NDIS Provider and Worker Registration Taskforce (the Taskforce) on behalf of the rare disease sector.

National Strategic Action Plan for Rare Diseases

RVA's Submission is closely aligned with the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan)[1], the first nationally coordinated effort to address rare diseases in Australia.

The foundational principles of the Action Plan are also at the heart of the challenges facing the NDIS and are areas of focus for this Submission:

- Person-centred
- Equity of access
- Sustainable systems and workforce.

National Disability Insurance Scheme Independent Review

In October 2022, the Australian Government commissioned the NDIS Independent Review to examine the design, operations, and sustainability of the NDIS and to consider ways to make the market and workforce more responsive, supportive, and sustainable.

In June 2023, RVA was pleased to provide a detailed submission to the NDIS Review[2] for consideration.

The *Working together to deliver the NDIS: Independent Review into the National Disability Insurance Scheme Final Report (NDIS Review Report)*[3] was released on 7 December 2023.

The NDIS Review final report recommends the development and delivery of a graduated risk-proportionate model for the visibility and regulation of all providers and workers, and strengthening of the regulatory response to long-standing and emerging quality and safeguards issues (**Recommendation 17**), specifically to:

- Design and implement a graduated risk-proportionate regulatory model for the whole provider market (17.1)
- Develop a staged implementation approach to transition to the new graduated risk-proportionate regulatory model (17.2), and
- Amend the National Disability Insurance Scheme Act 2013 to remove the link between a participant's financial management of their plan and the regulatory status of their support providers (17.3).

The scope of the Taskforce is to provide expert advice on:

1. The design and implementation of the recommended graduated risk-proportionate regulatory model, as it relates to upholding the rights of people with disability to exercise choice and control
2. A Provider Risk Framework that identifies and evaluates the risk profile of different types of supports and providers
3. Arrangements for platform providers and circumstances where participants directly employ their workers also referred to as 'services for one'.

RVA's Submission to the Taskforce

In preparing this Submission, RVA engaged with our RVA Partners (rare disease groups/organisations) and individuals and families living with rare disease, including convening a virtual national roundtable. We have included quotes and excerpts from their responses in this Submission and thank them for their contribution.

Graduated Risk-Proportionate Regulatory Model

RVA agrees that the current regulation of the NDIS sector requires an overhaul to provide appropriate safeguarding, monitoring, and oversight, and a one-size-fits-all regulatory approach is inadequate in addressing the varying levels of risk and complexity inherent in disability support.

RVA supports a tailored regulatory framework aligned with the specific risks posed by different types of supports and providers.

However, while registration and regulation are part of a quality assurance framework, they do not necessarily guarantee the quality or effectiveness of services.

Therefore, RVA believes the framework must integrate workforce capability, skills, and training to ensure equitable and quality outcomes. RVA Partners expressed concerns that implementing mandatory registration without addressing underlying issues related to workforce training, support, and quality monitoring may not lead to the desired outcomes of improving service standards and safeguarding the rights of people with disabilities.

"Registration doesn't necessarily mean quality or an engaged person – can we expand registration to not only consider the risk of the service, but the skill and training required?"

We caution that any changes to the registration process must protect the human rights of people with a disability, preserve the principles of choice and control, and not impact people's access to known and trusted providers or workers.

This is especially relevant to NDIS participants living with a rare disease who often require complex, intensive, and bespoke models of support to meet their disability impacts. Providers and workers supporting NDIS participants living with rare diseases and disability impacts often require extensive training to deliver quality care, including through the provision of disability-related health supports, supporting intellectual and communication disabilities.

NDIS Review Proposed Model

The proposed model outlined in Recommendation 17 delineates four levels of registration:

1. Advanced registration
2. General registration
3. Basic registration
4. Enrolment.

Each level is designed to correspond to the level of risk associated with the supports provided, with advanced registration imposing "*more intensive regulatory requirements and oversight*".

RVA believes that the scope and terminology of the four levels of registration should be refined for clarity and consistency. For example, the Advanced registration group refers to 'high-level technical competence', while the General registration is for all medium-risk supports it refers to 'high-intensity daily supports that require additional skill and training'.

NDIS Quality & Safeguards Commission and the National Disability Insurance Agency (NDIA) identify disability-related health supports as high-intensity activities due to the potential risk to the participant and the requirement for additional competency-based training and assessments. This is described in the NDIS Quality and Safeguards Commission NDIS Practice Standards: High-intensity support skills descriptors[4].

It seems inconsistent that high-intensity daily personal activities with high-risk competencies such as complex bowel care and severe dysphagia management should be considered 'general' supports. There is also no mention of registration for the implementation of intensive behaviour support or regulated restrictive practices.

We find the use of the term 'Basic' for the provision of support to people who have significant and permanent disability to be problematic.

RVA emphasises the importance of preserving access to mainstream supports that pose minimal risk to NDIS participants. RVA Partners shared many examples where NDIS participants currently purchase services and items such as continence aids from the local discount pharmacy or have the NDIS-funded communication device repaired at a small mobile technology repair outlet.

"What do we do when we are traveling or away from home and need to find registered or enrolled services easily, especially in a crisis? How far will we have to travel to find an enrolled or registered service to get our assistive technology repaired? What do we do if we are overseas?"

Mandatory registration or enrolment could potentially limit access to necessary mainstream services, particularly in areas where registered providers are scarce or choose not to participate in the scheme. This could have significant consequences for individuals living in regional, rural, and remote areas, as well as First Nations people who already face challenges in accessing adequate support services.

RVA proposes the following alternative model for consideration:

1. **Intensive registration** - for accommodation supports including Supported Independent Living, Group homes, and high-risk accommodation settings and/or all high-intensity supports including disability-related health supports, intensive behaviour support, and implementation of restrictive practices.
2. **General registration** – for standard intensity provision of support, including in social, community, and employment settings, including for targeted foundational supports.
3. **Enrolment** – for provision of disability-specific consumables, equipment, technology, home, and vehicle modifications. This category would also apply for allied health practitioners and other services registered with their regulatory authority (e.g. Physiotherapists, Social Workers, Master Builders Association, Accountants etc).
4. **No enrolment (Mainstream)** – for low-risk mainstream services including house cleaning, gardening, transport services, and retail providers including supermarkets, pharmacies, and general and online vendors.

Worker Screening

RVA supports the proposal for mandatory worker screening identification (ID) in mitigating risks associated with the provision of disability supports.

RVA recommends a national integrated approach that would expand the NDIS Worker Screening ID process to include foundational supports, through the creation of a new **Disability Worker Screening ID**.

A national Disability Worker Screening ID could be combined with the proposed graduated Worker Registration (i.e. intensive or general) to streamline administrative processes and reduce the cost and burden on both participants and government agencies.

Leveraging the existing NDIS digital platform PACE to link provider Australian Business Number (ABN) and Disability Worker Screening IDs could enhance efficiency and minimise duplication, thereby alleviating administrative burdens.

"Self-managers and Plan managers already enter lots of details into the NDIS portal to access the funding. Some small additional drop-down menus and mandatory fields for ABNs or Worker Screening IDs would not be prohibitive and may save the government a huge amount of money administering a complex registration/enrolment process."

Workforce Considerations

The proposed model must also consider the implications for the disability support workforce, including recruitment, retention, and training.

Worker screening is not sufficient to guarantee all NDIS workers can deliver safe and quality supports. We have heard concerns about whether workers have the necessary skills, competencies, and qualifications.

Therefore, the Taskforce should explore ways to expand registration criteria to encompass the skill and training levels necessary to provide effective support to individuals with disabilities.

"If registration, enrolment or screening is too hard, too costly or inaccessible, people will just leave the sector….and we will be left vulnerable."

RVA Partners expressed concerns about workforce shortages, particularly for NDIS participants living with rare disease where demand for specialised care and support is high. This is exacerbated in underserved areas such as regional, rural, and remote communities.

Mandatory registration requirements could exacerbate these challenges by imposing additional barriers to entry for new providers and limiting the flexibility of informal support networks.

Incentivising registration and workforce training is crucial for promoting compliance and quality improvement within the NDIS sector. This could include tax incentives, training subsidies, and workforce incentives to build capability and attract providers in thin markets including provision of complex/intensive supports for people living with rare disease.

The Action Plan emphasises the importance of building workforce capacity and expertise in rare diseases, including healthcare professionals, support workers, and allied health professionals. The taskforce should consider strategies to enhance the training and skill development of NDIS providers to effectively support individuals with rare diseases.

By investing in the professionalisation of the disability support workforce, Recommendation 17 can enhance the quality and sustainability of supports provided under the NDIS.

Governance

Any changes to the registration process must be made with careful consideration of equity and accessibility for all NDIS participants, including people with rare diseases and complex support needs. This includes ensuring culturally sensitive approaches to registration and screening, as well as addressing the unique needs of individuals in regional, rural, and remote communities. The Action Plan emphasises the importance of recognising diversity within the disability community and avoiding regulatory measures that may disproportionately affect marginalised groups.

"What will people living in regional, rural or remote communities do if providers choose not to register or enrol? Is the government going to be the 'provider of last resort'?"

The proposed model for registration and enrolment within the National Disability Insurance Scheme (NDIS) introduces several key considerations that the government should thoroughly assess in terms of privacy, accessibility, cultural sensitivity, cost, and administration.

- **Privacy Concerns**

Individuals who self-manage their supports may have heightened privacy concerns, particularly in smaller communities where identification as an NDIS participant could lead to exploitation or stigma. The Taskforce should address these concerns by implementing robust privacy safeguards and ensuring that registration processes prioritise participant confidentiality and autonomy.

- **Accessibility of Registration Processes**

The government should ensure that the registration and enrolment processes are accessible and user-friendly to all participants, including people in regional, rural, and remote areas, as well as individuals from culturally and linguistically diverse (CALD) backgrounds. It must consider digital literacy, digital access, and supporting infrastructure. This may require investment in technology, training, and outreach programs to promote inclusivity and equity.

- **Cultural Sensitivity**

The Taskforce must recommend a culturally sensitive approach to registration, enrolment, and worker screening, particularly for First Nations participants and other culturally diverse communities. This approach should acknowledge and respect diverse cultural norms and values, ensuring equitable access to supports and services for all individuals, regardless of their background.

"We must have a culturally sensitive approach to any discussion about mandatory registration, enrolment or worker screening especially for First Nations participants where the notion of the 'family unit' is different."

RVA Partners recommended the NDIS clearly define what constitutes a 'family member' to determine whether they can be engaged to support a NDIS participant in a paid capacity. Current NDIS guidelines state that in some cases friends may also not qualify as suitable paid supports.

RVA believes that the confusion and uncertainty regarding this definition and NDIS may be a cause for angst regarding mandatory registration due to fear of loss of suitable, essential supports.

- **Cost Implications**

Any proposed model must clearly articulate the benefits of registration and the value proposition. RVA believes it is essential to have clear links to improved quality, not just compliance, oversight, and fraud detection.

The current regulatory framework is cost-prohibitive for sole traders and small businesses, provides no registration benefits, and does not incentivise ongoing registration.

RVA Partners expressed concern that an overly costly and burdensome regulatory framework would be a significant barrier to registration and drive workers from the sector.

They also advised that NDIS participants with rare disease who engage with unregistered or mainstream services were able to do so at a reduced rate compared to the NDIS registered providers, thus enabling more flexible use of their NDIS plan funds. They expressed concern that the registration model would unnecessarily inflate the cost of services without any realised benefit to the NDIS participant.

- **Monitoring and Evaluation**

Transparency and quality reporting are essential components of an effective regulatory framework.

RVA calls for improved mechanisms and criteria for evaluating the effectiveness of registration and Worker Screening in safeguarding human rights, upholding quality standards, and preventing fraud and that these be regularly reported.

Registration and enrolment processes should be integrated with other government systems and recognise similar compliance of providers operating in other parts of the care and support sector to guard against regulatory creep, ensure proportionality, and minimise unnecessary burdens.

RVA believes that regular monitoring and evaluation of registration and enrolment processes are essential to identifying barriers to access and evaluating the effectiveness of interventions. The government should establish mechanisms for collecting feedback from all stakeholders during any pilot and phased implementation including in regional, rural, and remote areas, as well as First Nations communities, to inform ongoing improvements.

"The current complaints process does not give us much comfort – it is piecemeal and doesn't address systemic quality."

Market rating scales akin to My Aged Care star ratings can empower participants to make informed choices about service providers, thereby driving continuous improvement and accountability within the NDIS sector. RVA recommends a similar model for the NDIS and broader disability sector.

Services for one/Direct Employ

The Taskforce should consider several key points regarding individuals who self-manage and employ their own support workers. RVA seeks to prevent any unintended consequences that may disproportionately affect these NDIS participants.

NDIS participants living with rare disease and significant disability impacts can experience challenges accessing appropriate support given the complexity of their needs.

When they require more intensive support and highly trained staff to meet their daily needs, some NDIS participants have elected to directly engage and employ their workers and to create bespoke models of support tailored to their individual circumstances.

In some cases, this is simply a personal choice to create, develop, and manage their own support team, to provide continuity and sustainability of their individual support model.

RVA Partners reported that this can also occur through necessity because service providers may not have the capacity to train their workforce to meet the needs of the person with rare disease, they may have a casualised workforce that does not assure consistent quality of support or may not prioritise individualised training requirements.

The current NDIS allowance for 6 hours of shadow shift support is wholly insufficient to train new support workers for people with intensive and complex support needs with the added complexity of a rare disease and multiple health impacts.

NDIS participants with a rare disease can be perceived by service providers as requiring significantly higher operating costs and a less economically viable client than their less complex counterparts, resulting in under-trained staff, poor service quality, service cessation, or even service refusal.

This has created a thin market for NDIS participants with rare disease and complex/intensive support needs.

> *"While not every person with a rare disease will have an associated disability, those who do will often require assistance in activities of daily living. However, unlike many other conditions that cause disability such as intellectual disability or paraplegia, rare diseases often progress over time and change the nature of an individual's needs. Any system providing support to people with rare diseases therefore needs to be flexible and responsive."*

- The McKell Institute Disability and Rare Disease Report (2019)[5]

The Service for One/Direct Employ model enables the person living with rare disease to develop a bespoke training, supervision, and monitoring plan for their staff and to allocate their funding to ensure appropriate quality and competency. This self-directed self-management of service delivery and funding can demonstrate value for money and improved outcomes through longer staff retention and high-quality support.

"Self-managers are excellent at checking invoices, ensuring value for money, protecting against overbilling etc, because budget management is key to the success of the support model."

RVA heard from NDIS participants living with rare disease of their concern that a costly overly bureaucratic approach to the proposed model of registration would be a barrier to their staff and would place their individual model of support at immediate risk.

Any change to the support team for a person with a rare disease and disability results in a significant loss of quality and support until the next person is trained and competent in the delivery of their supports. This creates vulnerability and disruption and can directly impact the well-being of the NDIS participant, especially in areas where replacement support staff are limited (e.g. regional rural and remote).

"We need to fix the hidden costs to people with rare disease and more complex and intensive support needs who self-manage and directly employ. Support worker churn creates an endless cycle of training and re-training particularly for disability-related health supports."

The Action Plan emphasises the importance of supporting individuals with rare diseases in self-management and empowerment, enabling them to actively participate in decision-making processes regarding their healthcare and support needs. The proposed model must incorporate mechanisms to facilitate self-management and empower individuals with disabilities to exercise choice and control over their supports.

RVA partners raised concern about NDIS participants with rare disease unable to access adhoc services and support in the event of worker shortages, turnover, or illness. Currently, NDIS participants may be able to access paid adhoc support from unregistered supports in their network. This provides essential support and in some can prevent social admission to hospital.

“What happens to a NDIS Participant if they need short notice adhoc support from someone who is not yet registered, enrolled, or does not have a worker screening ID? Do they just have to go without? That is a scary proposition.”

We are concerned that informal supports will play a crucial role in absorbing any workforce and market shortfalls associated with the proposed model of registration and its implementation RVA requests that the Taskforce advises on mechanisms for short notice, time-limited or pending approvals.

Summary

RVA and the rare disease sector acknowledge the transformative role the NDIS has played in funding and supporting disability in Australia.

RVA supports all efforts that seek to provide an integrated person-centred support model for people living with rare disease and disability impacts and equitable access to services, supports, and quality outcomes.

RVA supports a tailored regulatory framework that is aligned with the specific risks posed by different types of supports and providers. We have recommended several amendments to the proposed model including the need to integrate workforce capability, skills, and training, improved governance, and quality monitoring.

We caution that any changes to the registration process must protect the human rights of people with a disability, preserve the principles of choice and control, and not impact people’s access to known and trusted providers or workers.

Thank you for the opportunity to engage with the Taskforce on this important proposed reform.

References

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