NDIS Quality and Safeguards Commission

Registration of NDIS Participants Who Self-Direct Their Supports

Rare Voices Australia Submission
February 2025

About Rare Voices Australia

RVA is the national peak body for Australians living with a rare disease. Nearly all of the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability. The disability impacts of living with a rare disease often aren't recognised by policymakers.

RVA provides a strong, unified voice to advocate for policy and systems that support equitable and effective access to disability, healthcare, 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 led the development of 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. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector.

Australians with rare diseases face unique and systemic challenges, including complex support needs, limited specialist knowledge, and fragmented services. Nearly all of the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability. The disability impacts of living with a rare disease often aren't recognised by policymakers.

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. Therefore, while the occurrence of individual rare diseases is uncommon, having a rare disease is in itself relatively common.

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 can 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.

Most people with a rare disease meet the Australian government's definition of having a disability, being a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities". Based on NDIS data, RVA estimates 100,000 NDIS participants are living with rare disease disabilities.

For key decision-makers at all levels, greater knowledge of rare diseases can facilitate more responsive and appropriate services for people living with a rare disease and their families and carers.

RVA's Submission

Rare disease and Self-directed supports

Rare Voices Australia (RVA) appreciates the opportunity to provide input into the NDIS Quality and Safeguards Commission's consultation on the registration of NDIS participants who self-direct their supports.

Many people with rare diseases rely on self-directed supports to ensure flexibility, continuity, and high-quality care that meets their complex and evolving needs. NDIS Participants with rare disease disabilities and their carers have shared that they achieve a better quality of care through their self-directed supports. Self-directed supports deliver highly personalised, lasting solutions to individuals' needs across social care, education, and health sectors at lower costs compared to traditional, inflexible, and top-down approaches.

For individuals with rare diseases, the ability to train support workers in the unique and individualised requirements of their condition is paramount. This includes increasing the health literacy of their workforce, investing in specialised training beyond standard disability service provisions, and building exceptional capacity within their support teams to maintain longevity and consistency. Such personalised training ensures that support workers are well-equipped to address the specific challenges associated with rare diseases, leading to improved participant outcomes.

Personalised solutions enhance the quality of life, facilitate greater societal participation, and position individuals at the centre of decision-making processes. Personal budgets enable people to obtain the kinds of services they desire and to be more socially engaged.

RVA acknowledges the importance of implementing quality and safeguarding measures. We advocate for flexibility and innovation in how NDIS participants engage their supports, balancing the dignity of risk while strengthening safeguards where required. .

RVA advocates for flexible and innovative approaches that empower participants to engage supports tailored to their unique needs, balancing the dignity of risk with strengthened safeguards where necessary. We recognise the intent behind the proposed registration process to enhance quality and safety within the NDIS. However, we have significant concerns regarding its implementation, potential risks, and unintended consequences for participants who self-manage and self-direct their supports.

Mandatory registration may increase bureaucracy, reduce workforce availability, and disproportionately affect participants with rare diseases who depend on individualised support arrangements. RVA urges the NDIS Commission to adopt a risk-proportionate approach that prioritises participant autonomy while ensuring appropriate safeguards.

This Submission provides feedback on the proposed registration framework, identifies potential risks and barriers, and offers recommendations to improve regulatory approaches for participants who self-direct their supports.

Key Concerns Regarding Mandatory Registration for Self-Directed Supports

1. Impact on Choice and Control

The NDIS is designed to empower participants with choice and control over their support services. However, imposing mandatory registration for participants who self-direct their supports introduces additional regulation that may undermine this foundational principle. Many individuals with rare diseases depend on non-traditional, flexible arrangements—such as directly employing support workers or engaging unregistered providers—due to various factors, including negative experiences with registered providers, market failures, limited availability, or the necessity for a highly individualised approach.

Important Factors for People Living with A Rare Disease

- **Specialised Skill Requirements**: Participants with rare diseases often need highly specific support that registered providers may not offer. For instance, individuals with neuromuscular disorders might require caregivers trained in complex lifting and positioning techniques not typically included in standard provider training.
- **Continuity of Care**: Maintaining long-term, trusted support workers is crucial, especially for those with progressive conditions or complex behavioral needs. Mandatory registration could disrupt this continuity if longstanding support workers opt not to register.
- **Geographical Barriers**: In regional and rural areas, the scarcity of registered providers leads participants to rely on local community members, including family, friends, or independent contractors who may not meet formal registration requirements.
- **Behavioral and Communication Barriers**: Some individuals with intellectual disabilities face challenges that make traditional service provision difficult, potentially leading to restrictive practices. These individuals often find that their goals and needs are better met within community settings rather than through specialised disability services.

RVA advocates for preserving self-directed supports as a viable, flexible model that enables participants to address their unique needs without encountering unnecessary obstacles. This requires a regulatory approach that is proportionate to risk, rather than enforcing a blanket registration requirement.

2. Definition of Self-Directed Supports

The consultation paper defines self-directed supports as arrangements where participants directly employ their own workers or establish a "service-for-one" model. RVA acknowledges the distinction between self-management (financial management of funds) and self-directed supports (direct employment of workers). However, clarity is needed on several aspects including:

- **Role of Nominees and Informal Carers**: It is unclear whether nominees or informal carers who assist with employment arrangements are subject to registration requirements.
- **Application to Hybrid Arrangements**: Clarification is needed on how the model applies to participants who utilise a combination of registered and unregistered providers.
- **Engagement Through Digital Platforms**: It is uncertain whether participants who engage providers via digital platforms (e.g., Hireup, Mable) are required to register.

Many participants engage independent contractors, sole traders, or other non-registered providers without establishing a direct employment relationship. Additionally, some NDIS participants have individuals who volunteer their time and share their lives in exchange for a stipend, general reimbursement, or reduced rent. This is particularly important in situations where other support approaches have been unsuccessful.

Participants should also have the flexibility to self-direct while using a plan manager or a combination of self-management and plan management. Combining different arrangements is common and allows individuals to determine the setup that best suits their needs and preferences. This flexibility is especially crucial in regional and remote communities, where registered providers may be scarce.

RVA recommends that the definition of self-directed supports be clearly articulated to encompass various models, including direct employment, contracting, and hybrid arrangements.

3. The Role of Peer Support and Capacity Building

Participants who self-direct their supports often lack access to structured peer support or training on regulatory obligations. Without investment in capacity building, mandatory registration could create additional challenges rather than improving outcomes.

People with lived experience of disability bring unique insights and expertise that can guide others in navigating the challenges of self-management, building relationships, and exercising their rights. Peer support networks create a sense of solidarity and shared purpose, offering practical advice, emotional encouragement, and a strong foundation for collective advocacy. By fostering peer support alongside other strategies, we can further strengthen the ecosystem of safety and empowerment for NDIS participants, reducing the risks of violence, abuse, neglect, and exploitation.

RVA supports Australian Government investment in peer support and capacity-building programs to assist self-directed participants to effectively engage in the NDIS regulatory framework. Training and resources should include information on worker rights, employment obligations, and risk management.

4. Proposed Obligations and Potential Challenges

Individuals with rare disease disabilities and their carers are required to dedicate substantial time to navigating healthcare, education, and disability services. For those who self-direct their supports, responsibilities encompass recruitment, training, payroll, and adherence to employment laws.

The proposed obligations for registered self-directed participants encompass adherence to the NDIS Code of Conduct, implementation of worker screening processes, establishment of complaints mechanisms, incident reporting, participation in audits, and ongoing monitoring. While RVA acknowledges the necessity of appropriate safeguards, the extensive scope of these obligations raises concerns regarding their feasibility and proportionality.

The proposed registration model introduces significant administrative challenges for participants and their families. Participants may find it challenging to meet requirements such as worker screening, complaints management, and incident reporting. Increased bureaucracy related to audits, compliance, and reporting could reduce the time and energy available for essential caregiving activities, discourage participants from self-managing, thereby diminishing their autonomy, and leading to financial strain due to compliance costs, insurance requirements, and registration fees.

Additionally, self-directing supports entails navigating complex obligations under the Work Health and Safety (WHS) Acts, Australian Taxation Office (ATO) regulations, and NDIS Commission standards and practices.

These challenges are exacerbated for individuals with limited digital literacy, restricted access to technology, or for whom English is a second language. Consequently, participants may unintentionally fail to comply with requirements or opt out of self-direction due to the perceived burdens, thereby limiting their autonomy and choice, and potentially rendering them vulnerable and unsupported.

RVA believes it is essential that the government provides information that is clear and accessible to ensure participants understand their rights and obligations concerning self-direction and self-management. Additionally, financial support should be available to assist participants in meeting compliance costs related to registration, such as insurance or auditing requirements.

RVA emphasises that the primary focus should be on ensuring participants have access to quality supports. RVA recommends that there be robust support structures, including clear guidance, templates, and access to peer support. To effectively implement this approach, RVA recommends that the NDIS Commission address the following specific areas of concern within the proposed obligations:

a. **Worker Screening:**

While worker screening is vital for safeguarding, the current system presents challenges for self-directed participants. Such issues include difficulties accessing the NDIS worker screening database due to identification requirements, navigating screening tools, processing delays, and limited workforce availability, especially in regional areas, need to be addressed.

Navigating a complex registration process may lead many workers, particularly those in rural areas or lower-paid positions, to opt out of self-directed roles. Participants who depend on self-directed employment models could face challenges in recruiting and retaining support workers due to these added requirements.

RVA supports making the application process user-friendly for both participants and workers, ensuring accessibility. This includes ensuring that applications can be submitted online without the need for a pre-existing employer or in-person visits, accommodating individuals in remote areas.

- **Complaints and Incident Reporting:**

Participants should not be held to the same reporting obligations as large-scale service providers. A streamlined reporting process should be introduced for self-directed participants to reflect the individualised nature of their arrangements.

It is important to consider the impact of mandatory reporting on participants' privacy and autonomy. Participants should manage their supports in a manner that best suits their needs without feeling subjected to undue scrutiny.

- **Audits:**

RVA believes that audits assessing compliance with practice standards are unsuitable and should not be required for self-directed participants.

Safeguarding measures should be proportionate to the level of risk, ensuring that individuals with stable, long-standing self-directed arrangements are not subjected to excessive regulatory oversight. The NDIS Commission should adopt a complaints-based monitoring approach rather than imposing routine audits on all self-directed participants.

All self-managed participants are already subject to financial audits conducted by the National Disability Insurance Agency, and this practice should continue.

- **Regular Check-Ins:**

The requirement for regular check-ins with the NDIS Quality and Safeguards Commission raises significant concerns about privacy, unnecessary surveillance, and potential disruptions to participant autonomy.

The NDIS Commission may need to invest in workforce professional development and skill-building to engage effectively with participants during meaningful check-ins.

RVA supports an annual check-in for all self-directed participants and nominees. Check-ins should be led by participants, be flexible in format (e.g., online, phone, in-person), and be scheduled at a frequency that respects participants' capacities. Participants should have the ability to involve family members, as well as formal and informal supports, as appropriate during check-ins. It is crucial that, in cases where a nominee is self-directing, the Commission makes efforts to communicate not only with the nominee but also directly with the NDIS participant.

RVA recommends there be robust support structures, including clear guidance, templates, and access to peer support. Suspension or revocation of registration should be considered strictly as a last resort, applied only when a participant is at risk of harm, and only after ensuring continuity of support has been established.

Summary of recommendations

1. **Establish a Co-Design Working Group**: Form a collaborative working group comprising a majority of self-directed NDIS participants to partner with the Commission in developing the self-direction registration category.
2. **Anchor the Framework in Human Rights Principles**: Ensure the framework is rooted in human rights principles such as autonomy, inclusion, dignity of risk, equity, and accountability, consistent with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).
3. **Expand the Definition of Self-Direction**: Widen the definition of self-direction to encompass all methods of worker engagement, including both self-managed and plan-managed participants. The definition should retain flexibility to accommodate blended arrangements and allow adjustments as needed.
4. **Ensure Continuity of Supports**: Participants currently engaging with self-directed supports automatically receive provisional registration for a period of up to 12 months to ensure continued access to their trusted providers of support and provide time to understand the scope of requirements and transition to the new registration arrangements.
5. **Provide Clear Guidance and Support**: Ensure that information from government agencies is clear and accessible, assisting participants in understanding their rights and obligations related to self-direction and self-management. Streamline administrative

requirements to reduce the burden on participants, allowing them to focus on training and maintaining a skilled support workforce.

6 **Invest in Capacity Building and Self-Advocacy**: Recognise the value of, and invest in, existing peer networks and resources. Strengthen supported decision-making practices to assist participants in understanding their rights and obligations for self-management and self-direction.

7 **Developing Easy-To-Use Compliance Tools** (e.g., templates for employment contracts, risk assessments, and incident reports) to reduce administrative burden. Streamlining administrative requirements can reduce the burden on participants, allowing them to focus on training and maintaining a skilled support workforce.

8 **Ensure Legal Compliance Support**: Provide resources and assistance to help participants manage legal responsibilities under Work Health and Safety (WHS) Acts, Australian Taxation Office (ATO) requirements, and NDIS Commission standards. Ensure all resources are provided in clear, plain-language, and easy-read formats to mitigate risks associated with self-directed supports.

9. **Establishing A Dedicated Self-Direction Support Unit Within the NDIS Commission** to provide guidance and capacity-building. Providing resources and assistance to help participants manage legal responsibilities under WHS Acts, ATO requirements, and NDIS Commission standards can mitigate risks associated with self-directed supports.

Conclusion

RVA remains committed to working with the disability community and policymakers to ensure that any regulatory model enhances, rather than limits, the rights of people with rare diseases and complex disabilities.

We urge the NDIS Quality and Safeguards Commission to work in genuine partnership with people with disabilities, their families, and representative organisations to ensure that any changes to registration requirements do not compromise the rights and autonomy of NDIS participants who self-direct their supports.

We welcome further discussion on this matter and look forward to engaging in co-design efforts that reflect the lived experiences and needs of people with disabilities, particularly those with rare diseases.

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References

1. Commonwealth of Australia, Department of Health. *National Strategic Action Plan for Rare Diseases*. Canberra; 2020. Available from: https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf [Accessed December 2024].