



**Department of Health, Disability and Ageing**

**Supported Independent Living (SIL):  
What Does Good Look Like?**

**September 2026**

**Rare Voices Australia Submission**

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## Introduction

Rare Voices Australia (RVA) welcomes the opportunity to provide feedback on the Department of Health, Disability and Ageing consultation paper '*Supported Independent Living (SIL): What Does Good Look Like?*'

RVA is the national peak body for Australians living with a rare disease and led the development of the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (Action Plan)<sup>1</sup>. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector.

The Action Plan recognises the need for person-centred approaches, equity of access and sustainable systems. These principles directly support the recommendations in this submission.

## Recognising Rare Disease Disability

Most people with a rare disease meet the Australian Government's definition of disability.<sup>2,3</sup> This includes an estimated 100,000 National Disability Insurance Scheme (NDIS) participants with severe and profound rare disease disability impacts.

NDIS participants living with rare disease disabilities often have highly individualised support requirements arising from the combination of disability impacts, complex health needs, intellectual disability, communication disability and progressive or fluctuating conditions. This cohort includes people living with neurodevelopmental syndromes, mitochondrial disorders, progressive neurological conditions, metabolic disorders and undiagnosed rare diseases. Many have high-intensity, lifelong support needs and are likely to be eligible for SIL supports.

RVA acknowledges the extensive work already undertaken through the Disability Royal Commission, the Independent Review of the NDIS, the NDIS Quality and Safeguards Commission (NQSC) and related SIL reform activities. RVA broadly supports these findings. However, the **needs of people living with rare disease disabilities were not explicitly considered** in this work, despite the significant proportion of participants with rare and complex conditions who rely on specialist supports. In addition to challenges shared across disability cohorts, they often face diagnostic rarity, complex and poorly understood health conditions, progressive deterioration, communication difficulties, and a shortage of providers with the capability to support their highly specialised needs.

For many people living with rare disease disabilities, disability support and healthcare cannot be neatly separated. SIL providers must be able to identify emerging health concerns, respond appropriately and co-ordinate effectively with healthcare providers. These skills are essential to preventing health deterioration, avoiding hospitalisations, and maintaining safety, wellbeing and independence.

**RVA recommends recognising people living with rare disease disabilities as a priority cohort within SIL reform and commissioning approaches.**

The experiences of people living with rare disease disabilities highlight the importance of a workforce with strong health literacy, ongoing training, access to specialist knowledge, and clear pathways for coordination across health and disability systems.

## **Recommendations**

RVA recommends that SIL reforms:

### **Recommendation 1**

Explicitly recognise people living with rare disease disabilities as a priority cohort.

### **Recommendation 2**

Strengthen workforce capability, health literacy and clinical escalation pathways for people with rare and complex conditions.

### **Recommendation 3**

Preserve participant choice, continuity of support and access to specialist rare disease disability providers, including in thin markets and regional, rural and remote areas.

### **Recommendation 4**

Ensure funding and commissioning reflect the true cost of supporting people with rare and complex conditions.

## **Detailed Responses to Consultation Questions**

### **Question 1: Which SIL participants could benefit most from additional government oversight of planning, delivering and monitoring SIL supports?**

Many people living with rare disease disabilities need highly individualised supports that combine disability assistance with disability-related health supports. This may include support for seizure management, respiratory conditions, swallowing difficulties, enteral feeding, progressive neurological conditions, or significant communication impairment. When SIL providers lack the right skills, knowledge, or experience, the consequences can be serious. Participants may have important support needs go unmet, experience avoidable health complications, lose independence, or require hospital treatment that could otherwise have been prevented.

While some participants may benefit from additional safeguards, RVA believes reforms should focus on stronger quality standards, workforce skills and effective oversight, rather than creating new barriers in the SIL market.

Many people living with rare disease disabilities rely on small specialist providers that understand their unique support needs. Any new oversight arrangements should recognise the value of these providers and avoid unnecessary administrative burdens that could reduce flexibility, disrupt existing support arrangements, or discourage providers from supporting people with rare and complex conditions.

RVA supports strengthening the NDIS Practice Standards and Quality Indicators for providers supporting participants with complex support needs. This should include stronger requirements around health literacy, recognising and responding to health concerns, staff training, and working effectively with healthcare professionals. Increased oversight through the NQSC could strengthen safeguards while maintaining participant choice and control and continued access to trusted specialist providers.

### **Question 2: What do high-quality SIL supports look like?**

For many people living with a rare disease disability, high-quality SIL is highly individualised. A support model that works well for one person may be unsuitable for another person, even when they share the same diagnosis.

High-quality SIL relies on workforce continuity, trusted relationships, and support workers who understand the person's communication style, health needs, preferences and goals, and who can recognise when health concerns require further support. Staff should have knowledge of the rare conditions they support and access to appropriate clinical advice when required.

Importantly, quality is not necessarily related to provider size. Some of the most effective supports are delivered by smaller specialist providers that have developed expertise through lived experience, long-term relationships and a strong understanding of the people they support. Reforms should preserve opportunities for these providers to continue operating and innovating within the sector.

### **Question 3: How should SIL supports protect the safety, health, wellbeing and rights of participants?**

Effective safeguards should help prevent health deterioration, avoidable hospitalisation, and other harms that occur when support workers are not equipped to identify or respond to emerging health concerns. This is especially relevant for individuals living with rare disease disabilities who are unable to communicate pain, illness, distress or unmet needs easily. Poor outcomes can occur when support workers do not identify early signs of deterioration or lack the confidence to escalate concerns.

A skilled workforce is therefore a critical safeguard and should include:

- Escalation pathways that support early identification of emerging health concerns.

- Workforce health literacy to ensure support workers can recognise and respond appropriately to changing needs.
- Communication support for people who use alternative communication methods or require supported decision-making.
- Collaboration with families and carers, who often have valuable knowledge about an individual's condition and support needs.

#### **Question 4: How can innovation be encouraged while maintaining quality and accountability?**

People living with rare disease disabilities have often developed innovative and highly individualised support arrangements because mainstream service models have not always met their needs.

Reforms should retain opportunities for innovation and flexibility within the SIL market. Innovation may include greater access to specialist expertise through technology, workforce development initiatives, and shared learning opportunities that build expertise in supporting people with rare and low-prevalence conditions.

RVA notes that innovative provider-led approaches already exist within the SIL market, including models that improve coordination between disability supports and primary healthcare. For people living with rare disease disabilities, these approaches can help create more responsive and coordinated supports.

#### **Question 5: How should participant choice and control be supported?**

For many people living with rare disease disabilities, meaningful choice depends on both the availability of providers and their expertise. Rare disease disability often creates a thin market, with only a small number of providers having the knowledge, skills and confidence to deliver safe and effective support. While this can limit choice even in metropolitan areas, the challenges are often magnified in regional, rural and remote communities.

Many people living with rare disease disabilities spend years finding providers who understand their condition and support needs. These relationships play an important role in maintaining stability, continuity of support and quality outcomes.

As commissioning reforms are developed, care should be taken not to disrupt arrangements that already meet a participant's needs. Supporting people with rare and complex conditions often requires additional expertise, workforce development and time to build knowledge and trust. Funding and commissioning models should reflect these realities, particularly in thin markets where fewer provider options may be available.

Reforms should also support workforce development and encourage providers to work with people who have rare and complex conditions. This will help build skills and strengthen the sector over time.

### **Question 6: What do providers need to remain financially sustainable while delivering high-quality, safe and innovative SIL supports?**

Delivering high-quality support for people living with rare disease disabilities requires investment in workforce training, condition-specific knowledge, coordination across health and disability systems, and long-term relationships with participants and families. These activities must be recognised as key factors in all funding and commissioning arrangements.

Reforms should recognise the additional costs associated with supporting participants with rare and complex conditions. Funding models should be designed so providers are not financially disadvantaged for supporting participants who require more intensive or specialised support.

This is particularly important in thin markets, where it can take years to build workforce capability and sustainable services. Efforts to improve quality and oversight should include measures that support workforce capability, provider confidence and long-term service viability. Commissioning arrangements should avoid creating incentives for providers to exclude participants with rare and complex support needs.

RVA acknowledges that people living with rare disease disabilities in regional, rural and remote communities often face significant barriers in accessing high-quality SIL supports. In areas where service options are limited, commissioning arrangements may help build local provider capability and improve service availability. This may allow people to remain connected to their families, local communities and support networks, rather than needing to relocate to access suitable supports.

At the same time, reforms should maintain a diverse provider market that includes smaller specialist providers. Many of these providers have developed expertise in supporting people with rare and complex conditions and continue to play an important role in the sector.

## **Conclusion**

RVA acknowledges that commissioning may improve access to SIL supports in some areas, particularly in regional, rural and remote communities. However, reforms should build on what is already working well and avoid disrupting support arrangements that meet people's needs. Maintaining access to specialist providers with rare disease expertise will be critical.

RVA welcomes the opportunity to continue contributing as consultation on future SIL reforms progresses.

## 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 September 2026]
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