Rare Disease Disability Project

Stakeholder Reference Group Terms of Reference

Rare Voices Australia (RVA) is leading the Rare Disease Disability Project (the Project) and proudly delivering projects for the Peer Support and Capacity Building grant for the National Disability Insurance Scheme (NDIS).

About Rare Voices Australia

RVA is the national peak body for Australians living with a rare disease. We advocate for the best outcomes for Australians living with a rare disease. Our work is non-disease specific and is based on the commonalities of the approximately 7,000 different rare diseases. Learn more about RVA on our website.

There is significant unmet need for mainstream, community, and foundational supports among Australians living with rare disease disabilities, including families and carers. 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[1]. RVA estimates that there are approximately 100,000 people living with a rare disease disability currently receiving NDIS funding. This Project will address the unmet needs of people living with a rare disease disability outlined in the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan). The Action Plan is the first nationally coordinated effort to address rare diseases in Australia.

Overview: The Rare Disease Disability Project

This 2-year Project focuses on peer support and capacity building and will conclude in December 2026. The Project will be guided by a Stakeholder Reference Group (SRG) comprising people with lived experience of rare disease disability and diverse representation from priority populations (Aboriginal and Torres Strait Islander people; culturally and linguistically diverse communities; people living in regional, rural and remote areas; and other groups). SRG members will be selected by an expression of interest (EOI) process. Building on the existing strengths of the rare disease sector, the Project's activities will identify and aim to address gaps in peer support and self-advocacy for people living with a rare disease disability.

Self-Advocacy and Capacity Building

To address gaps identified in peer support and self-advocacy, the Project will codesign a collection of supports and resources, and will include resources to respond to the unique needs of the following rare disease disability types:

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[1] Australian Public Service Employment Database (APSED) - Australian Institute of Health and Welfare

- Neurological/neurodevelopmental
- Progressive/degenerative
- Episodic/fluctuating
- Children with delayed development
- People suspected of having an undiagnosed rare disease

The Rare Disease Disability Network

A Rare Disease Disability Network (RDDN) will be formalised to collaborate and share learnings to enhance the rare disease sector's capacity to increase the skills, knowledge, and confidence of those with lived experience to access and navigate supports. The RDDN will comprise of community-led rare disease organisations and other stakeholders in the rare disease sector. Members of the RDDN will be invited to submit grant proposals for self-advocacy support navigation and/or peer support projects. The SRG will assess the proposals and select the grant recipients. Five grants of up to $25,000 each will be awarded. All funded projects are required to be codesigned and delivered in partnership with RVA. RVA will also provide peer support and capacity building directly to rare disease organisations and stakeholders through the RDDN.

Virtual Kitchen Table Sessions

Through virtual kitchen table drop-in sessions, RVA will provide direct peer support to people across Australia living with a rare disease disability, and their family and carers. These sessions will also help to inform the development of a Rare Disease Disability Toolkit.

Role of the Stakeholder Reference Group

- Share their lived experience and help to identify gaps to establish priorities
- Select 5 projects to receive grants to develop resources for specific groups of people living with rare disease disabilities
- Help to codesign the Rare Disease Disability Toolkit
- Help oversee program quality and evaluate effectiveness

Membership Criteria

Successful candidates will be selected through an EOI process. At least 50% of SRG members will have direct lived experience of a rare disease disability. The remainder of the SRG will comprise family, carers, disability and other experts.

RVA will use the following criteria when appointing SRG members:

- People living with a rare disease disability or support someone who does (family/carer/professional)
- People with an understanding of the disability reform activities underway in Australia, including the NDIS, foundational supports and mainstream supports
- Independently or with support, people who:
    - Want to respond to questions and share ideas
    - Use a computer, iPad or phone for meetings and discussions
    - Can access the necessary support to participate in the group (for example, a support worker, communication device, or interpreter)

Participation in the Stakeholder Reference Group

SRG members will be expected to:

- Participate in several activities, including online discussions, meetings, interviews/surveys, and workshops
- Review and comment on documents and resources

The SRG will be offered multiple opportunities and methods to provide feedback, including in writing, during meetings, verbally and so on. SRG members will be asked to participate in as many engagement activities as possible, and members will receive an honorarium payment that aligns with the Health Consumers New South Wales Remuneration and Reimbursement of Health Consumers Position Statement. Up to 15 hours each year will be allocated to each member for SRG-related activities from May 2025.

Governance

- RVA will facilitate the SRG meetings and activities
- RVA will provide administrative and secretariat support
- Translation and support services may be available; requests are welcomed
- SRG members will:
    - Maintain confidentiality in alignment with the SRG Participation Guidelines and RVA's core ways of working
    - Maintain a current Register of Interest to enable the effective management of potential conflicts of interest
    - Ensure a person-centred approach to rare disease disability informs all aspects of the Project