Rare Disease Disability Project

Stakeholder Reference Group Terms of Reference

Rare Voices Australia (RVA) is leading the Rare Disease Disability Project (the Project).

About Rare Voices Australia

RVA is a group that helps people with rare diseases. We want to make life better for people who have rare diseases. This Project will help people with rare disease disabilities.

The Rare Disease Disability Project

This Project will run for 2 years and finish in December 2026. The Project will focus on helping people with rare disease disabilities with support and building skills.

A group called the Stakeholder Reference Group (SRG) will help guide the Project. The SRG will have people with rare disease disabilities and other people who help these people. People who want to join the SRG can show their interest.

The Project will build on what is already helping people in the rare disease community. It will find ways to help people speak up for themselves.

Speaking Up and Learning New Things

The Project will work with others to create helpful resources to meet the needs of different rare disease disabilities, including:

- 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 begin. This will allow people to work together and share ideas. It will help the rare disease community learn new skills and share ideas. This way, people can use support services better.

People in the RDDN can apply for money to help with speaking up or support projects. The SRG will look at the applications and decide who will get the money. There are 5 grants of up to $25,000 each. All projects must be made and run with RVA.

Online Kitchen Table Sessions

RVA will offer online sessions for people with a rare disease disability and others who help them. The sessions will help people learn things that can help people with a rare disease disability.

Role of the Stakeholder Reference Group

- Share their personal stories and help find what is missing to set important goals
- Choose 5 projects to get grants
- Help design the Toolkit
- Help make sure the program is working well

Who Can Join

RVA will select SRG members through a way where people show their interest. At least half of the SRG members will have personal experience. Other members will include family, carers, and others.

RVA will use the following guidelines to select SRG members:

- People living with a rare disease disability
- People with an understanding of the disability changes in Australia
- People who can by themselves or with help:
    - Respond to questions and share ideas
    - Use a computer, iPad or phone for meetings
    - Access what they need to take part in the group

Taking Part

SRG members will:

- Take part in different activities, like online discussions and meetings
- Read and give feedback

SRG members will have many ways to share, including in writing, in meetings, or by speaking. They will also receive a payment for helping according to the Health Consumers New South Wales rules. Each member has up to 15 hours per year for SRG activities starting from May 2025.

Governance

- RVA will run the SRG meetings and activities
- RVA will write down what happens and make sure everyone can join in
- Translation and support services may be available if needed; please ask RVA
- SRG members will:
    - Keep information private and follow RVA's ways of working
    - Keep an updated Register of Interest to manage any possible conflicts of interest
    - Make sure the Project focuses on the needs of people with rare disease disabilities