

**Position:** Disability (Rare Disease) Project Officer

**About the Organisation**

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease. We advocate for the best outcomes for Australians living with a rare disease, including families and carers. RVA estimates that over 100,000 National Disability Insurance Scheme participants live with a rare disease comorbidity.

- We provide a strong unified voice to advocate for rare disease policy reform, as this is essential to improving the lives of Australians living with a rare disease.
- We work with key stakeholders to progress the collaborative implementation of the Australian Government’s [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). RVA led the collaborative development of the Action Plan, which was launched in February 2020 with strong bipartisan support. Developed ‘by the rare disease sector, for the rare disease sector,’ the Action Plan is the first nationally coordinated effort to address rare diseases in Australia.
- We provide leadership and advocacy, raise awareness of issues, and influence policy by engaging with all key stakeholders in the rare disease sector.
- Our solutions and results oriented approach to working with stakeholders, including rare disease organisations/groups, ensures our actions are well considered and well targeted, sustainable, and geared towards achieving a high collective impact.
- Our national team is small, cohesive, and strategic. We are innovative thinkers who are nimble and proactive. We are comfortable working remotely as our team members are located across Australia. We all pitch in when needed, and act with the highest level of integrity and respect for our stakeholders. We thrive on achieving progress on the big issues for people living with a rare disease.

<b>Position</b>	Disability (Rare Disease) Project Officer
<b>Salary</b>	\$86,300 per annum, based on a 38-hour week, pro rata, plus super
<b>Benefits</b>	Not for Profit Salary Packaging Benefits which reduces your taxable income
<b>Work location</b>	Flexible within Australia. Current staff work from home offices. The successful applicant may be based in a city or major regional centre
<b>Hours</b>	Full time – we are willing to negotiate hours with the right applicant. Flexible office hours with occasional overtime work required. Some interstate travel is anticipated – we will work with the right applicant to ensure specific support-related travel needs are met
<b>Length of the role</b>	Fixed term contract ending 31/12/2026

## Responsibilities

Reporting to RVA's Disability Advocacy Manager, the Project Officer will deliver grant project outcomes for the Rare Disease Disability Network. This project is funded by the [National Disability Insurance Agency Peer Support and Capacity Building grant opportunity](#). Responsibilities include:

- Building and maintaining effective working relationships with people living with rare disease disability, including families and carers.
- Building and maintaining effective working relationships with rare disease organisation/group leaders.
- Consulting with rare disease disability experts (medical and allied health).
- Project planning to ensure grant deliverables are completed to a high quality and in a timely manner.
- Administration support and co-ordination of Stakeholder Reference Group activities.
- Developing resources in line with grant deliverables based on codesign input from the Stakeholder Reference Group.
- Supporting RVA's Disability Advocacy Manager in the coordination of, and reporting on, the Rare Disease Disability Network.
- Working with RVA's communications team to develop content about this project, including monthly rare disease disability newsletters and social media.
- Liaising with rare disease organisations/groups undertaking projects as part of this grant to ensure projects are delivered.
- Organising and coordinating online and face-to-face meetings for stakeholders.
- Reporting on project deliverables.

## Key Selection Criteria

- Relevant experience in the disability sector, including working with stakeholders to improve outcomes for people living with a disability.
- An understanding of, and sensitivity to, the challenges faced by Australians living with a rare disease and associated disability impacts.
- Proven experience in a similar role.
- Appropriate qualifications suited to this role and/or experience working in the non-profit sector.
- Commitment to improving the lives of Australians living with rare disease disabilities.
- Excellent communication and people skills. Strong skills and experience in workshop facilitation and public speaking. The ability to communicate with diverse audiences across all mediums.
- A collaborative and inclusive approach to working with others. Ability to engage effectively in teamwork.
- Relationship-building and engagement skills and experience with a diverse range of stakeholders such as people living with a rare disease, advocates, clinicians, researchers, government, key peak bodies and industry.
- Organised, detail-focused and able to manage priorities to deliver outcomes. The ability to multi-task and work to timelines and deadlines.

- Demonstrated ability to work effectively remotely and with appropriate levels of autonomy, transparency and accountability.
- Aligned with the culture and values of the organisation: respect and care for others, supporting people to succeed, recognising and valuing different strengths and capabilities of team members, collaboration and cooperation, and a person-centred approach in decision-making.

### **Other Relevant Information**

- The appointee will be subject to a probation period of six months.
- The position will be subject to a National Police Records Check and Working with Children/Working with Vulnerable People check, as applicable.
- Applicants must be an Australian citizen, permanent resident or hold a valid work permit or visa.
- RVA is an equal opportunity employer and welcomes applicants from a diverse range of backgrounds.

### **Queries**

Please contact Louise Healy, RVA's Education and Advocacy Manager, with any questions you may have about this role.

**Phone:** 0455 053 877

**Email:** [louise.healy@rarevoices.org.au](mailto:louise.healy@rarevoices.org.au)

### **Apply for This Position**

Please forward your application, addressing the Key Selection Criteria, as well as a copy of your CV to [louise.healy@rarevoices.org.au](mailto:louise.healy@rarevoices.org.au) by 5pm AEDT Monday, 3 February.