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Department of Social Services

National Carer Strategy Consultation

Rare Voices Australia Submission #2
October 2024

About Rare Voices Australia

Rare Voices Australia is the national peak body representing the estimated two million Australians living with a rare disease, the majority of whom also meet the Australian government definition of living with a disability. We estimate that over 100,000 National Disability Insurance Scheme (NDIS) participants live with a rare disease disability comorbidity.

RVA advocates for policy and systemic support to improve the lives of Australians with rare diseases, including families and carers.

On 13 September 2024, RVA made a submission to the National Carer Strategy consultation. RVA welcomes this opportunity to provide additional feedback on the Draft National Carer Strategy, on behalf of the Australian rare disease community.

RVA proposes specific, targeted recommendations to enhance the Draft National Carer Strategy's responsiveness to the unique and multi-faceted needs of rare disease carers, including carers with multiple and/or dual roles.

The additional recommendations outlined in this submission align with the National Strategic Action Plan for Rare Diseases (the Action Plan)[1], in particular Priority 2.1 "*Provide rare disease care and support that is integrated and appropriate for all Australians living with a rare disease, while being both person and family-centred."*

Recognition of Rare Disease Carers

Recognition of Rare Disease Carers including carers with multiple and/or dual roles

RVA acknowledges the effort to increase visibility and support for Australia's carers in the Draft National Carer Strategy.

Rare disease carers face heightened caregiving demands due to complex health and disability requirements. RVA urges the inclusion of rare disease carers as a distinct group within the strategy, alongside recognition of carers with multiple roles (i.e. individuals caring for multiple people with rare diseases and conditions) and/or dual roles (i.e. carers living with rare diseases who also care for loved ones with a similar or different condition).

These carers experience an additional layer of burden by managing their own rare disease or condition alongside caregiving responsibilities. Recognising these groups will ensure they are not overlooked and can access specialised support aligned with their distinct needs.

Recommendation:

1. **The National Carer Strategy explicitly acknowledge rare disease carers, dual-role carers and carers with multiple carer roles in the strategy's objectives and principles**.

Recognition of Unique Needs and Health Literacy Demands for Rare Disease Carers

Caring for individuals with rare diseases involves unique and intensive demands, including advanced health literacy, complex and specialised caregiving and medical support, and emotional resilience. Carers often perform complex medical tasks, including medication administration, tube feeding, and managing high-dependency care, and often lack adequate support.

While the Draft National Carer Strategy acknowledges the complexity of care roles generally, it lacks specific mention of the unique skills rare disease carers require, such as health literacy and specialised medical training.

Recommendation:

2. **The National Carer Strategy explicitly recognise the high level of health literacy and specialised caregiving responsibilities required for rare disease carers.**

Tailored Respite Services for Rare Disease

Traditional respite services are often unsuitable for rare disease care recipients due to complex medical, communication and/or behavioural needs. Tailored respite services that are available both in the home and outside of the home will reduce burnout and support carer well-being while ensuring consistent care for loved ones.

Recommendations:

3. **Develop and fund flexible, in-home and out-of-home respite services tailored to the high-complexity, high-dependency needs of rare disease carers and multiple and dual-role carers, particularly in rural, regional and remote areas.**
4. **Develop training for respite providers to effectively support people with rare, high dependency needs through collaboration with rare disease organisations.**

Enhanced Mental Health and Psychosocial Support for Rare Disease Carers

Rare disease carers frequently experience isolation and unique stressors that are not adequately addressed in mainstream mental health programs. Multiple and dual-role carers need support systems that understand their compounded challenges and help them maintain emotional resilience.

While the Draft National Carer Strategy recognises the mental health impact of caregiving broadly and includes psychological support as a priority, rare disease-specific mental health resources, such as those addressing the unique stresses associated with complex, often progressive conditions, are not explicitly addressed.

Recommendations:

5. **Explicitly identify the mental health needs for rare disease carers, emphasising accessibility for multiple and/or dual-role carers.**
6. **Fund tailored mental health programs that specifically address the unique psychological burdens of rare disease carers, including chronic stress, isolation, and anticipatory grief.**
7. **Increase funding for rare disease-specific peer support networks in collaboration with RVA and its partners (rare disease organisations), including virtual support options to address geographical isolation.**

Recognising Economic Contributions of Rare Disease Carers

The Draft National Carer Strategy makes brief mention of the integral role carers play in the nation’s health and social care systems, however RVA believes they offer crucial unrecognised contributions that translate into considerable financial benefits for governments, and the community as a whole.

For example, rare disease carers play a critical role in the broader healthcare ecosystem, providing complex care at home that prevents hospitalisations and mitigates healthcare costs. RVA believes it is important to recognise and quantify their contributions to support resource allocation that accurately and adequately reflects the full value of their caregiving.

Recommendation:

8. **Commission research to quantify the economic value of the support provided by rare disease carers and dual-role and multiple-role carers, including the contributions made through home-based medical care and its substantial cost savings to healthcare systems.**

Financial and Employment Support for Rare Disease Carers

Rare disease carers, particularly carers with multiple and/or dual roles, face significant financial strain due to the unpredictability of health and disability care needs and personal health demands. Some rare disease carers need to reduce their work hours due to the high-dependency, intensive care needs of their loved one/s, including during palliative and end-of-life periods. Additional financial and employment supports will help alleviate economic hardship and support long-term financial security for rare disease carers.

Recommendation:

9. **Implement targeted financial support policies for rare disease carers including:**
    a. **Increase the Carer Payment and Carer Allowance for carers supporting individuals with high-dependency needs, and multiple and/or dual-role carers.**

b. Introduce flexible employment policies, including enhanced carer leave, remote work options, and superannuation protections for carers who reduce their work hours due to caregiving.

Improved Data Collection and Representation of Rare Disease Carers

Data is essential to understanding the challenges rare disease carers face and ensuring tailored services. Targeted data collection will allow the strategy to evolve with a clearer understanding of rare disease carer needs, while helping to allocate resources effectively.

Recommendation:

10. **Incorporate specific data collection initiatives in the Carer Gateway and Survey of Disability, Ageing, and Carers (SDAC) to capture information on rare disease carers and dual-role carers, to identify gaps and areas for targeted improvement.**

Awareness and Training for Health and Social Service Providers

Rare disease carers frequently encounter misunderstandings and inadequate support from healthcare and social service providers. This can be exacerbated for carers with dual and/or multiple roles. Training and awareness initiatives will bridge this gap and ensure a more supportive, responsive environment.

Recommendation:

11. **Implement training programs for healthcare, disability and social service providers to improve understanding of rare disease carer needs and ensure culturally competent, trauma-informed support. This includes the dual-role and multiple-role carer experience to reduce barriers to support and foster empathetic service delivery.**

Sustainable Peer Support Programs for Rare Disease Carers

The Draft National Carer Strategy reinforces the importance and value of peer support for carers, including how it contributes to improved carer wellbeing, information and knowledge sharing.

Peer support offers immense benefits for rare disease carers, particularly in terms of mental health, well-being and resilience. Given the rarity of their conditions, rare disease carers benefit enormously from networks where they can connect with others who truly understand their experiences and can help them navigate the complexity of services and supports.

Recommendation:

12. **Provide grants or dedicated funding for peer support groups specific to rare disease carers, with a focus on geographical inclusivity and digital accessibility to enhance knowledge sharing and reduce isolation.**

Conclusion

RVA welcomes the Draft National Carer Strategy as a positive step towards improving the lives of Australia's carers. By implementing RVA's targeted recommendations, the Draft National Carer Strategy can more fully recognise and support rare disease carers and multiple and dual-role carers, ensuring their unique needs are met.

RVA remains committed to working collaboratively to create a National Carer Strategy that truly reflects and addresses the diverse and vital contributions of rare disease carers.

Thank you for the opportunity to contribute to this consultation.

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 October 2024]

2. Rare Voices Australia. *Submission to the National Carer Strategy consultation*. September 2024. Available from: https://rarevoices.org.au/wp-content/uploads/2024/09/RVASubmission_NationalCarerStrategy.pdf [Accessed October 2024]

3. Commonwealth of Australia, Department of Social Services. *National Carer Strategy – Draft for Consultation*. October 2024. Available from: https://engage.dss.gov.au/wp-content/uploads/2024/10/National-Carer-Strategy-Draft-for-Consultation.pdf [Accessed October 2024]