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Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Response to Recommendations

Rare Voices Australia Submission | January 2024

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body for the estimated two million Australians living with a rare disease.

We welcome the opportunity to provide a Submission to the Australian Government regarding the Final Report and Recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability [1] (Disability Royal Commission).

RVA provides a strong, unified voice to advocate for policy as well as health, disability and other systems that work for people living with a rare disease. RVA's work is non-disease specific and is based on the commonalities of the approximately 7,000 different rare diseases.

Our person-centred focus sees us working with all key stakeholders, including people living with a rare disease, over 100 RVA Partners (rare disease groups/organisations), governments, key peak bodies, researchers, clinicians, and industry.

RVA advocates for the best outcomes for Australians living with a rare disease, including those impacted by disability.

What Is a Rare Disease?

A disease is rare if it affects fewer than five in every 10,000 people. There are approximately 7,000 different diseases and an estimated two million Australians live with a rare disease.

Around 80% of rare diseases have a genetic origin and due to the hereditary nature of some rare diseases, multiple people within the same family can be impacted.

Rare diseases are often serious and progressive, exhibiting a high degree of symptom complexity, leading to significant disability, health, and psycho-social challenges.

While not all people with a rare disease have an associated disability, those who do experience substantial and permanent disability impacts.

National Strategic Action Plan for Rare Diseases

RVA led the collaborative development of the Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan)[2]. The Action Plan is the first nationally coordinated effort to address rare diseases in Australia. It was launched by the Minister for Health in 2020 with bipartisan support.

RVA is pleased that the important principles, themes, and priorities of the Action Plan have been echoed through the Disability Royal Commission's (DRC) Final Report and Recommendations, including the calls for:

- The adoption of a cross-jurisdictional and cross-sectoral approach to inform effective policy and legislative reform
- Increased education and awareness for all Australians
- The development of a workforce strategy to respond to current and future demands
- The provision of care and support that is integrated and appropriate for all Australians living with a rare disease and disability, while being both person and family-centred
- Improved access to care and support services for Aboriginal and Torres Strait Islander people, those from culturally and linguistically diverse (CALD) backgrounds, those living in regional, rural and remote areas, and other priority populations
- Equitable access to the best available health technology
- Integrated mental health, and social and mental well-being into rare disease/disability care and support
- Coordinated and collaborative data collection to facilitate the monitoring and cumulative knowledge of rare disease, including those with disability impacts, informing care management, research and health and government system planning
- Ensuring research is collaborative, person/family-centred, contributes to agreed priorities, systematically addresses gaps and translates research findings into improved models of care and support.

"The complex nature of rare diseases requires the integration of numerous public domains that extend beyond health to disability, social/welfare, education, employment, housing and many other areas. At a national level, policy leadership is required to enable the effective and efficient delivery of integrated whole-of-life care that supports and responds to people's needs. Similarly, national policy leadership is also required to seamlessly address health and social system challenges."

- National Strategic Action Plan for Rare Diseases p46

Disability and the National Strategic Action Plan for Rare Diseases

These Principles are the foundation for the Action Plan:

- Person-centred
- Equity of access
- Sustainable systems and workforce.

Specific disability-related actions and implementation steps from the Action Plan include:

Action 2.1.1: Provide rare disease care and support that is integrated, incorporating clear pathways throughout health, disability and other systems.

Implementation

2.1.1.2. To reduce fragmented care, ensure policy meets people's full range of needs, including health, disability and education. Support this work with a cross-jurisdictional, cross-sectoral working party.

Action 2.1.2: Build a broad range of care and support services that are responsive to the changing needs of people living with a rare disease and their families.

Implementation

2.1.2.1. Develop an accessible multi-purpose digital repository, incorporating elements targeted at the workforce that supports people living with a rare disease. With access to adequate information, health care and social support professionals will be equipped to support people living with rare disease and their families to navigate health, disability and other systems.

2.1.2.3. Through regular stakeholder consultations, determine strategies to improve access to rare disease care and support services for Aboriginal and Torres Strait Islander people, those with CALD backgrounds, those living in rural and remote areas, and other priority populations.

Rare Voices Australia's Disability Royal Commission Recommendations Submission

The Australian Government published the DRC's Final Report on 29 September 2023. Subsequently, minor corrections were made and an updated report was published on 2 November 2023.

RVA recognises, and is grateful to, the rare disease groups/organisations and individuals living with a rare disease and disability who lodged submissions, presented to the DRC, and contributed to facilitated sessions to ensure their experiences and vision for the future were captured. We appreciate the courage it takes for people to share their experiences—which often comes at great personal cost—to guide policy development for better outcomes for Australians living with a rare disease and disability.

The contributions from the rare disease community are recognised as crucial in ensuring that future policies are more inclusive and responsive to the unique needs of people with rare diseases and significant disabilities.

The DRC's extensive examination highlights systemic issues relating to violence, abuse, neglect, and exploitation of people with disabilities across various settings. As the national peak body for Australians living with a rare disease, RVA recognises the scope and depth of this inquiry, noting its importance to understanding and addressing government policies at all levels that contribute to these systemic issues.

RVA acknowledges and thanks the DRC for its formidable undertaking and role in shaping future disability policies and societal reform.

The DRC's Final Report contains 222 Recommendations and RVA seeks to highlight specific themes and recommendations in this Submission.

There is a synergy and consistency between the goals and priorities of the Action Plan and the DRC's Recommendations, including the calls for collaborative policymaking, integrated care models, joint advocacy, enhanced data collection, and research initiatives.

1. Intersectionality and Diverse Experiences

The DRC's Final Report underscores the diverse experiences of people with disabilities, including Aboriginal and Torres Strait Islander people, women, girls, and those from CALD backgrounds.

RVA emphasises the importance of acknowledging and addressing these intersectionalities to create truly inclusive practices and policies, and wishes to highlight the challenges of people living with a rare disease and disability, including the additional vulnerabilities of people with intellectual and cognitive disabilities, communication disabilities and rare disease.

RVA strongly supports the DRC's Recommendations that advocate for a societal perspective that sees disability as an integral part of human diversity and the human condition. This perspective is essential for developing policies and practices that are truly inclusive.

2. Legal and Policy Framework Enhancements

RVA is a strong proponent of developing coordinated strategies and policies at national and state levels and encourages the Federal Government to engage broadly with stakeholders across sectors to inform all policy development and reform.

Creation of the Disability Rights Act: RVA supports the introduction of the Disability Rights Act (DRA) to embed international human rights standards for people with disabilities into Australian domestic law. A stronger, more comprehensive and transformative legal framework that fully implements the *Convention of the Rights of Persons with Disabilities*[3] *(CRPD)* is required to achieve equality and inclusion and advance the human rights of people with disability, including their right to live free from violence, abuse, neglect and exploitation.

The DRA would serve as a foundation for ensuring that people with disabilities are treated with dignity and respect and take a preventative approach to protect these rights.

RVA supports the DRC's Recommendation that the Australian Government introduce legislation into parliament as soon as possible, following close consultation with people living with disability, relevant peak bodies, and disability representative organisations, including RVA, and other key stakeholders.

RVA believes collaboration and harmonisation across government jurisdictions is critical for the successful implementation of disability rights protections and policies, including the DRA across all states and territories and all sectors, including public health, public education, public housing, child protection, and corrections.

Recommendations for the Disability Discrimination Act: RVA supports amendments to strengthen the *Disability Discrimination Act 1992* (Cth)[4] *(DDA)* to reduce complexity, and make it more accessible and effective, particularly in encouraging proactive measures to prevent disability discrimination and remove barriers faced by people with disabilities in making complaints.

Achieving substantive equality requires positive action to remove systemic barriers. It means shifting the focus from a reactive model to one of preventing and eliminating systemic barriers for people with disability more broadly.

RVA supports the Recommendations that strengthen legislation to eliminate all forms of discrimination, including harassment and victimisation, on the grounds of disability.

Australia's Disability Strategy 2021–2031: This strategy is pivotal in shaping future disability policy and practice, with a focus on inclusive outcomes across various domains, including health and wellbeing.

Australia's Disability Strategy 2021 – 2031 (2021) (*ADS*)[5] recognises that Australian state, territory, and local governments, along with businesses, the community and the non-government sector, all play a role in supporting people with disability to enjoy their human rights on an equal basis with others.

The Action Plan emphasises the need for integrated care and support and the requirements to develop clear pathways throughout health, disability, and other systems.

RVA is pleased that the DRC's Final Report emphasises the need for integrated care systems and inclusive policies and welcomes the opportunity for collaborative efforts that focus on creating seamless care pathways and policy frameworks to cater to both rare diseases and broader disability needs.

RVA supports the Recommendations for the Australian Government and state and territory governments, through the Disability Reform Ministerial Council, to commission the development of a workforce strategy to support the implementation of the *ADS* and that workforce capability development be closely monitored by Health Ministers.

3. Healthcare Access and Quality

The DRC's Final Report reveals significant gaps in equitable healthcare access for people with disabilities, noting poorer health outcomes and lower life expectancy. RVA is deeply concerned with the DRC's findings that people with cognitive disability continue to be subject to systemic neglect in the Australian health system.

National Roadmap for Healthcare: RVA commends the Australian Government's commitment to implementing the *National Roadmap for Improving the Health of People with Intellectual Disability* (2021)[6].

Framework for Cognitive Disability Healthcare: RVA supports the DRC's call for a comprehensive framework to improve the quality of healthcare for people with cognitive disabilities.

Mental Health Care: RVA supports the DRC's recommendation that state and territory governments fund, establish and evaluate specialised health and mental health services for people with cognitive disability to provide specialist assessment and clinical services.

RVA underscores the need for systemic changes to ensure integrated healthcare access, equitable outcomes and upholding the rights of people with disability and the calls for a workforce strategy to deliver sustainable improvements in healthcare quality and training.

This includes training for healthcare providers to improve diagnosis, treatment, and communication and a review and amendment to accreditation standards to ensure the needs of people with disability and rare disease are met.

We support the recommendation that the Australian Government and state and territory governments, in consultation with people with disability, identify and publish a list of frequently needed adaptations and supports to enable all people with disability to receive high-quality health care.

4. Data and Research for Disability Policy

It is noteworthy that the DRC reported that it had difficulty during the inquiry obtaining reliable and useful data and research to fully understand the level and scope of violence against, and abuse, neglect, and exploitation of, people with disability, and how to address and prevent it.

High-quality data and research are essential for evaluating the effectiveness of disability policies and holding governments accountable. The report calls for strategies to improve data collection, especially among hard-to-reach groups.

The DRC recommends a more systematic approach to disability data collection. RVA supports this, highlighting the importance of accurate data for policy development and evaluation.

The DRC's Final Report recommends developing a nationally consistent approach to collecting disability information and establishing a National Disability Data Asset[7] (NDDA). RVA supports the proposed establishment of an NDDA to facilitate better understanding and policymaking.

RVA welcomes the opportunity to collaborate and co-design the NDDA to ensure people with disability who live with a rare disease are also captured. Data collection and research initiatives could provide deeper insights into the needs of people with rare diseases and disabilities, leading to more effective policy and service design.

We advocate for data-driven and evidence-based research and information sharing to support best practices and encourage innovative approaches to improving outcomes for people with disability.

We acknowledge the Australian Government's National Disability Research Partnership[8] (NDRP), an initiative facilitating a more collaborative approach to disability research.

5. Advocacy and Support Systems

The DRC’s emphasis on advocacy and tailored support systems for people with disability presents an opportunity for joint actions with RVA to raise awareness and develop support mechanisms that address the specific needs of people with rare diseases within the broader disability context.

RVA stresses the importance of independent and systemic advocacy for people with disability, including those living with a rare disease and encourages ongoing support through programs like the National Disability Advocacy Program [9](NDAP).

In November 2023, RVA applied for the Disability Representative Organisation (DRO) grant opportunity to support our systemic advocacy programs and initiatives for Australians living with rare disease and disability. RVA continues to actively engage with other disability advocacy services.

RVA welcomes the establishment of a First Nations Disability Forum to address the unique challenges faced by this priority population and to ensure the delivery of culturally appropriate services and support.

6. Role of Government and Institutional Responses

RVA commends the DRC for its formidable undertaking and the number of Recommendations that strengthen disability policy and government strategy arrangements.

Establishment of the National Disability Commission: RVA supports the proposal for the establishment of the National Disability Commission, an independent statutory body that would oversee the implementation of Recommendations independently reporting on outcomes for people with disability. It would also assess progress on the implementation of *ADS* and the performance of each jurisdiction.

RVA recommends that the National Disability Commission engage closely with people with disability, including those living with a rare disease, when reporting on the Recommendations.

Strengthening the National Disability Agreement: RVA supports the recommendation for a new, stronger National Disability Agreement that provides the intergovernmental structure for disability policy and reform.

The Productivity Commission reviewed the National Disability Agreement in 2019, concluding that the Agreement was no longer fit for purpose and had a weak influence on policy.

Government Responsibility in Disability Policy: The DRC’s Final Report suggests a more focused and dedicated approach to disability policy at the governmental level, including the establishment of a specific ministerial position and department for disability dedicated to disability strategy and programs.

The DRC recommends moving responsibility for disability policy from the Australian Government's Department of Social Services, which oversees a range of other policy and program issues alongside disability, to a new portfolio focused specifically on disability. This should include a new dedicated, ministerial position responsible for disability strategy, policies and programs.

To lead disability policy and programs in the Australian Government, the DRC also recommends creating a new department, the Department of Disability Equality and Inclusion. RVA supports changes to government portfolios that deliver focussed and improved policy, services and oversight for disability programs and initiatives.

Coordinated Response Across Governments: The importance of inter-governmental coordination in implementing the DRC's Recommendations is highlighted, with a focus on ensuring a unified and effective approach to disability policy and services.

The role of the Disability Reform Ministerial Council in coordinating responses to the DRC's Recommendations across jurisdictions is emphasised, ensuring a unified approach to disability policy. RVA believes this is appropriate as the Disability Reform Ministerial Council is the current ministerial intergovernmental forum for disability issues. Its members include the Australian Government and state and territory government ministers responsible for disability policy.

Summary

In summary, the DRC's Final Report and RVA's response collectively underline the necessity for comprehensive, inclusive, and intersectional approaches to disability policy and practice in Australia. Such policy and practices include legal reforms, healthcare improvements, enhanced data collection, advocacy, support systems, and a coordinated governmental response to ensure the rights and well-being of people with disabilities, including those living with a rare disease.

These insights reinforce the importance of a collaborative, multi-faceted approach to addressing the complex needs of the disability community and to create a more inclusive society where people living with disabilities, including those with rare diseases, can live with dignity, equality, and respect.

RVA eagerly awaits the Australian Government's response to the DRC's Final Report and Recommendations. We welcome all opportunities to collaborate and co-design to implement meaningful reforms to Australian law, policy and society that authentically and comprehensively embed human rights principles for people with rare disease and disability impacts.

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