



**Department of Social Services**

**Foundational Supports (General Supports)**

**Rare Voices Australia Submission  
December 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.

RVA provides a strong, unified voice to advocate for policy as well as disability, health, 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, governments, key peak bodies, researchers, clinicians, and industry. RVA collaborates with over 100 rare disease groups/organisations in Australia that are consumer-led, not-for-profit groups and organisations. A complete [list of RVA Partner organisations](#) is available on our website.

RVA advocates for the best outcomes for Australians living with a rare disease, and their families and carers.

RVA welcomes the opportunity to provide a Submission to the Department of Social Services (DSS) regarding *Foundational Supports (General Supports)*.

## 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. Therefore, while the occurrence of individual rare diseases is uncommon, having a rare disease is relatively common.

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.

Most people with a rare disease meet the Australian Government's definition of having a disability, being a "limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities". This includes the estimated 100,000 National Disability Insurance Scheme participants with severe and profound rare disease disability impacts.

For key decision-makers at all levels, greater knowledge of rare diseases can facilitate more responsive and appropriate services for people living with a rare disease and their families and carers.

## National Strategic Action Plan for Rare Diseases

RVA led the development of the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan)<sup>1</sup>, the first nationally coordinated effort to address the needs of rare diseases in Australia. RVA is now leading the Action Plan's collaborative implementation on behalf of the rare disease sector. In keeping with the cross over between many rare diseases and disability, aspects of the Action Plan specifically address the NDIS and the arbitrary and unhelpful line that is often drawn between health and disability. In particular, the Action Plan highlights the need for coordinated and integrated care (see Appendix 1).

RVA also commissioned The McKell Institute's 2019 report, [Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases \(the Disability & Rare Disease report\)](#)<sup>2</sup> which informed the Action Plan.

The Disability & Rare Disease report made seven recommendations (see Appendix 2). The *Disability & Rare Disease Report* identified that over 80 percent of people living with rare disease in rural Australia reported not having their health and disability care needs fully met, including over one in four people reporting that their needs for assistance were not met at all.

*“Successfully navigating separate systems that are supported by a mix of commonwealth, state and private funding with services delivered by government, for-profit and non-profit providers requires detailed knowledge of each system.”*

*– The McKell Institute*

RVA encourages the government to adopt the foundation principles of the Action Plan and the recommendations from the Disability & Rare Disease Report when designing the Foundational Supports Strategy:

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

Foundational Supports must be designed with a focus on sustainability, equity, and accessibility, ensuring they empower individuals while bridging gaps in existing systems.

## RVA's Submission

RVA is pleased to contribute to the DSS' consultation on the [Foundational Supports – General Supports](#).

In preparing this Submission, RVA engaged with individuals and families/carers living with rare disease disability impacts. We also hosted a virtual rare disease disability roundtable engagement session in October 2024 with 9 of our RVA Partners (consumer-led rare disease organisation representatives) and their observations, concerns, and recommendations are reflected in this Submission. Quotes are included throughout the document.

RVA wishes to acknowledge the contribution from the following RVA Partners (listed in alphabetical order):

- Angelman Syndrome Association Australia
- Children's Tumour Foundation
- Fragile X Association of Australia
- Homerhack Foundation
- Huntingon's Australia
- Immune Deficiency Foundation Australia
- Mito Foundation
- Neuromuscular WA
- Save Our Sons Duchenne Foundation.

DSS engaged communication supplier The Social Deck to support consultation activities and RVA arranged for a private consultation session in October 2024. We provided a briefing on the rare disease disability sector, the outcomes of the Rare Disease Disability roundtable discussion, and showcased navigation services and resources currently provided for people living with rare disease disabilities by rare disease organisations.

Both RVA and RVA Partners found engaging on the topic of foundational supports challenging and frustrating for several reasons:

- It is impossible to identify what gaps Foundational Supports will fill when many of the other disability and mainstream service reforms are not yet contemplated, let alone implemented
- The government has not formally responded to the NDIS Review report and recommendations making it impossible to know how the disability ecosystem will continue to change
- NDIS legislation, associated NDIS practices and definitions of NDIS supports are undergoing significant changes and narrowing, adding additional uncertainty regarding what will continue to be covered by the scheme in the future, or the size of the gaps in disability-related supports

- The consultation was initially limited to general foundational supports, with no opportunity to identify how targeted foundational supports would fit within the strategy. This was later revised to include Targeted Foundational Supports but only for children with developmental delay.

Therefore, it is necessary to contemplate Foundational Supports using several assumptions, recognising we are currently operating within an imperfect and fragmented disability ecosystem that will remain in a state of flux for the foreseeable future.

## Key Considerations for Good Foundational Supports

RVA Partners shared the following key considerations for the development of Foundational Supports:

- Foundational Supports should be based on nationally agreed principles and incorporate the principles from the Action Plan
- Foundational Supports need to be individual, tailored and meaningful for the person. They need to be place-based, person-centred and culturally sensitive
- Delivery of Foundational Supports needs to be through a range of channels including a peer-based channel that is appropriate and provides trusted information and guidance. They cannot solely be digital resources as practical in person support may still be required, including support to access and process information
- Foundational Supports must help build people's capacity to self-advocate and self-navigate but should not be time-limited as self-advocacy may not be possible for people with rare disease disabilities and/or their families and carers
- Foundational Supports must be flexible and responsive to all aspects of the person's life noting the compounding impacts of disability, including situational and environmental factors (e.g. homelessness, domestic/family violence, financial issues, health literacy and stability of the condition, employment challenges etc.)
- Foundational Supports must be sensitive to intersectionality, and culturally safe, particularly for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities and people who identify as LGBTIQ+
- There must be mechanisms to identify gaps, with flexibility to rapidly respond to the needs of people, including in cases where people with rare disease disabilities need higher levels/more intensive support
- Resources such as a Health/Disability Passport that capture a person's information and story in one place should be available to support people to have informed conversations about their needs, while also helping them to move seamlessly between services and supports.

## Issues Specific to the Rare Disease Community and Recommendations

The [Independent Review into the National Disability Insurance Scheme \(NDIS Review\)](#)<sup>3</sup> proposed significant reforms to enhance support for all Australians with disabilities, including recommendations for the development of a new system of supports known as ‘foundational supports’.

Foundational Supports are intended to assist individuals who may not be eligible for individual NDIS funding and are designed to complement and bridge the gaps between the disability-specific and mainstream supports such as health, education, housing, and community services. An estimated two million Australians live with a rare disease, of which approximately 100,000 are receiving NDIS-funded supports.

The NDIS Review identified two types of foundational supports:

- **General foundational supports** would include programs and activities like information and advice, individual and family capacity building, peer support, self-advocacy, and disability employment supports.
- **Targeted foundational supports** would include home and community supports, such as shopping and cleaning or assistive technology for people who require early intervention or less intensive support but are not eligible for the NDIS.

RVA is aware that the goal of the Foundational Supports Strategy is to ensure a holistic and inclusive disability support ecosystem by providing essential, capacity-building resources such as information, navigation, and advocacy to individuals who may not qualify for individual NDIS funding but still require significant assistance. We recommend significant parallel investment in disability inclusion across all mainstream services, including childcare, education, employment, public and social housing, transport, and justice.

## Rare Disease Sector Mapping - Navigation Supports

RVA understands that, in addition to the DSS-led Foundational Supports consultation, states and territory governments are also engaged in planning foundational supports.

The rare disease sector has long highlighted the importance of navigation services to help individuals access health services, the NDIS, and other community supports. It is vital to recognise the critical role community-based and non-governmental supports play in addressing gaps unmet by formal care and support systems.

*“Our rare disease sector is providing the ILC approach in a whole of person, family-centred approach across the whole of life impacts of living with a rare disease.”*

*- RVA Partner*

People with rare disease-related disabilities face numerous challenges, including inadequate or inconsistent support systems, long waiting lists, limited service availability, and financial barriers. Families and carers frequently bear the burden of providing extensive support, which can lead to burnout and financial strain. During these times, rare disease groups/organisations and peer support groups play an essential role, offering navigation services, counselling support, resources, and referrals.

RVA Partners report that newly diagnosed people with rare diseases often self-refer or contact rare disease groups/organisations directly. A lack of awareness among health professionals about groups/organisations providing Information, Linkages, and Capacity (ILC)-style activities, or the absence of established referral pathways, often results in significant delays or the complete absence of support for some individuals.

A balance must be struck between centralisation and the risks of oversimplifying services within the Foundational Support framework, particularly for individuals with rare disease-related disabilities. RVA Partners emphasise the need for specialist navigation approaches within the rare disease sector due to the high levels of intersectionality and lifelong support required, particularly during milestones, transitions, acute medical issues, and chronic condition management.

### **Rare Voices Australia Stresses That Urgent Investment Is Required to Address Long Waitlists and Ensure Timely Access to Appropriate Services**

Information, advice, and capacity-building supports alone will be insufficient if the necessary services remain inaccessible. Specialised support is essential for people with rare disease-related disabilities, including people living in rural and remote areas, culturally and linguistically diverse (CALD) communities, and Aboriginal and Torres Strait Islander populations.

**The rare disease sector is deeply concerned about the survival of small peer-support organisations.** These groups are under immense pressure due to rising operational costs and declining income streams. This financial strain comes at a time when the demand for their services is increasing, driven by gaps in service delivery arising from the narrowing scope of NDIS supports and reductions in funding.

## **A Selection of Existing Programs, Initiatives and Resources Already Providing Foundational Supports**

Several organisations, including RVA, are already providing foundational supports for the rare disease community, including information, linkages, and capacity-building. RVA initiatives are currently funded through a range of time-limited government grants, while most organisations are reliant on donations to fund their work.

### **RARE Helpline**

The RARE Helpline was established in July 2023 as part of the Australian Government-funded initiative, [The Navigator Project](#). The RARE Helpline aims to provide timely access to information and answer key questions people living with a rare and complex disease and their families/carers often face. The RARE Helpline is staffed by RVA personnel, including those with qualifications/training in psychology, social work, and Mental Health First Aid.

### **RARE Portal**

RVA is leading the collaborative development of the [Rare Awareness Rare Education \(RARE\) Portal](#) which was launched in March 2023 and contains current, reliable, and straightforward information and resources for all rare disease stakeholders customised for the Australian context. Information includes resources for families and rare disease carers, including information about mental health services and resources available in Australia. The RARE Portal has been funded by the Australian Government until at least September 2025 and is a key deliverable of the Action Plan.

### **Rare Disease Awareness, Education, Support and Training (RArEST) Project**

The [RArEST Project](#) is an Australian Government-funded collaboration between RVA, the University of New South Wales, the University of Western Australia, and Macquarie University. The RArEST Project developed and delivered rare disease awareness resources, education, support, and training.

### **Rare Care Clinical Centre of Expertise for Rare and Undiagnosed Diseases (the Rare Care Centre)**

Located at Perth Children's Hospital, the [Rare Care Centre](#) was launched in 2022 to address the challenges faced by children and families living with rare and undiagnosed diseases. The Rare Care Centre operates within a carefully constructed Framework designed to deliver

comprehensive, equitable, sustainable, and scalable care to children and families living with rare and undiagnosed diseases in Western Australia.

*“Children and families living with rare and undiagnosed diseases have multidimensional and compounding needs that impact not only their physical and mental health, but every aspect of their lives, including education, finances, social activities and employment.”*

*– Rare Care Centre Year 2 Impact Report<sup>4</sup>*

### **Mito Foundation NDIS Navigation Service**

Mito Foundation launched the [NDIS Navigator Service \(NNS\)](#) in 2022 in response to a review of the experiences of people impacted by mitochondrial disease (mito) when accessing disability support. The NNS plays a crucial role in providing NDIS and disability-related information, educational resources, and personalised one-on-one guidance and coaching for members of the mito community. For people with mito associated disabilities who are unable to access the NDIS, the NNS also helps connect them with alternative supports and develops tailored action plans where possible.

*“Delays in accessing disability support can have a profound impact, particularly for individuals with complex or progressive conditions. For many people with mito, a prolonged diagnostic odyssey often mean[s] they are unable to provide the detailed evidence needed to access the NDIS, leaving them without support for long periods. In these cases, foundational supports during the interim period can play a crucial role in providing the necessary assistance and helping individuals manage the challenges they face.”*

*- Mito Foundation*

### **Neuromuscular WA System Navigation Service**

Neuromuscular WA developed the [System Navigation Service](#) in 2021 to address the key gaps in services and supports people living with neuromuscular conditions and their families experience. System navigation covers many systems, including the NDIS, Centrelink, advocacy, equipment, transport, education, housing and mental health – not only health and disability. The service encourages self-referrals and referrals from medical and allied health professionals.

## **Fragile X Association of Australia (FXAA) Helpline**

[FXAA](#) provides a Helpline, counselling services, webinars and peer support and connections to the Fragile X community. This work is funded through donations and in-kind support from the community. FXAA is a member of the Disability Representative Organisation (DRO) Consortium led by Down Syndrome Australia (DSA), representing people with intellectual disability and chromosomal variations.

## **Angelman Syndrome Association Australia (ASAA) First 100 Days Guidebook**

ASAA is an all-volunteer support and advocacy organisation for the estimated 500+ people living with Angelman syndrome and their families. In 2024, ASAA developed the [First 100 Days Guidebook](#) to provide system navigation guidance to families and carers of people diagnosed with Angelman syndrome. ASAA is also a member of the DSA-led DRO Consortium.

**There is currently no DRO for the estimated two million Australians living with rare disease-related disabilities.**

## **Recommendations**

1. RVA recommends funding a DRO for this cohort and will continue to apply for DRO grants to address this ongoing and significant gap.
2. All governments to collaborate with RVA as the national peak body for Australians living with a rare disease to conduct a comprehensive sector mapping of existing rare disease sector foundational supports and navigator services. This will identify opportunities to fund and support existing, operationally ready programs and organisations, and identify gaps that need to be addressed.
3. Recognise the unique needs of the rare disease disability sector and allocate funding for a DRO to represent the needs of the estimated two million Australians living with rare disease-related disabilities.
4. Develop nationally consistent guidelines to integrate Foundational Supports with mainstream health and community services, ensuring a seamless interface and reducing service fragmentation.
5. The Australian Government to fund the expansion of The Navigator Project to enable the RARE Helpline to provide disability-related system navigation services and foundational supports for the rare disease, including for people with a condition where there is no Australian support group; those without a diagnosis; and other priority populations.

## Health and Disability Interface

RVA remains deeply concerned about the persistent and arbitrary division between health and disability systems. This hinders care integration and creates confusion and delays in accessing necessary support resulting in significant negative outcomes for children and adults living with rare diseases.

Living with a rare disease brings unique difficulties, as neither the health nor the disability systems are adequately structured to address the compounded, multi-system needs of this population. High levels of unmet need and a widespread lack of expertise and knowledge about rare diseases result in fragmented and inconsistent services. RVA urges mainstream health systems to prioritise building capacity to provide integrated, seamless patient pathways and navigation support tailored to people with rare disease disabilities.

To address these challenges, it is critical to establish a strong, nationally consistent, and seamless interface between Foundational Supports, mainstream health, and community services.

### Recommendations

6. Develop Rare Disease Centres of Expertise to deliver integrated, evidence-based disability and health care pathways. Adapt and expand successful models of rare disease expertise, such as the Rare Care Centre, to other states and territories.
7. Create Disability Liaison Officer or navigator roles within hospital and health services to support people with disabilities and chronic health conditions to access integrated care pathways, as well as foundational supports such as peer networks.
8. Design patient pathways and support systems that are flexible and responsive to the episodic, fluctuating, or progressive nature of rare diseases.
9. Fund education and awareness campaigns to increase health professionals' understanding of rare diseases and available referral pathways to foundational supports and specialised services.

## Sustaining the Rare Disease Sector

As noted, RVA Partners have highlighted the significant challenges faced by organisations. The rare disease sector struggles with critical workforce and financial challenges due to current funding models, jeopardising the sustainability of peer support services that are foundational to disability advocacy and capacity-building. Peer support groups, which are lifelines for many individuals with rare diseases, are often underfunded, leading to an over-reliance on volunteers.

*“We’ve been providing foundational supports for years now, since governments vacated the space when the NDIS was implemented. We do so for free, as volunteers, without any support.” - RVA Partner*

*“Our peer support NFP workforce is exhausted, with a 17% increase in SCHADS Award and skyrocketing costs in electricity and rent. Many organisations are operating in deficit, with over 50% of NFPs losing money annually and more than 10% shrinking or folding.” - RVA Partner*

*“We can’t meet the demand we have now. As our volunteer workforce is depleted, the carer will be forced to absorb the impacts of this shrinking sector.” - RVA Partner*

Sustainability in service delivery, including IT, cyber security, and infrastructure upkeep, is also a major concern across the rare disease disability community. Many organisations also face systemic barriers in accessing government grants, such as the ILC program, which often favour larger entities, generalist services, or more common disabilities.

*“We are a small organisation trying to do what’s necessary, but we don’t quite fit into the ILC. In a cost-of-living crisis, fundraising is drying up and the charitable funding is unsustainable.” - RVA Partner*

*“Our lived experience may not fit neatly into governance standards, and this presents barriers to inclusion and consideration in grant applications.”*

*- Family/Carer of a person living with rare disease disabilities*

Government grants frequently require high levels of representation of people with disabilities on boards, which can exclude rare disease groups/organisations, especially those serving communities with severe intellectual or communication disabilities.

RVA Partners emphasised that programs and funding should target smaller groups/organisations that deliver tailored services for rare diseases. Additionally, the short two-to-three-year grant timelines make it difficult to measure impact in the rare disease space.

The sector urgently requires a large, trained, and qualified workforce, including peer support workers, navigators, social workers, and allied health professionals. However, the disability sector is facing high rates of staff burnout and struggles to retain skilled workers, which significantly impacts the quality of care and support. These workforce challenges are further exacerbated in regional, rural, and remote areas, as well as among underserved cohorts, such as Aboriginal and Torres Strait Islander, CALD and LGBTIQ+ communities.

## Recommendations

10. Develop a Digital Support Fund for consumer-led NFP organisations to maintain their digital presence and ensure resources are accessible in a variety of formats, such as easy-read, audio, and translated materials.
11. Develop a Foundational Supports Workforce Strategy that prioritises urgent and sufficient investment into foundational workforces to improve retention and meet the increasing demand for services.
12. Engage with the rare disease sector to identify the specific services, skill sets, and knowledge navigators require to assist individuals with rare disease-related disabilities in accessing mainstream, foundational, and NDIS supports.
13. Collaborate with RVA to co-design and develop training programs and resources that build workforce capability to deliver foundational supports for people with rare disease-related disabilities.
14. Provide targeted funding and capacity-building initiatives for small, community-based peer-support groups/organisations to ensure their sustainability amidst rising operational costs and growing demand.
15. Develop funding models with longer grant cycles to ensure stability and enable strategic, long-term planning for foundational supports, including navigation services, peer support, and resource development. [OBJ]

## Inclusion, Equity and Accessibility

RVA strongly advocates for Foundational Supports that are inclusive, equitable, accessible, place-based, and culturally sensitive. Accessible and inclusive information is essential to address the needs of all disability experiences, intersectional identities, and geographic locations. This includes providing resources in easy-read, audio, and screen-reader-friendly formats, rather than relying solely on digital options like websites and QR codes.

Foundational Supports also need to address the significant barriers that exist for individuals with communication or behavioural disabilities and those with fluctuating, episodic, or invisible disabilities.

RVA Partners identified the need for equitable supports across different age cohorts and for people over the age of 65. For example, local government services may exist, but they are often age-related for specific cohorts meaning someone with the physical limitations of an older person cannot access community transport or other services.

*“We are always having to prove our disability. What will be the evidence needed to access Foundational Supports?” - Person with rare disease-related disabilities*

*“We saw what happened with COVID-19 information. Culturally appropriate content, delivered by trusted people in First Nations and CALD communities, is critical when it relates to government services.” - RVA Partner*

Telehealth and Telehelp are transformative tools for improving accessibility to disability-related foundational supports, especially in rural and remote areas. However, RVA Partners shared that smaller groups/organisations often lack the necessary telecommunications and technology infrastructure to adequately engage their communities. This includes IT support, accessible websites, easy-read documents, and funding to keep resources current. RVA Partners reiterated the importance of sustaining initiatives like the RARE Helpline and the RARE Portal, which are trusted, evidence-based Australian resources providing reliable information.

RVA Partners also noted the under-representation of CALD and Aboriginal and Torres Strait Islander people in their membership, citing limited funding and opportunities for engagement to reach these harder-to-access populations.

## Recommendations

16. Design Foundational Supports that meet the intersectional needs of people with disability and are delivered in a person-centred, place-based and culturally sensitive approach, while building capacity in the local community.
17. Make Foundational Supports universally available to all individuals with disabilities residing in Australia, regardless of their visa status.
18. Provide targeted funding for small groups/organisations to enhance their digital and technological capabilities, including accessible websites, telehealth services, cyber security and resource maintenance.
19. Allocate funding to engage and support underrepresented populations, including CALD and Aboriginal and Torres Strait Islander communities, ensuring equitable access to Foundational Supports.

## Advocacy and Capacity Building

RVA supports building capacity and fostering self-advocacy among individuals living with rare disease-related disabilities. However, RVA recognises that not everyone will have the ability or interest to engage in self-advocacy.

Advocacy plays a vital role in empowering individuals and their families, but many lack the skills or capacity to effectively advocate for themselves or their loved ones. This is particularly true for those with degenerative rare conditions, cognitive decline, or complex health needs that require ongoing navigation support rather than a progression toward self-advocacy. Therefore, access to advocacy and navigation supports should not be restricted by arbitrary limitations, such as time caps or rigid transition timelines.

*“What if you can't self-advocate or find services? People with degenerative rare conditions may have cognitive decline and increased navigational supports as opposed to moving toward self-advocacy.” - Person living with rare disease-related disabilities*

RVA underscores the importance of peer support networks, which reduce isolation and help individuals take control of their lives. Peer networks provide a space where individuals can ask questions and find solutions and build their self-advocacy skills.

RVA Partners stressed the need for flexibility in the transition from navigator-supported services to self-advocacy, as timelines for this transition should not be rigid.

*"We can't rush people into self-navigation when there are too many external factors— housing instability, health literacy, or financial constraints—that impede their progress." - RVA Partner*

*"Foundational Supports need to meet people where they are and adapt to their changing needs." - RVA Partner*

The complexity of accessing disability supports, particularly for people with rare diseases, remains a significant concern. Carers often lack the time or ability to complete this research, leaving many unsupported.

*"The system is so complex that many people can't navigate it without extensive research skills". - RVA Partner*

Carers in the rare disease community may be caring for multiple family members or have a rare disease themselves. Many do not know who to contact, let alone how to advocate across health and disability services.

*"People are burning up all of their informal supports. They just keep doing the best they can because they don't know where to turn or there just isn't someone to give them the guidance they need." - RVA Partner* Family support networks are equally critical, as families often act as the primary advocates for individuals with rare disease-related disabilities. Evidence-based programs that support families can enhance their capacity to navigate the complex systems of health, disability, and community services. However, access to such resources is hindered by long waitlists and funding challenges, particularly for programs like Carer Gateway.

*"Since the NDIS was introduced, many community programs that allowed families to share everyday life experiences have evaporated. We now see one-on-one therapy sessions that don't translate into real-world applications." - RVA Partner*

We acknowledge that capacity-building supports should empower both individuals and their families, helping them navigate these complexities more effectively. But this cannot be time limited or capped.

*"Peer support is a critical component of the disability landscape, and without it, we are left to navigate complex systems alone." - Family of a person living with rare disease-related disabilities*

## Recommendations

20. Remove time restrictions and caps on advocacy and navigation supports. Instead, provide ongoing functional supports tailored to a person's disability that are reflective of their changing needs.
21. Incorporate principles that allow individuals and families to progress toward self-advocacy at their own pace considering external factors such as financial constraints, housing instability, and health literacy.
22. Develop user-friendly, integrated pathways for disability support, ensuring that carers and families can access clear guidance without requiring extensive research or expertise.

## Conclusion

Foundational Supports present a vital opportunity to bridge the gaps in Australia's fragmented disability support ecosystem, particularly for the rare disease disability community. By adopting inclusive, culturally sensitive, and flexible approaches, Foundational Supports can empower individuals and families, address unmet need, and reduce the inequities exacerbated by systemic barriers and funding constraints.

RVA strongly urges the government to take a collaborative, evidence-based approach to the design and implementation of Foundational Supports. Leveraging the principles outlined in the Action Plan—**person-centred, equitable, and sustainable**—will ensure these supports effectively complement existing systems and empower Australians living with rare diseases and rare disease-related disabilities to lead fulfilling lives.

We look forward to continued engagement with the DSS and all levels of government to co-design solutions that address the unique needs of the rare disease community and sector.

### Contact:

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RARE Helpline – 0499 549 629; operates Monday to Friday 9:00 AM to 5:00 PM (AEST)

## Appendix 1

### Disability and the National Strategic Action Plan for Rare Diseases

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.

## Appendix 2

### Recommendations - The McKell Institute, Disability & Rare Disease Report

The following are the seven recommendations from The McKell Institute report, Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases

**RECOMMENDATION 1:** Australia develops, endorses and implements a Rare Disease Strategy.

**RECOMMENDATION 2:** Australia establish a model of rare disease centres of excellence to address knowledge gaps and ensure all Australians with a rare disease have access to the best evidence-based care.

**RECOMMENDATION 3:** Australia introduce personal care plans to cover an individual's health, education and disability care needs. These overarching integrated care plans would allocate responsibility for the delivery of services to specific levels of government.

**RECOMMENDATION 4:** The Government centralise existing information on rare disease with a searchable data base of information on rare diseases which health and disability professionals, patients and families, can access and inform.

**RECOMMENDATION 5:** Introduce mandatory training of relevant health and disability care professionals on the nature of rare diseases, effective management strategies, how to locate information and referral pathways to support and advocacy groups.

**RECOMMENDATION 6:** Urgent review of delays in access to equipment to ensure that NDIS participants receive approved equipment in a timely manner.

**RECOMMENDATION 7:** NDIA to incorporate a 'fast tracking review' category for people with rare diseases who have been identified as having permanent and significant disability. This would allow quicker access to additional supports when required through consultation with clinicians

## 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 December 2024]
2. Jackson, A. The McKell Institute. *Disability and Rare Disease: Toward person-centred care for Australians with Rare Disease*. Oct 2019. 33 p. Available from: <https://mckellinstitute.org.au/research/reports/disability-rare-disease/> [Accessed December 2024]
3. Commonwealth of Australia, Department of the Prime Minister and Cabinet. *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*. Oct 2023. Available from: <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis> [Accessed December 2024]
4. Government of Western Australia, Child and Adolescent Health Service. *Rare Care Centre Year 2 Impact Report*. Feb 2024. Available from: <https://pch.health.wa.gov.au/Our-services/Rare-Care-Centre> [Accessed December 2024]