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Review of Australia's Disability Strategy

September 2024

What is MS?

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

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Review of Australia's Disability Strategy

MS Australia welcomes the opportunity to contribute to the review of the Australian Disability Strategy (ADS) and provide insights from the perspective of people living with MS. MS Australia welcomes the review of the ADS and the Government's commitment to ensuring that the Strategy is working effectively and meeting the needs of people with disability.

In completing this submission MS Australia has drawn on the experiences of our [Lived Experience Expert Panel](#), a panel of people living with MS who provide MS Australia with expert advice to inform our advocacy work. Their feedback reflects the lived experience of people living with MS and interacting with the ADS.

MS Australia Recommendations

- Implementing the five draft recommendations set out in the *ADS Review Discussion Paper* including clear deadlines for implementation, mechanisms to ensure accountability and consultation with the disability community.
- Improving the Outcome Areas of Australia's Disability Strategy through clear and more specific goals and align with global standards such as the United Nations Convention on the Rights of Persons with Disabilities.
- Enhancing the proposed policy priorities for future work by integrating them into action plans that are regularly reviewed and updated and supporting pilot projects and innovative approaches.
- Expanding the scope of the Outcome Area: Economic and financial security to address employment barriers within the workplace including support to maintain employment; access to education, training, career progression and capacity building; and addressing workplace discrimination.
- Improving the involvement of people with disability in the ADS through:
 - ❖ Genuine and meaningful co-design processes
 - ❖ Accessible engagement processes including appropriate timeframes, materials in multiple formats and accessible venues and platforms
 - ❖ Establishing ongoing committees/working groups of people with disability to advise on the ADS implementation including diverse membership, compensation and empowering members to provide honest and direct feedback
 - ❖ Capacity building for the disability sector to improve leadership and advocacy
 - ❖ Regular feedback mechanisms and updates for the disability community including subject-specific lived experience panels, surveys, and public consultations

Implementation of Australia's Disability Strategy

While the ADS has laid important groundwork for improving the lives of people with disability, including those with MS, its implementation has not been without challenges. MS Australia believes more could be done to improve the current implementation including government coordination, reporting and communications.

MS Australia welcomes the draft findings and recommendations set out in the *ADS Review*

Discussion Paper, in particular:

- **Draft Finding 1 - government coordination:** There is currently a lack of consistent and coordinated approaches across different levels of government which has led to significant disparities in service delivery and accessibility. People with MS often face barriers in accessing the support they need due to these inconsistencies.
- **Draft Finding 2 – targeted action plans:** the introduction of new Targeted Action Plans (TAPs) ensures a stronger focus on areas of importance for people with disability. Further consultation with the disability community should be undertaken to determine what topics should be included.
- **Draft Finding 3: - accessible information:** Currently, the strategy does not adequately address the need for accessible information that meets the needs of people with disability. For example, many people living with MS experience fatigue and vision issues and would benefit from information being available in video or audio format. Further consultation should be done with the disability community to determine the accessible information gaps. This work should be led by standards and procedures already in place including the [Web Content Accessibility Guidelines](#) (WCAG) developed by the World Wide Web Consortium (W3C).
- **Draft Finding 4 – reporting:** Data collection and reporting under the ADS can be significantly enhanced by taking into consideration the intersectional experiences of people with disability including understanding how factors such as gender, age, socio-economic and cultural background can impact the lived experience of disability.
- **Draft Finding 5 – engaging with people with disability.** Engaging with people with disability should be the cornerstone of implementing the ADS. See the section below for further detail.

These recommendations could be further improved with clear deadlines for implementation and mechanisms to ensure accountability. Without these, there is a risk that important actions will be delayed or overlooked.

MS Australia recommends implementing the five draft recommendations set out in the *ADS Review Discussion Paper* including clear deadlines for implementation, mechanisms to ensure accountability and consultation with the disability community.

Outcome Areas and Policy Priorities

The outcome areas of the ADS are crucial to its overall success. MS Australia recommends they can be further improved through:

- Making the goals under each area clearer and more specific, particularly in how they will address the diverse needs of people with disabilities.
- Aligning the outcome areas with global standards such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This alignment will help ensure that Australia is meeting its international obligations, and that the strategy is informed by best practices from around the world.

MS Australia supports the proposed policy priorities for future work as set out in the *ADS Review Discussion Paper*. MS Australia recommends the priority areas can be further enhanced by:

- Integrating future priorities into targeted action plans that are regularly reviewed and updated.
- Supporting pilot projects and innovative approaches to address emerging challenges in the disability sector.
- Expanding the scope of the *Outcome Area: Economic and financial security* to include more

support for people with disability once they are employed. Many of the employment barriers for people with disability are within the workplace and include support to maintain employment; access to education, training, career progression and capacity building; and addressing workplace discrimination.

Involvement of People with Disability in the ADS

The involvement of people with disability in the implementation of the ADS is critical to its success. However, the current strategy does not go far enough in ensuring meaningful engagement from those with lived experience. Co-design should be a fundamental principle in the development and execution of all disability-related policies and programs. Future implementation, including the draft recommendations and proposed policy priorities, should be done with extensive consultation and co-design with the disability community.

The recommendations outlined below are based on the experiences of people living with MS engaging with the government on disability policy and programs during the last few years of extensive reform. To date, engagement processes have been limited, difficult to access and provide limited information with short time frames. People must be given the information and time they need to adequately respond to consultation. All engagement processes, including meetings and documents, must be fully accessible to people with disabilities. This includes providing materials in multiple formats and ensuring that all venues and online platforms used for consultations are accessible. Additionally, genuine co-design processes should engage with people with disability in a way that is meaningful and impactful and should not appear rushed or tokenistic.

The government should establish ongoing committees/working groups to advise on the ADS implementation and incorporate a diverse range of people with disability. People should be compensated for their time and empowered to provide feedback that is honest and direct. The focus of membership should not always be on those at the senior executive level in disability organisations but on disability advocates who can genuinely speak to the lived experience of disability. There should also be a diverse range of voices that cover a broad range of disability experiences. This should be further supported by capacity building within the disability sector, including providing training and resources to support people with disabilities in leadership and advocacy roles.

Any committees/working groups should be further supported by regular feedback mechanism and updates for the disability community including subject specific lived experience panels, surveys, and public consultations (both in-person and online).

MS Australia **recommends** improving the involvement of people with disability in the ADS through:

- Genuine and meaningful co-design processes
- Accessible engagement process including appropriate timeframes, materials in multiple formats and accessible venues and platforms
- Establishing ongoing committees/working groups of people with disability to advise on the ADS implementation including diverse membership, compensation and empowering members to provide honest and direct feedback
- Capacity building for the disability sector to improve leadership and advocacy
- Regular feedback mechanism and updates for the disability community including subject specific lived experience panels, surveys, and public consultations.

MS Australia is committed to supporting the development and implementation of a robust and inclusive ADS. By addressing the unique challenges faced by people with MS and other disabilities, we can work towards a society that is truly inclusive and supportive of all Australians. We look forward to continued engagement with the Department of Social Services and other stakeholders to ensure that the ADS delivers meaningful outcomes for our community.



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