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# Disability Royal Commission Government Response

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# SUBMISSION



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# Disability Royal Commission Government Response

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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.

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.

# Disability Royal Commission Government Response

MS Australia welcomes the opportunity to provide feedback on the Australian Government's response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission). MS Australia welcomes the final report from the Disability Royal Commission and the recommendations which seek to ensure a more inclusive and just society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

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 and responses of people living with MS to the recommendations of the Disability Royal Commission.

## Recommendations of the Disability Royal Commission

MS Australia welcomes the 222 recommendations of the Disability Royal Commission and believes these recommendations will significantly improve the lives of Australians living with disability. Outlined below are the recommendations that have the most importance for people living with MS and any recommendations that raise concerns.

### *Volume 4: Realising the human rights of people with disability*

MS Australia supports the recommendations under Volume 4 relating to recognising the human rights of people with disability. These major reforms will have a significant impact on the daily lives of people living with disability. This includes:

- **Recommendation 4.1 Establish a Disability Rights Act** – MS Australia and our LEEP members are strongly supportive of the establishment of a Disability Rights Act and believe this recommendation is the foundation of all the work of the Disability Royal Commission and leads the way for implementing the other recommendations. This new Act should guide the development of policy, legislation and programs relating to people with disability. It should also ensure that governments, business/employers and the general community respect and protect the rights of people with disability.
- **Recommendation 4.2 Objects of the Disability Rights Act** – It is essential that the Objects of the Act are clearly set out in the intentions of the Act and provide a legislative link to the Convention on the Rights of Persons with Disabilities (CRPD).
- **Recommendation 4.3 Principles in the Disability Rights Act** – The guiding principles should encourage and support governments, businesses/employers, schools and the broader community to follow their obligations under the Act.
- **Recommendation 4.4 Future review of the Disability Rights Act** – A 5 yearly review of the Act is essential to ensure that the Act is fit for purpose and achieving the purposes outlined by the Disability Royal Commission. This review should include extensive consultation with people with disability.
- **Recommendation 4.9 The right to equitable access to health services** – Many people with disability regularly interact with health services and face a range of challenges including navigating the complex health system, access to transport and support during appointments and assistance with the organisational and emotional burden of appointments, tests and treatments. This is especially important for people living with MS who often experience fatigue, brain fog and memory issues. It is critical that people with disability are empowered to make informed decisions about their health care and have access to accessible information and support.
- **Recommendation 4.11 Consultation with people with disability** – For too long changes have been made in the disability sector without considering the lived experience of disability. People with disability have had enough. To quote a LEEP member: 'As a person living with a disability and complex health issues – I hate anything that is decided for me without me.' It is critical that the policies, programs and strategies developed to support people with disability are informed by lived experience and by the needs of people with disability, rather than purely based on bureaucratic assumptions or academic observations or datasets. Consultation helps to ensure that outcomes are not only relevant but are helpful to people with disability, which on an individual scale benefits the person and on a national

scale ensures that funding is allocated to the places and programs where it is most needed and most effective.

Consultation with young people living with disability is of particular importance because those people will engage with and enrich society as their life experience develops. They bring unique and diverse perspectives to discussions and will further contribute to the work of the Act and the National Disability Commission. Their inclusion will benefit not only others living with disability but society more broadly.

- **Recommendation 4.14 The duty to provide accessible information** – Many of our LEEP members are educated, health-informed people who still struggle to access and understand government information. We recognise there has been an increase in accessible information, however, there is still a large gap in this area. For example, the Final Report of the NDIS Review was not published in a format that could be read on screen readers used by blind people. Accessible information is crucial to support people with disability to take control of their lives.
- **Recommendation 4.21 Strengthening awareness and understanding of disability rights** – The Act should also provide the National Disability Commission with the statutory function to inform people with disability of their rights. Many people with disability are unaware of their rights and as a result continue to suffer unlawful discrimination. Strengthening awareness and understanding of disability rights should include robust educational and training programs co-designed and co-delivered by people with disability. These have the potential to change entrenched norms and increase drivers for inclusivity.

MS Australia believes that an essential part of improving understanding of neurological conditions and disabilities is the establishment of a NDIA Neurological Advisory Group. The advisory group would seek to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA. The establishment of an advisory group will contribute to ensuring the people living with these conditions gets access to the NDIS supports and services they need at the right time in their disease journey. It will also reduce complaints, improve outcomes measures and ensure this population is treated equitably when accessing the NDIS.

- **Recommendation 4.23 Strengthening the Disability Discrimination Act** – Strengthening the Disability Discrimination Act is an important accompaniment to the new Disability Rights Act. In particular, placing the burden of proof on the alleged discriminator, rather than asking people with disability to constantly prove they are being discriminated against.
- **Recommendation 4.25 Adjustments** – The removal of 'reasonable' from 'reasonable adjustments' is an important and welcome change. The notion of 'reasonable adjustments' makes it difficult for people with disability to ask for help in contexts like a workplace, as it puts the focus on whether they are creating a burden versus what is needed for a person to thrive.
- **Recommendation 4.27 Positive duty to eliminate disability discrimination** – The introduction of a positive duty to eliminate disability discrimination is very welcome and will ensure that the burden for reducing discrimination is not always place on people with disability.

#### *Volume 5: Governing for inclusion.*

MS Australia supports the recommendations under Volume 5 relating to governing for inclusion, including:

- **Recommendation 5.1 Development of a National Disability Agreement** – The Agreement should focus on reducing the current divide in experience for people with disability across Australia's state and territories. It should set out the roles and responsibilities of each state and territory but also ensure more standardisation across the country and a unified experience for people with disability.
- **Recommendation 5.3 Review and update of disability strategies and plans** – Ensuring that all state and territory strategies and plans align with the recommendations of the Disability Royal Commission will ensure that wherever a person with disability is living in Australia they are heard, respected and can live free from discrimination, neglect and abuse.
- **Recommendation 5.5 Establishment of a National Disability Commission:** MS Australia and our LEEP members see the establishment of a National Disability Commission as a very important recommendation and an avenue to bringing lived experience to disability governance. Monitoring and oversight by a Commission with diverse lived disability

experience is critical to delivering on their specific remit to promote best practice and innovative approaches to improve outcomes. It will also ensure greater input from the people who are affected the most. People with disability will feel that their lived experience and voice is valued, rather than the current situation where people with disability are often told what is best for them from people with no lived experience.

- **Recommendation 5.6 New governance arrangements for disability:** This is an important recommendation to ensure that Australian Government oversight is led by a Minister and Department with a strong focus on disability inclusion and equity.

### *Volume 6: Enabling autonomy and access*

MS Australia supports the recommendations under Volume 6 relating to enabling autonomy and access, including:

- **Recommendation 6.1 A national plan to promote accessible information and communications** – Accessible information and communications should also be location specific, especially for people living in regional, rural and remote areas where access to information and supports can be very limited.
- **Recommendation 6.19 Data collection on support and representation arrangements** – MS Australia supports improved disability data collection and reporting; however, we have some concerns regarding the collection and management of such important and sensitive data. In the current environment of heightened cybersecurity threats, it is extremely important that the data of vulnerable members of our society is heavily protected by the agencies collecting and storing it. When data must be retained a risk analysis and security strategy (including the selection and implementation of an appropriate cybersecurity framework) should be developed prior to that collection commencing. In the event of a data breach, immediate reporting to the appropriate regulatory agency (e.g. the OAIC) and disclosure to the affected people is also critically important so that steps can be taken to protect against identity theft, minimise further disclosure of private data, and/or prevent the compromise of that person's other accounts.
- **Recommendation 6.21 Additional funding for advocacy programs** - For people with disability, it can be overwhelming trying to navigate the bureaucracy surrounding disability services and advocacy provides crucial supports to help people access services, fight discrimination and advocate for improvements. Currently many disability advocacy organisations are at capacity with long waitlists.
- **Recommendation 6.25 Expand the scope of health workforce capability development to include all forms of cognitive disability at all stages of education and training** - People living with MS are frustrated by the current the lack of understanding by health professionals of disability, including MS, and how best to support people with disability. They often have to educate people on their disability, and this can be especially difficult for people with MS experiencing cognitive issues, speech difficulties, fatigue and memory loss.
- **Recommendation 6.32 Increase capacity to provide supports and adaptations through improved guidance, funding and accessible information** - Providing a list of frequently needed adaptations and supports would be very useful for people newly diagnosed with MS and those suffering from a relapse or change in symptoms. Many people living with MS relies on their GP or specialist to provide this advice, however, many health professionals are currently unable to do so and there is a large knowledge gap.

### *Volume 7: Inclusive education, employment and housing*

MS Australia supports the recommendations under Volume 7 relating to employment, including:

- **Recommendation 7.5 Careers guidance and transition support services** – Providing education and training opportunities to young people with disability underpins the way that person is able to access society, lead an engaging life, and potentially access employment (depending on their circumstances).
- **Recommendation 7.9 Data, evidence and building best practice** - Improved data and evidence will ensure that changes made in the disability sector are resulting in improvements and can be regularly reviewed. As outlined above under Recommendation 6.19, any data collection must include a risk analysis and security strategy and have clear plans for what to do in the case of a data breach.

- **Recommendation 7.16 Priorities for inclusion in the new Disability Employment Services model** - Engagement with employment provides many benefits across financial growth, social engagement, skills development, and a sense of achievement. Making work arrangements accessible to people for less than eight hours a week opens up these benefits to a significant group of people living with disability who would have previously been excluded, and also provides new options to businesses looking for employees. This should be further supported through expanded resources and education for businesses to ensure they can best support a person with disability to flourish as an employee and to also benefit the business' operations.
- **7.18 Employment targets** – MS Australia welcomes the introduction of targets for disability employment in the public sector. However, this should be accompanied by clear guidance on what meets the criteria for disability employment to avoid employers counting people with minor adjustments. For example, MS Australia has been made aware of a local council measuring employees wearing eyeglasses as people with disability.
- **Recommendation 7.21 Introduce consistent adjustment principles and adjustment passports** - People living with MS currently struggle to maintain employment due to employers not being prepared to make reasonable adjustments and provide a flexible workplace. The introduction of clear adjustment policies and adjustment passport will ensure that people with disability can continue in employment and make use of their skills and knowledge. These policies should be used beyond the public sector to support people working in other sectors.
- **Recommendation 7.24 Convene a Disability Employment Rights Council** - Providing consistent guidelines, practices and support mechanisms ensures that the experience for a person with disability engaging in the workforce is fair and equitable no matter their location, background or requirements.
- **Recommendation 7.27 Enable a Fair Work Ombudsman referral mechanism** - Many people living with MS chose not to disclose their diagnosis to their employers for fear it will open them to discrimination and be a career limiting disclosure. Enabling a referral mechanism to the Fair Work Ombudsman would provide an independent authority that people with disability can take their workplace concerns to. This will ensure more people feel comfortable disclosing a disability and being free from workplace discrimination.

Further comment on Inclusive Education and Inclusive Employment is below:

### *Independent Support Coordination*

#### **Recommendation 10.2 Independent support coordination**

MS Australia supports the overarching goal of this recommendation to safeguard the interests of NDIS participants. However, we advocate for a nuanced approach that considers the unique needs of specific disabilities, including MS. We believe such an approach aligns with the spirit of the NDIS, ensuring that all participants receive the most appropriate, effective, and empathetic support.

MS Australia's state and territory member organisations are registered NDIS providers that provide a unique array of integrated services tailored for individuals living with MS and other neurological conditions. This includes expert support coordination alongside specialised services like allied health, employment support, and accommodation.

The cohesiveness of these services, driven by deep understanding and expertise in MS, significantly enhances accessibility and effectiveness. Many people living with MS receive both support coordination and other NDIS services from these providers. The complex nature of MS necessitates a nuanced approach in support coordination, where an understanding of specific challenges such as brain fog, fatigue, and memory issues is crucial. Our member organisation's focused expertise ensures that participants receive support that is not only comprehensive but also empathetic to their unique needs. These services are especially important for people who have no carer or informal support network.

MS Australia proposes a framework that maintains the integrity of support coordination while allowing for specialised service delivery. This could include rigorous internal checks, transparent reporting mechanisms, and regular independent audits to ensure no conflict of interest. Further to this, the appropriate separation between support coordinator and provider can be demonstrated by actual data that confirms the support coordinator not preferencing itself as the provider of other supports/services.

## *National Worker Registration*

### **Recommendation 10.8 A national disability support worker registration scheme**

MS Australia strongly supports the introduction of a national disability support worker registration scheme including a code of conduct, minimum standards, worker screening and professional development. This aligns with MS Australia's recommendation to the NDIS review to professionalise the disability workforce. Currently, the disability workforce is made up overwhelmingly of part-time, untrained and low paid support workers. There are high rates of turnover and casualisation across the sector. Professionalising the disability workforce makes it an attractive career prospect and would ensure that people with disability are provided care and services by trained, motivated and experienced professionals.

## *Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT)*

**Recommendation 11.6 Enshrining key provisions of OPCAT in legislation** – MS Australia strongly supports this recommendation and believe there should be a clear and achievable timeline for the full implementation of OPCAT.

## *Diverse Needs Groups*

MS welcomes recommendations that recognise the unique challenges faced by First Nations, culturally and linguistically diverse and LGBTIQ+ people with disability. Improved data collection, cultural safety, safeguarding and culturally appropriate services and assessments will improve outcomes for these groups and ensure they have access to services and supports specific to their needs. The Taskforce should be consulting with the relevant peak bodies and consumer groups to ensure that the lived experience of these groups is considered in the implementation of recommendations.

## **Reducing and ending segregation**

MS Australia strong supports the focus of the Disability Royal Commission on reducing and ending segregation for people with disability.

## *Inclusive Education*

Participation in the school community - adjustments and support for schooling – the inclusion of people (students) with disability in the school environment cannot be undervalued and for some time has left many students missing out on important schooling events and learning opportunities. Given the many varied circumstances in which a disability is present, the inclusion of all students should be paramount and with the right education, training and resources/technology, can be achieved. An Australia wide approach to adjustments in learning and exams should be implemented.

The implementation of inclusive education should not remove the option for people with disability to access disability specific education options if they choose. For example, some students may wish to have a combination of both specialised, disability focused subjects and mainstream subjects. People with disability should be allowed to learn in the environment that best suits their needs and allows them to develop the skills they need for further education, employment, independent living and engagement in their community.

## *Inclusive Employment*

People with MS can contribute a range of skills, talents and qualifications to the workplace. Employing people with disability can bring diverse and unique perspectives and skills to the workplace including creativity, problem solving, persistence and resilience. People with disability generally take fewer days off work, stay in jobs longer, build strong connections with customers/clients and boost staff morale<sup>1</sup>. Achieving inclusive employment will require education and training to ensure employers understand that people with disability can continue to be valued employees, who contribute significantly to the workplace. A trained advocate within a workplace or HR department could assist with the business becoming a disability friendly workplace.

The Final Report recommends the introduction of a scheme to ensure that employees with disability are paid at least half the minimum wage (recommendation 7.31). MS Australia believes that people with disability should receive the full amount of the minimum wage. We cannot have inclusive employment in Australia if people with disability are receiving half the wages of their non-

disabled colleagues.

Many people with disability are employed through supported employment, often operated and funded by not-for-profit organisations (known as Australian Disability Enterprises (ADEs)). These ADEs can provide workers with skills, a strong work ethic, sense of purpose and improve their wellbeing and engagement in the community. It can also be a 'stepping stone' to a traineeship, apprenticeship or employment in the private or public sector. The government needs to ensure these positions are adequately funded so that people with disability can receive full wages and that additional costs are not borne by not-for-profit organisations.

## What's Missing

### *Aged-related discrimination*

There are 1.9 million Australians aged 65 years and over who live with disability. This means 50% of people aged 65 and over have disability and this represents almost half (44.5%) of all Australians with disability<sup>23</sup>. Older Australians with disability face both aged related and disability discrimination, which significantly impacts on their ability to access services and be active members of their community. Given the strong attention to disability discrimination in the Final Report, it is concerning that there is no reference to aged related discrimination. This should be considered in all recommendations relating to removing discrimination for people with disability.

Currently, many people over the age of 65 cannot access the NDIS and there is a significant disparity between supports available in the NDIS and aged care systems. The NDIS Review recently recommended that people over 65 have access to both the NDIS and aged care and receive the relevant supports for either or both systems. In order to remove discrimination for older people with disability, it is crucial this recommendation is given support by the Disability Royal Commission Taskforce.

### *Employment supports*

The majority of the recommendations in the Final Report relating to employment supports have a focus on people entering the workforce. There should be a clear strategy for assigning those already in employment to continue working and to educate and support their employers to make that possible.

There are also a range of recommendations relating to improving the workplace for people working in the public sector. However, many people with disability work in the private sector where their skills set can provide extensive value to private business. Employers in the private sector need to be better supported to engage in this process and improve employment outcomes for their employees.

## Implementing Recommendations

MS Australia recognises there are 222 recommendations in the Final Report of the Disability Royal Commission and it will take many years to fully implement them all. We believe the first focus of the taskforce should be establishing mechanisms for including people with disability, incorporating:

- The appointment of staff with lived experience into key roles
- A mechanism for consulting with the disability community including the establishment of a lived experience panel/working group
- Implementing co-design processes
- Educating all staff working on these reforms on disability and how to incorporate lived experience.

Following this, the implementation of the legislative and governance recommendations that underpin all recommendations are crucial, including:

- Establishing a Disability Rights Act
- Establishing a National Disability Commission

- Developing a National Disability Agreement
- Appointing a Minister for Disability Inclusion
- Establishing a Department of Disability Equality and Inclusion

The next stage of work should focus on the reform, expansion and improvement of the disability workforce including:

- Establishing a national disability support worker registration scheme including code of conduct, minimum standards, screening checks and professional development
- Varying the Social, Community, Home Care and Disability Services Industry Award in accordance with the Fair Work Act

The Taskforce should also focus on ensuring that any recommendations are implemented in line with reforms already across the disability, aged care and health sectors and other inquiries including:

- [Final Report of the NDIS Review](#)
- [Joint Standing Committee on the National Disability Insurance Scheme](#)
- [National Housing and Homelessness Plan](#)
- Establishment of a [Disability Employment Centre of Excellence](#)
- Establishment of a [new Aged Care Act](#)
- Establishment of a [new specialist Disability Employment Services model](#)
- The Senate Standing Committees on Community Affairs [inquiry into the extent and nature of poverty in Australia](#)
- Standing Committee on Social Policy and Legal Affairs [Inquiry into the recognition of unpaid carers](#)
- [Select Committee on Cost of Living](#)

## References

- <sup>1</sup> Department of Social Services (2022). *Benefits of employing people with disability*. Retrieved from: <https://www.jobaccess.gov.au/employers/benefits-employing-people-with-disability#:~:text=Once%20in%20the%20right%20job,image%20in%20the%20general%20community>
- <sup>2</sup> Australian Bureau of Statistics. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. ABS. Retrieved from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
- <sup>3</sup> Australian Institute of Health and Welfare (2022) *People with disability in Australia 2022*, catalogue number DIS 72, AIHW, Australian Government.

