

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Department of Social Services consultation on the National Disability Advocacy Framework (NDAF)

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**Assoc Prof Desmond Graham
President**

**Rohan Greenland
Chief Executive Officer**

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988

Introduction

MS Australia (MSA) is pleased to provide a submission to the Australian Department of Social Services' consultation on the National Disability Advocacy Framework.

We welcome the increasing recognition by governments at all levels of the vital role that advocacy plays in promoting and protecting the rights, interests and well-being of people with disability and in contributing to the proper functioning of systems established to provide services and supports for people with disabilities.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MS Plus (providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services and advice to people living with MS regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Summary of recommendations

MS Australia recommends:

Recommendation 1

That together with the stated commitment to person-centred approaches, that the principles to guide advocacy in this Framework such as 'lived experience', 'co-design', 'co-production' or 'evidence-based co-design' must be clearly defined

Recommendation 2

That the Work Plan indicated in the implementation section of the Framework clearly state how the Framework outcomes will be achieved, by whom and by when and further, set out a mechanism for regular and transparent reporting on Framework outcomes.

Recommendation 3

For people with the lived experience of disability to truly have a voice, minimum data sets should reflect the broad range of disability types (including invisible disabilities) and be provided in an accessible format to:

- **allow for business decisions and innovations,**
- **inform investments,**
- **identify service gaps and**
- **create sustainable business models particularly in thin markets and rural and remote locations.**

Recommendation 4

MS Australia calls on all governments to commit to inclusive practices that places people with lived experience at the centre of what we do.

Introduction

Organisations such as MS Australia specialise in advocacy and support for those with lived experience of diseases such as MS. We aim to guide and provide support for people with MS, their loved ones and family members, throughout the dynamic and changing disease trajectory and continuum of care. Our aim is always to achieve the best possible outcomes, optimise their quality of life and facilitate a seamless and collaborative approach as they navigate complex service systems.

MS Australia and its member organisations are in a unique position to provide specialist MS-related support with years of experience and a highly trained and skilled workforce. Many people living with MS, their family, friends and carers appreciate this specialist support, mitigating the need to describe and explain their disease journey repeatedly when engaging with various agencies.

Living with a chronic, progressive, neurological condition such as multiple sclerosis (MS) is a health-related concern, however many people diagnosed with MS do not regard themselves as 'disabled', especially in the early stages after diagnosis.

Looking at the ways people with MS integrate living with MS into their daily lives, the compounding functional impacts, the triangulation of symptoms, the impacts of various medications and treatments, barriers to access and participation, and the difficulties in system navigation then points to the very complex intersectionality of living with an invisible disease and the often, resulting disability.

Accepting the decline in function associated with MS and identifying with the concept of 'disability' are often seen as a low point of a person coming to terms with loss - loss of function, loss of quality of life, loss of participation in the workplace, loss of a life before MS.

This specialist knowledge of MS is important in being able to advocate effectively for the MS community.

MS Australia welcomes the opportunity to advance this important Framework. We value the purpose, role and benefits of individual and systemic advocacy in disability in Australia, particularly for those living with invisible disability. We will also demonstrate the importance of disease-specific organisations contributing to this ongoing conversation.

About MS

Multiple Sclerosis (MS) is an immune-mediated, chronic inflammatory disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The 'multiple sclerosis' or 'many scars' ¹ are the result of an auto-immune response where the immune system, almost at random, attacks the fatty layer around nerves in the brain, optic nerve and spinal cord, resulting in a variety of disabling neurological symptoms². MS damages the whole brain from disease onset. Every system in the Central Nervous System or CNS (myelin, white matter, neurones, axons and blood vessels) can experience damage and loss as a result of MS³. MS is further characterised by focal or diffuse inflammation, demyelination, axonal loss and neurodegeneration⁴ and progressive brain atrophy.

The position where these attacks occur within the CNS corresponds with the potential impacts or symptoms experienced i.e. if an attack occurs in the optic nerve a person can experience double vision or diplopia; attacks in the spinal cord might result in weakness and numbness in their limbs; the cerebellum - loss of balance⁵. MS is therefore a very individual disease as the effects of the attacks are unique. Similarly, the progress, severity and specific symptoms of MS cannot be predicted. Many of the symptoms of MS are invisible but can have profound impacts on a person's day-to-day ability to function and tackle everyday roles and responsibilities.

1 Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222386/>

2 Høglund, R. A., & Maghazachi, A. A. (2014). Multiple sclerosis and the role of immune cells. *World journal of experimental medicine*, 4(3), 27–37. <https://doi.org/10.5493/wjem.v4.i3.27>

3 Cerqueira JJ, Compston DAS, Geraldes R, et al Time matters in multiple sclerosis: can early treatment and long-term follow-up ensure everyone benefits from the latest advances in multiple sclerosis? *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:844-850.

4 Andravizou, A., Dardiotis, E., Artemiadis, A. et al. Brain atrophy in multiple sclerosis: mechanisms, clinical relevance and treatment options. *Autoimmun Highlights* 10, 7 (2019). <https://doi.org/10.1186/s13317-019-0117-5>

5 Institute of Medicine (US) Committee on Multiple Sclerosis: Current Status and Strategies for the Future; Joy JE, Johnston RB Jr., editors. Multiple Sclerosis: Current Status and Strategies for the Future. Washington (DC): National Academies Press (US); 2001. 2, Clinical and Biological Features. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK222386/>

Management of the disease course and symptoms associated with MS requires regular contact between the person with MS and their healthcare team.

Demographics and disease course

There are over 25,600 people living with multiple sclerosis (MS) in Australia. Most people are diagnosed with MS between the ages of 20-40, but it can affect younger and older people too.

In young adults, MS is the most common acquired disease of the central nervous system and the leading cause of disability in young adults. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

MS, like other autoimmune diseases, is more common in females. Roughly three quarters of all people with MS are women.

There are three courses MS can take. Around 15 per cent of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progress may vary, but the declining neurological progression is constant. Relapsing-remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called exacerbations, relapses, or flares). 70 to 75 per cent of people affected by MS initially begin with a relapsing-remitting course. Secondary progressive MS (SPMS) is a relapsing-remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75 per cent who start with relapsing-remitting disease, more than 50 per cent will develop SPMS within 10 years; 90 per cent within 25 years. A further differentiation is made by categorising disease activity as active (with or without worsening) or stable.

A vision for Advocacy

1. Do you believe the new NDAF encompasses your vision of advocacy? If not, what changes are required?

“The complex characteristics of neurological disease yield exceptional challenges to plan for and implement advocacy activities on all levels. All stakeholders are challenged to provide the support patients need; advocacy facilitates this process and bundles efforts to reach the objective of the advocacy task.”⁶ As stated above in the introduction, those who work in such specialist advocacy environments acquire a skill set that goes beyond the generic.

The Framework highlights that, reflecting on the multiple current concerns and opportunities for advocacy in Australia. MS Australia believes that the new NDAF does encompass our vision for advocacy.

Principles to Guide Advocacy

2. Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

To genuinely deliver advocacy for people with disability in a changing disability landscape, in the context of the NDIS and the Royal Commission outcomes, the principles to guide advocacy in this Framework such as 'lived experience', 'co-design', 'co-production' or 'evidence-based co-design' must be clearly defined. Whilst there is a stated commitment to 'person-centred approaches and co-design principles' these terms are not clearly defined nor crystallised in the principles.

MS Australia believes that the Framework can only be successfully implemented if people with lived experience are included in the very architecture of the framework.

Recommendation 1

That together with the stated commitment to person-centred approaches, that the principles to guide advocacy in this Framework such as 'lived experience', 'co-design', 'co-production' or 'evidence-based co-design' must be clearly defined

Outcomes

3. Are the outcomes of the NDAF clear and achievable? Should different ones be included? If so, what should be included?

The Outcomes section of the Framework is a comprehensive set of clear statements that MS Australia broadly agrees with. Whilst these are necessarily a set of broad statements in keeping with the design of a Framework, they are highly ambitious with little detail on how the outcomes will be achieved, who will be responsible for them and by when. These details will no doubt be set out in the forthcoming Work Plan indicated in the "Implementation" section of the Framework.

We recommend that the Work Plan will also set out a mechanism for the transparent and regular reporting on Framework outcomes. It is therefore not possible at this stage to assess if they are achievable.

Recommendation 2

That the Work Plan indicated in the implementation section of the Framework clearly state how the Framework outcomes will be achieved, by whom and by when and further, set out a mechanism for regular and transparent reporting on Framework outcomes.

Responsibilities, Reform and Policy Directions

4. Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?

MS Australia supports the commitment of all parties and signatories to ensure ‘the funding of disability advocacy is transparent, equitable and accountable, and geographical coverage and services gaps are identified and addressed.’

In supporting this commitment, we note that:

- We remain concerned about the unintended consequences of the previously named Disability Reform Council decision to replace the term ‘Tier 2’ with “Information, Linkages and Capacity Building or ILC” within the National Disability Insurance Scheme.⁷ State funding that previously supported organisations such as MS organisations to provide disease specific supports, advocacy, information and coordination of supports were siphoned into the scheme.
- These policy decisions were further exacerbated when ILC was transferred to the Department of Social Services in October 2020.
- The impact was what Bruce Bonyhady referred to as the NDIS becoming the ‘oasis in the desert’⁸, abandoning the 4 million Australians with disabilities that are not eligible for the scheme.
- MS Australia suggests consideration of one solution to remedy this, to fund organisations such as MS Australia and our member organisations to provide disease-specific advocacy support to those people with MS who are outside of the NDIS due to its eligibility criteria.
- Ultimately, it seems that previous budget allocations and policy decisions were made on economic grounds only, with a disregard and de-prioritisation of the actual impacts of the changing landscape of disability policy on people with disability, their families and carers.
- Consequently, those advocacy organisations fortunate to receive some government funding, noted that funding levels were not enough to meet growing demand. For those organisations who are not government funded (after any initial Tier 2 funds were lost), the drain on in-kind support, financed through fundraising dollars is becoming increasingly difficult to maintain. This is further impacted by the current cost of living crisis and a decrease in disposable income which discourages people from making donations or supporting for-purpose organisations.
- “There is an urgent need for increased advocacy funding given the difficult circumstances people with disability face, so people with

⁷ National Disability Insurance Scheme, A Framework for Information, Linkages and Capacity Building, July 2015

⁸ <https://www.smh.com.au/national/you-re-either-in-or-you-re-out-ndis-architects-say-scheme-is-inequitable-20210722-p58c3o.html>

disability have the certainty to get the help they need. People with disability are facing vast uncertainty ... as the evidence heard in the Disability Royal Commission has proven.”⁹

5. Does the NDAF identify what is needed in the current and future disability environment? If not, what changes are required?

Evidence-based data

The Framework sets out a commitment by all levels of government to the collection, use, and reporting of evidence-based data for administration and planning of disability advocacy and improvement of services systems.

MS Australia supports this commitment, noting that:

- Data collection should include an *outcomes-based* approach, not only counting outputs and deliverables against a finite cost ledger
- There is a need to educate the Australian community and key decision-makers of the value of investing in people with disability. As Percapita’s report, entitled *The False Economy: The Economic Benefits and the consequences of government cost cutting*¹⁰ pointed out, the benefits to employment within the service economy, the resulting increases in economic activity (direct and indirect) and the benefits to people with disabilities and their carers, are the ‘spill overs’ that make a compelling argument to also consider the beneficial multiplier effects of such investment
- To date, the onus has been on small organisations to commission independent surveys or reports to provide an evidence base for systemic advocacy efforts and to wear the costs of this work, often financed through fundraising dollars. This is not sustainable, nor does it put all consumer advocacy organisations on an equal footing
- Data collected from people with disabilities does not belong to government agencies: it belongs to those people with disabilities who are sharing their personal information.

Recommendation 3

Minimum data sets should reflect the broad range of disability types (including invisible disabilities) and be provided in an accessible format to:

- **allow for business decisions and innovations,**
- **inform investments,**
- **identify service gaps and**
- **create sustainable business models particularly in thin markets and rural and remote locations.**

⁹ <https://pwd.org.au/peak-disability-org-slams-2022-federal-budget-for-short-changing-people-with-disability/>

¹⁰ https://percapita.org.au/our_work/false-economy-the-economic-benefits-of-the-ndis-and-the-consequences-of-government-cost-cutting/

Improving coordination and communication

The Framework also sets out a commitment to improving coordination and communication between disability advocacy organisations, disability services, the National Disability Insurance Agency, mainstream services, community-based services and governments to develop the overall capacity of the disability sector, including promoting linkages between individual and systemic advocacy.

MS Australia supports this commitment, noting that:

- We understand the appetite to only fund larger advocacy organisations through government compacts who would act as the liaison point between government and smaller advocacy organisations.
- MS Australia has worked hard to make connections, alliances and partnerships with relevant larger peak bodies.
- There is however a constant imperative to ‘compete’ with the needs of organisations supporting people with congenital disabilities. We believe that too often the collective voices of smaller organisations, particularly disease specific organisations, or those advocating for invisible disabilities are not heard.
- The coordination and communication between disability advocacy organisations, government, mainstream services, the NDIS and community-based services should be designed to provide a real power sharing opportunity.
- The deep involvement of people with lived experiences is essential to conversations that result in effective solutions. As Lauren Weinstein, a principal of design research and inclusive innovation at The Australian Centre for Social Innovation, stated, “Social innovation is inescapably intertwined with power.” She further points out that, “Acknowledging there is a lack of nuanced understanding of the role of power in co-design is an essential growth step for the sector.”¹¹
- It is time to restore the power imbalance that currently exists and create real opportunities for people with lived experience to collaborate with decision makers to inform solutions.

Recommendation 4

MS Australia calls on all governments to commit to inclusive practices that not only put people with lived experience at the centre of what we do.

¹¹ <https://probonoaustralia.com.au/news/2019/02/shifting-powerplay-co-design/>

Conclusion

The last decade of disability support in Australia has left the disability community with a sense of hopelessness and desperation and a lack of trust in mainstream agencies. They have lived with the tightening of Disability Support Pension measures resulting in intergenerational poverty, significant issues of trust in accessing individual funding packages through the NDIS, lost mainstream and community-based supports, and experienced difficulties in accessing appropriate housing and other supports. These issues have not only impacted on the person with the disability, but also on their families, loved ones and children.

The implementation of the NDAF is an opportunity to work together to create a brighter future for all people living with disability and to ensure people with disabilities are central to every step of the journey.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- 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.