MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Review of the National Disability Advocacy Framework

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Multiple Sclerosis Australia
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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the Australian Government's Department of Social Services Review of the National Disability Framework

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

As stated above, MSA's advocacy remit is with a focus on systemic and collaborative advocacy as described below:

Systemic advocacy: to make systemic changes to improve the situation of a whole group of people who share similar issues, such as people with multiple sclerosis. This is achieved by encouraging changes to the law, government and service provider policies and community attitudes. MSA's annual Statement of Priorities highlights those issues that are the focus for systemic advocacy work each year.

Collaborative advocacy: People with MS share many of the same issues as others who may be affected by disability or other conditions, such as a progressive neurological and neuromuscular conditions. MS Australia seeks opportunities to work collaboratively with other representative organisations to increase the voice and profile of advocacy for people with MS, such as MSA's active participation in the Neurological Alliance Australia.

Our submission is framed around the 6 questions provided in the discussion paper.

1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?

At MS Australia we advocate for people with MS across a broad range of issues that have an impact on the lives of people affected by MS, than those focused simply on disability concerns. For example we advocate on issues such as: energy rebates for people with MS (who often use considerable power for cooling to relieve MS symptoms), provision of safe and affordable medicines (especially to have MS-related medicines listed on the PBS) and many other health and wellbeing issues. We operate outside the disability advocacy remit as many people with MS do not regard themselves as disabled and many do not meet the eligibility requirements of the NDIS, and yet have some sort of impairment that needs to be addressed or supported. We also operate outside the specific disability advocacy remit as we believe that a person with MS has a life and expectations that are more than that defined by their disability.

For example, MSA and its member organisations are currently very concerned about determining and supporting the needs of people with MS with a disability over the age of 65, who are not eligible to register for the NDIS, but for whom the aged care sector does not meet their needs.

There are also people in the MS community who believe they are managing adequately at home with a primary carer and have not made themselves aware of or who have not accessed information about the NDIS, or have not considered that they might need this support at some stage as their MS progresses.

MSA's vision for advocacy in the future is very broad and includes a focus on empowerment for individuals and capacity building, to ensure people affected by MS have the awareness, information, skills and tools necessary to advance their own interests and to join with others via mechanisms such as social media and the web, when the need arises. The current Framework allows for this broad vision, although the details of how and when and how thoroughly the principles, outcomes and outputs are achieved is yet to be described.

2. Are the principles of the Framework 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?

MSA is concerned that with the introduction of the NDIS a societal attitude has emerged that all aspects of disability support and services will be met through the full implementation of the NDIS. This attitude means, for example, that fundraising and philanthropic activity has become more difficult as many funding bodies and members of the general public believe that the NDIS meets all disability needs. It also means that there is a lack of understanding that there is a different system for those who are disabled over the age of 65. Whilst NDIS participants who turn 65 have a choice about whether to remain in the NDIS or switch to the aged care sector, there are people with MS who have been managing at home, often with a partner or carer, till age 65 who are then precluded from accessing the NDIS and can only access Home Care Packages and Commonwealth Home Support Programs. The assumption here is that there is a degree of equivalence between supports available for people with a disability in the aged care system and those provided by the NDIS, but in reality this is not the case.

MSA understands that there is increasing evidence of unmet needs in Home Care Packages and Commonwealth Home Support Programs such as a shortage of packages in some areas and lower level packages that are not enough to maintain independence at home leading to rationing of services. We believe that this will lead to more and more people being forced into aged care accommodation through lack of choice and a sense of inevitability in the decision-making process.

Therefore, overall MSA supports the stated Principles of the Framework, but with the addition of the wording set out in the introduction to the Framework, paragraph 8, which recognises and acknowledges that people with disability can experience additional disadvantage and be precluded from one sector or another, for example, on the basis of age.

Principle 2 of the Framework could be expanded to read,

"Disability advocacy promotes the interests and wellbeing of people with disability and promotes their full and valued inclusion as contributing and participating members of the community regardless of gender, age, education, sexuality, geographic location, ethnicity and cultural background".

3. Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?

Paragraph 12 (f) of the Framework refers to people with disability experiencing multiple disadvantage having their needs met. MSA would like to see an extension of this outcome to say, "having their needs met from whichever sector is relevant to meeting those needs, whether it be health, disability, aged care, housing, transport, education, employment, or any other relevant sector".

Our vision is for collaboration, integration and streamlining of supports and services across sectors. This helps people with MS be more independent in navigating, planning and establishing a network of support relevant to their individual needs and situations. This is very relevant and important because often people affected by MS require supports and services from several sectors at any one time.

In addition, approximately 75% of the 23,000 people in Australia with MS have been diagnosed with the relapsing remitting form of MS, which means that their needs change as the disease progresses but with periods of remission. These people need to be confident they can access support and services from the relevant source as and when they are needed.

4. Are the outputs of the Framework still relevant or should different outputs be included?

MSA supports the stated outputs set out in the Framework and looks forward to receiving further information about how the processes associated with these outputs will be implemented. For example, the establishment and dissemination of the evidence base referred to in Output 13 (b) will be important to advancing advocacy around issues such as effective early intervention mechanisms. It will also assist with providing a trusted source of reliable data and information regarding such matters as the number of young people in nursing homes, which was reported as a difficulty in the report of the recent Senate inquiry into young people in nursing homes.

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

In the section of the Framework entitled Reform and Policy Directions, paragraph 15 (d) states that a key policy direction is to ensure that the funding of disability advocacy is transparent, equitable and accountable, though the mechanisms for this funding are not described. It would be helpful if supplementary information could be provided regarding how this and the other policy directions will be brought into effect.

Also in the Reform and Policy Direction section, there is no clear detailed indication of how the efficacy of the Framework will be evaluated and reported upon. Presumably this work will be undertaken through the development of the National Disability Quality Framework and a National Quality Assurance system for disability services, and the outcome based reporting and evaluation that is mentioned in paragraph 15 (c), though further details of these mechanisms would increase confidence in the value of the Framework.

6. **Do you have any other comments, thoughts or ideas about the Framework?**

MSA has no further comments and once again thanks the Department of Social Services for the opportunity to participate in this Review.

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