

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

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Introduction

MS Australia, in conjunction with its state member organisations, is pleased to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

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

Dual diagnosis

MS Australia understands that responsibility for providing services to people with a mental illness lies primarily with the state health departments across Australia. We further understand that the NDIS is concerned with 'providing disability support so that people can enjoy an ordinary life', specifically to fund 'supports that help participants increase the independence and social and economic participation'¹. It is clearly stated in the NDIS fact sheet regarding psychosocial disability that the NDIS does not fund health related services.

Our state member organisations report that they often provide services to people with MS with a dual diagnosis, that is, a mental health issue or illness in addition to MS. These clients are often quite challenging to support. In some cases their MS symptoms can be less severe and other issues associated with their mental illness greater and vice versa, but also neither set of issues could potentially be significant enough, on their own, to qualify for NDIS support.

Our state organisations also support people with MS with varying degrees of cognitive impairment associated with the progression of their MS; from mild to severe enough to be considered a functional impairment. Those with mild cognitive impairment can be poor decision-makers and vulnerable but physically present well. This can also be an issue especially if they are not supported through the NDIS pre-planning and planning stages.

Many of these cases of dual diagnosis are complex; there may, for example, also be people with MS with a post-traumatic stress disorder and it is still unclear if this is covered by the NDIS.

Like other organisations, MSA recognises that disability associated with mental illness was a later addition to the range of supports covered by the NDIS and we expect that much work needs to be done to increase supports and improve outcomes for people with disabilities associated with mental illness. We also recognise, through widespread reporting, that Federal funding for many recovery programs that were helping people with mental health problems were block funded and that this funding has ceased, probably with the expectation that there would be coverage through the roll out of the

¹ NDIS Fact Sheet, "Psychosocial disability, recovery and the NDIS", updated November 2016, <https://www.ndis.gov.au/medias/documents/heb/h21/8799160959006/Fact-Sheet-Psychosocial-disability-recovery-and-the-NDIS-PDF-774KB-.pdf>

NDIS, however many people that were being helped are not eligible for NDIS support under the existing criteria so inevitably gaps in support have occurred.

Many organisations in the disability sector hold a long-standing concern that people with a dual diagnosis including a mental illness and another disability may lead to abrogation of responsibility for treatment, with each system seeking to transfer responsibility from one to another. The improved integration of support through the disability, health and aged care systems has been a point of concern and on-going advocacy work by MSA for many years and we are keen to support any initiatives that will advance this integration.

**Recommendation 1:
Co-ordination and integration of services and support across disability, health and aged care be a continuing priority.**

Episodic nature of MS and mental illness

The NDIA fact sheet regarding psychosocial disability acknowledges the often episodic nature of psychosocial disability, and this characterisation is often used when describing the episodic nature of the symptoms of MS, especially for the majority of people with MS who are diagnosed with the relapsing-remitting form of MS.

MS Australia is very keen for the NDIA to build on any existing effort to find models of support to match these episodic needs.

A person experiencing a sudden relapse of either their MS or any mental illness is often not in a position to undertake a time-consuming planning process to access the supports needed through the NDIS. They often have fluctuating capacity, capability and motivation and without appropriate support through existing agencies they can easily fall through the gaps.

Supports should be planned to be made available as soon as they are needed, and it may even be better to plan to provide supports when they are not immediately necessary to ensure they are accessible when needed urgently. Clearly this approach mitigates against crisis situations and the risk of people presenting to the emergency departments of hospitals and greatly reduces the burden on the healthcare system.

**Recommendation 2:
Recognition of the often episodic nature of MS and mental illness be addressed and models of appropriate support be developed.**

Expertise of NDIS planners

MS Australia would like to add its voice to the widespread concern in the disability sector regarding the lack of knowledge of NDIS planners of specific disabilities associated with chronic diseases such as MS and the related needs of participants. This is a major area of concern for the MS organisations and the ten members of the Neurological Alliance Australia (NAA), of which MSA is a member.

This concern coupled with the point made earlier, that participants with mild cognitive impairment can be poor decision-makers, but physically present well makes it essential for NDIS planners to have themselves, or have access to, a higher level of expertise regarding specific chronic illnesses and associated disabilities.

A common factor for all cognitive impairment is that the impairment makes it difficult for the participant to understand, ascertain and determine the implications of the supports they need.

This issue can largely be overcome by the mandatory inclusion of Coordination of Support into the plans of all participants with a progressive neurodegenerative disease and/or a mental illness. Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease and mental illness have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual.

Recommendation 3:

MS Australia through the NAA is particularly concerned to see:

- (i) Improved pre-planning support for people with a progressive neurodegenerative disease, especially when coupled with a mental illness**
- (ii) NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease and/or a mental illness**
- (iii) Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease and/or a mental illness**

MS demographics

KEY FACTS

- Multiple sclerosis (MS) is a degenerative neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic degenerative 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; with progression of disability over time. For all, it is life changing.
- Symptoms vary between individuals and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and / or thinking and memory problems.
- There is no known cause or cure.