MULTIPLE SCLEROSIS AUSTRALIA

Joint Standing Committee on the National Disability Insurance Scheme inquiry into the NDIS Quality and Safeguards Commission

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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 causes, prevention, improving treatments, 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 positive 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:**
  Who, as MS specialists, are 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, which 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 Joint Standing Committee on the National Disability Insurance Scheme inquiry into the NDIS Quality and Safeguards Commission.

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

MSA'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)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis 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.

Terms of reference:

The terms of reference provided by the Joint Standing Committee on the NDIS for this inquiry are:

a. The monitoring, investigation and enforcement powers available to the Commission, and how those powers are exercised in practice;
b. The effectiveness of the Commission in responding to concerns, complaints and reportable incidents – including allegations of abuse and neglect of NDIS participants;
c. The adequacy and effectiveness of the NDIS Code of Conduct and the NDIS Practice Standards;
d. The adequacy and effectiveness of provider registration and worker screening arrangements, including the level of transparency and public access to information regarding the decisions and actions taken by the Commission;
e. The effectiveness of communication and engagement between the Commission and state and territory authorities;
f. The human and financial resources available to the Commission, and whether these resources are adequate for the Commission to properly execute its functions;

g. Management of the transition period, including impacts on other commonwealth and state-based oversight, safeguarding, and community engagement programs; and
h. Any related matters.

This submission

This submission has been informed by information provided by our state member organisations and their clients and seeks to address the terms of reference holistically.

Implementation of the Commission and general impressions

Overall, the MS organisations across Australia have had positive interactions and experiences with the Commission since its inception and are generally very satisfied with its operations to date.

Some examples of general feedback from staff in our MS organisations are:

- "My dealings with the Commission have all been fair. My interactions with the Commission with an incident recently was extremely positive and they made it clear that the outcome would be to deliver on continuous improvement if need be – they were willing to work with us instead of against us. The information that they provide has been useful via their email updates particularly during COVID-19. Overall, my experience with the implementation of the Commission has been positive. "
- "I've had to deal with the Commission a couple of times to ask questions in recent months and I've had a great experience. "
- "I've had lovely people answer the phone and I've had call backs when I've had difficult questions that someone wasn't able to answer. They also appear to appreciate the impact that rapport building has."

Reportable incidents

Our state colleagues report that there have been times when there was uncertainty as to whether a matter was a reportable incident or not. Over time the reportable incident officers at the Commission have been of great help in educating relevant staff in our state organisations and they have been very supportive and understanding of the need for the development of continuous improvement for providers.

Complaints

Similarly, positive experiences are reported when communicating with the Commission about complaints. Advice from the Commission regarding clarity of the roles and responsibilities of both providers and participants has been helpful.

Provider registration

There is a perception that the provider registration team are extremely busy which may impact on the time taken to complete the provider registration process. This in turn can have a negative flow-on effect on the cashflow of providers, as a provider cannot claim for services until registered.

One of our member organisations noted that there is an additional administrative and resource burden in both the preparation and re-registration process and in the auditing following that process. The move to enhancements such as the heightened timeframes for reporting serious incidents, the introduction of behaviour support plans, and generally higher levels of expectation for compliance, are welcome improvements, but once again organisations have to self-fund all of the preparation, staff training and other administrative arrangement to meet the new regulations.

Overcoming the fear of making complaints

On its web-site, under the Working With People With Disability tab, the Commonwealth Ombudsman makes the following statements regarding complaints,

"We know that some people don't like to make complaints. There are lots of reasons, including:

- *feeling scared*
- *feeling unsure about how to explain the problem*
- *feeling like there's no point making a complaint because it won't change anything."*

Anecdotal evidence received by MSA indicates that some people in the MS community feel that their NDIS plan or services may be adversely affected if they complain, that they will be "punished" in some way. They do not want to jeopardise their future interactions with a provider or with the Agency and feel they may get an adverse "file note". We need to work together to overcome this "fear factor".

Page 7 of the NDIS Quality & Safeguards Framework states:

"A connected approach to quality and safeguarding is needed to empower and support participants to make informed choices about providers, and to equip them to raise issues or make complaints when needed. This system will need to provide information about rights and options, build participants' skills and confidence, help them to make connections, and provide decision-making supports to those who need them. Focusing on building the capability of participants and supporting them to make connections recognises that the actions people take themselves—or that their family, friends and others around them take—are likely to be the most important component of the quality and safeguarding system. It also recognises the need for participants to be informed and discerning 'consumers' for the benefits of a market-based system to be realised, in particular to encourage providers to be flexible, responsive to participants' needs and innovative."

On the Commission web-site, under the Rights of Participants tab, in regard to upholding the rights of people with disability, including the right to dignity and respect, and to live free from abuse, exploitation, and violence, it says, "the Commission will achieve this through:

- empowering people with disability to exercise choice and control in the support services they receive, while ensuring appropriate protections are in place

- building the capacity of people with disability, their families, and their carers to make informed decisions about NDIS providers
- responding to and managing concerns and complaints
- supporting a strong and viable market for disability supports and services."

Whilst the Commission has made a series of "speak up" resources available on its web-site, at this stage we feel there is more work to do regarding the empowering, supporting and equipping of participants to feel comfortable about making complaints. It is also important to ensure that the Commission reports publicly, transparently and regularly regarding the numbers and types of complaints and how they were resolved. This will help build confidence across the sector and in the community.

Regular, transparent report will also allay concerns that have been reported in the media regarding the number of complaints received by the Commission and what has been reported as a low level of compliance or enforcement actions.

Conclusion

As stated earlier, overall, the MS organisations across Australia have had positive interactions and experiences with the Commission since its inception and are generally very satisfied with its operations to date.

There is also more work to be done by peak organisations such as MS Australia in informing our own communities about the aims and objectives of the Commission, its independence, and its role to "improve the quality and safety of NDIS supports and services".

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.
- There is no known cause or cure