

## **MULTIPLE SCLEROSIS AUSTRALIA**

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# **Submission to the NDIS consultation on Access and eligibility policy with independent assessments**

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## Introduction

MS Australia (MSA) is pleased to provide a submission to the NDIS consultation on Access and eligibility policy with independent assessments.

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. The comments have been provided by representatives of our state organisations who assist people to navigate the NDIS and in some instances, directly from people living with MS. MSA's role is to work on behalf of all of our 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.

## Consultation questions

The consultation questions posed are structured as such that they do not allow for feedback on the Access and Independent Assessment Policy itself, but rather how it will be implemented. Significant concerns are held regarding the use of Independent Assessments for both access and planning, including:

- The expectation that an independent assessor is able to complete accurate assessments for such a wide range of disabilities - generalist therapists will not have the knowledge and experience to provide accurate outcome measures for specialist or rare disabilities ie. progressive neurological conditions
- This assessment framework does not capture fluctuation in condition or the impact of external factors on functional capacity
- Many participants over estimate their level of functioning, particularly those with cognitive deficits and limited insight
- IAs disregard the benefits of the therapeutic relationship, and the importance of developing rapport and trust with a person to be able to accurately reflect their functional capacity

- Much of the reasoning for IAs is for to improve consistency - was providing a standard template or required standardized assessments from the participants usual therapy team ever considered? These professionals have the trust, therapeutic relationship and rapport to provide the most accurate functional assessment.

### **Learning about the NDIS**

#### **1. What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?**

- The purpose and overall process for the assessment, including the logistical details – who, what, where, when, i.e. how long the meeting is expected to go for (fatigue is a major issue for people with MS), who can attend the meeting, where will it take place
- The requirements and expectations of the applicant
- Check the applicant’s understanding of time frames; are they clear about next steps and other expectations
- Who will be making the assessment, their qualifications and experience, including the assessor’s understanding of progressive, degenerative neurological conditions like MS
- Check the applicant’s understanding of what to do if the meeting goes wrong, if there is a major communication breakdown or if they need “time out”
- If participants are unhappy about their plan, what are the next steps. Check the applicant’s understanding of their rights to challenge decisions, request information about the decision-making process e.g. if they feel pressured into choosing a provider.
- Information is best provided in accordance with the applicant’s preferred method e.g. email, phone, or face-to-face.
- The assessors experience of working with people with a progressive, fluctuating condition. How will they capture the participant’s ‘worst’ case scenario. Can the assessment be scheduled over multiple appointments to more accurately capture fluctuation in functional capacity
- Multiple methods of providing this information needed to allow for cognitive deficits and cognitive fatigue – participants may not have capacity to comprehend and recall this information – in person, via phone, email and letter form
- The participant requires a consistent contact person (ie. LAC), current NDIS general line can provide vastly inconsistent information causing undue stress and confusion. Additional training and guidance need by NDIS to these contact persons to ensure information is consistent and accurate
- How their intersectionality will be taken into account, that they have a right to appeal, that they can choose the agency their independent assessor works for
- Ensure all information re: Independent Assessments has an EasyRead version. Currently, EasyRead NDIS information in different LOTE (languages other than English) is lacking.

### **Accessing the NDIS**

#### **2. What should we consider in removing the access lists?**

- In removing the access lists, it is important that people with MS can still access the NDIA according to early intervention requirements.

- Early intervention (EI) is a misunderstood concept - it is not just for children or the early diagnosed. It is a pathway to the NDIS that does *not* have criteria around substantially reduced functional impact. Its purpose is to provide eligible applicants with supports that; *mitigate or alleviate impairments* to, *prevent deterioration* of, or *improve functional capacity* (OR "strengthen the sustainability of informal supports" - often used when someone's condition does not meet the above criteria but have a risk of carer burnout). It means that EI participants are re-assessed regularly (usually every 12 months, but sometimes at different times) to see if a) they now meet full access to the scheme, b) require ongoing EI supports or c) no longer require NDIS services at all and are exited from the scheme.
- Given the variability of presentation at diagnosis and functional impact (which can be minimal at that point) and also the stability of disease until 6-12 months post diagnosis, assessment of likely impact of functional capacity at diagnosis is often a challenge in clinical practice.
- Any person with MS who has just been diagnosed, has never received funding for supports/services for their functional impairments, or has begun to have functional impacts (i.e. progression of MS) that are impacting them, ***should meet EI criteria inherently.***

### **3. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?**

- Multiple sclerosis is a progressive neurological condition for which there is no cure, by its nature it is lifelong and permanent. Most people with MS will be providing this evidence from their neurologist, so should not require further clarification, though it should be recognised that in many cases, permanency is not able to be established clinically until disease has been stabilised on treatment at diagnosis.
- Each of our state MS organisations makes available information to neurologists and health care professionals about the type of information required to support an application from someone with MS to the NDIS
- NDIA should provide documentation that makes it clear that evidence should be about the condition's impact rather than the condition itself

### **4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?**

- In the case of MS, a diagnosis is made by a neurologist according to very specific criteria.
- For progressive, degenerative, neurological conditions such as MS, it is not possible to distinguish between "disability" and "chronic health condition".
- To sort out which sector is responsible for what, a list of examples of supports provided by the health sector and supports provided by the NDIS may assist.
- More consistent and accurate information to be provided by the NDIS contact centre

### **Undertaking an independent assessment**

### **5. What are the traits and skills that you most want in an assessor?**

- Broad understanding of types of symptoms (objective and subjective) and functional impact of progressive, degenerative neurological conditions like MS, especially a willingness to understand the unique, invisible symptoms being experienced by an applicant with MS
- Specialist IAs with a high level of experience with the participant's disability. Many conditions have a number of hidden or invisible symptoms that a generalist assessor would not have the understanding of or be able to accurately the impact on functional performance
- experience working with fluctuating conditions and understanding that presentation at any given moment is not necessarily reflective of functional performance across a day, week or year
- understanding that newly diagnosed clients may under report functional difficulties as their strategy of coping with diagnosis and progression of condition, and can have difficulty acknowledging challenges as they can focus on strengths
- understanding of cognitive deficits that can lead to inaccurate self-reporting of functional capacity and using a holistic approach to gather evidence
- What mitigations will be put in place to address concerns about supply of suitably qualified assessors (including in already thin market areas) eg allied health and behaviour support staff who are already in high demand for service delivery.
- High level interpersonal skills, demonstrating self-awareness and active listening skills, capability to ask the right questions, social awareness and emotional intelligence, including good oral communication skills e.g. speaks respectfully and explains issues and information clearly
- It is important to recognise this is a skilled role; not just a “form filling exercise”, so the assessor needs to be qualified, preferably at least to graduate level in some medical or therapeutic or nursing area
- Understanding of the barriers created by social determinants of health and poor health literacy and capabilities to assess needs where support maybe required
- High level assessment and interviewing skills including ability to actively support the consumer to provide and accurate account of the impact of their disability on their everyday lives
- Understanding of the common adaptability of people with long-term chronic health that results in consumers reports of impact on quality of life lacking clarity and requiring in depth interviewing
- Inclusive approach that demonstrates a broad understanding of the needs of diverse groups and recognises individual rights including: empathy, care, understanding, emotional intelligence, human rights, and knowledge of the social model of disability
- A clear understanding of what ‘choice and control’ means and how to align their decisions to that ethos
- There should be no assessor KPI’s around plan value. Plans should be valued according to the applicant’s needs.

**6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?**

- There should be applicant choice about where the assessment takes place – (most will likely be) at home, at work, but could be somewhere neutral e.g. a friend’s house
- There must be sufficient notice of the assessment date to allow applicants to prepare themselves for the process and invite a support person if desired, including

provision for weekend/outside business hours meetings for those who are still in the workforce

- Functional capacity is most accurately represented when observed in the usual environment
- Inclusion of support persons in assessment
- Assessment format takes into consideration MS specific needs – ie. Fatigue, thermoregulation difficulties, cognition and cognitive fatigue when offering assessment location, time of day and length
- Allowing the appropriate time to develop a therapeutic relationship and explore functional domains in detail; 1-4 hours is not sufficient.

#### **7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?**

- Include assessment tools, guides and measures that can support assessors' interviewing and decision-making process
- Support assessors with comprehensive diversity and inclusion learning and development tools and ensure compliance with these
- Ensure processes and procedures developed for assessment are underpinned by an inclusive framework and are equitable and respectful
- Ensure consumers have access to information that is culturally relevant, meets health literacy requirements and assessor ensures and checks that the consumer is well informed about the process e.g. ability for consumer to engage in advocacy support if required
- Ensure consumer engagement in process of development and review of assessor tools and processes are inclusive and seek perspectives and contributions from diverse groups
- Ensure assessment tools capture intersectionality of the demographic and personal characteristics of the consumers that will support the respect for their individual identity
- Ensure a diverse and inclusive team of assessors that is representative of many communities
- Ensure assessors prepare well before the assessment takes place and have a good understanding of the applicant's background
- Acknowledge the benefit of rapport building and development of a therapeutic relationship to accurate assessment outcomes, and acknowledge the time this can take to develop
- Provider of choice should be able to conduct access assessments. May participants have allied health and other support services in place who have an extensive background and understanding of their social and cultural needs who will therefore achieve more accurate assessment outcomes in a shorter period of time.

#### **Exemptions**

#### **8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?**

- Where the assessor may be assessed as at risk in relation to their safety

- Where the consumer may be assessed at risk in relation to their safety including where the process of an in depth assessment with an unknown person will cause harm or distress to the participant.
- If a participant already has specialised allied health supports in place these providers should be able to provide functional capacity assessments to support access and planning, funded by the NDIS. The NDIS should provide a template and standardised assessments for existing providers to utilise, to provide the consistency and equity the NDIS is seeking. This will ensure best and accurate outcomes of the functional capacity assessment, as the assessment is based on a therapeutic relationship and specialised knowledge and experience.

### **Quality assurance**

#### **9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?**

- Employ a comprehensive feedback and engagement strategy that ensures feedback can be provided in a variety of ways (including face-to-face), is regular and inclusive of consumers and providers and other relevant stakeholders.
- Ensure transparency of information obtained through feedback and regular reporting to consumers and providers
- Ensure this feedback is reported on, transparently, to the public
- Ensure this feedback is acted upon
- There should be some brief feedback opportunity offered after every interaction; this is now commonly offered by many professional and retail organisations; it should be genuinely offered and should not be something the participant has to go searching for
- There must be a very clear process and guidelines around how an applicant or participant can seek a change of assessor
- Appropriate pathway to dispute assessment outcomes if needed and appropriate supports to do so
- Ability for an additional assessment to be funded if the outcomes of the independent assessment is poor
- It is highly concerning that a participant disagreeing with the outcomes of an independent assessment is not enough to fund an alternative assessment. There needs to be a process for the participant to dispute the outcomes if they are not accurate and seek re assessment.

### **Communications and accessibility of information**

#### **10. How should we provide the assessment results to the person applying for the NDIS?**

- Establish process and expectations at beginning of assessment and check that the applicant understands them
- Communication should be according to the applicant's preference e.g. in writing, by email and/or by post, including information about next steps and what to do if they don't understand something.
- Ensure the applicant's level of literacy is assessed and information is provided to meet literacy needs

- Engage and communicate with applicant's advocate(s) with the applicant's approval
- Any communication must be clear, accurate and within reasonable, agreed timelines including a clear pathway to dispute assessment outcomes.

**KEY FACTS:**

- 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.