Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012

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MSA agree for our submission to be made public
MS Australia (MSA) appreciates the opportunity to comment on the National Disability Insurance Scheme Bill 2013.

MSA thanks the government for the extensive consultation and commitment to establishing and implementing an insurance scheme for all people with a disability.

It is very encouraging that neurological diseases are proposed for inclusion in the legislation and importantly that they will meet the early intervention requirement specified in Section 24 & Section 25 of the Act. MS is one of the most common acquired neurological diseases with the majority of people being diagnosed between 20 and 40 years of age. The experience of the disease varies greatly from individual to individual; however, for many impairment and disruption impact on areas such as family roles/relationships, employment and daily functioning.

The impact of the disease on individuals, their families and the community can undermine the resilience that is needed for individuals to remain purposeful and in control of their lives. The characteristics of this disease can threaten the sustainability of friendships, social interactions and partnerships — and many relationships fail, thus causing further isolation and increased reliance on social services. Consequently, the consideration of such disease characteristics is crucial when considering any intervention or policy regarding service delivery for example the fluctuation in symptoms in mobility/vision/thinking and the unpredictability.

Early intervention is required at each disease transition point/change across the disease journey, as are mechanisms that will assist individuals when planning so that they can maintain economic independence and social interactions for as long as possible. Access to quality disease-specific information is important as is information that is relevant to each individual’s personal social contexts and health needs. Critical to achieving this is support for psychological and emotional adjustments, thus sustaining and strengthening informal supports. Appropriate mechanisms include, targeted, timely supports and brokerage, such as: home help, community respite and emotional support which can assist with minimising the impact of a debilitating and commonly occurring symptom such as fatigue. Left unaddressed it can significantly impact both on emotional wellbeing and physical functionality. The opportunity for there to be brokerage for these types of interventions will allow people to have the capacity required to focus and maintain their employment, which
in turn maintains financial suitability. It also helps keep capacity to maintain social activities with family and friends.

**Chapter 2, Section 13 & Section 14 states,** ‘...the Agency may provide coordination, strategic and referral services etc. to people with disability...’ and in 14 it states, ‘...the Agency may provide funding to persons or entities’.

The importance of getting these functions right, for people affected by MS, relies on the ‘Agency' recognising and understanding the need for seamless anticipatory support. This needs to be based on comprehensive information and assessment of an individual’s life journey so that the individual can maintain focus on his or her participation in social and economic activities. Providing specialist knowledge and experience of the disease — in particular for the impact of hidden symptoms — will ensure appropriate and relevant referrals. In turn, such referrals provide for timely and early intervention; specialist planning; assessment and coordination of supports. This includes a pro-active — rather than reactive — framework for decision-making and communication. This plays a vital role in preventing individuals from becoming ‘lost’ or overwhelmed due to duplication or fragmentation between sectors, systems and programs.

**Section 31 (k) - principles relating to plans point states:** ‘...Participant’s plan, should so far as is reasonably practicable, provide the context for the provision of disability services to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.'

This is an important principle for progressive neurological diseases, such as MS, because of the changing and degenerative nature of the disease and the complexity of health and social situations. People affected by MS require timely services from the health, disability and aged care sectors; often at the same time. Therefore, the need is, not only for the effective coordination of disability services, but for access to comprehensive co-ordination within and across sectors to organise care, service delivery and manage risk. People with MS, and for that matter any person with a disability, must be given the opportunity to have support with coordination when multiple service sectors and programs are involved, not only disability services. This must be able to happen without the barriers that currently exist. Therefore, MSA strongly encourages the NDIS to recognise and acknowledge the importance of clear protocols, articulated roles and a collaborative cross-sector team approach with the health and aged care sectors to achieve the required outcomes documented in a participant plan.

**Section 47 - Reviewing and changing participant plans**
The very nature of neurodegenerative disorders, such as MS, mean that symptoms change, and general increase, resulting in a greater level of disability. This often has a domino effect, impacting family relationships, social and societal involvement and economic status. For this reason, it is imperative that people affected by MS be able to change their statement of goals and aspirations at any time; however, the process
must be simple and be responsive to the changed circumstances. Assessment and planning are not one off activities - they are part of the cycle of review and reassessment, ensuring the individual, carer and family remain at the centre of control, choice and decision making. Reassessment is about understanding what has changed and the context of this change. A proactive approach for an ongoing assessment process that can anticipate and respond to changing need is warranted for people with progressive neurological disorders. This approach provides scope for family, carers, and coordination roles etc. to initiate this process, with the consent of the participant, thus avoiding crisis situations and consequently minimising the stress and burden of the interruption.

Section 22 – Age requirements, A person meets the age requirements if: (a) the person was aged under 65 when the access request in relation to the person was made.

The age of onset and the timeframe of progression can vary significantly between individuals. For many people their MS symptoms significantly progress during 10 to 15 years post diagnoses or first symptoms. In the current disability system, regardless of which state or territory people 50 - 65 years are not given equal priority to disability funding as those under 50 years and nor does the system prioritise lower level supports that may delay progression, sustain a person for a long period and avoid more intensive supports early. If the Bill maintains the wording as it reads currently in section 24 and section 25 many people affected with MS will be eligible for supports early on in their disease, giving more opportunity to continue to be economic and social contributors to the communities in which they live and more likely to be able to remain at home and retain all the benefits of informal care and social enrichment of normal domestic life.

A genuine interface between aged care and the NDIS is required to provide a specialist service to support the needs of people acquiring a disability over 65 years of age and allow ongoing and seamless service provision.

Person under the age of 65 years of age residing in residential aged care

What is not clear in the legislation is the funding from NDIS for a person with a disability who is under the age of 65 years and residing in a residential aged care or who will be required to enter aged care for some of the reasons listed below. The issue of people under 65 years entering aged care has been a significant and long standing issue. The circumstances why this is happening range from ‘thin markets’, remote locations, lack of any other alternative to inadequate funding and a lack of effective protocols and interface between the disability, aged care and health sectors.

People with MS residing in residential aged care generally have a poor quality of life because the operating paradigm is different to that of the disability services sector. What MSA and young people placed in aged care residences need to be reassured of is that the legislation allows for the NDIS to fund specialist equipment, support and
transport costs for appropriate and relevant social activities and gaps in personal needs as assessed as being reasonable and necessary.

With the establishment and implementation of NDIS and the *Living Better, Living Longer* age care reforms, it is imperative that an interface between the aged care sector and the NDIS be developed to ensure health, disability needs and social context are well understood, as this in turn ensures every individuals’ goals and aspirations can be achieved.

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