

Tessa Thompson
Senior Policy Advisor
National Disability Services



Tuesday, 17 December 2013

Dear Tessa,

Thank you for the opportunity to provide comments for the National Disability Services (NDS) submission to the Australian Law Reform Commission on the issue of legal capacity for people with a disability.

MS Australia is the national peak body representing the needs and views of more than 23,000 people living with Multiple Sclerosis (MS) across the country as well as their carers, loved ones and the broader MS community.

As an organisation we are specifically interested in the issue of legal capacity for people with a disability, particularly the considerations for people living with progressive neurological disabilities and whether the issues of legal capacity will be considered under the National Disability Insurance Scheme.

We have first-hand knowledge of operating within the National Disability Insurance Scheme (NDIS) as one of our state societies MS Australia ACT/NSW/VIC is operating as a service provider within the Barwon and Hunter trial sites.

This has provided valuable insight into the pertinent issues for people with MS under the new scheme. It is evident that there is a need to consider new nationally consistent legislation for a range of issues to ensure a seamless implementation of the NDIS.

Thank you again for the opportunity to provide the following comments for reference in your submission. Please contact us if you would like to discuss further.

Regards,

Lee Davelaar
National Communications Manager
MS Australia

Legal capacity for people with Multiple Sclerosis

People with Multiple Sclerosis can experience particular deficits regarding cognition. In fact, approximately 50% of people diagnosed with MS will experience some impact on cognition during the course of their disease.

These changes may present as obvious demonstrated deficits in regards to memory and thinking but may also present in a more subtle manner. For example, people with MS may be able to conversationally interact and engage, and be able to maintain reasonable social interactions, but fall short where more complex thinking tasks are required. They may experience severe difficulties with:

- Problem solving, reasoning and planning
- New learning
- Problems in initiating and commencing tasks and following through
- Memory problems
- Attention and concentration
- Poor or impulsive decision making with limited self-awareness and poor self-management.

These deficits in thinking and memory may compromise decision making regarding financial, health management and lifestyle issues.

Where deficits (attributable to MS) are present, and impacting in such a way as to significantly impair a person's decision making capacities, alternate decision makers may be required.

These persons may be appointed via Enduring Powers of Attorney (EPOA) or Enduring Power of Guardianship (in Vic), or through more formal processes such as the appropriate State guardianship/administration board or tribunal i.e.: the appointment of a formal administrator to manage financial/legal matters or a guardian to make decisions regarding lifestyle.

MS Australia envisages this could pose a real risk in the continued rollout of the NDIS. For example, where evidence of cognitive impairment is apparent but no alternative decision maker is in place, what protocols and procedures will NDIS assessors and administrators take into account to ensure that client driven decisions are made with legal capacity?

The complexities of State schemes could pose further difficulties in this regard. On this basis, MS Australia would welcome a nationally consistent definition of legal capacity and a consistent assessment tool/criteria to identify decision making deficits. Such consistency could provide the framework for optimal management of people with cognitive and neurological difficulties.

Disparity and lack of uniformity across states

Currently each Australian state and Territory has differing processes and legislation governing Powers of Attorney and appointments of alternate decision makers. There are differing Boards or Tribunals governing such matters and different 'titles' for each of the orders or powers across each jurisdiction. Simplistically, the Commonwealth presently has no power to specifically legislate in this area, so it would be up to the individual State (or Territory) to enact similar legislation or to vest power in the Commonwealth to create uniformity.

Whilst respective States and Territories have tended to recognise EPOA's or Enduring Guardianship appointments from other states, this is not guaranteed and in the event of conflict the matter would have to be determined by the appropriate State Board or Tribunal.

Likewise for recognition of Guardianship or Administration orders made by another Tribunal or Board: the appointment of an alternate decision maker would usually be acknowledged but this is not necessarily straightforward and may create burdens for clients and their decision makers as well as for agencies attempting to deal with such institutions and processes.

There has been a push by the respective state/territory boards and tribunals to seek a 'national harmonisation' of these provisions in order to gain a consistency of approach across all jurisdictions.

Given the complexities that currently exist between various state legislations, MS Australia would welcome the consideration of nationally consistent legislation regarding legal capacity.

Issues as noted in the current NDIS trial sites

The focus of the NDIS is to empower people with a disability to have greater choice and control over their lives and to provide them with the means and interventions to achieve their lifestyle goals.

To date, information from the pilot group in Barwon, Victoria, indicates Local Area Planners and co-ordinators have experienced some difficulties in dealing with clients with a neurological condition who demonstrate cognitive impairment and who may require, or have, alternate decision makers in place.

There have been some examples that suggest that for individual clients, goals have been identified and progressed that have been contrary to their best interests and their alternative decision makers. It is possibly less likely that if professional /independent Guardians or Administrators are in place (outside of immediate family/friends) that the ability to interface with NDIA planners and assessors might be less intimidating and more collaborative.

MS Australia recommends that as part of the continued rollout of the National Disability Insurance Scheme a key focus be education and information sessions be held in relation to legal capacity and alternative decision makers.

Whilst the focus of any education session is to inform people with a disability about their rights and responsibilities, alternative decision makers cannot be excluded from these processes where impaired decision making is evident. It should be recognised that the involvement of alternate decision makers is not contrary to achieving the best interests of the client.

Legal Capacity:

Currently, there is no consistency in relation to what constitutes legal capacity and how this is assessed. In Victoria for example, capacity is to 'have the ability to reason things out.' That is to:

- Understand, retain, believe, evaluate (i.e.: process) and weigh relevant information.¹

¹ Office of Public Advocate *Fact sheet: Advice for Enduring guardians*, 05/10: Victoria.

A guardian or administrator might be required, depending on the nature of decisions to be made, where the following criteria are met:

- The person has a recognised and identified disability
- By reason of that disability, the person is unable to make decisions in regards to their finances, lifestyle etc.)
- There is a need for an alternate decision maker to be appointed where less restrictive options have failed to assist.

The same observation can be made about the definition of capacity across Australia. There are many similarities across States (and Territories), but no uniform criteria or approach to assessment.

It is not difficult to imagine that the lack of consistency of terminology and processes, and definitional criteria could result in inequality and difficulties in the administration of a national insurance scheme like the NDIS.

More specifically, the recognition of cognitive issues as a clear criterion for provision of supports is one hurdle for the scheme to address. Where the definition is not clear across jurisdictions, it could have adverse outcomes for clients in regards to assessing eligibility for supports in the first place. For example, perhaps excluding clients from services in one State over another (where criteria may be less stringent or flexible).

Secondly, discrepancies in processes and protocols across borders may impact the determination of funding and administrative processes that should occur with regards to management of funds on behalf of clients through the scheme.

As such MS Australia would welcome clear, definitive, nationally consistent legislation that outlines the criterion for legal capacity and the appointment of administrators or guardians.

Further issues for consideration:

MS Australia believes there are a number of additional considerations that should be taken into account when contemplating nationally consistent legislation regarding legal capacity for people with a disability.

These include how NDIS local planners and assessors interact and interface with the following processes:

- Where alternate decision makers are in place (or nominees under the scheme), what role does this person play in the planning and assessment process?
- How will financial matters in relation to payment of service providers, tracking of funds and self-managed funds be dealt with when there are formal alternate decision makers in place?
- At what point is it determined that a person has 'lost capacity' and alternative decision makers are required to manage their affairs, including their funding decisions?