Response to the National Disability Regulatory Impact Statement 2012

Submitted on: 24\textsuperscript{th} January 2013 by:

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MND Australia and MS Australia would be happy to have any comments reflected in the Regulation Impact Statement made public after COAG's consideration
We appreciate the opportunity of commenting on the options set out in the consultation paper on the Regulatory Impact Statement for the NDIS, dated December 2012, in relation to the client groups our organisations support.

The Nature of Progressive Neurological Disease

Progressive neurological diseases (PND) are by definition incurable and the cause is often unknown. Most conditions follow a relatively predictable path, i.e. motor neurone disease is usually rapidly progressive while others may have a progressive course over many years or follow an unpredictable relapsing and remitting course with progression and are harder to forecast, such as multiple sclerosis. The nervous system controls our movements, communication, sensations, thoughts, memory and emotional responses. Mood, behaviour, personality and judgment can all be disturbed. Therefore, the impact of these diseases can leave the individual physically, cognitively and socially disadvantaged and sufferers of PND have a high rate of social and financial disadvantage.

The age of onset and the timeframe of progression vary between individuals. Onset in young adulthood or middle-age can cause the early loss of employment. The attributes of these diseases threaten the sustainability of friendships and partnerships and many relationships fail, causing further isolation and increased reliance on social services. Therefore, the disease attributes must be taken into account when considering any intervention or policy regarding service delivery.

Individuals with PND often have frequent presentations to hospital emergency departments, crisis admissions with protracted hospitalisation, and are at high risk of being inappropriately placed in residential aged care. Timely early intervention, and specialist planning, assessment, and coordination of care, including a pro-active framework for decision-making, play vital roles in the prevention of these situations. The costs of time, duration of unnecessary supports, resourcing of avoidable hospital admissions, and cost associated with poor outcomes as a result of ill-informed/inadequate assessments or irrelevant/inappropriate choices, all bear a financial and personal penalty.

Appropriately targeting financial and social supports early in the disease and before significant evidence of functional disability, can be expected to sustain
individuals directly affected, and their family and social relationships, to a greater degree. In turn, the client retains all the benefits of informal care and the social enrichment of normal domestic life – a situation which, once lost, is hard to recapture as the disease progresses.

**Overview of Regulatory Impacts for this Client Group.**

It is important when addressing the issue of regulatory control, to differentiate the aspects of vulnerability relevant to this discussion. Increasing freedom of choice inherently increases vulnerability, and this should not be underestimated. Regulation must recognise the different life narratives and processes of disability. In the neurodegenerative group, specialist involvement is imperative to understanding the disease process, the different forms of disability, and therefore the support options which must be determined by a person’s social context, their care plans and prognosis/trajectory of disease. For this group, it is more appropriate to emphasise participant risk and the capacity of an individual to assess and manage risk, such as: cognition and insight, physical functionality, level of social (informal) and family involvement. It is recognised nonetheless that the coupling of participant risk with provider risk is a good way to safeguard the most vulnerable clients.

Defining provider risk will be a task requiring considerable thought but considerations with respect to this client group (and probably the broader disability community) need to include for example:

- that specialist/professional services have some kind of minimum requirement (eg. only qualified Occupational Therapists/physiotherapists should be making recommendations about appropriate walking aids; capacity assessments should be conducted by neuropsychologists);
- that services with potentially far reaching consequences for the client should involve greater regulation (eg spinal manipulation should be carried out by a physiotherapist as opposed to a massage therapist who has completed a 2 week course);
- that attendant care services staff receive education and training specific to understanding the characteristics of these diseases and how to work in partnership with the individual to ensure care & support continues to meet the changing needs of the individual.

Equally, integrated service provision across sectors is imperative for positive outcomes, including appropriate choice and efficiency for the consumer and the cross sector services involved. Specialist provider organisations are the interface across sectors and levels of government. The level of regulation applied needs to reduce fragmentation across service sectors in order to support a client-centred, well informed and efficient approach.
Consideration of the Options Proposed

Option 1: Choice limited to government funded providers
We agree in principle that this option does not progress the social reform intended by the NDIS; that is, to increase choice and control for people with disability and more adequately meet the costs of reasonable and necessary support, including by a more competitive market mechanism. Its strength however is that it provides security to participants and services, simplicity, and protection.

We believe that within the NDIS reform there is an essential place for some block funding, as described in Option 2. Specifically, this includes:
- funding in ‘thin markets’;
- funding for the transition of services to the NDIS; and
- funding for supports identified as more efficiently provided through a block grant.

In the case of our services, a key function in this category is the provision of individualised specialist information and support at the time of diagnosis across each transition point of the disease; and subsequent regional specialist support workers to assist with coordination of the network of supports and services. Accurate information is paramount to people making appropriate choices and these functions are a key to positive early intervention outcomes. Ensuring that this information is individualised and personalised for each person’s life experience and support networks is essential. These information and support processes are known to require 40 hours of worker time with a new client with motor neurone disease, and clearly are better block funded. Similarly, as reported through the 2012 National Needs analysis of people living with MS, is the requirement for information across the disease journey and relating to various stages of adjustment and change resulting in disease progress.

There is also an argument for a minimum level of block funding to ensure availability of staff and timely responsiveness to new client requests, rather than to incur the costs and delays of continuous recruitment.

In relation to pricing, joint price setting should be agreed between government and providers, with a range that reflects both complexities of support and practicalities of delivering service, linked to quality and skill levels of staff.

Option 2: Choice from providers that meet regulatory standards
This option makes clear the tension between minimising risk and increasing individual choice. It places emphasis on the importance of safeguarding a diverse group of people receiving support funded from the public purse. The application of regulation in itself sends an important message to potential providers about the rights of participants and expectations of quality and safety. At the same time, this option increases choice and control by the allocation of nationally portable, individual support packages and thereby
encourages innovation and a market approach. The benefits to participants of greater control over their life choices, leading to increased wellbeing and higher life satisfaction as described by the Productivity Commission, can be significantly anticipated from this option. However, as outlined in our response to Option 1, we believe that the block-funding features outlined in this option are essential.

This option also captures reporting of data useful to measuring performance and outcomes; identifying good practice, and alerting to emerging gaps or risks. The disruption to providers is a key feature and funding of transition support, through an eligibility process, is necessary to ensure supply. However, as long as the range of block funding, transition support and price setting considerations raised is addressed, we support the social reform to be achieved under this option.

Of the sub-options outlined, number iii is preferred - regulation based on risk. With this option, clear definitions of what constitutes high risk are important, and need to be linked to training requirements. The point of reference for our client groups should primarily be client capacity and family/social support considerations, more than the nature of the support; for instance, those whose executive functions are declining may be compromised in their decision-making about basic supports and therefore will benefit from safeguards even for those services. In the application of regulatory requirements, there needs to be consideration of preserving pre-existing relationships with support staff valued by the client, allowing a transitional period for staff who may need to increase their compliance to regulatory standards.

There is also a need for a process for capturing and dealing with the burden where problems or delays occur that are borne by the end user. For example, when a home modification is required and trade delays impact on the individual who has to find interim measures themselves, generally with significant financial and emotional hardship.

We do not support benchmark price setting, as indicated above: price setting should occur as a joint process between government and providers in the first instance. Agreement needs to be reached as to what is and is not included in the price build, including some capital and infrastructure costs, for example research and service development, and risk management.

Regarding compliance, the costs of compliance to regulatory standards have already been borne by registered providers in Victoria. It is important that any regulatory burden be equal nationally across providers, including during the Launch period. Equally, mutual recognition of existing quality systems in other sectors in relation to a national disability quality framework, is important to mitigate multiple compliance requirements.
Option 3: Choice limited only in higher risk circumstances

We support the higher level of protection for participants whose support needs, functioning or social circumstances place them at higher risk and, as in Option 2, clear and comprehensive definitions of the features of high risk are required. However, this option misses the potential for increased vulnerability for participants and carers at the lower risk end of the spectrum, resulting from a more competitive and expanded market and increased freedom of choice, especially in the absence of accurate and consistent quality outcome measures. Safe-guarding should not be minimised, nor reasonable guarantees for the expenditure of public funds. This option assumes people have the time and mechanisms to sift through supplier information and are able to make effective comparisons, and at this stage we are concerned that the benefits to participants are over-stated under this option. There is a need for comprehensive preparation for participants and their families to use this model.

The benefits of this option may be more realistic when the scheme is mature but it requires a managed and gradual transition process for participants and their families. As discussed in Options 1 and 2, we believe there is also a need in this option for block funding of not only general coordination but specialist information and coordination, even at early stages of the disease, to help individuals achieve the best outcomes from their support choices.

Option 4: No limit to choice

A vulnerable client group needs appropriate conditions to help manage their risk in terms of quality assurance, protection, and outcomes. We do not support this option as it does not recognise the need for safeguarding and has the potential to create exploitative or unsafe arrangements. Neither does it provide assurance of appropriate expenditure of public funds. In this instance, any balance between choice and protection is missing.

SUMMARY

The four options presented cover a wide spectrum; from full protection through regulation, to no specific protection. Our view is that the balance between choice and protection is best achieved at this beginning stage of the NDIS by Option 2 iii, regulation based on risk, including elements of block funding as described above to ensure the retention of specialist functions essential to good client outcomes for people with progressive neurological diseases. In preferring this option, we emphasise the importance of linking risk to the capacity of the participant (or their social support) to recognise, understand and manage their risk, as well as the risk level of the support being provided.
Flexible implementation is important; regulation needs to be able to accommodate trialling and adjusting to the individual circumstances if need be, without the individual having to go back to the beginning of a process or queue for reassessment.

If Option 3 were to be implemented because of its greater emphasis on choice, there should be a gradual transition to this higher level of deregulation to ensure that participants and families are adequately prepared and not adversely affected in navigating the market place.