



Response to the National Disability Insurance Scheme Regulatory Impact Statement 2012

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Neurological Alliance Australia

Alzheimer's Australia
Brain Injury Australia
Friedreich Ataxia Research Association Australasia
Huntington's Australia
MND Australia
Multiple Sclerosis Australia
Muscular Dystrophy Australia
Muscular Dystrophy Foundation
Parkinson's Australia
Spinal Muscular Atrophy Australia



Introduction

The Neurological Alliance Australia (the Alliance) is an alliance of not-for-profit peak national organisations representing adults and children living with progressive neurological and neuromuscular diseases in Australia.

The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment. The Alliance represents over 500,000 Australians living with progressive neurological or neuromuscular conditions that have no certain cure. This group includes adults and children, carers, families, friends and workmates whose life is, or has been, affected by a progressive neurological condition. The impact of progressive neurological conditions on people and families can undermine their resilience to remain purposeful and in control of their lives and prevent financial and emotion burden.

The Nature of Progressive Neurological Disease

Progressive neurological and neuromuscular diseases (PND) are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, different disease trajectories and life expectancy, all are degenerative and incurable. This results in significant disability, grief and need for expert care and personal assistance.

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: indeed people living with PND have a high rate of social and financial disadvantage.

The age of onset and rate and pattern of progression vary between individuals affected by this group of diseases. Onset in young adulthood or middle-age can cause the early loss of employment for both the person diagnosed and their carer. In many cases relationships fail, causing further isolation and increased reliance on social services. Therefore, the impact of this group of diseases on individuals and families must be taken into account when considering any intervention or policy regarding service delivery.

Timely early intervention, specialist planning and assessment and coordination of care, including a proactive framework for decision-making, play vital roles in the prevention of crisis and avoidable hospital/residential aged care admissions. Appropriately targeting financial and social supports early in the disease, before significant evidence of functional disability, will support people to maintain relationships. In turn they will retain 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.

The National Disability Insurance Scheme Regulation Impact Statement

The introduction of a National Disability Insurance Scheme (NDIS) has the potential to transform the lives of people living with progressive neuromuscular and neurodegenerative diseases by offering more choice and responsive funding that enables access to services and allows for incremental support as a person's circumstances change.

As the Alliance represents people living with a variety of conditions no one option will meet the needs of all client groups. To support this client group to exercise choice and control in pursuit of their goals the NDIS design will need to include individualised, specialist, disease-specific information and assessment processes to support informed choice and a client focused risk management strategy.



The key considerations of Regulatory Impacts for people with PND:

Consideration 1:

Regulation must recognise the different life narratives and processes of disability.

Consideration 2

Specialist involvement is imperative to understanding disease processes and different forms of disability. Support options must be determined by a person's social context, their care plans and prognosis/trajectory of disease.

Consideration 3

Block funding the services provided by specialist organisations will ensure provision of individualised, accurate, disease-specific information to assist people to make appropriate choices and to support positive early intervention outcomes.

Consideration 4

For people with PND it is more appropriate to emphasise participant risk and the capacity of an individual to assess and manage risk through assessment of cognition and insight, physical functionality, and level of social (informal) and family involvement.

Consideration 5

People with PND need access to a range of specialist/professional services – these should 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).

Consideration 6

Assessors, case managers, attendant care service staff etc will need education and training to understand the specific characteristics of these diseases and how to work in partnership with the individual to ensure care and support to meet their changing needs.

Consideration 7

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

This option is simple and will provide security and protection to participants and services. It does not however progress the social reform intended by the NDIS; that is, to increase choice and control for people with disability.

A key function in this category is the provision of individualised specialist information and support at the time of diagnosis and as needs changes. There is a case, therefore, for block funding the services provided by the specialist disease-specific organisations that the Neurological Alliance represents. Accurate, disease-specific information is paramount to people making appropriate choices and is 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. Provision of disease-specific education and training to providers will also be a key role for specialist organisations under an NDIS and most organisations are well placed to roll out flexible and responsive training options in a timely manner.

Option 2: Choice from providers that meet regulatory standards

This option makes clear the tension between minimising risk and increasing individual choice. This option increases choice and control through the allocation of nationally portable, individual support packages and thereby encourages innovation and a market approach.

The absence of the block-funding under this option, however, is a concern and could limit access for people with PND to individualised specialist information and support to assist them to make informed choices at diagnosis and as the disease progresses and their needs change.

Of the sub-options outlined, number **iii** allows for regulation based on risk. This option would provide for a client focused approach to risk management; however, the point of reference for our client groups should primarily be client capacity and family/social support considerations, rather than the nature of the support. Individuals with cognitive impairment or with declining executive functions may be compromised in their decision-making about basic supports and therefore will benefit from safeguards even for basic 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.

Option 3: Choice limited only in higher risk circumstances

This option provides little protection and has potential to place people with PND who have complex and progressing needs at higher risk. Option 3 assumes people will have the time and mechanisms to sift through supplier information to make effective comparisons and informed choices.



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

This option more so than option 3 has potential to lead to poor outcomes for people with PND. This client group is vulnerable and needs appropriate conditions to help manage their risk in terms of quality assurance, protection and outcomes. This option does not recognise the need for safeguarding and has the potential to create exploitative or unsafe arrangements.

Conclusion

The Alliance is pleased to have had this opportunity to outline our views on the NDIS Regulation Impact Statement 2012 and we look forward to further discussion of any of the matters raised. The Alliance gives permission for this response to be made public and we are more than willing to participate in any hearings or community consultations.

For further information Carol Birks can be contacted at 02 9816 5322 or 0408 461 932.