



Response to the National Disability Insurance Scheme Bill 2012

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 that is needed to remain purposeful and in control of their lives and prevent financial and emotion burden.

Progressive neurological and neuromuscular diseases 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 National Disability Insurance Scheme Bill 2012

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 responsive funding that enables access to services and allows for incremental support as a person's circumstances change.

The Alliance is therefore pleased to have the opportunity to comment on the NDIS Bill 2012, which is fundamental to the implementation of the NDIS.

The key recommendations of the Alliance are as follows:

Recommendation 1: The NDIS Bill 2012 is to be accepted as a substantive solution to the chronic unmet need for early intervention and lifetime care and support services;

Recommendation 2: The NDIA draws on the expertise of organisations such as the NAA to fulfil the Agency role outlined in the NDIS Bill 2012;

Recommendation 3: People diagnosed with rapidly progressive neurological diseases must be eligible for and have access to NDIS services including, in some cases, support after the age of 65;

Recommendation 4: People diagnosed with rapidly progressive neurological disease must be eligible for and have access to early intervention services across disease transition changes;

Recommendation 5: People with rapidly progressive neurological and neuromuscular disorders should be able to access qualified, experienced assessors to assist them with their individual service plans;

Recommendation 6: The NDIS Bill 2012 should include reference to the inter-relationship of the NDIS and the aged care sector with relation to individual service plans and budgets.



General Principles

The Alliance supports the general objects and principles of the NDIS Bill 2012 given they relate closely to the key objectives of the Alliance; that is:

- To support the independence and social/economic participation of people with progressive neurological and neuromuscular disorders;
- To enable people with progressive neuromuscular and neurodegenerative diseases to exercise choice and control in the pursuit of their goals;
- To provide a broad range of supports to people with a progressive neuromuscular and neurodegenerative disease;
- To promote early intervention in order to reduce the economic and social burden as well as improve the quality of life of the individual and their carer;

These principles will go a long way towards providing an appropriate support structure for people in need of urgent and sometimes complex support services following a diagnosis of a progressive neurological or neuromuscular disease. Early intervention will assist people diagnosed with this group of diseases to plan ahead, maintain employment and to remain as independent as possible for as long as possible.

Recommendation 1: The NDIS Bill 2012 is to be accepted as a substantive solution to the chronic unmet need for early intervention and lifetime care and support services.

The Role of the National Disability Insurance Agency

Given that the Agency may provide coordination, strategic and referral services to people with a disability, the Alliance calls for ongoing engagement between the Alliance and the Agency in order that:

- the needs of people with a progressive neurological and neuromuscular disorder are appropriately understood;
- the Agency is able to draw on the extensive body of evidence (research, evaluation, pilots and practice examples) in the sector;
- the Alliance can provide the Agency with appropriate information, education and training, volunteer support, assessment and referral guidelines.

Recommendation 2: The NDIA draws on the expertise of organisations such as those represented by the Neurological Alliance Australia to fulfil the Agency role outlined in the NDIS Bill 2012.

Participants

The Alliance is satisfied that people with a progressive neurological and neuromuscular disorder are included in the definition of eligibility provided in Chapter 3, sub-section 24. However, we hold some concerns about the age requirements in sub-section 22. Although we are aware that the NDIS is not designed to support the needs of people who are ageing, the aged care system in its current form is unable to appropriately meet the disability needs of people diagnosed with rapidly progressive neurological diseases. As people with a progressive neurological condition age, their care needs typically increase because of disease progression rather than ageing. As such, the Alliance proposes that specialist disability services need to be available to support older people with complex needs created by disability.



Recommendation 3: People diagnosed with rapidly progressive neurological diseases must be eligible for and have access to NDIS services, including, in some cases, support after the age of 65.

Early Intervention

Significant costs can accrue for many of people with a progressive neurological and neuromuscular disorder. However, there is evidence to support the notion that timely and targeted financial and social supports offered earlier in the disability, and at times of disease transition or change, may help to retain relationships, sustain informal care and social supports.

Recommendation 4: People diagnosed with rapidly progressive neurological disease must be eligible for and have access to early intervention services across disease transition changes.

The Alliance also seeks further clarification be included in the NDIS Bill 2012 regarding the ability of the Agency to prescribe or apply criteria to disability requirements and/or early intervention requirements.

Principles relating to Individual Service Plans

The focus of the NDIS Bill 2012 in maximising choice and independence of individuals with a disability is to be applauded. The dual focus on a person's goals and aspirations as well as the practical supports required to help them fulfil these means that individual service plans (ISPs) should be well balanced.

However, assessors involved in creating ISPs must be cognisant of the importance of disease-sensitive and ongoing assessments that are undertaken by experienced practitioners. Assessment tools must be sensitive to the diversity of the groups/clients and assessors must have access to the right assessment tools – which should be sensitive to the fluctuations, progression and 'hidden symptoms' of an individual with a progressive neurological and neuromuscular disorder. Assessors must also be trained and informed around specific disease processes and diversity within groups.

Recommendation 5: People with rapidly progressive neurological and neuromuscular disorders should be able to access qualified, experienced assessors to assist them with their individual service plans.

Equally important is that the process for triggering the creation of a new plan is simple, timely and responsive. The ability to easily instigate a new plan (described in Chapter 3, sub-sections 47-48) is imperative for people living with a progressive neurological and neuromuscular disorder, where goals, aspirations and needs can change rapidly as the disease progresses.

Lifelong seamless anticipatory care

The Alliance supports the notion that people with progressive neurological conditions should continue to receive seamless care and support throughout their life journey. For this to occur, there must be cross-sector engagement and funding to facilitate timely, coordinated inter/multidisciplinary care and to reduce duplication and crisis management.



However, the Alliance is concerned that the NDIS Bill 2012 has not made reference to the process through which a person receiving NDIS funding will transfer to the aged care system at the age of 65. Not only is the aged sector still significantly underdeveloped in terms of individual service plans (with a stronger focus on consumer-directed care principles which are adapted to fit existing residential aged care and community care programs) but there are many disability services that are not as easily accessible to those in the aged care system.

The Alliance therefore calls on the NDIS Bill 2012 to include some reference to the fact that people diagnosed with rapidly progressive neurological diseases have equal access to needs based care and support even after they reach the pension age.

Recommendation 6: The NDIS Bill 2012 should include reference to the inter-relationship of the NDIS and the aged care sector with relation to individual service plans and budgets.

Conclusion

The Alliance is pleased to have had this opportunity to outline our views on the NDIS Bill 2012 and we look forward to further discussion of any of the matters raised. We are more than willing to participate in any hearings the Senate Standing Committee on Community Affairs