NEUROLOGICAL ALLIANCE AUSTRALIA

Alzheimer's Australia
Living with dementia

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Key responses from Neurological Alliance Australia (NAA)

Neurological Alliance Australia (NAA) congratulates the Productivity Commission on the breadth and depth of this draft report. Recognition that the current disability support system be totally reformed as it is "underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports" is welcomed.

The proposed framework for a national disability insurance scheme will go a long way in providing an appropriate support structure for people in need of urgent and complex support services following a diagnosis with a progressive neurodegenerative disease (PND).

The recognition in the report of the need for:

- early intervention for people with PND
- an assessment process that can anticipate changing need
- effective protocols for timely and smooth referrals to and from the different sectors

is integral in providing disability support for people diagnosed with PND.

1. Funding responsibilities of the aged care and disability sectors

The report states that the needs of those who acquire a disability after age 65 would be best met by the aged care system. This is not the case. Most people with progressive neurological diseases over the age of 65 will need services from both systems.

NAA asks the commission to ensure that all people with a disability will be eligible to seek support from the new system in response to the needs created by their disability. People must have access to address disability related needs no matter the age they acquire those needs.

The option for the disability sector to fund services for people up to the pension age and for the aged care system to fund services for people over the pension age is a simplistic approach that denies the complexity of support required by people living with a progressive neurological or neuromuscular condition. A bridge of continuity of support service funding is imperative. People must be able to access services from both sectors to meet their needs irrespective of which sector is responsible for funding the package of care.

The draft report suggests that those who acquire the disability before aged 65 can elect to either stay with NDIS or transition to aged care services when they turn 65. This will mean that NDIS recipients will be able to purchase or acquire the equipment they need, but someone who acquires a disability over 65 will be left to Aged Care for a response.

The Productivity Commission review on Aged Care makes no provision for the supply of the full range of disability aids and equipment for people over 65. This will be a significant gap which must be addressed by the Commission’s report on Disability Care and Support.

The existing Aged Care funding system does not provide adequate funding to support most people with progressive neurological and neuromuscular disease who wish to remain living at home assisted by their family and partners. The existing system provides limited support for people to remain at home and, when that support is inadequate, only offers residential care in high care settings.

To achieve lifetime care and support in their chosen setting people need to be able to access services based on needs related to their disability and their age.

The draft report proposes establishing no-fault lifetime care and support for all catastrophic injuries. The scheme established for this purpose would be the national injury insurance scheme (NIIS) which would operate alongside the NDIS. The commissions view for people over the pension age who have a catastrophic accident related injury is that the NIIS would fully fund people's support needs attributable to the injury and that the aged care system would meet any ageing related care and support costs as the person grew older.

A similar approach could also be taken for people over the pension age who acquire a disability that is not a normal part of ageing.

2. Early Intervention

NAA congratulates the commissioners on their acknowledgement of the importance of early intervention for those newly diagnosed with PND. Early access to information and counselling creates a solid base upon which the needs of people diagnosed with degenerative disease can be addressed through appropriate levels of support. Anecdotal evidence indicates that preventing crisis phases in care delivery is an effective mechanism to address needs and maintain quality of life whilst reducing the need for services and support.

For people with PND, early intervention must include immediate access to assessments and initial low care services through the scheme as well as counselling and information. Varying levels of service support will ensure that people newly diagnosed with degenerative disease have access to services based on need from diagnosis onwards and with the knowledge that services can be rapidly increased as needs change. A seamless approach to service provision and better support for the family carer is the most effective and efficient use of resources for people living with progressive neurological disease.

3. An end to falling between the gaps of service provision

Draft recommendation 3.4 acknowledges the need for MOU's with health, mental health, aged and palliative care to ensure that people do not fall through the gaps of the respective schemes and have effective protocols for timely and smooth referrals. Evidence confirms better outcomes for people living with progressive neurological and neuromuscular disease who are able to access inter/multidisciplinary – they live longer and have a better quality of life. Coordination is therefore critical for people living with progressive neurological diseases who currently consistently fall through the gaps of service provision.

A national pathway of care for people with progressive neurological and neuromuscular disease is vital in streamlining referrals to and from the health and disability sectors and palliative care and ensuring swift access to the NDIS. The NDIS should draw on the expertise and experience of the disease specific organisations and innovation funding to develop these pathways.

4. Individualised supports funded by the NDIS

A national and timely approach to the provision of disability services is welcomed by the NAA. In particular the full funding of home and vehicle modifications and aids and equipment, including communication aids, is a positive outcome of the proposed scheme as is the inclusion of PEG feeds. We would also see a range of other products being similarly funded for people with a progressive neurological or neuromuscular condition such as non-PBS medications, dietary supplements, non invasive ventilation and personal alarms,

5. Role of the assessment process and case managers in the context of an NDIS

We congratulate the commissioners on acknowledging the need for the assessment process to anticipate changing need. A fast track process for people with rapidly changing needs is imperative.

The interim report proposes that the NDIA employs case managers and engages independent assessors to establish needs and design service programs. The commissioners will need to consider how this model will build on the experience and expertise of existing aged care assessment teams and disability service assessors and case management and care coordination services. Consideration should be given to the NDIA decentralising these roles and integrating them into a strengthened Disability Support Organisation (DSO) model, thereby utilising agencies who are hold the specialist knowledge around coordination and case management for specific groups, such as people with progressive neurological and neuromuscular conditions. This not only puts the coordination and dynamic care management closer to the individual and their family, but ensures that specialist knowledge, expertise and experience related to lower incidence diseases and disabilities is not lost. It will be almost impossible for the NDIA to hold expert knowledge remotely for every disability and injury type.

Under the proposed arrangements model the quality of the briefing to assessors from NDIA officials will in large part dictate the longer term outcomes, and open up risks of conflict with clients that is seen in no-fault environments that do in-house case management.

The NDIA/S needs to fully utilise the expertise and experience of the disease specific organisations to develop national guidelines for neurodegenerative assessment and case management. As described below, this can be achieved through a well articulated (contracted) partnership approach with specialist DSO. Integrating decision making across the funding and DSO levels will be expected to reduce risks around articulating services to meet identified individual need, scheme viability and over-dependence on the scheme.

Assessment for carers is a welcome inclusion - carers are integral to the care and support of people living with progressive neurological diseases and invariably provide a large share of the care thereby reducing costs to the health and residential aged care systems. Assessment and funding of their needs will enhance the support of people with disabilities.

The NDIA assessors and case managers will need to understand progressive neurological disease and the impact of progression and rapidly changing needs. Disease specific organisations can play a vital role within the proposed NDIA in the provision of tailored education and information to stake holders, as well as effective case management and coordination.

6. Disability support organisations

The role of specialist disease specific organisations and whether the Disability Support Organisations (DSO) would include existing specialist disease specific organisations is unclear in the report. It is essential that NDIA utilise the existing knowledge, expertise and experience of specialist disability agencies to ensure that the unique issues related to progressing and escalating needs in low incidence diagnoses and disabilities is not lost.

Neurological and neuromuscular disease specific organisations are ideally positioned to take an active role within the proposed NDIS. These organisations are trusted advisor's to their clients, have strong relationships with them, understand their challenges, have expert knowledge and are well positioned to scale up activity to enhance services within a broader context and to the required level. To introduce another entity would be to duplicate and to only introduce another layer for clients, and create confusion.

The Alliance agrees strongly with the need for an intermediary layer in the scheme and the concept of the DSO.

While the DSO role has been expressed largely as a financial intermediary in the draft report, the Alliance believes that the role of the DSO should be strengthened to enable them to provide a major influence in the community as well as the provider market.

As we said in our original submission people living with a progressive condition generally want to remain closely connected with their professional, family and friendship networks, and not become defined by their disability and characterised by a dependent service user status. A DSO that has responsibility for community connections as well as service packaging will be able to better balance citizenship with service usage than leaving it separately to individuals, providers and/or bureaucracies.

In a lifetime support context assessments can be linked to dynamic service plans and keep up with the sometimes rapid changes that occur for people in this group without becoming disjointed and intrusive. The trust of individuals in skilled DSO's will be a major success factor in the ongoing management role.

Even with one funder for disability services, the service system for people with a neurological impairment will still be relatively complex, with people needing to access a range of health and community services, information and family support. Detailed work will need to be done at the individual level to design and coordinate services across program areas, as well as systemic work to define and negotiate the service pathways.

At both the individual and systemic levels the skills that exist in the disease specialist agencies will be required in an ongoing way to complement the funding and service provision resources. We think that the NDIA has an important role in developing overarching protocols to link people with mainstream services (4.24), it will need specialist DSOs to provide technical advice as to the machinery required to make these connections effective and efficient.

The DSO would operate best by being a not-for profit organisation taking on the key care management and coordination role which is are best done close to the individual and their family. The mission driven nature of NFPs would provide a useful safeguard in the proposed marketplace against commodification of individuals by providers.

As the care coordination/lifetime support management sits with the DSO, the NDIA key function becomes claims management. We would not envisage the DSO being a fund holder (perhaps other than some restricted brokerage for immediate non-recurrent assistance), but would package up plans for approval by the claims manager. Working together, the two functions could jointly manage the tensions around client need and scheme viability, while having a role in assisting in supporting essential informal care arrangements (peer and carer support, volunteers, community networks). The alliance believes these informal connections are priceless for this group and should not be lightly given up or usurped by paid services.

In an enhanced role for the DSOs, individual roles should include:

- Case planning, coordination and lifetime care management
- Jointly managing assessments with the ‘claims’ manager in the NDIA
- Carer support and advising on community networks
- Provider management vis-à-vis care plans
- Secondary consultancy for providers
- Information and advocacy
- Financial intermediary services
- Service procurement

Wider community roles should include

- Training and awareness
- Tertiary consultancy
- Information
- Service development and innovation in service design
- Community Development
- Peer support
- Provider management
- Research and evaluation

The range of collaborative care projects delivered by neurological organisations (Collaborative Care in Motor Neurone Disease (VIC) , Continuous Care Pilots (Vic and NSW) and the Neurodegenerative Conditions Coordinated Care Program (WA) would be impossible to do without the skills and expertise that resides in these organisations, and long term their coordination and integration role will be critical to a system that is structured primarily as a market.

6.1 Specialisation of DSOs

The provision of effective lifetime care management requires organisational specialisation and a mandate to effect change across the community and with service providers. This is a particularly important issue for people with PND because of the complex and dynamic nature of the conditions, but is an issue for other groups with proposed eligibility for the NDIS and NIIS. It is essential that the specialist skills reside in a sector that is accessible from above (the scheme), below (providers) and across (the community). The placement of people with PND in the early intervention group means that a lifetime support approach needs to be applied that is fundamentally distinct from claims management, and one that can bring in different expertise with different intensities at different times to assist individual and to maximise service delivery efficiency.

Particular skills required include

- knowledge of lifecycle disease/disability (clinical and social)
- the ability to assess client needs and create, implement and evaluate practical service plans
- be able to assist individuals to integrate professional advice into their lives
- be able to advocate effectively
- be conversant with the operation of the wider service system and companion programs
- service development and networking

6.2 Funding of Disability Support Organisations

With the dual roles of individual lifetime care and support management as well as community/policy development, the DSO could be jointly funded through by State/Territory Governments and the NDIA. The funding for DSOs would need to be a mix of block funding and fee for service funding, to reflect the different roles that they need to perform.

DSO's would be essential to the operation of all proposed tiers in the NDIS, as they would be in a position to work with the NDIA and governments on disability awareness, create and manage the cross sector pathways needed for tier 2, and to negotiate sometimes complex arrangements for people in tier 3. The movement of individuals across all 3 tiers will be a feature of a well functioning NDIA.

Governments would have an interest in strong and influential DSOs to achieve good citizenship outcomes for people with a disability and to get policy advice in the companion portfolios to the NDIA. The NDIA could fund DSOs via fee for service arrangements via individual packages where individuals select a DSO to perform the financial intermediary role to broker services.

6.3 Individual choice

The expanded DSO role would enable individuals to opt in to the level and types of supports they require, from simple information, through to financial intermediary services to comprehensive lifetime support management. Many of the services provided through the DSO should not be 'for sale' to individuals as the types of community supports should not be only available on a financial transaction basis. The DSO would also be available to people not eligible for the scheme (tier 2).

6.4 Advocacy

The practice of advocacy would substantially alter under the proposed arrangements. In a fully funded environment the imperatives of the independent advocacy we have in Australia would be less about service access and more about system compliance, provider behaviour, policy gaps and systemic change. It would be important to retain an independent advocacy sector for human rights compliance across the community.

The DSOs would assist individuals to negotiate with providers, broker agreements and plans with the NDIA, assist in reviews of decisions and advocate for service access outside the NDIA provider market.

7. Research

The NAA welcomes the discussion about Research in the interim Report. Scientific, clinical and applied research are core parts of the overall response to progressive diseases in Australia. While the NHMRC is the key body to fund basic scientific research, there is a significant gap in the ability to undertake translational research that can result in changed clinical offerings or service design.

The NDIA will have a strong business interest in investing in research to inform the operation of the scheme and improve the effectiveness and efficiency of funded offerings. It needs to create a rigorous and comprehensive research function that can be a companion program to the NHMRC, the ARC and FAHCSIA as well as the research programs of the TAC and the Motor Accident Authority. The recent example of the Victorian Neurotrauma Initiative in Victoria ($65m over 5 years for brain and spinal cord injury) has shown how a targeted research program can generate significant activity and benefit in areas that are a relatively low priority for the NHMRC - www.vni.org.au

There is not a culture of evaluation in Australian disability services, and the NDIA offers an opportunity to develop a system where evaluations are a routine part of the cycle of funding and service provision. This is essential for measuring value for money and long term clinical and social outcomes.

The three approaches (in-house NDIA activity, contracting to universities and the establishment of a disability research institute) canvassed in the Interim Report are all important components of an overall research strategy and the scheme needs to implement all 3 options as part of its structure.

- The NDIA will need to do research in-house to test and evaluate new program proposals, new products and treatments, administrative arrangements and intra-scheme relationships. The NDIA will also need to collect and analyse data related to the scheme and its use. NDIA funding agreements can include requirements for service and program evaluation for all services funded, including those individually purchased (and more informal service transactions) to ensure additional rigour in the funding and service cycle.
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- NDIA research funding to universities will be needed to build capacity in the first instance (as we do not have a viable long term care research community in Australia) and to target program funding. The increasing number of high quality research project submissions to the NHMRC in the neurological and related disability area demands that the NDIA take an approach that can fund those projects that miss out on NHMRC funding but have a direct bearing on the scheme.

  This would create the additional benefit of bolstering the Australian research industry by enabling the growth of expert centres keeping scientific talent in

Australia and potentially attracting overseas investment in these areas.

- A National Disability Research Institute (as recommended in the Disability Investment Group's The Way Forward report in 2009) is a useful way of focusing attention on research in the area and to ensure effective knowledge transfer into the service sector and to individuals and families utilizing the NDIS and NIIS. Such an institute can also assist the NDIA in its ambitions to strengthen the disability workforce, engage in Tier 1 disability awareness campaigns and engage with industry.

Given the scale and national penetration that the proposed NDIA would have in the Australian community it may well be worth investigating the feasibility of establishing a Co-operative Research Centre for Long Term Care. The CRC structures demand industry participation, knowledge transfer and commercial returns, all of which would complement the long term aims if the NDIA and the sector at large. It may be that the National Disability Research Institute becomes a partner in a CRC in the longer term.

8. Scheme Governance

The NAA recognises the need to apply business principles to the governance of the schemes as described in the Interim Report. From various discussions and reading of new submissions to the inquiry, the NAA believes that consideration needs to be given to a permanent role for State/Territory Governments in the governance structure.

This would make them genuine stakeholders in the scheme and improve the cross program linkages that are so important to the viability of the NDIS, and also hopefully improve the chances of success in the negotiations with them over the transition to an NDIS.

The scale and value of the NDIA schemes warrants the establishment of parliamentary standing committees at State, Territory and Federal Government levels. This would entrench the schemes (and disability and caring more generally) firmly in the public policy life of Australia.

9. About Neurological Alliance Australia

The Neurological Alliance Australia (NAA) is an alliance of national not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life for people living with these conditions and funding to support research.

People living with progressive neurological or neuromuscular conditions includes adults and children who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates and any other person whose life is, or has been, affected by a diagnosis of a progressive neurological or neuromuscular disease.

Progressive neurological and neuromuscular diseases are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, all are degenerative and incurable, resulting in significant disability, grief and need for expert care and personal assistance. A large number of diseases and diagnoses are represented by this definition, and include Huntington's disease, motor neurone disease, Alzheimer's disease, Muscular Dystrophy, Multiple Sclerosis, Parkinson's disease, Spinal Muscular Atrophy and Freidrich's Ataxia to name a few.

In most cases the cause of these diseases is unknown and there are no effective treatments and no cure. Optimal care and support is therefore vital whilst research is promoted and funded to find the causes, effective therapies and ultimately a cure.

Neurological Alliance Australia welcomes this draft report and is available to provide further information if required.

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