Response to NDS discussion paper, ‘The Place for Block Funding in the NDIS’

Submission to NDS from the Neurological Alliance Victoria

Submitted Wednesday 22nd January 2014 by Deborah Farrell on behalf of:

Rodney Harris – CEO MND Victoria
Sharon Strugnell – CEO BrainLink Services
Emma Collins – CEO Parkinson Victoria
Robyn Hunter – CEO MS (ACT / NSW / VIC)
Graeme Shears – CEO Epilepsy Victoria
The Place for Block Funding in the NDIS

The following comments are from the Neurological Alliance Victoria.

The Neurological Alliance Victoria is made up of:

- MS (ACT/NSW/Vic)
- Parkinson’s Victoria
- BrainLink Services
- Epilepsy Foundation
- MND Victoria

Our focus is on the support of people affected by neurological conditions and progressive degenerative disease that creates disability¹.

We would like to affirm support for the NDS’s action in placing the need for block funding from the NDIS on the agenda for discussion.

The following comments are structured around the two objectives and six streams identified in the NDS paper. We have addressed each stream separately noting there is interdependency enabling the principles of individualised services that support the exercise of choice and control to be realised.

To manage the future liability of the NDIS

1. Invest in timely information, advice and community development support

We affirm support for the recommendation by NDS that timely information, advice and community development support should be block funded as it can reduce the financial impact on liabilities.

We represent a cross section of urban and rural services, big and small, community and hospital based and the majority of our clients are not yet NDIS participants.

We acknowledge that at the moment the NDIA is focussed on clients in Tier 3 requiring high intensity supports. We are very interested in progressing the discussion for the majority of our clients who are sitting in Tier 2 who require incidental/ad hoc/not high level/targeted supports.

We strongly believe that investment in timely information, advice and community development support in Tier 2 will reduce/avert the need for intensive crisis centred information, advice and support and navigation/complex case management for our

¹ Note that terminology is different in organisations – while some refer to “disease” causing disability, others may refer to “conditions” causing disability. Similarly, some neurological conditions are progressive and degenerative, while others may be episodic. Both create disability which requires an effective response
neurological cohort. Furthermore we believe that access to support in Tier 2 will keep neurological clients out of Tier 3 and reduce/ avert the need for intensive and costly services and the associated financial liability.

The early signs of financial pressure and the slower throughput through the scheme are worrying. We acknowledge that the neurological cohort are ‘sleepers’ and we believe we have the collaborative intellectual property to prosecute the case for Early Intervention for the neurological cohort to assist the NDIA manage the liability. One of the levers is access to therapy, prevention and wellbeing – lower cost interventions now - to reduce future need for day to day high cost services such as attendant care, equipment and home modification, transport. Early intervention services will allow economic and social participation and a simple example is the approach to fatigue management for MS where air-conditioning and cooling vests are simple measures that improve job retention. Other examples of Early Intervention supports include symptom management to alleviate the impact on functional capacity, or prevent deterioration – avoid the avoidable. In some cases early intervention supports may improve functional capacity. The key question is what will be funded for Early intervention supports under Tier 2 and what is not more appropriately funded by other sectors. We are very keen to be at the table for discussions as the focus shifts to Tier 2.

We have a strong track record of genuine collaboration and information sharing. With ongoing support from the NDIA we will conduct surveys of those clients accessing the information service as well as other health professionals in the area and produce an evaluation report on role and efficacy of information exchange.

There are examples of intense financial risk and costs facing the NDIA that rely on information exchange. These risks and costs can be addressed by accepting the practical on the ground experience and understanding of the challenges facing clients which our specialist organisations have developed and share as a reservoir of knowledge and collective experience in the specific disease/condition and associated disability. Information is generated through the increasing knowledge and expertise of staff, who develop many years of experience in a relatively narrow diagnostic area/ lower incidence diseases. There is significant value adding for the person, their family and service providers when they have a good understanding of the disease/condition and the related disability it has and may create in the future as it progresses.

There are a variety of modes of delivering personalised information and all are relevant to different diagnoses. For example, the one to one approach undertaken by MND Victoria involves the MND Regional Advisor visiting the family, sharing information requested by them, and ensuring that it is in the context of the family. The Regional Advisor is well trained and highly experienced in MND, and is able to address issues that arise in the conversation that go beyond the specific issues discussed. They can also respond to information requests that arise from the person or their family, and offer alternative information processes for friends, colleagues and other people in the community that form a team around the person.

It is essential that information provision for other service providers be supported. The context of delivering support for people living with low incidence progressive diseases/conditions causing disability is as important as the service being delivered. The unique issues surrounding each diagnosis impacts on the way services are delivered and the confidence of staff.
Our experience is that understanding of these diseases/conditions and disabilities declines significantly when services do not have a reasonable number of clients supported over time. There is limited knowledge retention, and that which is retained tends to be very general and not beneficial to addressing the needs of individual clients. Services need to have education, training, information and support for a specific client and their needs – such education, information and support needs to be personalised for the client and the staff, address the unique needs of the client within the operations of the workplace, and provide information and support on call where the client is known to both the specialist disability organisation and disability service provider.

Where a neurological disease or condition is episodic, the level of disability and support required from NDIA may vary over time. Continuity of support and expertise that maximises the individual’s functioning and participation in the community is essential.

2. Support ongoing production of social capital

Effective recruitment, training, support and coordination of volunteers are essential elements in enhancing community investment in disability services.

Investment via social capital is essential to underpin the value added services that are provided within disability services for people with disabilities. The roles undertaken by volunteers provide significant value for people with disabilities.

There is a substantial dependence on the use of volunteers not only to support the various functions of an organisation but more importantly the value reported by NAV constituents of volunteer lead supports such as Peer Support groups (F2F and through technology) - sharing the lived experience and increasing the communities awareness.

The maintenance of volunteer investment requires and demands appropriate coordination and support through dedicated staff focussed on ensuring that all volunteers are respected and valued, protected through safe practices and training, and that their valuable time is allocated and properly managed.

Block funding for this role is essential.

3. Seed innovation, research, and evaluation to identify and build good practice

Neurological Alliance Victoria (NAV) members work across a number of systems, including disability, aged care, health, mental health, palliative care, children and education and have vast collective experience in managing and developing the interfaces between these systems.

In parallel to service provision, perceived unmet need has frequently been a driver of collaboration between neurological organisations and there are many examples where NAV have come together around key practise to ensure that a ‘whole of life support’ is available to people with neurodegenerative conditions who need it, and so that these interfaces work seamlessly to provide efficient and effective support at the best/lowest cost to government and the community.

An example of where interface issues are being focussed on is with NAV members, Calvary Health Care Bethlehem, Barwon Health and the Department of Health (Victoria) have been expanding on an established and unique developmental program for people
with progressive neurological conditions to create pathways between acute, sub-acute and community based services. The focus of the program is to identify people at risk of acute care placement and to identify and implement interventions that will help them remain living at home with their needs addressed by their local communities wherever possible, thus reducing the underlying costs to service delivery sectors.

A further example - BrainLink, through a 12 month pilot project at Royal Melbourne Hospital, is establishing Community Liaison positions in major hospitals. The focus of the program is to develop effective working relationships between community services, medical teams and allied health, generate an effective referral system to community services, and provide education and referral to community providers. It will improve patient care by developing methods of support for patients and families whilst in hospital, ensuring patients do not fall through ‘the net’, and providing support, advocacy, and a point of contact for the patient and families through their journey in various hospital settings and back in the community.

Block funding to support the investment in programs and demonstrating their value and building the body of evidence to demonstrate the value for money is required.

We should be exploring models of care including those from overseas which could be considered for trial in Australia. This will provide a body of evidence that services are being developed through research, evidence and the expressed needs of customers. If these are lost through individual funding models there will be a group of future customers that will miss out at the early intervention stage. This could mean a loss of quality of life and bring forward exacerbations of symptoms and greater dependence on the system at an earlier stage.

To ensure all participants are able to exercise choice and control

4. Ensure reasonable and necessary support options where markets are thin

NAV supports this proposition.

However, we wish to highlight that “thin markets” arise when there are geographic challenges which mean there are no or a limited number of providers, and also when there is low incidence, and where knowledge of the disease/condition causing disability is low amongst services and the community.

Thin markets like these require support from organisations with the specialist knowledge and skills that come from a throughput of clients and collective experience that has been supported by a block funding approach that has supported engagement across a much larger area or State.

Thin markets also arise where knowledge of neuro-degenerative diseases or conditions in service providers (respite, home care etc) is low, resulting in a lack of context and understanding for the delivery of services.

Block funding would ensure that expert knowledge is developed and enhanced, and then shared with providers to ensure that they deliver the best possible response to the needs created by disease or specific conditions. Retention of block funding supports the development of knowledge and building a “reservoir” of knowledge and support accessible as needed. The sharing of knowledge and lived experiences help to increase resilience
that is needed for individual’s to remain purposeful and in control of their lives and minimise the disruption and impact on areas such as family roles and relationships, employment and daily functioning.

5. **Enable informed choice and expand knowledge of options**

NAV supports this proposition.

We wish to highlight the needs of people experiencing progressive neurological disease/conditions that create disability and changing responses over time to the needs created.

At and following diagnosis, people with progressive diseases/conditions creating disability require significant support to both accept and understand their newly acquired disability, and to understand the progressive and/ episodic nature and the changing needs the disability will create.

Informed choice about service options requires an understanding of the disease/condition and the needs it will create, and capacity to plan for the future. The delivery of informed choice requires personal and family support, counselling and information (see “timely information, advice and support”) but also strategic support for disability that is created and requires response before a person is eligible to become an NDIS participant.

Clearly, funding for this support is outside the current individualised funding model as it arises before the person becomes a NDIA participant, but is essential to establish good foundations of knowledge and understanding, and to enable informed choices that will delay or defer the need for participant status and for NDIS funded services.

Organisations with unique experience and specialist knowledge of the neurological disease/condition, the needs it creates, generic services available in the community and capacity to provide support to those services in relation to the disease/condition are best placed to work closely with the person, their family and the community to address emerging needs and delay participant status and the need for more intensive services.

Building the capacity of the individual person to understand their own health and specific condition and the service systems is required. The Office of the Senior Practitioner has found that only 16% of people who have an intellectual disability and epilepsy are seen by a specialist.

Building the individual’s capacity through support is particularly necessary to increase their understanding of the many options available with self-directed funding and how systems such as the health, education and employment operate.

Education for the person and family to understand their disease/condition, related disability and the treatment and support options available is essential. This will assist them to self-manage their health, dental and other needs through peer support and other mechanisms.

6. **Sustain and build service capacity**

NAV supports this proposition.

There is an ongoing need for service capacity to be available, prepared and sustained to
respond to the needs of people with neurological diseases/conditions that cause episodic and/or progressive degenerative disability.

Specialist disability organisation such as within NAV have built and developed knowledge and capability to support service providers in the unique issues that progressive or episodic disability creates. In particular, they have worked to develop relationships and partnerships with services, including aged care, acute and sub-acute health, palliative care, and services for young people, to support and guide transitions and interactions between these sectors, and optimise the person’s independence and their ability to remain living within their community.

It is imperative that the collaborative interface and the ability of the health, aged care and disability sectors work together as we know through effective cross sector partnerships that a proactive approach can reduce the impact (avoid the avoidable) if the right supports and services are provided at the right time.

Both disability and ‘mainstream’ service providers require additional support to cater for the needs of people with neurological diseases and conditions living with a disability.

The need to increase disability service sector knowledge of specific conditions and related disabilities is paramount. The majority of people employed in the disability sector have Cert III or IV in disability services but this does not adequately cover neurological conditions which are person specific condition.

The completed and reported MND Collaborative Care project (Collaborative Care in Motor Neurone Disease in Victoria –April 2009) and The Continuous Care Pilot (CCP) – partnership MS Australia (ACT / NSW / VIC) and Calvary Health Care – Bethlehem – support this.

Both the MND project and the CCP have independent evaluations and both proposed a structure inclusive of community and community services, disability and health sectors, clients, primary carers and families. The models integrated clinical care with the delivery of community support services.

Central to the models is a communication process, pathways and a coordination role that facilitates collaboration, a transfer of knowledge and effective responses from all sectors to deliver an integrated approach to disease management for the progressive neurological sector.

Conclusion

NAV is of the view that block funding for early and timely interventions is required at each condition/disease transition/change across the journey by services that specialise in diseases/conditions that create disability and is essential to optimise the benefits of the NDIS for people with these disabilities by:

- providing information, advice and support for people and service providers;
- ensuring that social capital is retained and grown in this challenging client group;
- supporting research and service development, especially in the interface areas between sectors;
- recognising thin markets in service provision, client numbers and provider skills and knowledge;
• supporting informed choice and decision making before a person becomes a NDIS participant, and
• sustaining and building service capacity.

Block funding of specialist neurological organisations is more cost effective than equipping the NDIA.

...to better ensure individuals and their family retain control and community connections with informal and generic supports, maintain economic independence, social and community interaction for as long as possible.

It is cost effective, has equitable state and national impact, and improves the effectiveness of the individualised approach of the NDIS. It is also imperative that the introduction of NDIS delivers systemic reform that consists of a collaborative interface that supports the ability of health, aged care and disability sectors to work together, that strengthens the roles for the NDIS, both within the disability sector, the non-disability and community sectors in order to be effective, efficient and sustainable.

We are available to meet with you and discuss this submission with you and other interested parties.
APPENDIX

Below is a response to one of the NDIS rule discussion papers submitted in March 2013. The relevance of including this as an appendix is that our comments and position on the need to retain the involvement of specialist providers particularly for the early intervention, linking of the multiple sectors and connecting communities and the most efficient means is block funding.

The different functions of the NDIS

Rule 1

Questions

- What sorts of general information and referral services should the Agency provide for people with disability who approach the NDIS?

and

- What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?

We endorse that the support the Agency provides must be much more than information and referral, but ensure that a mechanism exists for connection to occur and a service is provided in an appropriate timeframe. Ensuring that people are connected is necessary for all people. However this is non-negotiable for people with complex social and health needs to reduce any increased risk of poor social and health outcomes due to hidden symptom, poor symptom and support management (e.g. fatigue, changes in memory, thinking and mood), resulting in depression, reduced motivation and initiation. A proactive approach to co-ordination and follow through is imperative.

For these conditions, information must be individualised and personalised; this is a ‘light touch’ form of support which should be provided by specialist services using block funding. The Agency needs to take account of the lack of knowledge in generic services of the disease symptom management and disease trajectory of people with progressive neurological disease, such as multiple sclerosis and motor neurone disease. We emphasise that people who are transitioning out of other systems, such as hospital or community aged care, also require active support and liaison rather than simply information and referral.

The Agency workforce must have a good understanding of the roles and functions of other sectors and professional roles, and will need to develop pro-active working relationships with other portfolio areas; including health including primary care, rehabilitation and housing. It will also need to:

- Identify what is available and when, eg service directory
- Identify which is the most appropriate of what is available
- Be sure that these services are financially and quality robust
- Draw on resources and pre-existing relationships with services which have worked well for the person and their needs previously.

The Agency should not assume that there are adequate services or supports for people in other systems; and, if available, waiting periods frequently increase the risk for the person with a disability and their family. In addition, because the person with a disability and/or
their family does not always know what they do not know, or need, it is important to ensure that the process for access to coordination/service navigation is funded.

- What guidance should the rules provide the Agency about funding of persons or organisations so that those persons or organisations may assist people with disability to realise their potential, and participate in, all areas of life?

It is important to value and support organisations with specialist, evidence-based practice and experience with specific conditions such as multiple sclerosis and motor neurone disease. We strongly support the block funding of specialist organisations to undertake the assessment, planning, and local area coordination functions for people with these conditions. These organisations have national and international links to research and evidence-based practice, and long-term experience in optimising outcomes for these groups.