

Information, Linkages and Capacity Building Policy Framework online consultation

Information, Linkages and Capacity Building (ILC) is the new name for “Tier 2” of the National Disability Insurance Scheme (NDIS). It was agreed that this title better reflects the supports it would provide and removes potential for misinterpreting the NDIS as a hierarchy of supports, which was implied by the term “tiers”.

ILC is a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers, and greater community inclusion. Over time, these can reduce the demand for and level of support required from individually funded responses.

Disability Ministers have agreed on the ILC Policy Framework and have requested targeted consultations. This framework was developed by the Commonwealth, states and territories and is intended to guide the National Disability Insurance Agency (NDIA) in developing a transition and implementation strategy for ILC. This framework explores the types of supports ILC will offer, how it could be implemented and how people might access ILC supports.

ILC supports will be delivered through five streams of activity (these are further outlined in the ILC Policy Framework):

1. Information, Linkages and Referrals
2. Capacity building for mainstream services
3. Community awareness and capacity building
4. Individual capacity building
5. Local area coordination

For more information - <http://www.ndis.gov.au/document/1421>

Feedback submitted to the NDIS online from MND Australia

1. What are the most important elements of ILC?

The most important elements of the framework for Information, Linkages and Capacity Building (ILC) are information, timely referrals, disease specific information and education for mainstream services, access to assistive technology, volunteers and carer and peer support.

We strongly believe that investment in timely information, referral to the right service at the right time, ongoing support, cross sector collaboration and support for carers will effectively support people at diagnosis and in the early stages of disease. This initial investment is cost effective and will

be integral in delaying the need for people diagnosed with motor neurone disease (MND) and other progressive neurological conditions to access individually funded packages (IFP).

MND associations provide individualized support and services for people living with MND throughout the disease trajectory that aim to inform and empower the individual, their family and significant others. MND Advisors act as a person's key worker to ensure early intervention and timely referral. The MND Advisor provides disease specific information tailored to the needs of the individual and their family at diagnosis and then as needs change. They work with the individual to assist them to adjust to their diagnosis and to plan ahead. The MND advisor facilitates the provision of assistive technology, volunteers experienced in MND support and MND specific carer and peer support groups. MND Advisors provide quality, trusted information, education and support to a wide range of mainstream services. Their MND specific expertise will be vital in assisting new services and organisations entering the market as a result of the NDIS to understand the complex needs of people living with rapidly progressive neurological disease.

The services provided by the MND Association Support Service are closely aligned with the proposed supports offered through ILC. Our services are focused on a simple strategy to address the key needs of people living with MND. The focus is to ensure that no person with MND has a high level of unmet needs and to ensure that mainstream services of health, disability, palliative and aged care are able to provide a timely, coordinated response to meet the complex and changing needs of people living with MND. The MND Association support service effectively assists cross sector coordination and acts to smooth the way for people who have little or no experience of health and community services. In effect, the MND Advisor (key worker) acts as a navigator for people living with MND interacting with the complex service system.

2. What is missing?

Assistive technology: It is proposed that the NDIS should have capacity to provide ease of access to one off low cost supports or equipment to facilitate independent living and social participation. Assistive technology is vital for people living with MND and some people may require access to one or two simple items such as a communication aid, shower chair or walking frame to enhance independence and community participation. Timely access to these types of equipment has potential to delay the need to access IFP. A wide range of assistive technology may be available for loan from the person's MND association which will minimise the need to purchase initial items of equipment that may not be needed for very long.

Block funding to support this type of timely response, short term loan service for people prior to them accessing an IFP needs to be considered. Evidence supports the cost effectiveness of this model of equipment loan as an alternative to purchase for people with rapidly progressive disease.

Care coordination: Timely, multi/interdisciplinary, coordinated care is imperative for people with complex and progressing needs. MND Advisors provide a vital early intervention role in facilitating timely referral to health and community services and coordinated cross sector collaboration. Our experience in the trial sites confirms that MND advisors play a key role in preparing and supporting people to access the NDIS. Their involvement in the planning process supports both the planner and the person with MND to develop a responsive plan that will take into account their progressing

needs. Block funding for the MND Advisor, or specialised disease specific key worker model, will delay the need for a person to become a participant and ensure that we have informed and empowered participants.

Flexible respite: Some state MND Associations have received funding to support the provision of flexible respite for people living with MND and their families. This has enabled families to spend quality time together by taking a short break or holiday or having special days out and meals together before MND progresses to such a degree that these types of outings become impossible. Flexible respite can assist the family to adjust to the diagnosis and strengthen relationships to build the capacity of carers and families. Flexible respite should be included as an element of ILC.

Volunteer: 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. Support to maintain disease specific volunteer support services must be an element of the ILC framework.

Disease specific information lines: For people diagnosed with conditions that will result in increasing disability, complex needs and ultimately death, access to disease specific telephone support and counselling is vital. MND Associations provide a national 1800 number for people diagnosed with MND, family, friends and the mainstream services involved in their care. Some states are funded by State governments to provide this service five days a week but some are not. As the NDIS is rolled out nationally access to block funding to support this specialist service nationally will promote early intervention and assist mainstream services to access information and support whenever they are referred an MND client.

3. How will we know the ILC streams are meeting their objectives/vision?

- People with MND will continue to have access to block funded specialist early intervention and supports from MND Associations
- People with MND will be secure in the knowledge that as their disease progresses they will be supported to access experienced planners to develop an individualized IFP to meet their reasonable and necessary support needs
- Carers will feel well supported to enable them to maintain their caring role
- Mainstream services will be knowledgeable about the needs of the individual living with MND.
- MND Associations will be block funded to support effective cross sector collaboration and care coordination
- Improved interface between NDIS and aged care

4. What would be the implementation challenges?

Lack of clarity around the roles and responsibilities of specialist disease specific organisations and NDIA staff impacts negatively on the people we are aiming to support. The interface between specialist disease specific organisations and NDIA staff needs to be strengthened to minimise

implementation challenges and to 'smooth the way' for people living with rapidly progressing and complex conditions.

Loss of state government block funding will impact disease specific organisations putting at risk the services they provide. ILC block funding opportunities for specialist support organisations will need to be rolled out prior to loss of this funding as a cost effective measure to support ILC implementation and the NDIS roll out.

Specialist disease organisations are best placed to support the people with the diseases they represent. Our experience has demonstrated that generic information, peer and carer support and counselling is not effective for this cohort of people.

5. Which aspects of a person's life do you think ILC could have the greatest impact on?

Specialist early intervention and support is imperative for people in assisting them to adjust to diagnosis and to effectively plan ahead. Most people would prefer to stay as independent as possible for as long as possible. The introduction of a key worker such as the MND advisor at diagnosis, able to support the individual and their family throughout the disease trajectory as and when requested, will impact significantly on their ability to access the right care, at the right time, in the right place.

MND is a complex and little known disease. Many mainstream service providers will not have had experience in MND and will have little knowledge about its progression and consequent ever changing needs. The expert disease specific knowledge of the MND Advisor will increase the person's confidence that mainstream providers will be supported to understand MND and its impact.

Prior to needing an IFP the ILC framework will be vital in preparing and supporting people to access the NDIS when and if required. The involvement of specialist disease specific organisations from diagnosis and through the planning process will support the person with MND to develop a responsive plan that will take into account their complex and progressing needs.

6. What are some of the principles that should guide investment across ILC streams?

It is imperative that people diagnosed with conditions that will lead to complex and changing needs, increasing carer burden, possible cognitive impairment, reliance on a wide range of assistive technology and ultimately death have access to services and support from specialist organisations. Recognition and funding to support the services and support provided by these specialist disease specific organisations should be a guiding principle across the ILC streams. Organisations such as the MND Associations have developed models of support that align with the ILC framework and empower the individual and their significant others. Utilisation of this experience and specialist knowledge will be a cost effective investment for the NDIS.

7. How do you see the interface between ILC functions and activities and the interaction with the mainstream service system? (housing, education, employment, health, family, accessibility and transport)?

It is essential that disease specific information provision for the mainstream service system be supported. The context of delivering support for people living with low incidence progressive diseases 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.

Mainstream 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 mainstream service provider.

The MND Advisor acts as an interface between the person living with MND and mainstream services. This key worker type model effectively assists cross sector coordination and acts to smooth the way for people who have little or no experience of health and community services. In effect, the MND Advisor acts as a navigator for people living with MND and their carer to empower them when interacting with the complex service system. This was recently very eloquently described by a participant in an MND Association Carers Education Program who commented *“I learnt to feel confident and good about being a carer for my husband. I learnt the importance of taking care of myself. I learnt to be proactive in putting in place all the support available to my husband and myself, which enabled us to have the best quality time together. I learnt there is so much support available within my community and being too proud to ask or accept it was not life-giving to this illness. I learnt there is still beauty and joy to travel the uncertain road of MND, when you are equipped to traverse this journey with support and knowledge”*.

MND Associations ensure that local health, disability, aged and community providers understand the specific needs of people living with MND and their families through the provision of an information line, printed and online information, education, training and support. This model has proven to be effective for people living with complex and progressing conditions such as motor neurone disease and younger onset dementia.