



13 March, 2015

## **Submission to NDIS Information, Linkages and Capacity Building (ILC) Policy Framework online consultation by the MS organisations**

### **What are the most important elements of ILC?**

MS Australia welcomes each stream within the ILC and sees them all as important to providing a support network for people with MS and neurological conditions more broadly.

The provision of timely, accurate and targeted information is essential to good decision making and planning for individuals and is needed before people access the NDIS or any other services and supports. We strongly believe that investment in timely information and advice helps to give people the tools, early in their disease, to identify what is important for them and allow them and their families to adjust to a diagnosis and to place how it will impact them into context.

We are confident that people affected by multiple sclerosis, and the neurological sector more broadly, would benefit greatly from early support that can be offered within the ILC framework that promotes a well-articulated pathway and continuous model of care. Accessing an articulated pathway early on will allow people to determine what exists within their own network of support and in many situations, provide the individual with the confidence to explore and link with services that best suit their needs and situation. Building the capability of people to navigate across service sectors and within their community is vital and will reduce the need for intensive crisis-centred information, advice, support and complex case management.

We believe that access to the supports in ILC will significantly delay or prevent people affected by neurological conditions to remain out of Tier 3 and reduce the need for intensive and costly services and the associated financial liability. This will help significantly to ensure the NDIS is sustainable and that supports in Tier 3 are available for people who have broader and more complex needs.

However this will only be achieved with significant considerations given to the operational framework that recognises and manages the access differences represented across urban and rural communities.

There will be difficulties with implementing the ILC and to date, efforts to support people with navigation and to establish informal networks have been hindered by the lack of systemic cross-sector coordination, collaboration, co-funding and community integration. There is definitely a need to address this in the continued rollout of the NDIS.

Overall, we are encouraged by the ILC and see potential in the policy framework. People affected by multiple sclerosis are a significant group in the ILC space; information gathered through the NDIS trial sites to date indicates that approximately 50 to 60 per cent of people affected by multiple sclerosis will have supports met within the ILC framework.

This portion is likely to grow in years to come as more and more treatments become available that will enable people with multiple sclerosis to prolong progression of the disease and experience a higher quality of life, for longer.

As such we anticipate increased demand on the ILC portion of the scheme and view the framework as vital to engaging people early, so they are more in control of addressing their needs and that they are able to build resilience with the knowledge that there are articulated pathways across the health and community sectors that they can navigate. This greater independence and control will deliver improved health outcomes and reduce the burden of multiple sclerosis on the latter stages of the scheme and, more broadly, the national economy.

### **What is missing from the ILC Policy Framework?**

Advocacy is not referred to in the framework. Many of the activities described in the ILC structure are often performed very effectively by advocacy organisations, including the provision of information, linkages and referrals, community awareness and individual capacity building.

Supporting advocacy will require a policy to promote cross-sector collaboration and sharing of information as well as well-articulated pathways across the multiple sectors.

An example: MS Australia is about to commence advocating for a national energy rebate system to help people who need to use significant levels of household energy to mitigate their symptoms. This type of advocacy can only be done successfully at the national level, using recent research outcomes. It is not possible at the individual level.

It is also important to recognise that specialist community organisations and peak bodies are best placed to promote the streams of the ILC as these organisations have built, developed and maintained a significant body of knowledge and experience. This capability supports service providers in identifying the unique issues associated with the disease. In particular, the MS organisations 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 individual's independence and their ability to remain living within their community.

Furthermore, the ILC space is owned by specialist community organisations such as MS Australia's state members. We know it is imperative for this cohort to have a collaborative interface and the ability to facilitate the health, community, aged care and disability sectors working together. We also we know through effective cross-sector partnerships that a proactive approach can reduce the impact and "avoid the avoidable" if the right supports and services are provided at the right time. The ILC framework focus is wider than the disability sector and must be flexible and responsive to a broad set of needs and circumstances.

### **How will we know the ILC streams are meeting their objectives/vision?**

There will be a need to implement a variety of user feedback systems and measures to ensure the broadest possible feedback is obtained and that this is customer focused.

Furthermore, we believe strongly that a trial or pilot of the ILC framework will be required to determine how it will be optimised and to work through any potential teething issues of this stage of the scheme.

Successful implementation of the ILC framework will be evident when feedback and user experiences start to mirror the principles outlined in the NDIS strategic plan. For example evidence of people self-managing and living well after accessing early support and information will highlight the importance the ILC in the overall NDIS framework.

There will also be flow on effects for Tier 3. By providing the right information and support, at the right time for people with MS and other neurological conditions it will limit the need for them to draw further on resources in Tier 3, delivering savings and greater capacity for that portion of the scheme over the long term, which will assist the scheme in becoming sustainable.

### **What would be the implementation challenges?**

The ILC framework is comprehensive, however there will be considerable work required to operationalise the policy framework and given the progress that is being made through trial sites for the NDIS, it would be worth considering a similar pilot model for the implementation of the ILC.

MS Australia, our state members and colleagues from peak bodies representing other neurological conditions, are of the strong view that a pilot project could test the application of the ILC framework and allow valuable information regarding the utility of the scheme and the social and economic benefits.

The neurological sector has a strong track record of genuine collaboration and information sharing and partnership with the health and community sectors as evidenced by joint projects and pilots undertaken previously.

Within the trial sites there are examples of increased time and costs for NDIA as a consequence of the nature and differences within the neurological sector. These risks and costs can be addressed by utilising the practical, “on the ground” experience and understanding of the challenges that face people with which our specialist organisations have developed and share as a reservoir of knowledge and collective experience with the specific condition and associated disability.

There is significant value-adding for the person, their family and service providers when they have a clear understanding of the disease and any related disability now and in the future as the condition progresses. We believe that testing the elements of the ILC framework with the neurological sector will be informative and translatable to other sectors.

We would welcome the opportunity to work with the NDIA as part of any such trial and we have been encouraged by consultation with the NDIA about plans to roll out the ILC framework to date.

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

The challenges faced by people affected by multiple sclerosis can be significant and can have a devastating impact on families, and the wider community. Relapses can result in short-term or long-term disability, resulting in the need for physical and psychological care and support, medical investigations, treatments and hospitalisation.

In many cases however, the earlier people with multiple sclerosis receive access to tailored information and support the better their outcomes, which is why the ILC framework is so important.

Being able to better manage and limit the impact of relapses and disease creep helps give people with multiple sclerosis greater certainty to get on with their lives, and helps them to maintain important parts of their lifestyle for longer, such as employment, physical activity and exercise, as well as travel and socialising with friends.

Whilst these elements may not seem particularly significant, together, they give a person with multiple sclerosis purpose, focus, independence and drive which can be very useful in maintaining a high quality of life and staying on top of their symptoms. They also aid in reducing the burden of multiple sclerosis on the economy and the need for more complex supports through the NDIS.

### **What are some of the principles that should guide investment across ILC streams?**

The success of the ILC will play a large part in the overall sustainability of the NDIS. As such sustainability and foresight will need to guide investment across the streams and there needs to be recognition that investment and interventions provided at this point can significantly improve the economic viability of the scheme and reduce the burden on Tier 3.

There is also a need to promote flexibility, particularly during the early stages of the ILC framework implementation. It would be encouraging to see recognition and promotion of successful models and initiatives under the ILC as well as investment shifted away from unsuccessful projects or streams.

Furthermore given MS is a condition characterised by unknown periods of symptoms and issues, MS Australia and our state members believe the scheme should recognise the needs of relapsing, remitting, episodic conditions, so that people can dip in and out of the system as needed, without the need for complex re-application and reassessment processes.

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

Co-funding for cross sector coordination is imperative at the ILC level to achieve the required outcomes for people who have a disability or are likely to develop a disability. It is also important to sustain the principles of the NDIS and not to cap packages.

Barriers and restrictions around each of these service systems need to be identified and removed to allow people where possible, to independently explore and navigate access.

Policy that endorses and rewards systemic pathways of cooperation will streamline the experience of many and will alleviate the intense frustration experienced by those seeking services. This will limit the time expended by providers and importantly, deliver better productivity, financial and social outcomes to the entire NDIS.

### **Other comments (optional)**

MS Australia is pleased to have the opportunity to respond to the National Disability Insurance Scheme Information Linkages and Capacity Building Framework (ILC) on behalf of our state member organisations.

Currently, our state member organisations are positioning the needs and desired outcomes of people with multiple sclerosis within the NDIS. We have great confidence that the ILC framework is aligned with our favoured approach. The ILC framework is a positive step in the ongoing development of the NDIS and importantly, a way forward for sectors to work together more seamlessly than ever before. The potential of a well-articulated pathway will provide more opportunity for people to make adjustments in their lives that will enable them to maintain important parts of their lifestyle for longer such as employment, exercise and socialising with family and friends.

We would welcome the opportunity to discuss how the framework can deliver the best outcomes for people with multiple sclerosis, and more broadly, neurological conditions. We also look forward to better understanding the operational details including the funding process and associated allocation for this critical area.

Collectively, we believe this framework is comprehensive yet it will need to be tested to determine how to best achieve the potential systemic benefits and efficiencies.

MS Australia and our state members feel well placed to pilot some streams to determine how it can be operationalised within different regions across the progressive neurological sector, which is characterised by regular users of services across multiple jurisdictions. A pilot, working collaboratively with various neurological organisations, would provide adequate scope and scale. We would be happy to further discuss the potential of such a project.

We congratulate the NDIS on this draft framework and thank you again for this opportunity to provide feedback.

\*\*\*