ONE YEAR OF NDIS

ABOUT OUR NDIS PROJECT

Multiple Sclerosis Limited (MS) initiated a National Disability Insurance Scheme (NDIS) project to determine how the NDIS impacts the lives of people affected by multiple sclerosis, and share our findings with the broader MS community.

We’re sharing some of the insights and experiences of people with multiple sclerosis from the first year of this significant reform of the disability sector. The NDIS trial sites began on 1 July 2013 in Hunter and Barwon.

GENERAL REFLECTIONS

People with multiple sclerosis are receiving greater access to funded supports under the NDIS. Participants have expressed an overall level of satisfaction with their planning conversation and their supports.

The processes to access the scheme challenged all stakeholders in the first six months of the trial and the ‘goodwill’ of providers was stretched. A new page turned in January 2014 with lessons learned being implemented and the National Disability Insurance Agency (NDIA) having the space to action improvements.

Full scheme rollout will benefit people affected by multiples sclerosis compared to the current system which is not tailored to individual needs, choice and control.

There are diverse views and levels of interest about the NDIS across Australia.

THE MS TEAM HAS BEGUN THE NDIS JOURNEY

Here at MS we’ve begun the NDIS journey in a service environment that is transforming the disability sector to a competitive market place. Customers (people with a disability / people living with multiple sclerosis) now have control over who provides their supports; and when and where supports are purchased and received. The supports and services focus on meeting person centred goals of the individual with a permanent disability or significant impairment.

THE TRIAL SITES: HUNTER AND BARWON
REAL STORIES FROM PEOPLE LIVING WITH MULTIPLE SCLEROSIS

“It has had a huge impact in relieving financial stress and helping me to feel normal and not a burden as I can now get to and from shops and exercise classes with taxi vouchers.”

“The agency was professional and friendly, everything flowed smoothly and I have received everything that I had identified.”

O is very happy with the support, and feels the agency and the planner have been very helpful, even if they had to amend the plan a few times.

H felt that the NDIA staff were responsive, good listeners, and she felt acknowledged. Although she comments on the long delay, she realises that it is a big job and that she must be patient.

WHAT DOES THE INTRODUCTION OF THE NDIS MEAN?

The introduction of NDIS in July 2013 is contributing to a significant transformation of the disability sector. The NDIS is a new way of delivering and funding individualised disability supports for people with permanent and significant impairment and linking up the individual’s network of supports.

The NDIS gives choice and control to people living with a disability, as well as a lifetime approach to meeting an individual’s person centred goals. The NDIS is a shift from a charitable/welfare model where organisations receive block funding to provide supports.

The NDIS is expected to support 460,000 Australians living with a disability when it’s fully rolled out from July 2016. The NDIS has bipartisan support, so all governments are working together to ensure its success.

The NDIS will:

- be a single national system
- be administered by a Commonwealth statutory authority, the National Disability Insurance Agency (NDIA)
- have no impact on the Disability Support Pension and is not a means-tested entitlement
- meet many unmet needs, such as equipment, home modifications, coordination and respite

The NDIS is partially funded by an increase to the Medicare levy, which means that all of society is contributing toward the funds needed to run the scheme.

THE MOST SIGNIFICANT FINDINGS

We have discovered that:

- it’s very important to help the MS community understand NDIS — both inside and outside the trial sites; and particularly the opportunities it brings
- supporting people with multiple sclerosis to prepare for their conversation with NDIA had a positive impact on their planning experience and the outcome of supports
- in most circumstances people with multiple sclerosis are in receipt of the right supports, for improved participation in their life

People with multiple sclerosis who became Participants in the first year of the scheme rated their NDIS planning experience as consistent and a positive experience. One common piece of feedback was that the planning conversation was positive but the time between the planning and implementation of supports was slow. They also said completing the required forms was “not easy”.

ONE YEAR OF NDIS continued
WHAT THE MS TEAM HAS BEEN DOING

- Delivered 22 Community Conversation Forums across ACT/NSW/VIC, both in and outside of the trial sites, sharing the real time experience, benefits and impact of funded supports on the lives of people with multiple sclerosis.

- Made more than 500 calls and assisted 76 people living with multiple sclerosis to consider the support opportunities and prepare for their planning conversation. We also followed up with them to hear about their experience, and see if they required advocacy support from us or further explanation of the steps to make their plan active.

- Developed checklists to help people with multiple sclerosis prepare for their NDIA conversations. These have really helped people articulate the impact of their multiple sclerosis on their life.

- Developed checklists for NDIA Planners, will valuable examples of how multiple sclerosis symptoms may manifest in functional impairment, and providing suggestions about how to frame questions to recognise hidden symptoms.

- Played a strong representational role on issues of process and operation rules with NDIA, because of the impact they may have for some people with multiple sclerosis. As a register provider of NDIA supports in Barwon and Hunter, our team are very engaged in the journey we are on and are able to provide individual advocacy. This has generally involved supporting the person to articulate the impact of their multiple sclerosis symptoms and the implications for their life and family.

WHAT WE’VE SEEN

- 115 people with multiple sclerosis became participants of the Scheme in Barwon and Hunter (Newcastle only) from 1 July 2013 to 30 June 2014. This is 30.2% of the people living with multiple sclerosis in Barwon and Newcastle and is within the expected range of people to be eligible and access the scheme at any one point in time.

- MS assisted 76 of these 115 people to begin the access process and / or prepare for their planning conversation/assessment.

- Of these 76, 57 people declined to access the scheme.

- The common theme of people who declined to access the scheme was; ‘they felt they were living well with their multiple sclerosis and did not require any supports at this stage’. As one person said, “I don’t feel I require supports right now, but will contact MS if this changes”.

- Others said they didn’t want to engage in the NDIS process; or that during planning they determined they may be worse off under the scheme at this stage of their journey due to the implications associated to the mobility allowance and concession card.

- Any of the 57 people who chose not to access funded supports from NDIA can make a new access request at any time.

- The funded supports included in each of the 115 plans vary according to their personal circumstances and their person centred goals.
REASONABLE AND NECESSARY SUPPORTS

NDIA funded supports must be deemed what they call ‘reasonable and necessary’.

This is determined using a set of criteria which take into account whether:

- the supports are effective and beneficial and are based on current good practice
- the supports represent value for money
- what is reasonable to expect from family carers, other informal supports, and from community and mainstreams services

Supports that will not be funded include those that are:

- likely to cause harm to the participant or pose a risk to others
- unrelated to the participant’s disability
- duplicated by other supports provided under alternative funding
- part of the day-to-day living expenses that are incurred by the general public (eg. rent, groceries, household bills) and not related to disability support needs and related to income replacement
- the NDIA has also made it clear that providers may not claim for services and supports that are not delivered as a result of a cancellation or ‘no show’ — providers and participants are encouraged to enter into an agreement stating the notice required if either party cancels an appointment, and the terms of business for payment of any cancellation fees.

NDIS IN ACTION — CHARLOTTE AND MARTHA’S STORIES

Charlotte* fulfils many roles within her family and community. She wants to maintain her local networks, her health and wellness, remain independent and be able to sleep well. To achieve these goals the NDIS is supporting Charlotte with:

- taxi vouchers so she can independently access weekly social and exercise classes
- a new scooter to improve her ability to independently access local services
- weekly cleaning support
- an air conditioner for her bedroom
- a physiotherapy assessment for equipment to assist C to walk without falling
- following an OT assessment, home modifications were approved allowing C to live independently in her home.

Charlotte was “stunned” she could access these supports, as she would never have been able to afford them herself.

Martha* is in her mid-forties, is working and owns her own home, which she lives in with her elderly mother. Martha has a mortgage and her goals are to remain working, manage her home and contribute to her community. To achieve these goals the NDIS is supporting Martha with:

- house cleaning on a weekly basis
- fortnightly gardening/mowing

Martha is now able to continue working. She said it was amazing to think that she has access to support that will help her remain independent, a contributing member of society and have the security of her own home, and she now has a greater level of independence.

*Not their real names

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