

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Productivity Commission's Position Paper on National Disability Insurance Scheme (NDIS) Costs

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia (MSA) is pleased to provide a submission to the Productivity Commission's Position Paper on NDIS Costs.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS. As stated above, MSA's role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country.

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited covering Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, education and information workshops, seminars and webinars, psychology, financial support, accommodation, respite, peer support co-ordination, employment services.

Our submission is framed around the draft recommendations, findings and information requests in the position paper relevant to the MS community and the work of MS Australia and provided in italicised text below.

How is the scheme tracking?

Draft finding 2.1

The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious. It risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.

MSA believes that the NDIS will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception.

At this time of never before seen change to the disability sector and the highlighted risks to the financial sustainability of the Scheme, all levels of Government have a responsibility to share the economic benefits of the NDIS more widely to increase understanding of the potential scale of economic benefit it will bring to Australia. For example, the NDIS will support 25,000 - 40,000 people to find work and 34,000 carers to return to the workforce. Through the increased additional tax revenue and reduced income support this will bring, it has been reported that \$1.5b - \$1.9bn per annum will eventually be saved from the Commonwealth Budget.

Whilst MSA acknowledges that this risk has been identified, we are keen to repeat our call for an ongoing commitment to the full funding and timely roll out of the Scheme. Any scaling back of funding or timing would unfairly disadvantage those anticipating the roll out in their area.

Draft finding 2.2

While a different methodology is used, the National Disability Insurance Agency projections of scheme costs are broadly consistent with the Productivity Commission's modelling of the scheme in 2011, after accounting for sector-specific wage increases, population changes, and costs associated with participants aged over 65 years (who were not included in the Commission's estimates).

MSA is pleased with this finding. The NDIA and Productivity Commission need to find ways to promulgate this outcome widely to prevent ongoing media speculation regarding NDIS cost "blowouts".

Draft finding 2.3

The National Disability Insurance Scheme, at the end of trial, came in under budget. This was in large part because not all committed supports were used (in 2015-16 the utilisation rate was 74 per cent). Based on trial and transition data, scheme costs are broadly on track compared to the National Disability Insurance Agency's (NDIA) long-term modelling. At this stage, early cost pressures (such as greater than expected numbers of children and higher than expected package costs) have been offset by lower than expected levels of utilisation. The NDIA has put in place initiatives to address emerging cost pressures. It is too early to assess the effectiveness of these initiatives.

The Productivity Commission might consider looking at emerging cost pressures against the outcome for the individual and the long term economic benefit of the NDIS. The lower than expected levels of utilisation may also be the result of significant inefficiencies experienced through poor communications and relationships with participants and poor utilisation of funding.

Some examples of inefficiencies reported to MSA include:

- *unscheduled reviews, particularly regarding the inclusion of assistive technology (AT), triggering the movement of participants from receiving Support Co-ordination to the Local Area Co-ordinator while they still have Support Co-ordination funds remaining*
- *funding for Support Coordination is being used up in reviews that are not planned and are often only for review of only one element of the plan such as AT. an NDIS participant had a review for funds for AT to be added to their plan. When the participant received the reviewed plan, the budget for Support Coordination had been removed.*
- *participants are delaying unscheduled plan reviews as they are fearful of losing their support coordination*
- *service agreements are still in place for Support Coordination, yet the Support Coordinator has not been notified or not been provided sufficient notice.*

Draft finding 2.4

Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report more choice and control over the supports they receive and an increase in the amount of support provided. However, not all participants are benefiting from the scheme. Participants with psychosocial disability, and those who struggle to navigate the scheme, are most at risk of experiencing poor outcomes.

MSA agrees with this finding and acknowledges that this finding describes the experiences of people with MS interacting with the NDIS.

MSA is aware that questions have been raised around the capacity of the LAC to engage with families who may need a complex level of Support Coordination but have not been given a Support Coordination budget as part of their plan. The family of a participant with complex

needs requires a high level of Support Coordination as they are overwhelmed by having to manage the various services and associated budgets and will no doubt have a number of stakeholders involved with the family.

We are aware of circumstances where a plan review occurred due to a change in services following a crisis situation. Unfortunately, the family did not receive any further Support Coordination funding and are now find themselves too overwhelmed to implement the review to the plan.

When NDIS participants receive their reviewed plan, there appears to be no mechanism to explain the loss of any Support Coordination funding, the transfer of responsibility to the LAC, and what the next steps are. It should be recognised that time is needed for participants and their families/carers to build a new relationship with the LAC, though we understand many Support Coordinators are willing to help in this process.

Scheme eligibility

Draft recommendation 3.1

When determining that an individual is eligible for individualised support through the National Disability Insurance Scheme under the disability requirements, the National Disability Insurance Agency should collect data on which of the activity domains outlined in section 24 of the *National Disability Insurance Scheme Act 2013* (Cwlth) are relevant for each individual when they enter the scheme.

MSA agrees with this recommendation and believes it can be achieved.

MSA is aware of a pilot project where improvements in physical and psychosocial health parameters have been documented through to completion of Assessment of Quality of Life (AQoL) 8D, for physical and psycho-social health to be measured. Obtaining information from health professionals who regularly provide services, support and care for people living with a progressive neurological disease such as MS, is important to assessing the link between disability support and health services.

Obtaining information from customers through AQoL-8D and primary carers (through another measure) is essential to tracking the progress on outcomes such as improving the physical and psycho-social parameters of health of customers, and reducing the strain of caring for someone living with a progressive neurological disease such as MS financially, socially and personally.

Scheme supports

Information request 4.1

Is the National Disability Insurance Scheme Act 2013 (Cwlth) sufficiently clear about how or whether the 'reasonable and necessary' criterion should be applied? Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary? Is better legislative direction about what is reasonable and necessary required? If so, what improvements should be made?

What would be the implications of these changes for the financial sustainability of the scheme?

Whilst the definition of 'reasonable and necessary' may be quite clear, due to LAC and Support Coordinator' lack of knowledge regarding all conditions and the individual impact they have on each individual person, the interpretation of what is 'reasonable and necessary' is not always easily understood or identified. Using the expert knowledge that many existing disease-specific organisations have acquired over many years would ensure greater clarity, understanding and ultimately, best outcomes for the customer and the Scheme will be achieved.

For eg MS is a chronic progressive neurological condition that affects the brain, spinal cord and optic nerves. Every person is affected differently. However, due to the effect of nerve damage, MS causes an inability to regulate core body temperature. 90% of people living with MS are severely impacted by the heat often bringing an inability to function due to the effect of heat to the nerves and ultimately restrict the ability to pursue goals, objectives and aspirations. The provision of air conditioning in people's home for people living with heat affected medical conditions should be included as reasonable and necessary assistive technology.

Information request 4.2

Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators? What are the costs, benefits and risks of doing so? How can these be managed?

MSA would feel more comfortable in agreeing to this proposal if training and information was in place to ensure LACs have the understanding of progressive neurological diseases such as MS needed to successfully determine what is needed in the participant's plan.

Draft recommendation 4.1

The National Disability Insurance Agency should:

- implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review
 - review its protocols relating to how phone planning is used
 - provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options
- ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.

MSA agrees with all aspects of this recommendation and hopes that the process, protocol review and information provision is applied consistently across all areas.

Draft recommendation 4.2

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

MSA supports this recommendation. As we have stated earlier, training and information regarding progressive neurological diseases such as MS is needed to successfully determine what is needed in the participant's plan. The State MS societies having been providing this specialist knowledge and expertise for many years.

MSA is aware of a pilot project for a coordinated care service delivery model developed where strong success has been achieved for people living with MS and other progressive neurological diseases; the main enablers being:

- *A local team with knowledge and experience of local providers and systems*
- *Collaboration with academics to provide an evidence base*
- *Engagement of allied health, GPs and specialists (such as neurologists)*
- *Community engagement strategies such as interaction with support groups*
- *The level of support provided by existing disease-specific providers through organisational resources (involvement of staff was a major contributing factor to the success of the project)*
- *Attending NDIS preparation workshops*
- *Establishing and implementing a successful pre-planning process (although this is not funded by the NDIS)*
- *Establishing links with support groups and referrals from clinics*

Barriers to effectiveness have been:

- *The lack of public understanding re the NDIS*
- *Fulfilling staff quota*

Boundaries and interfaces with the NDIS

Draft finding 5.1

It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.

MSA supports this recommendation.

Draft recommendation 5.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget. The effectiveness of the ILC program in improving outcomes for people with disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

MSA supports this recommendation.

Draft recommendation 5.2

The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme.

The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.

MSA supports this recommendation. Continuity of support must be maintained, cross sector collaboration encouraged and service gaps and actions to address barriers implemented and reported as suggested. Where possible this should reflect any health services that intersect with disability services so the jurisdiction and responsibility for service provision is clear.

Draft recommendation 5.3

Each COAG Council that has responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address the provision of those services and how they interface with NDIS services. This item should cover service gaps, duplications and other boundary issues.

Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

MSA supports this recommendation.

Provider readiness

Draft recommendation 6.1

The Australian Government should:

- immediately introduce an independent price monitor to review the transitional and efficient maximum prices for scheme supports set by the National Disability Insurance Agency (NDIA)
- transfer the NDIA's power to set price caps for scheme supports to an independent price regulator by no later than 1 July 2019.

The body tasked with price regulation for scheme supports should:

- collect data on providers' characteristics and costs. This should include appropriate funding to continue the business characteristics and benchmarking study currently undertaken by National Disability Services and Curtin University
- determine transitional and efficient prices for supports at a state and territory level
- comprehensively review and publish its price model on an annual basis. This review should be transparent, have public consultation, be evidence-based and evaluate the effectiveness of prices in meeting clearly-defined objectives
- assess and recommend when to deregulate prices for supports, with particular regard to the type of support and region, on the basis that prices should only be regulated as narrowly, and for as short a time, as possible.

MSA supports this recommendation.

Draft finding 6.1

In a market-based model for disability supports, thin markets will persist for some groups, including some participants:

- living in outer regional, remote and very remote areas
- with complex, specialised or high intensity needs, or very challenging behaviours
- from culturally and linguistically diverse backgrounds
- who are Aboriginal and Torres Strait Islander Australians
- who have an acute and immediate need (crisis care and accommodation).

In the absence of effective government intervention, such market failure is likely to result in greater shortages, less competition and poorer participant outcomes.

MSA supports this finding, particularly where "out of hours" funding and support is needed such as in the case of a natural disaster, for example.

Information request 6.1

In what circumstances are measures such as:

- cross-government collaboration
- leveraging established community organisations
- using hub and spoke (scaffolding) models
- relying on other mainstream providers

appropriate to meet the needs of participants in thin markets? What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches?

Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets, and how should these conditions be measured? Are there any other measures to address thin

markets?

MSA suggests the Involvement of organisations that have a long-standing, proven capacity to deliver, are in good standing with the local community and have measures in place to evidence provision of quality services.

Information request 6.2

What changes would be necessary to encourage a greater supply of disability supports over the transition period? Are there any approaches from other consumer-directed care sectors — such as aged care — that could be adopted to make supplying services more attractive?

See details provided in response to draft recommendation 4.2.

Workforce readiness

Draft finding 7.1

It is unlikely that the disability care workforce will be sufficient to deliver the supports expected to be allocated by the National Disability Insurance Agency by 2020.

MSA supports this finding.

Draft recommendation 7.1

The roles and responsibilities of different parties to develop the National Disability Insurance Scheme workforce should be clarified and made public.

- State and Territory Governments should make use of their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.
- The Australian Government should retain oversight of workforce development, including how tertiary education, immigration and aged care policy interact and affect the development of the workforce. In doing so, the Australian Government should pay particular attention to immigration policy to mitigate workforce shortages over the transition period.
- The National Disability Insurance Agency should provide State and Territory Governments with data held by the Agency to enable those jurisdictions to make effective workforce development policy.
 - Providers of disability supports should have access to a clear and consistent mechanism to alert those tasked with market development about emerging and persistent workforce gaps.

MSA supports this recommendation.

Draft recommendation 7.2

The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of participants, committed supports, existing providers and previous actual expenditure by local government area.

The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

MSA supports this recommendation.

Draft recommendation 7.3

The National Disability Insurance Agency's (NDIA) guidelines on paying informal carers who live at the same residence as a participant should be relaxed for core supports for the period of the National Disability Insurance Scheme (NDIS) transition. Such payments should be:

- accessible under clearly defined and public guidelines, which make reference to worker shortages in the relevant market using the NDIA's information about providers and supports in the participant's region

- set at a single rate determined by the NDIS price regulator in a transparent manner
- reviewed by the NDIA as part of plan reviews.

MSA is cautiously supportive of this recommendation though remains concerned that this may displace informal care, create complexities regarding insurance matters and may bring about a dependence on the income generated which will be hard to reverse post the transition period.

Information request 7.2

How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?

The option of facility-based respite should remain for participants. It has been reported to MSA that some participants with MS are not happy with "strangers in their home" and with respite arrangements that often do not provide adequate respite for carers and family members.

Participant readiness

Information request 8.1

Is support coordination being appropriately targeted to meet the aims for which it was designed?

As stated in the Neurological Alliance Australia position paper, March 2017, the number of NDIS participants that no longer have allocations in their NDIS plans for coordination of supports is cause for concern. Key issues with this approach include the following:

- *No allowance for a Coordinator of Supports takes away a valuable support mechanism at a time when these people need the most help (e.g. navigating a brand new disability system and often confusing technology such as the NDIS portal).*
- *Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual.*
- *Without intervention most people with progressive neurodegenerative diseases will be unable to navigate the review process and would be limited by their inadequate plan for the ensuing twelve months.*

Coordinators of Support play a vital role in negotiating support costs with providers, making arrangements for support delivery and providing information and ongoing support to providers regarding the specific needs of people with one of these diseases.

People with progressive neurodegenerative diseases are caught between a changing disability sector and aged care sector and there are limited options available to them within the marketplace. Without the support and advocacy of a Coordinator of Supports, many people with a progressive neurodegenerative disease may fall through the cracks and be unable to access appropriate services.

*This led to the recommendation by the NAA of **mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease.***

See also the MSA response to draft finding 2.3. There is considerable overlap and confusion with the LAC role and many participants still do not understand the need for support coordination to be included in their plan.

Draft recommendation 8.1

The National Disability Insurance Agency should implement the eMarketPlace discussed in the *Integrated Market Sector and Workforce Strategy* as a matter of priority.

MSA supports this recommendation.

Information request 8.2

Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators?

Are there any barriers to entry for intermediaries? Should intermediaries be able to provide supports when they also manage a participant's plan? Are there sufficient safeguards for the operation of intermediaries to protect participants?

Yes, see also MSA's response to Information Request 8.1. People with MS should have mandatory Support Coordination in their plans, ideally provided by an MS organisation. Long established and well respected organisations such as the State MS societies provide disease-specific expertise and understanding of the progressing and complex needs of people with neurodegenerative diseases such as MS. Well-established accreditation and governance processes in these organisations should provide a sufficient level of safeguards for participants.

Governance**Draft recommendation 9.1**

The requirement that changes to National Disability Insurance Scheme Category A Rules have unanimous agreement from the Australian Government and all host jurisdictions should be relaxed.

Draft recommendation 9.2

The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible.

Draft recommendation 9.3

The National Disability Insurance Agency should publicly report on the number of unexpected plan reviews and reviews of decisions, review timeframes and the outcomes of reviews.

Draft recommendation 9.4

The performance of the National Disability Insurance Scheme (NDIS) should be monitored and reported on by the National Disability Insurance Agency (NDIA) with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives.

The NDIA should continue to develop and expand its performance reporting, particularly on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities.

The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews).

The Integrated NDIS Performance Reporting Framework should be regularly reviewed by the NDIA and the COAG Disability Reform Council and refined as needed.

Draft recommendation 9.5

In undertaking its role in delivering the National Disability Insurance Scheme, the National Disability Insurance Agency needs to find a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability.

MSA supports these governance recommendations.

Information request 9.1

The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:

- prioritising potential participants with more urgent and complex needs
- delaying the transition in some areas
- an across-the-board slowdown in the rate that participants are added to the scheme.

The Commission is also seeking feedback on the implications of slowing down the rollout.

As stated in MSA's response to Draft Finding 2.1, we are keen to repeat our call for an ongoing commitment to the full funding and timely roll out of the Scheme. We feel that any scaling back of funding or timing would unfairly disadvantage those anticipating the roll out in their area.

Therefore we are opposed to the second and third options described above.

We would strongly recommend that priority be given to the more than 6,000 potential participants, aged under 65, currently living in residential aged care.

KEY FACTS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.