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Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) inquiry into the future of the NDIS: Scheme Implementation and Forecasting for the NDIS

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Introduction

MS Australia is pleased to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme's (NDIS) inquiry into the future of the NDIS.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our Member Organisations provide services and support. Included are comments provided by representatives of our Member Organisations and, in some instances, directly from people living with MS. MS Australia is Australia's national MS not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia's Member Organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA & NT (providing services and support in South Australia and the Northern Territory)
- MS Queensland (providing services and support in Queensland)
- MS Limited (providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these Member Organisations operates independently to provide a range of services and advice to people living with MS regardless of age, 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, online resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Summary of recommendations

Recommendation 1:
MS Australia recommends
That automatic access to the NDIS be granted to people diagnosed with multiple sclerosis (MS) to ensure the early intervention support provisions of the NDIA Operating Guidelines are applied at the earliest possible stage of the disease course.

Recommendation 2:
MS Australia recommends

That a systematic review be undertaken to investigate and address the apparent gender bias in NDIS participation rates.

Recommendation 3:
MS Australia recommends
That a portfolio approach to accommodation arrangements be adopted, utilising a co-ordinated business partner model to deliver improved and certain outcomes, working closely and transparently with providers.

Recommendation 4:
MS Australia recommends
The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems to ensure people affected by MS have their needs met, regardless of which system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

Recommendation 5:
MS Australia recommends
Consideration be given to mapping out the specialised skills and capabilities required to work with participants living with neurological conditions such as MS (who often also have high levels of complexity) as part of the proposed micro-credentials projects to engage more positively with this specialised cohort.

Who’s in and who’s out? The impact of boundaries

The main objective of the NDIS is to provide all Australians who acquire a permanent disability which substantially impacts how they manage everyday activities, with the reasonable and necessary supports they need to live ‘an ordinary life’[1]. This however covers *only* about 466,619 Australians[2], out of a total of 4.4 million (or one in six Australians) that live with disabilities in Australia[3]. Roughly a third of this cohort lives with what is termed ‘severe disability’ that requires assistance to participate fully in everyday life, including property maintenance, cognitive or emotional tasks, household chores, mobility and transport[4]. The majority of this cohort only have recourse to services outside the NDIS.

The *Disability Discrimination Act 1992 (Cth)*[5] defines disability as:

- total or partial loss of the person’s bodily or mental functions
- total or partial loss of a part of the body

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[1] https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis

[2] https://data.ndis.gov.au/

[3] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability

[4] https://www.aihw.gov.au/getmedia/ee5ee3c2-152d-4b5f-9901-71d483b47f03/aihw-dis-72.pdf.aspx?inline=true

[5] https://www.legislation.gov.au/Details/C2016C00763

- the presence in the body of organisms causing disease or illness
- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour.

This definition does not discriminate against age. According to a People with Disability Australia report (2020), [6]half (50%) of people aged 65 and over live with a disability. About 15% of males and 20% of females aged 65 years and over have severe or profound disability. The current NDIS legislation *does* discriminate against those who acquired a disability and are over the age of 65.

Figure 1

1 in 5 people
have a disability or long-term health condition

50%
of people over the age of 65 identify as having a disability.

Over 80%
of people over the age of 65 have at least one long-term health condition.

Only 10% of people with a disability are eligible for the National Disability Insurance Scheme (NDIS)

Graphic: Assistive Technology for All Alliance (https://assistivetechforall.org.au/)

People with disability are a very diverse cohort – representing all demographic and socio-economic groups, age and gender. They interact with all aspects of Australian life, across the spectrum of policy and program areas of health, education, employment, housing, social services, justice and community supports.

What about MS and other neurological conditions?

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[6] https://www.aihw.gov.au/getmedia/ee5ee3c2-152d-4b5f-9901-71d483b47f03/aihw-dis-72.pdf.aspx?inline=true

MS is the leading cause of disability in young adults. There are over 25,600 people living with MS in Australia. Most people are diagnosed with MS between the ages of 20-40, but it can affect younger and older people too. Roughly three times as many women have MS as men. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

MS, along with a number of other conditions, is often referred to as a neurological condition. The Department of Health website[7] refers to neurological conditions as chronic conditions, noting that there are over 600 diseases of the nervous system. According to a report noted in the Productivity Commission website[8], the 'total prevalence for neurological disorders in 2017 accounted for 10.6 million people or 43 per cent of Australian population'. The NDIA's own data[9] indicates that, there were 14,389 of 449,998 total scheme participants with a primary neurodegenerative condition[10] in the NDIS, making up 3.2% of all Scheme participants with an approved plan (as of 31 March 2021).

Congenital vs acquired disability

There are distinct differences in the concept of disability between those with an acquired and those with congenital disability. For many, the idea of accessing the Scheme and identifying with the fact that they might have a disability and not just a chronic illness, coincides with a public acknowledgement of the functional impacts that MS has on their lives. It is an acknowledgement that they might not be as independent as they once were; a realisation that they have to seek support to maintain or hang on to the "ordinary life" that they have had to date.

This is a crucial difference to acknowledge. People affected by MS and other neurological conditions have previously had choice and control. They had a sense of belonging, safety and security. They had opportunities and were making valuable contributions to society, but the symptoms associated with their experience of MS have caused their own barriers and functional impairments. Most people affected by MS and other neurological conditions will have already utilised *informal* supports – often exhausting these – before considering access to the NDIS.

Participants with a closer connection to the disability community note that there is a distinct difference in how people react to and perceive visible/obvious disabilities (often those living with physical disabilities)

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[7] https://www.health.gov.au/health-topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-neurological-conditions
[8] https://www.pc.gov.au/__data/assets/pdf_file/0020/239213/sub064-mental-health-attachment.pdf
[9] https://data.ndis.gov.au/reports-and-analyses/participant-groups/participants-neurodegenerative-condition-ndis
[10] This report only refers to Muscular Dystrophy, Huntington's Disease, Motor Neurone Disease, Multiple Sclerosis and Parkinson's Disease.

and invisible/nonobvious disabilities (particularly relevant for those living with MS or other neurological diseases).

The Concept of an Insurance Scheme and Early Intervention

The partitioning of eligibility to the scheme excludes those living with disability or functional impairments that are not deemed as 'substantial impacts' by NDIA decision-makers. This is no doubt bolstered by the current reform agenda of 'reigning in the spending' which saw the proposal of Independent Assessments as an attempt to ration the supports in personalised budgets.

People with MS who are newly diagnosed with active disease or those who might have episodic disabilities as a result of an exacerbation or relapse might experience very confronting symptoms such as sight impairment, changes in cognition, changes in mobility or severe pain, sensory changes or spasms outside their control that are often totally disabling and definitely impairing their functioning and ability to perform daily living tasks.

MS is episodic for some, and these symptoms, for some after a few weeks, for others after months, partially or fully repair. During these periods of active disease, people with MS often only have recourse to informal supports, if available, and their healthcare team to assist them.

As a recent systematic scoping review on MS caregiving pointed out, '*Multiple Sclerosis (MS) is a chronic, progressive neurological disease that often leads to limitations in a person's ability to fully engage in a wide range of daily activities, for example employment, home maintenance, childcare and self-care. Limitations may be a function of physical symptoms of the disease (e.g. fatigue, loss of balance, mobility, spasticity) or cognitive and emotional symptoms (e.g. cognitive impairment, depression), or a combination of factors (Camerson et al., 2013).*' Cost-of-illness studies have quantified the annual value of informal caregiving. The reality is, that without these informal supports, many people with MS will not be able to live independently and often delay points of crisis, need for hospitalisations of care. [11]

The NDIA Operating Guidelines state that 'the intention of *early intervention* is to alleviate the impact of a person's impairment upon their functional capacity by providing support at the earliest possible stage. Early intervention support is also intended to benefit a person by reducing their future needs for supports.'[12] A streamlined process for determining the early intervention requirements for children exists, but not for adults (who do not appear to be the focus of the operationalisation of this legislative provision).

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[11] Roshanth, R. et al., (2021) Multiple sclerosis caregiving: A systematic scoping review to map current state of knowledge. Health Soc Care Community. 2021; 00:1-23 doi:10.1111/hsc.13687

[12] See Access to the NDIS, Early Intervention requirements at ndis.gov.au

The onus is on the prospective participant to provide sufficient evidence to the NDIA, proving that early intervention support is most appropriately funded through the NDIA and not another general system, body or agency.

As a result of this partitioning, people who live with disability or chronic health conditions, who may benefit from early intervention, are missing out.

The Early intervention pathway is an important access route for relevant and pivotal supports, particularly when a person is on the trajectory to, but does not yet meet, the 'substantially reduced functional capacity' criteria. For incurable conditions like MS, with fluctuating functional impacts, and certainly with a trajectory to meet the Scheme's full access criteria within the lifetime of the participant, it is critical to have a streamlined access pathway to the Scheme prior to the substantially reduced functional impact, of which Early Intervention is the most appropriate access point.

Consideration should be given to automation of access to the NDIS for people with MS and other neurological conditions. This will also assist with the other caveats which underpin the intention of Early Intervention – that is, to mitigate or alleviate, prevent deterioration, or improve functional capacity.

Recommendation 1
That automatic access to the NDIS be granted to people diagnosed with multiple sclerosis (MS) to ensure the early intervention support provisions of the NDIA Operating Guidelines are applied at the earliest possible stage of the disease course.

Gendered decision making

It has long been recognised that MS is more common in women than men – in fact, three out of four people diagnosed with MS in Australia are women. Recent studies suggest that the total number of MS cases is increasing and that the increase is disproportionately affecting females. The female to male sex ratio of MS has risen in several countries in recent years, suggesting an environmental interaction increasing MS risk in women. In Canada, over a 50-year period, the gender ratio of women diagnosed with MS increased from 66% to 76%, and in Sweden, it has risen from 63% to 73%. Currently in Australia, 75% of people diagnosed with MS are women.[13]

A cost analysis that was completed for the Health Economic Impact of MS in Australia in August 2018[14] by the Menzies Institute of Medical Research (University of Tasmania), funded by MS Australia, provided an

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[13] https://www.msaustralia.org.au/news/ms-risk-increasing-for-women/#:~:text=It%20has%20long%20been%20recognised,MS%20in%20Australia%20are%20women

[14] https://www.msaustralia.org.au/amsls/

analysis of the Australian MS Longitudinal Study (AMSLS) which has been running since 2001. Over 3000 people living with MS participate in this study, completing various research surveys that provides real life data about MS in Australia to inform MS research project, medical and support services how to improve support and services for this cohort.

The *Health Economic Impact studies* are the biggest commitment of the AMSLS, and gather in-depth information on quality of life, and the direct and indirect costs of MS to both individuals and Australia as a whole. With the study repeated every 5-10 years, the most accurate picture of life with MS in Australia is kept up to date directly from those living it, and ensures the most important issues can be monitored, updated and addressed on a regular basis.

The study provided an analysis of the characteristics of respondents and non-respondents of the survey, also highlighting characteristics of age distribution, state of usual residence, MS Type, Disease Modifying Therapy (DMTs) penetration, disability severity and MS duration. Four out of five respondents were female. *Importantly, it found that over half were either moderately or severely disabled*.

This however contrasts strongly with the most recent NDIA Quarterly Report[15], noting a male to female ratio of 2.3 (males 7,411 vs females 3,165 living with MS currently accessing the scheme). In comparison, the overall gender distribution in the scheme sits at a male to female ratio of 1.7 (males 309,368 vs females 187,419).

This also contrasts with international evidence on gender distribution in disability, suggesting that women generally lives longer than men (longevity) and therefore have a longer lived experience with disability; generally have higher prevalence figures in non-fatal chronic conditions and have different constitutional factors such as lower muscle strength and bone density that impact on these prevalence figures. [16]

Our own Australian Bureau of Statistics survey, Disability, Ageing and Carers, Australia[17] in their most recent survey data (2019) suggest that disability prevalence was similar for males (17.6%) and females (17.8%).

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15 https://www.ndis.gov.au/about-us/publications/quarterly-reports

[16] https://pubmed.ncbi.nlm.nih.gov/10902052/ and https://pubmed.ncbi.nlm.nih.gov/30496104/

[17] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#:~:text=In%202018%20there%20were%204.4,down%20from%2018.3%25%20in%202015.&text=Disability%20prevalence%20was%20similar%20for,a%20profound%20or%20severe%20disability.

If compared with the recent Quarterly Report that suggest *62% of all participants are male whilst 37% are female – something is amiss.*

MS Australia's annual Women's Health week campaign[18], in partnership with Jean Hailes Foundation, received several accounts and examples of women feeling "fobbed off" by the system. Similar sentiments and questions were recently asked in an article entitled, "Why do women make up half the disability population but just over a third of NDIS recipients?" posted by Sophie Yates et.al in the Conversation, 2 February 2022. [19] Sophie Yates' questions about women's experiences of accessing individualised disability supports, has been further explored in the International Journal for Equity in Health Care[20]. The research study's findings suggest: "*Commonly reported gendered barriers to women being able to access the right supports for their disability involve a) confidence, negotiation and self-advocacy, b) gendered discrimination in diagnosis and the medical system, which has implications for disability support access, and c) support for and recognition of caring roles.*"

Clearly such gendered barriers appear to be supported by the participation and prevalence figures.

Recommendation 2
That a systematic review be undertaken to investigate and address the apparent gender bias in NDIS participation rates.

Barriers to accessing services outside the NDIS

People with disabilities outside the NDIS face daily challenges in fully participating in everyday activities as a result of their different disability types or severity, the availability of appropriate services, community attitudes, stigma and discrimination.

A recent survey with people living and those affected by MS, conducted by KPMG in 2019 on behalf of the MS member organisations delivering services throughout Australia, found that affordability was identified as a key barrier to receiving supports. Other barriers included lack of awareness, geographical location and eligibility. Affordability was listed as a barrier by over half of those living with MS under age 35 years and those living in lower income households. Eleven percent indicated that transport was a barrier to access services and supports.

One in six people with a disability live in poverty according to an ACOSS/UNSW report in 2018[21]. These numbers are likely to be under-

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[18] https://www.msaustralia.org.au/news/womens-health-week/

[19] https://www.abc.net.au/news/2022-02-02/women-make-up-half-disability-population-third-ndis-recipients/100796188

[20] https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-021-01571-7

[21] https://www.acoss.org.au/wp-content/uploads/2018/10/ACOSS_Poverty-in-Australia-Report_Web-Final.pdf

estimations as the report did not adjust for additional costs resulting from living with a disability day to day i.e. modifications at home, personal support and care, medical and pharmaceutical expenses and additional transport costs.

The idea of an ordinary life as a concept that is defined by the NDIS' Independent Advisory Council (IAC) as 'a life where people with disabilities have the same opportunities as people without disabilities. [22] Outside the NDIS, this ordinary life is costed at $967.50 a fortnight (DSP maximum individual payment)[23]. An average NDIS package or personalised budget (March 2020) sits at $67,000[24] per annum or $2,576.92 a fortnight.

Although there are safety nets, such as the Disability Support Pension (DSP), and some people living with disability do maintain some level of employment, "*people with disability generally have a lower level of personal income than people without disability. Having a person with disability living in the household is also associated with lower levels of household income*." They are also more likely to experience poor health, discrimination and violence than those without disability.

DSP levels are not adequate for those eligible and successful in claiming DSP. In 2017, the average cost of MS per person was $68,382 (comprising both individual and societal costs), similar to that of someone with Parkinson's disease or the first year after a stroke, triple that of a person with type 2 diabetes.[25] The societal and individual burden of disease for MS, in comparison to other disease and disability types are high. For those lucky enough to qualify for DSP, feedback from the MS community is clear that the support does not meet the day to day living expenses for someone living with ill health, a chronic condition or a disability associated with MS. More worrying, those unable to meet the eligibility criteria of DSP have to survive on other benefit types which have already been criticised broadly for being inadequate for those living with full health.

'*Multiple sclerosis (MS) is a challenging and disabling condition, predominantly affecting individuals in early adulthood. MS affects the physical, cognitive, and mental health of persons suffering from the disease as well as having a great impact on their financial status and quality of life.*' A systemic review (from 4,957 studies identified – 19 selected for inclusion) [26]assessing the socioeconomic consequences of MS for those with varying levels of disability and cognitive functioning

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[22] https://www.disabilityloop.org.au/news/iac_ordinary_life.html

[23] https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/how-much-you-can-get/payment-rates

[24] https://ndsp.com.au/are-you-using-your-plan-funds/

[25] https://www.msaustralia.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

[26] Kavaliunas, A et al.(2022) Systemic Review of the Socioeconomic Consequences in Patients with Multiple Sclerosis With Different Levels of Disability and Cognitive Function. Front. Neurol. 12:737211. doi: 10.3389/fneur.2021.737211

found that even in a population with low physical disability, substantial economic burden occurs due to indirect and informal care costs. It also found higher unemployment, higher rates of early retirement and higher odds for underemployment in relation to increased disability acquisition (physical disability and cognitive decline).

MS Australia, with a number of other peak bodies, believes that the DSP, in its current state, is not meeting its purpose in supporting people with a disability, their family and carers, to live independently, safely and have equal access and rights to participate in the community. We look forward to the Australian Government's implementation of the recommendations from the recent Senate inquiry into the DSP.

Accommodation

MS Australia's State Member organisations have perceived a shift in policy regarding the sustainability of NDIS accommodation options. Whilst supported accommodation is considered "necessary" by the NDIA, shared accommodation is considered "reasonable" and there is a shift towards shared services models and shared home arrangements, thus reducing participant choice and control, but presumably to reduce costs.

Whilst this shift in policy has not been publicised, there are many examples of it occurring. For example, if a participant moves home to be closer to family and friends, despite not requesting additional funding in their plan, it is often found that their plan is substantially cut, without communication and without substantiation. Once the move occurs it is very difficult to achieve the same level of SDA funding. Whilst the participant, by moving, is exercising "choice and control" they are effectively having their plan value "capped".

As a provider of accommodation it becomes very difficult to proceed with accommodation models in this state of uncertainty and, in some cases, SDA partners withdraw, as they cannot be given assurances of funding levels.

Shared accommodation models could work, but some system of collective assessment is needed. For example, recently, in one jurisdiction, it has taken six months to finalise a change in accommodation arrangements for just three participants.

We need to establish an understanding of how accommodation-related decisions are made by the NDIA, remove the guesswork and take into account the longer-term needs of the participant, rather than the current piecemeal approach delivering uncertain outcomes.

Most accommodation providers have a thorough understanding of how to manage the levels of accommodation and support needed to deliver quality, dignity and sustainability.

Recommendation 3

That a portfolio approach to accommodation arrangements be adopted, utilising a co-ordinated business partner model to deliver improved and certain outcomes, working closely and transparently with providers.

Need for service coordination and 'system wrangling' outside the NDIS

People outside the boundaries and eligibility of the NDIS, especially those living with fluctuating or episodic disability or chronic health conditions not deemed as permanent disability, are missing out.

Those living with neurological conditions or those living with mental health issues and illness are experiencing gaps in services delivery, access and continuity of care.

A recent cross-sectional study [27]into the health-related Quality of Life (QoL) in people with MS looked at which aspects of health-related quality of life are most negatively impacting on people with MS, compared to general population data. The study considered eight dimensions of health and found that *mental health influenced health-related QoL more than their physical health* – a difference particularly noted in those individuals newly diagnosed. Although not surprising for a population with a chronic health condition, data showed that respondents had a much poorer overall health in all domains than the general population and that cognitive impairments occur early in the disease course in the absence of other physical symptoms. Therefore, an increase in attention and resources should be directed to understanding and supporting those presenting with nonphysical or invisible health needs, early in the course of the disease, to influence more positive impacts and outcomes for this population group.

Prior to the NDIS, disease specific organisations were able to advocate and provide specialist service coordination to this cohort, providing that much needed 'system wrangling', that is, providing support and capacity building activities to link people to appropriate supports that may prevent the need for what was then called specialist disability supports. This support is now funded only for those accessing these supports through their NDIS personal budgets. Although MS Australia's member organisations and other disease specific peak bodies and organisations have chosen to continue providing service coordination to those outside the NDIS (and often topping up services coordination support for those already in the NDIS due to insufficient budgets for this support type), these instances of support coordination

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[27] Faraclas et al. Health-Related Quality of Life in people with Multiple Sclerosis: How does this Population Compare to Population-based Norms in Different Health Domains? Journal of Patient Reported Outcomes (2022) 6:12. See https://doi.org/10.1186/s41687-022-00415-4

are now funded through highly competitive and dwindling fundraising income.

Now called Information, Linkage and Capacity building (ILC), the previous recurring funding to such organisations is pooled in a national competitive grant round.

Information, Linkage and Capacity building

According to the strategic framework for the ILC, the:

> ‘ILC is an important part of the NDIS because it can enable greater access to the social and economic life of the community for people with disability, their families and carers. People with disability engage both directly and indirectly with a range of informal and formal supports and resources over their lifetime, to help them with their everyday needs and their social and economic participation. This is affected by a range of societal, environmental, demographic and disability-specific factors. Examples of these include age, location, socioeconomic and cultural background, type and nature of a person’s disability and level of functional impairment, the cyclical or episodic nature of disability, and importantly the capacity of the community and mainstream services to proactively respond to diversity and reduce the impact of disability.’

Although well-meaning, these competitive grant rounds provide one off funding for projects aiming ‘to build the knowledge, skills and confidence of people with disability, and improve their access to community and mainstream services’[28] but with little continuity, sustainability or strategic intent or linkage with measurement of the overall benefits or the identification of gaps in the market or individual quality of life indicators.

The ILC program was recently transferred to the Department of Social Services (DSS) to sit next to other government programs such as the Disability and Carer gateways. This move is concerning, as it creates a clear bureaucratic partition and signalling to the community - between the “haves” and the “have nots”.

MS Australia understands that DSS has been reviewing the ILC program since its transfer from the NDIA in October 2020 and further, that the department is proposing “a range of related foundational pieces of work to inform the development of a new strategy in the absence of data on the current strategy”, as set out on the DSS website.

Consideration should be given to utilising a research approach, looking back at what the ILC program has achieved then looking forward to an informed, evidence-based decision-making process about the future of the ILC. Complimentary to this suggested research project, consideration should also be given to a qualitative research approach

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[28] https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/information-linkages-and-capacity-building-ilc-program

that may include interviews through considered community consultations to fully explore the unintended consequences, benefits and gaps since its implementation. In the spirit of capacity building, a consumer informed approach to re-design should be adopted.

In addition, it might be beneficial to undertake these consultations with the organisations that previously were in receipt of Tier 2 recurrent funding and their cohorts to see what has improved, what has been lost, and how things might be able to improve in future.

The interfaces of NDIS service provision with other non-NDIS services

Health and the NDIS

This barrier or area of demarcation between the NDIS and other community or government services such as health, illuminates the regional differences, accessibility issues and availability of specialist disability supports outside the NDIS, and places the onus on the person living with MS to navigate these intersections.

The health system itself is a multifaceted web of 'arrangements, which are mixture of public and private funding involving blurred lines of jurisdictional responsibility, multiple providers and a variety of regulatory regimes, are 'nothing short of complex''.[29] For people living with MS, these intersections can become very problematic, complex, and hard to navigate.

MS specialist health professionals are central to the service and support needs of people living with MS, as many of the service needs relate to ongoing management of the condition. However, the role of these professionals is targeted and therefore may not consider other holistic needs.

Episodic and degenerative conditions, including chronic health conditions, require differences in service utilisation and the need for disease specific specialisation for optimal outcomes. Health and disability-related systems require flexibility and responsiveness - they must not add stress through administrative complexity. This lack of clarity and understanding is not only limited to the person living with MS, but also to their family and informal supports. Without articulated health pathways for specific disease groups, any formal supports within both sectors and mainstream services struggle to navigate these systems.

Aged Care and the NDIS

Another deliberate fiscal boundary of the Scheme is the discrimination against those who acquire a permanent disability, which substantially

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[29] https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/ pubs/rp/rp1314/QG/HealthAust

impacts how they manage everyday activities but who are over the age of 65. For this cohort, supports are available only if self-funded or through the aged care sector, which is capped and means tested. This discrimination based on age is unacceptable and unfair.

Case study

**Names changed and some details removed/ changed to protect people's identities. Narrative based on a private conversation with a National Advocate of MS Australia*

Siubhan* (age 67 years) lives in small town in southern Tasmania with her husband, John*, aged 71 years. Both retired, they enjoy the boating life and spending time with their family and friends – especially their grandchildren. Siubhan was diagnosed with MS in 1985 (now 37 years ago). She was originally diagnosed with relapsing remitting MS, but a few years ago, her neurologist informed her that she now most probably has secondary progressive MS. Siubhan was office based when not staying home when the kids were young, but had to retire early due to her MS. In the time following diagnosis, Siubhan did not have access to the type of disease modifying medication that people have access to nowadays.

She feels lucky to have had John as her main carer since his retirement from a senior role in the public service. John has contacted our MS service, feeling desperate and frustrated. He is struggling to navigate the Aged Care system and feels frustrated that everything is so hard. He feels that they are getting no support from Aged Care and that he can't go on the way he is currently. He fears that he might injure himself and feels overwhelmed.

Unfortunately, Siubhan health has deteriorated over the past few years. Her mobility decline has resulted in her need to change from using a walking stick, to now requiring a wheelchair or scooter. But they just can't afford one. There is a medication that Siubhan can take that improves her mobility, but it is not listed on the PBS and unaffordable to them.

Another symptomatic impact of living with MS, and probably the most felt and immediate physical and financial need, is that Siubhan lives with both urinary and faecal incontinence. Siubhan frequently suffers from recurrent urinary track and candida infections (Siubhan has an indwelling catheter), resulting in at least one previous hospitalisation. The hospitalisation was as a result of a fall, as Siubhan fell (due to her lost mobility) trying to reach the toilet in time. As a result, Siubhan now always requires supervision toileting and maintaining personal hygiene, for example having to have a shower or cleaning up after accidents or leakage. This is very humiliating for Siubhan to have John as her carer and has significantly changed their relationship. At night, Siubhan must wake John a few times each night, to assist her to go to the toilet. John reckons that they spent thousands of dollars a year on personal care products. But the cost and add-ons for attending doctors' appointments, travel costs for attending clinic appointments in Hobart, and the ongoing costs of filling scripts is not even included.

They still reside in their family home and want to find something more suitable, but the recent increase in house prices and availability of housing stock has made this an unobtainable dream. Their house is multi-level and Siubhan struggles to use the stairs without support. The bathroom was last updated in the 80's and is not disability accessible. Siubhan is not able to enjoy her garden anymore, due to the slight slope of the block, fearing that she might slip and fall. They have a few stairs at the front door and through the garage, that prevents Siubhan from going out without someone with her. This has resulted in Siubhan refusing a lot of social engagements and which has resulted in feelings of loneliness and depression. If they were to stay were to stay where they are, John reckons, the cost of home modifications would be huge and just not affordable on his pension. He doesn't think they will be able to use a wheelchair with ease in the bathroom or toilet and his back is giving in trying to transfer Siubhan to and from these rooms. There's just not enough room to turn the chair or put it next to the toilet or shower to make transferring easier. Currently Siubhan is using an over the toilet chair and a similar chair in the shower and holding on to John's neck to get in and out of the chairs.

They have applied for a home care package from MyAgedCare in the past and are waiting for a package of their newly approved level to become available. John explains that the whole application process was frustrating and confusing. Compared to people they know who have MS and were receiving an NDIS package, the difference is stark. With a home care package, they still have to pay a daily fee (as any supports are income-tested), to cover the service and management costs. Their budget covers some continence costs and personal care, but they are unable to provide Siubhan with suitable equipment. John and Siubhan asked their GP for a referral to an occupational therapist, who suggested Siubhan needs a motorised wheelchair and commode. But they simply can't afford the additional personal contribution – which will be thousands. John has a retired engineer friend who will try to build Siubhan one of the motorised commode chairs, but John says, this is a long shot.

And on top of that, there's Covid. John has psoriasis. Due to the medication he is taking, he is now deemed immune compromised. The additional expense and worry about paying for masks, gloves and sanitising products needed to keep them safe is described by John as, "just the straw that will break our backs".

Age is preventing Siubhan and many others like her from accessing specialist disability supports such as home modifications, assistive technology (large and small), respite options and support coordination to help navigate all the various supports and providers. Support that would enable her to partake in social activities without John, and would provide access to exercise physiologists, physio-therapists, dietitians and specialized continence care and products and in-home assistance and garden and lawn maintenance. Instead, any supports provided (if available) through the Aged Care sector are capped and subject to means testing. The future for Siubhan and John is unfortunately dire and inevitable.

Currently there is inequity in Government support of people living with MS diagnosed with MS and other neurological diseases under the age of 65 and those over the age of 65 years. The NDIS will provide access to specialised disability supports for eligible participants up to their 64th birthday at time of application, but for those aged 65 and over, they must rely on the aged care system (via the My Aged Care portal) which is designed to address ageing, not disability. This inequity is further illustrated by the Disability Doesn't Discriminate campaign, initiated by Spinal Life Australia.[30]

People affected by MS or another neurological conditions, aged over 65, with a disability, should be able to access whichever support system best meets their needs i.e. the National Disability Insurance Scheme (NDIS) or My Aged Care.

Integration between the aged care, health care and disability care systems are urgently required and the implementation of the recommendations of the Aged Care Royal Commission may go some way to addressing these inequities.

Recommendation 4
The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems to ensure people affected by MS have their needs met, regardless of which system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

The drivers of inequity

The scheme's initial regional roll out arrangements (in 'waves') during the transition from state to a national approach and the variations in priority between states and territories made the drivers of inequity apparent from the onset. Some potential participants missed out due to age-based rollouts, based on their dates of birth.[31] Others missed out due to the lack of availability of supports i.e. inability to access funded supports. Various barriers were identified, including waiting times, lack of availability or the quality of available providers, costs, or the fact that there was no local provider.[32]

Choice and control, utilisation and market concentration indicators data according to the NDIA Quarterly Reports are still identifying hot spots where participants experience inequity.[33]

Nationally, our MS member organisations have continued noting variations in NDIA staff experience of disability. Anecdotally it appeared that NDIA staff were more familiar with intellectual and physical disability (what they can easily observe) rather than dealing with people living with other types of disability i.e. neurological conditions. Some NDIA regional offices acknowledged the specialism and put together specialist teams focussing on neurological conditions, whilst other regional offices did not.

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[30] https://disabilitydoesntdiscriminate.com.au/
[31] https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf
[32] https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf
[33] https://www.ndis.gov.au/about-us/publications/quarterly-reports

The NDIS' National Workforce Plan 2021-2025[34] included consideration of specialised skills in areas such as psychosocial disability and working with high levels of complexity. As such, a review on qualifications is underway as part of the NDIS Quality and Safeguard's Commission's Capability Framework.

Recommendation 5
Consideration be given to mapping out the specialised skills and capabilities required to work with participants living with neurological conditions such as MS (who often also have high levels of complexity) as part of the proposed micro-credentials projects to engage more positively with this specialised cohort.

Variations in Plans

The national participation rate for participants with a neurodegenerative condition is relatively low compared to other disabilities. For those with a neurodegenerative condition, except for Parkinson's disease, the number of active participants with an approved plan continues to increase at a decreasing rate compared to the Scheme as a whole.[35] This might be because participants with a neurodegenerative condition have significantly higher average annualised committed supports compared with the Scheme overall ($70,000) - $108,000 for participants with MS.

A recent CSIRO publication in Australian Health Review entitled, "*Do people with multiple sclerosis receive appropriate support from the National Disability Insurance Scheme matching their level of disability? A description of disease burden and societal costs in people with multiple sclerosis in Australia (BAC-MS)*" published in September 2021[36] is the first paper in Australia that correlates disability with the approved package value. The study has found 'striking variability in packages approved' citing restricted mobility as the main driver or decision-making factor. This appears to be consistent with the idea that visible disability is more easily understood than invisible disability or functional impairments such as cognition decline.

Eligibility for the Scheme places the burden of proof, to evidence functional impairments, at the feet of applicants. For those who do not associate a diagnosis such as MS with the concept of 'disability' but rather a disease, the jump to making an application to the Scheme, heavily relies on their understanding of the purpose of the Scheme and their ability to reflect on the day to day functional impairments caused by the interaction of the various symptoms associated with MS.

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[34] https://www.dss.gov.au/disability-and-carers-publications-articles/ndis-national-workforce-plan-2021-2025

[35] https://data.ndis.gov.au/reports-and-analyses/participant-groups/participants-neurodegenerative-condition-ndis

[36] See https://www.publish.csiro.au/ah/pdf/AH21056 and an easy English summary at https://www.msaustralia.org.au/news/ndis-support-match-disability-needs/

Dealing with the NDIA is also thought by many in the MS community to be akin to dealing with any other government agencies, triggering a great amount of anxiety and distrust. For example, even with sufficient health assessments and reports, specialist health opinion is not always taken into account or respected.

The overriding factor or perception for many participants is a feeling that agency staff have been directed to achieve cost savings and to rein in spending.

Anecdotal evidence from our State Member organisations confirms that plans for those living with neurological conditions are scrutinised for possible savings, especially for reductions in Support Coordination budgets.

The Sustainability of the Scheme

A deep understanding is required to contemplate the interaction of socio-economic impacts and the costs of disability on the individual and society as a whole.

MS Australia consulted widely with our Member Organisations, who reported noticeable decline in especially Support Coordination budgets. The importance of Support Coordination for people living with MS and other neurological conditions has been highlighted by MS Australia in several of our previous submission on the NDIS[37]. Our members have highlighted the standard tasks associated with this support type:

Support Coordinator Standard Tasks	
TASK	**ESTIMATE OF TIME**
Plan Implementation • Help you understand what's in your plan and how payment will occur • Support to understand NDIS Legislation, including what they mean by "reasonable and necessary" www.ndis.gov.au/about-us/governance/legislation • Get an understanding of what is important to you in selecting a service provider • Ensure you have choice and control and are making all the decisions • Research service provider options • Complete referrals to service providers on your behalf • Ensure signed service agreements are in place with all your service providers • Link you in to mainstream and community services when required • Arrange specific assessments if you need them to achieve your goals • Support to set up the NDIS portal. Show you around the website, and show you how to claim	Approximately 10-15 hours, depending on complexity This includes: • Initial assessment • Clinical Notes and documentation • Research and referrals • Link to mainstream services • Liaison with you and your providers • Support to set up your NDIS portal • Setting up your plan

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[37] https://www.msaustralia.org.au/advocacy/submissions/

for reimbursements if you're managing your own funds • Complete your 8-week implementation report	• Travel and on-costs
Monitoring Phase • Make sure you are receiving quality service from your service providers • Work with your providers to make sure their services are helping you meet your NDIS goals • Resolve service delivery issues with your providers when you direct us to • Guide you through NDIS processes and explain how to provide feedback or make complaints to the NDIA www.ndiscommission.gov.au/about/complaints-about-ndia • Work with your planner or Local Area Coordinator to support your plan implementation • Offer Capacity Building Support: - Understanding the NDIS - Understanding how your funding is managed - Using the Participant Portal - Service Providers - Plan review - AT/Home Mods - Communicating with the Agency - Responding to a crisis	Approximately 10 -20 hours, depending on complexity This includes: • Liaison with you, your providers and other key supports • Completing plan implementation reports • Maintaining clinical notes and documentation • Capacity building supports as directed by you
Review • Work with you to review progress towards your NDIS goals • Request reports from your providers and compile 9-month outcome report • Support you at your plan review meeting	Approximately 10-15 hours, depending on complexity This includes • Liaison with you and other key supports • Reviewing providers reports • Completing end of plan reports • Travel and on-cost

They have provided case examples noting reductions in plans as much as 60 hours less than included in a previous year, highlighting the original support budget, utilisation, allocation further to review and subsequent risks to participants.

Participant- X
Original Plan duration- 1 year plan
Original Support Coordination budget- 36 hours
Utilization of hours- The allocated 36 hours of Support Coordination funding was fully utilized. An additional 2 hours of unfunded support provided by Support Coordinator to attend the Plan Review.

Factors that contributed to the utilization of Support Coordination hours in original Plan-

- Routine requirements for Support Coordination role including plan implementation monitoring and review.
- The participant had 4 major operations and hospitalization–Support Coordinator assisted to facilitate safe discharges, ensuring NDIS services were set up to support post discharge.
- Support to navigate major life changes- the participant ceased employment due to decline in health. This included support to link with mainstream supports and entitlements.
- Implementing home supports required more intensive navigation due to the participant disclosing problems with hoarding and significant cluttering in the home which was impacting her ability to access certain areas within her home safely. Frequent interaction between Support Coordinator and participant was required for service uptake to be achieved.
- MS related fatigue also impacts the participant's ability to maintain her home. Liaison between the participant, Support Coordinator and OT has been required to implement strategies to ensure that the participant's home remains safe and accessible.

Recommendation made for continued Support Coordination hours

- 80 hours of Support Coordination was recommended in the 9-month report and reflected at the review meeting, to support the participants to successfully utilize their future NDIA plan.
- This would assist in delivering the core components of Support Coordination, in addition to responding to crisis, and declining disability.
- Continued Support Coordination hours were integral to support the participant who is experiencing cognitive decline associated with MS. As a result, Support Coordinators often prompt participants to remember appointment, or are contacted by providers when participants are uncontactable.
- The participant requested ongoing Support Coordination hours to enable more frequent check-in with the Support Coordinator to enhance the utilization of her plan.
- Sufficient hours were also required to follow-up the applications made by the OT in relation to home & bathroom modification. Capacity building around low-cost AT purchases (and building skills with purchasing these items independently). Additionally, more Support Coordination hours are utilised following up with the NDIA as applications are often not actioned in a timely way when submitted to the enquires email address.
- Capacity building to support utilisation of my place portal. Participant experiencing cognitive decline, often require ongoing education.
- Risks were identified in the Plan Review Document, including unstable nature of disability, impact of Covid-19, many participants utilization of supports were reduced, and increased support will be required to re-engage once restrictions lift. Hoarding traits and low original budget of Support Coordination hours (36hr) to adequately support the participant.

Support Coordination hours allocated post Reviewed Plan

- **48 hours for 2 years (24 hours per year), 12 hours less than the original plan**

Risk to participant with reduced Support Coordination amount –

- Disengagement in services and the participant becoming overwhelmed with the navigation of her NDIS Plan and services. The hours allocated significantly reduces the communication frequency between participant, Support Coordinator and services providers, which is required to ensure achievement of NDIS goals and engagement with services.
- Symptoms of cognitive decline, and MS fatigue, combined with hoarding, highlight that a greater level of support is required to ensure services are

meeting the participant's needs, and maximum benefit can be achieved through the NDIS Plan.

- Minimal support available to facilitate the pursuit of new goals identified in the plan.
- Insufficient hours available to respond to an MS relapse.

Action to be taken: Review of a Reviewable Decision will be submitted

Such reductions as seen in the above case example, facilitate disengagement with support services, increased insolation and significant risks to participants, vulnerably living with progressive cognitive decline.

Participant: Y
Diagnosis: MS
Original Plan duration 1 year
Original Support Coordination budget - 70 hours
Utilisation of hours: The allocated 70 hours for Support Coordination were fully utilised. 3.3 hours unfunded.

Factors that contributed to the utilisation of original Support Coordination hours

- First plan implementation, requiring a considerable volume of guidance to understand NDIS landscape, the support coordinator role scope and processes for equipment applications.
- Limited ability to build capacity due to progression of MS, anxiety and adjustment to disability decline.
- Frequent contact with support coordinator and other providers engaged in providing supports for reassurance, despite attempts to build capacity to manage independently.
- Support Coordinator responding to carer burnout and stress despite linking in with carer support programs.
- Inappropriate behaviour and aggression.
- Routine requirements for Support Coordination role including plan implementation monitoring and review.
- Facilitating care team meetings to manage the complexities

Recommendation made for continued Support Coordination hours,

- The 9 -month report clearly highlighted multi-factorial issues impacting the participant and their carers ability to navigate the NDIS environment without considerable assistance from a support coordinator.
- Continued Support Coordination hours were integral in the sustainability of the participants informal supports, reducing carer burden out and stress aiming to minimise the potential for relationship breakdown.
- This would assist in delivering the core components of Support Coordination, in addition to responding to crisis, and declining disability.
- Adjustment to diagnosis and progression of disability has been difficult for the participant. Ongoing support needed to encourage utilisation of supports.
- Multiple Risks were identified in the 9 month report, including safety in the home, isolation ,financial burden and sustainability of informal supports.

Support Coordination hours allocated post reviewed Plan:
10 hours (1 year plan) – 60 hours less than initial plan.

Risk to participant with reduced Support Coordination amount –

- Increased stress on the participant and family who have required considerable contact with support coordinator to effectively engage in services and navigate the NDIS.

- Disengagement with supports as navigation of supports will become overwhelming, impacting physical and mental health of the participant.
- Increasing carer burden and possible relationship breakdown.
- Behaviours of concern being unaddressed, safety issues for both participant and wife/carer - further adding stress for his partner.
- Nil ability to facilitate care team meetings with all support providers which had been implemented and proving beneficial for a holistic approach to his care.
- Social isolation if participant cannot be encouraged/supported to access the community.

Action to be taken; Submit a request of a reviewable decision.

These reductions also have severe impacts on carers.

Participant; Z
Diagnosis – Parkinson's Disease
Original Plan duration 1 year
Original Support Coordination budget – 35 hours. 6.35 unfunded.
Utilisation of hours – Full utilization of hours.

Factors that contributed to the utilisation of Support Coordination hours/support -

- Routine requirements for Support Coordination role including plan implementation monitoring and review.
- Decline in Parkinson's disease and increase in care needs.
- Hospitalisation and support coordinator assisting in discharge planning, as per requirements of their role.
- Significant increase in the arrangements of supports including home mods due to disability progression.

Recommendation made for continued Support Coordination hours

- Original plan did not run the duration of the 12 months due to changing care needs, an unscheduled plan review occurred.
- Support coordinator needing to facilitate home modification processes and follow on.
- Ongoing and continual support required due to the nature of a progressive condition.
- The participant has an inability to build capacity to manage their own plan.

Support Coordination hours allocated post unscheduled review-
10 hours (2 year plan duration – 5 hours per plan)- 30 hours less than initial plan

The participant requested a one-year plan, however was given a two-year plan.

Risk to participant with reduced Support Coordination hours –

- Disengagement in services and the participant/ carer becoming overwhelmed with the navigation of her NDIS Plan and services.
- Increased risk of carer burn- out.
- Nil assistance to follow up on the home modification requests and other services.
- Financial risk due to husband's ability to maintain his employment while trying to support his wife and follow up with providers/ navigate the NDIS landscape. He is overwhelmed with the circumstances

surrounding his wife's progression and feels burdened by the lack of hours allocated and that his request for a one-year plan was ignored.

Action to be taken- Change of circumstances lodged by phone to NDIS

Apart from the few case examples noted above, the most recent discourse in our national media[38] has highlighted worrying and alarming trends of ongoing reductions to participant plans at the back end, through reviews, with catastrophic results. We have also noted a marked decrease in participants meeting the eligibility criteria in the front-end of the scheme, with a notable 11% drop from prior quarters in per cent of access decisions eligible for people living with MS, 12% drop from prior quarters, percent of access decisions eligible for people living with other Neurological Conditions and an overall decline of 10% for the Scheme overall in accordance with their 'Assessment of access by disability' tables[39].

The economic imperative to 'soften up the public' through alarmist reports projecting billions in scheme overspending and funding gaps,[40] has started the paradigm that the scheme is unsustainable. The original intent of the Scheme has been overshadowed in the public conversation with a focus on funding and expenditure rather than outcomes and benefits. The Productivity Commission report referred to a cost-benefit test stating that the "benefits of the scheme would outweigh the costs".

We support the comments from the Young People in Nursing Home National Alliance's October 2021 submission to this committee [41] that the government appears to measure the scheme's value in costs only, a measure of sustainability and performance, rather than considering the broader economic benefits within the context in which the scheme sits nor the individual participant benefits.

MS Australia believes that the most important measure to address inequitable variation in plan funding would be to commission an economic impact study costing the savings and benefits of linking

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[38] https://www.theguardian.com/australia-news/2021/nov/28/perth-mother-may-have-to-quit-work-to-care-for-autistic-son-after-ndis-package-cut-by-70; https://www.theguardian.com/australia-news/2021/dec/06/terminally-ill-ndis-patient-facing-re-hospitalisation-after-funding-cut-for-24-hour-nurse; https://www.abc.net.au/news/2021-12-08/father-of-woman-with-disabilites-dies/100681738; https://www.canberratimes.com.au/story/7510117/funding-cuts-remove-autonomy-from-people-with-disability/;https://gympietoday.com.au/news/2021/11/19/ndis-not-listening/;

[39] https://www.ndis.gov.au/about-us/publications/quarterly-reports

[40] https://www.smh.com.au/national/the-fatal-flaw-in-the-ndis-it-cries-wolf-but-has-no-shepherd-to-control-its-spending-20210708-p587ur.html

[41] See submission 21 https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/ImplementationForecast/Submissions

people with disability to appropriate supports, disability prevention measures and even Quality of Life measures tied to social and economic participation. Such a study could do much to challenge any community attitudes that people with disabilities are a drain on society.

Recommendation 6
Consideration be given to commissioning an economic impact study encompassing the savings and benefits of linking people with disability to appropriate supports, disability prevention measures and Quality of Life measures tied to social and economic participation.

The results from a recent ABC national survey, Australia Talks[42] showed that 82% of all Australians think we should spend as much as is necessary to ensure people with disabilities have the same opportunities as everyone else. The same survey (representing a majority of our voting population) stated that Australians did not believe that it is unsustainable to spend money to improve the lives of people with a disability.

Improved transparency and access to costing information including costed outcomes of factors such as keeping people with disability in employment and supporting people with disability to remain active in the community would benefit from a more balanced conversation. The importance of evidence-based decision making and optimal utilisation of the Disability Policy and Research Working Group could be utilised – selecting research projects that could provide the evidence of this expenditure against the economic and social benefits through the NDIS, ILC Grants and other disability supports such as the DSP.

The Australian Federation of Disability Organisations in a 2019 Pre-Budget submission stated that, “The NDIS is the greatest social reform of our time and, as such, it is critical that it is fully funded at the required level for the longer term. An indication that funding is outlined in forward estimates provides no certainty for people with disability, their families, or for any Australian who may acquire a disability in the future. As an insurance scheme it is counterintuitive that the NDIS remains the subject of annual reviews of funding at every Federal Budget. Other levels of government are also co-contributors to the scheme and this also needs to be addressed to ensure that full contributions continue to be made to the required levels. AFDO calls for the funding of the NDIS to be legislated so that future governments have this as a key component enshrined in every budget. The agreements with other levels of government must likewise protect the full amounts required for the scheme’s operation. This would provide the certainty that people with disability, their families, supporters and the wider Australian public require.”[43]

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[42] See https://australiatalks.abc.net.au/
[43] https://www.afdo.org.au/wp-content/uploads/2019/10/AFDO-Pre-Federal-Budget-Submission-2019-2020.pdf

MS Australia supports this recommendation. We also suggest establishing an independent pricing reference group and an independent pricing commissioner to advise the NDIA board on their annual risk appetite, market development and cost projections.

MS Australia also suggests that funding arrangements be reviewed as part of the Australian Productivity Commission's schedule of work for 2023.

Key facts about MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 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.