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Submission to the NDIS Review

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SUBMISSION

Submission to the NDIS Review

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MS Australia is Australia's national multiple sclerosis (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 represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

MS is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 25,600 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

NDIS Review

MS Australia welcomes the opportunity to make a submission to the National Disability Insurance Scheme (NDIS) Review and contribute to improving the NDIS to ensure it meets the needs of people with disability, including those living with MS. Over the past seven years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. We have written over 27 submissions relating to the NDIS, including submissions to the NDIS/NDIA, the Joint Standing Committee on the NDIS and the Productivity Commission. Additionally, on 18 July 2022, MS Australia launched a campaign A better NDIS for people living with MS to highlight essential areas for reform in the NDIS.

This preliminary submission aligns with our NDIS campaign and outlines outstanding issues from our submissions. We have sought to provide a broad overview of the issues facing people living with MS and recommended solutions for the NDIS Review Panel. MS Australia is currently commissioning economic modelling on the impact of early and appropriate access to the NDIS for people living with MS. We will provide the findings from this work in a further submission to the Review Panel in early 2023.

Overall, MS Australia recognises that the NDIS provides crucial supports and has improved the lives of many people with disability, including those living with MS. However, we believe there are some outstanding issues to be addressed, with a particular focus on improving the understanding of disability (including MS), making the NDIS more accessible and easier to navigate, the value of early access and access to the most appropriate supports, and a greater emphasis on participant choice and control.

MS Australia makes the following recommendations:

MS Australia Recommendations

1. Improved NDIS understanding of progressive neurodegenerative diseases:
   - Commit to educating and training NDIA staff and contractors about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS
   - Establish a resource library of disability materials for use by NDIA staff that includes the MS Australia ‘Snapshot’
   - Compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability
   - Increase the number of NDIA staff who have lived experience of disability
   - Establish a NDIA neurological advisory group, modelled on the NDIA Autism Advisory Group
2. Increased support for people accessing and navigating the NDIS including:
   - Improved and simplified pre-planning resources
   - Planning meetings held over multiple sessions
   - Examples of goals and corresponding services for a range of disability types
   - Best practice examples of Access Request Forms, Supporting Evidence forms and approved plans
   - Resources and training for health professionals in how to support patients accessing and navigating the NDIS

   - An increase nationally in the number of Local Area Coordinators (LACs) and the introduction of compulsory minimum training standards for all LACs.
   - Participants with progressive, degenerative, neurological and neuromuscular conditions such as MS are only required to have a plan review on an as-needs basis
   - Develop clear guidelines on which participants are eligible for support coordination, with an emphasis on listening to participants and making ongoing and episodic support coordination available where needed

3. Improved access to assistive technology and accommodation
   - Improved and timely access to assistive technology and accommodation with a focus on participant choice and control
   - The introduction of a single, nationally consistent assistive technology program to support people with disability who are not eligible for the NDIS
   - A renewed focus on supporting young people with disability to leave residential aged care and an increase in the availability of age-appropriate specialist disability accommodation
4. Extend *the Delivery of Disability Related Health Supports by a Nurse* category to include delivery of supports by a MS Nurse for participants living with MS
5. Amend section 22 of the *National Disability Insurance Scheme Act 2013* to remove the age limit for accessing the NDIS
6. Support people who are not eligible for the NDIS:
   - A review of disability programs funded outside of the NDIS with an emphasis on streaming programs and improving access.
   - An immediate increase in the rates of the Disability Support Pension and New Start Allowance and a more person-centred focus on the delivery of income payments to people with disability

NDIS Understanding of progressive neurodegenerative diseases

MS Australia has concerns regarding the current understanding of NDIA staff about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. Feedback from our Member Organisations indicates that people with MS have found that the limited understanding by NDIA staff of neurological conditions leads to ineffective planning sessions, inconsistent plans that do not address their needs and unnecessary reassessments or plan changes. There is also a lack of understanding of the importance of access to coordination of supports and assistive technology for people living with MS. Greater awareness, understanding and education of neurological and neuromuscular conditions such as MS are needed to ensure improved support, participant experience and outcomes.

In 2019, MS Australia collaborated with the Disability Advocacy Network Australia (DANA) and the NDIA to develop a participant-informed, e-learning, disability training package on MS for NDIA staff, referred to as a 'Snapshot'. This included a fact sheet, four 'at a glance' examples, practical suggestions for engaging with people living with MS and a video which included participants speaking to NDIA staff about the disease and its impacts. Effective dissemination of the 'Snapshot' materials will improve the understanding of NDIA staff of the needs of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS, with a particular focus on recognising and addressing invisible symptoms, such as neuropathic pain, fatigue and cognitive issues.

MS Australia recommends that the NDIA commit to educating and training all staff and contractors about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. Greater awareness, education and understanding of MS within the NDIA will ensure better support for people living with MS.

MS Australia recommends that the NDIA establish a resource library of disability materials for use by NDIA staff that includes the MS Australia 'Snapshot'. Prior to a planning meeting, staff would use the library to access the materials relevant to the participant's disability. MS Australia would be very willing to engage with the NDIS on any further training or education materials required for the resource library.

Disability Awareness & Understanding

Feedback from our Member Organisations indicates that people living with MS find NDIA staff do not have a good understanding of disability and are not well trained in how to appropriately engage with people with disability. There are also very few NDIA staff with lived experience of disability. The major concerns for people living with MS when engaging with NDIA staff are:

- Poor communication with participants including a lack of understanding of how the participants disability may impact their interactions. This includes the impact of fatigue, cognitive impairment and communication difficulties.
- Prejudging people by the way they look and/or sound and using this to determine what supports they need. This is especially concerning for those living with an 'invisible' disability such as MS.
- Limited preparation/pre-reading on the disability of the person they are meeting
- A lack of person-centred planning, including the inability to vary from a set of scripted questions
- Lack of understanding of how service types are interrelated, for example approving social supports but not the wheelchair or physiotherapy that is necessary for the person to access the social supports
- Failure to read reports provided by health professionals and service providers and/or dismissing their clinical observations and recommendations
- A focus on costs savings rather than participant outcomes or wellbeing.

MS Australia recommends compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability. Training should include:

- A background overview of disability including types of disability and how it impacts on a person's ability to complete everyday activities and engage in their community
- Communicating with people with disability including inclusive language and terminology
- Understanding the social, environmental and attitudinal barriers experienced by people with disability
- Understanding consent, decision making and choice for people with disability
- How to facilitate person-centred planning and creating plans with a focus on community participation and wellbeing

Improved disability awareness training for NDIA staff will lead to improved application processes, better plans that more accurately reflect the needs of the participant and reduced appeals and requests for reviews. On a broader level it will influence the NDIA's policies, resources, communication and overall interaction with participants. This training can be further supported by ensuring that staff have a comprehensive understanding of the rules and regulations of the NDIA and how the NDIS interacts with the rest of the health system and other state/territory funded disability supports

MS Australia acknowledges the recent changes to the NDIA Board and the inclusion of more people with disability to oversee the work of the NDIA. This can be further improved by increasing the number of NDIA staff with lived experience of disability. People with lived experience of disability can bring a unique perspective the NDIA and are better equipped to engage with people with disability and ensure they get the best outcome from the NDIS. It also increases confidence in the organisation and ensures the NDIA better reflects the cohort it represents.

MS Australia recommends the NDIA increase the number of NDIA staff who have lived experience of disability.

Better representation of people with MS and other progressive neurological conditions within the NDIA

Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over $36 billion. The Neurological Alliance 0f Australia (NAA), of which MS Australia is a member, estimates that around 15% of NDIS participants have a progressive neurological or neuromuscular condition.

MS Australia believes that creating a neurological voice within the advisory and consultative structure of the NDIA will ensure fairer representation for those living with progressive neurological or neuromuscular conditions and improve the understanding of the NDIA in relation to these conditions.

MS Australia recommends establishing a NDIA Neurological Advisory Group. The advisory group would seek to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA. The establishment of an advisory group will contribute to ensuring the people living with these conditions gets access to the NDIS supports and services they need at the right time in their disease journey, reduce complaints, improve outcomes measures and ensure this population is treated equitably when accessing the NDIS.

MS Australia proposes that the Neurological Advisory Group would provide the NDIA with expert advice on the following issues:

- The most appropriate evidence-based model(s) for assessing NDIS eligibility and improving outcomes for people with neurological and neuromuscular conditions
- How the NDIS participant experience for people with neurological and neuromuscular conditions can be improved and better tailored for differing disease journeys
- How the skills of NDIA staff, Local Area Coordinators and Planners can be enhanced for the benefit of participants with neurological and neuromuscular conditions
- Systemic and other improvements that can be made to provide greater mainstream and community inclusion for people with neurological and neuromuscular conditions - both participants and non-participants

Early access and support

For many people accessing the NDIS is complex, time consuming and overwhelming. People with disability and their families need support to access the Scheme and navigate the various stages of assessment, planning and service access. Most people living with MS will receive a diagnosis in adulthood and may have no previous experience interacting with the disability system and limited understanding of the disability providers and services in their area. They are also likely to be overwhelmed by their diagnosis and unsure of what supports and services they need.

MS Australia acknowledges that the NDIS currently provides participant booklets for people that cover applying for the NDIS, creating a NDIS plan and using a NDIS plan. While these booklets provide an introduction to these areas, they present a version of the NDIS that does not match the experience of many people accessing the NDIS. Many people find that accessing the NDIS and getting a plan is not the streamlined and straightforward process outlined in NDIS resources. The resources also assume that all NDIS applicants are actively participating in their community, have clear pre-determined goals and know exactly what supports and services are available.

The NDIS advises participants that Local Area Coordinators (LAC) will help them to understand and access the NDIS and create, implement and change their plan. However, feedback provided to MS Australia indicates that this is not the reality for people accessing the NDIS. In many regions LACs are not able to provide these services because they either do not have the appropriate skills and training or cover too large an area to provide individual support. There is also no required minimum training for LACs and many have limited understanding of how to support people accessing and navigating the NDIS

MS Australia has received feedback that people living with MS and accessing the Scheme, find there is limited information available on the level and type of detail required in the access request and supporting evidence forms. They also find that many medical professionals struggle to know what level of information is required and are overwhelmed by NDIS processes.

Investing in assessment and pre-planning support will significantly reduce the stress of accessing and navigating the NDIS and ensure participants get a plan that meets their needs. It will also reduce access and plan reviews and appeals and enable LACs to focus on linking and connecting people with services. Greater support for medical professionals will increase their confidence in making referrals and supporting patients through their NDIS journey. Additionally, for many people living with MS, fatigue, pain, 'brain fog' and memory issues can make planning meetings a tiring and overwhelming process. The ability to spread planning over several sessions would be a significant improvement and make the process more accessible for all people with disability.

MS Australia recommends increased support for people accessing and navigating the NDIS including:

- Improved and simplified pre-planning resources
- Planning meetings held over multiple sessions
- Examples of goals and corresponding services for a range of disability types
- Best practice examples of Access Request Forms, Supporting Evidence forms and approved plans
- Resources and training for health professionals in how to support patients accessing and navigating the NDIS
- An increase nationally in the number of LACs and the introduction of compulsory minimum training standards for all LACs.

Currently, the NDIS requires participants to reassess their plan approximately every 12 months. For people living with MS, once they are assessed as eligible and receive an approved NDIS plan, the progressive, degenerative nature of MS means that their support needs will not decline over time. The requirement to have 12-monthly reviews is unnecessary, causes considerable stress for participants and in many instances can result in crucial services being removed or reduced. Constant turnover of NDIS staff mean that participants may have to meet with a new planner every 12 months and explain their disability all over again. Participants with progressive, degenerative, neurological and neuromuscular conditions such as MS should be only subject to reviews as needed e.g., when their needs increase or there is a change in their carer/living situation.

MS Australia recommends that participants with progressive, degenerative, neurological and neuromuscular conditions such as MS are only required to have a plan review on an as needs basis.

Support Coordination

Support coordination is an important component of the NDIS and provides participants with crucial support in managing their plan. For many people living with MS, brain fog, memory and fatigue issues make it difficult to manage their plan. Access to ongoing support coordination ensures they can access the services and supports they need and manage interactions with providers. Support coordination is especially important for people who have no carer or informal support network. Once a participant with MS receives support coordination this should be approved ongoing as the need for this support will not go away with time. Participants also need to be able to have increased support coordination during periods of crisis.

The NDIS has no clear guidance on which participants will have support coordination approved in their plans. Feedback received by MS Australia indicates an inconsistency across planners, with no clear reason for why some participants do not get support coordination approved. Also, many participants have experienced plan reviews where their support coordination is removed or significantly reduced, causing great distress and limiting their ability to fully operationalise their plan. Participants and their carers are often the best source for understanding if support coordination is needed and planners should be guided by their feedback on this component of their plan.

MS Australia recommends the NDIS develop clear guidelines on which participants are eligible for support coordination, with an emphasis on listening to participants and making both ongoing and episodic support coordination available where needed.

Early Intervention

MS is an incurable, progressive condition and most people are on a trajectory to meet the Schemes full access criteria within the lifetime of the participant. Most people are diagnosed with MS between the ages of 20-40, with 75% being women. Often a diagnosis of MS occurs when people are fully employed, consolidating income, planning a family and/or making significant career choices. The early stages of MS are an ideal time for access to early invention supports that allow them to continue working, being an active member of their community and slow the progression of their MS. Early intervention supports that can help people living with MS include (but are not limited to):

- Allied health services including physiotherapy, occupational therapy, dietetics and exercise physiology to improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time
- Assistive technology and home modifications to allow participants to continue living in their home and engaging in employment
- Psychological services and counselling to manage depression and anxiety, which are common symptoms of MS
- Support coordination to help participants with MS understand their plan and enter the disability marketplace and find services.

Feedback received by MS Australia indicates that the early intervention pathway for adults is unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria. Investing in a clear, streamlined early access pathway for adults with disability will slow the progression of their disability, allow them to continue in employment and community engagement, reduce carer burden and have long term economic benefits to the NDIS.

MS Australia recommends an improved, clearly defied and streamlined early intervention pathway for adults with disability

Access to assistive technology and accommodation

Assistive technology and home modifications play a critical role in the lives of people living with MS by facilitating independence and participation in everyday activities. This includes wheelchairs, scooters and mobility aids; ramps and grab rails; communication devices; hoists and shower chairs; car modifications and pressure care mattresses and adjustable beds. Access to appropriate accommodation is also crucial to people living with MS maintaining their independence. People should be able to choose the living arrangement that best meets their needs and long and short-term goals.

There are also supports that are specific to people living with MS. Approximately 60–80% of people living with MS suffer temperature sensitivity where neurological symptoms can temporarily become exacerbated by environmental or exercise induced increases (or decreases) in body temperature causing a worsening of symptoms[1]. Access to air conditioning and cooling vests/suits can significantly reduce symptoms, however, many people need to financial support to access these. Impairments in bladder and bowel function are common with MS and access to continence products and supports is crucial for maintaining good health and dignity for people living with MS.

Feedback received by MS Australia indicates that people living with MS struggle to get approval for the assistive technology, home modifications and supported accommodation they need and to access it in a timely manner. Access to these supports is not driven by participant choice and control but by the decisions of planners and NDIS delegates. Planners often only approve assistive technology and home modifications that are immediately obvious to them and do not recognise that people with 'invisible' disability may have needs that are not immediately obvious. In particular, they do not understand the assistive technology needs specific to people living with MS. Planners also make assumptions about the accommodation needs of people living with MS, often with a focus on shared accommodation or living with family members. This disregards the choice of the participant, especially if they wish to remain living independently.

There are long delays in approvals for assistive technology and supported accommodation. This delay can result in increased costs and the need for new quotes and in the meantime, participants may have to fund items themselves and/or providers carry to the costs, which is often substantial in the case of accommodation. This delay in access to supports also means a faster disease progression and ultimately a need for increased supports.

MS Australia recommends improved and timely access to assistive technology and accommodation with a focus on participant choice and control

Non-NDIS Assistive Technology

On 30 September 2022, there were 10,366 people living with MS who were assessed as eligible for the NDIS, including 9,739 with active plans[2]. This means that approximately 60 per cent of Australians living with MS do not access NDIS supports including assistive technology which must be through state and territory-based aids and equipment programs. Many of these schemes are underfunded or have reduced funding over time as the assumption is that people will receive these services under the NDIS. Many people may have to a pay large financial contributions towards the cost of items and have long wait lists and limited number of aids and equipment from which they can choose.

A study of assistive technology undertaken by Monash University[3] found that there are currently 87 Government funders, administering 108 assistive technology and home modifications schemes outside the NDIS. There is a distinct lack of equity and consistency across the 108 schemes and people with similar needs receive different amounts of support depending on their age, geographic location and when and where their disability was acquired. The eligibility criteria across many of the schemes are historic in nature and are not fully aligned with assistive technology provision guidelines or good practice standards. Many schemes do not provide wraparound services to ensure appropriate customisation, training, set up and maintenance.

The Assistive Technology for All (ATFA) Alliance, of which MS Australia is a member, proposes the establishment of a national assistive technology program for people who are not eligible for the NDIS. Access to a national scheme would maximise the safety, independence, inclusion and participation of people with disability, reduce the burden on families and carers, drive nationally consistent outcomes, reduce administrative burden on governments and minimise downstream costs by reducing demand in other areas such as acute health, community services and aged care This also aligns with Australia's obligations under the Article 20 of the *United Nations Convention on the Rights of Persons with Disabilities*[4].

MS Australia recommends the introduction of a single, nationally consistent assistive technology program to support people with disability who are not eligible for the NDIS.

Younger people in residential aged care

Many young people with disability live in aged care because there is nowhere else for them to live. MS Australia welcomed the release by the Australian Government of the *Younger People in Residential Aged Care Strategy 2020-25* and the commitment that by the end of 2025 no younger person (under the age of 65) is living in residential aged care unless there are exceptional circumstances. While there has been a substantial drop in the number of younger people entering and living in residential aged care, the latest data[5] shows that the two targets set for 2022 have not been met:

- **Target 1 - No people under the age of 65 entering residential aged care by 2022:** During April to June 2022, 99 people under the age of 65 were admitted into permanent residential aged care in Australia.
- **Target 2 - No people under the age of 45 living in residential aged care by 2022:** At 30 June 2022, there were 68 people aged under 45 living in residential aged care in Australia.

Given that these targets have not been met and there are still 2,934 people aged under 65 living in residential aged care in Australia, more resources need to be dedicated to supporting young people with disability to access the accommodation that best suits their needs and person goals.

MS Australia recommends a renewed focus on supporting young people with disability to leave residential aged care and an increase in the availability of age-appropriate specialist disability accommodation.

MS Nurses

Multiple Sclerosis (MS) Specialist Nurses or MS Nurses are an integral part of the multidisciplinary healthcare team of specialist healthcare professionals providing support, education, advice, and care for people with MS. Access to MS Nurse care brings health benefits for people with MS. These include lower disability level, slower self-reported disease progression, less severe symptoms, lower levels of depression and anxiety, and a higher quality of life.

The *MS Nurse Care in Australia Report*[6] by MS Australia, in collaboration with the Menzies Institute for Medical Research and MS Nurses Australasia found that one-third of Australians living with MS (equivalent to 8,000 people) do not have access to life-changing MS nurse care and have consistently worse health outcomes. MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions. It is a highly cost-effective model of care.

If every Australian with MS had access to MS Nurse care as part of their ongoing MS management plan this would result in significant cost savings for MS healthcare in Australia. It would significantly delay disease progression and the need to rely on supports and services from the

NDIS. The NDIS currently funds some disability-related health supports that are delivered by a registered nurses and these could be extended to include MS Nurses. The provision of MS Nurses under the NDIS would significantly reduce the overall costs of supporting participants living with MS.

MS Australia recommends that the NDIS extends the *Delivery of Disability Related Health Supports by a Nurse* category to include delivery of supports by a MS Nurse for participants living with MS.

Older people with disability

Australians living with MS aged 65 and over when the NDIS was introduced and those who develop a disability and/or first access services after turning 65 are ineligible for the NDIS and must either self-fund their care or pursue their disability needs through the aged care system. Older people living with MS want support to remain independent and living in their home, to have a high quality of life and to remain engaged in their community

The current aged care system does not cater to the needs of older Australians living with fluctuating or episodic disability or health conditions. Aged care services do not meet the disability specific needs of people living with MS, including providing appropriate assistive technology and supported independent living. Currently the average spend on assistive technology and home modifications per person per year for NDIS participants is $2,500, compared with just $51 per person per year for aged care recipients[7]. The funding cap on home care packages leaves many people receiving only limited basic services such as cleaning, personal care and meals. There is limited funding left for essential services for people living with MS including access to allied health and therapeutic services and supports for social and community participation. Residential aged care is focused on care for frail, older people and is not a suitable environment for people living with MS who are still active in their community.

Older people living with MS must either self-fund the shortfall in aged care services or go without, causing greater decline in their health and disability and leading to increased hospitalisation and greater long-term burden on the health and disability systems. There is also a long wait list for home care packages and all aged care services are means tested, causing great financial impact for older people living with disability. There is limited support in navigating the complex aged care system and no availability of support coordination which is crucial for people living with MS (as outlined above).

Further to this, MS Australia believes that the current age limit for the NDIS contravenes Article 19 of the *United Nations Convention on the Rights of Persons with Disabilities*[8], that the Australian Government has ratified. This article recognises the right of all people with disability to live independently and be included in the community, including equal access to community and support services.

MS Australia recommends that section 22 of the *National Disability Insurance Scheme Act 2013* be amended to remove the age limit for accessing the NDIS. Removing the age discrimination for NDIS eligibility will ensure that older people with disability can access to the support and services they need from a system specifically designed to address the needs of people with disability.

People with a disability who are not eligible for the NDIS

Currently there are 4.4. million Australians who have a disability[9] and as of 30 September 2022 there are 554,917 NDIS participants with approved plans[10] (12.6 per cent of the disability population). As a result, the overwhelming majority of Australians with disability are reliant on programs outside of the NDIS to access supports and services. Unfortunately, since the introduction of the NDIS many state and territory governments have reduced or removed funding for disability programs with the claim that people can access these supports through the NDIS.

Many people living with disability struggle to access the support and services they need and must either self-fund or go without. This creates significant economic stress, carer burden, poor mental health and significantly increase the burden of disease and disability. As the NDIS Review will be reporting to state/territory disability ministers this provides an opportunity to address these outstanding issues and to review the disability services funded outside the NDIS and how they can be streamlined and improved. For example, as outlined above the introduction of a national assistive technology scheme can significantly streamline and improve access to assistive technology for people with disability.

MS Australia recommends a review of disability programs funded outside of the NDIS with an emphasis on streaming programs and improving access.

Disability and Poverty

Research undertaken by UNSW and ACCOSS11 found that people with disability face an elevated risk of poverty and it is estimated that the rate of poverty among adults with disability is 17 per cent (compared with 13.2 per cent across the whole population) and that people with disability make up 38 per cent of all people in poverty. In households whose reference person receives the Disability Support Pension, 36 per cent live below the poverty line. The researchers have acknowledged that this research under-estimates the rate of poverty for people with disability as it did not consider the extra costs of a disability when assessing whether people are living below the poverty line.

Further to this research, the AIHW found that 38 per cent of people with disability and 51% of people with severe or profound disability have a low level of personal income, compared to 27% without disability. Government pensions or allowances are the main source of income for 56% of people with disability and up to 76% for people with severe or profound disability. The most common payment type is the Disability Support Pension (DSP) followed by New Start Allowance.

It is clear that the rates of both the DSP and the New Start Allowance are not adequate to meet the costs of those living with disability and need to be raised immediately. Feedback received by MS Australia from people living with MS is clear that these government payments are not adequate to meet the full costs of people living with MS. It places substantial economic burden on people living with MS and their carers and directly influences their health and wellbeing and the rate their disease progresses at. They are also difficult to access and maintain and do not provide adequate support and flexibility for those seeking employment. There is a strong focus on compliance rather than supporting individuals to meet their needs.

MS Australia recommends an immediate increase in the rates of the Disability Support Pension and New Start Allowance and a more person-centred focus on the delivery of income payments to people with disability.

MS Australia supports the ongoing work of the Minister Shorten, and the NDIS Review Independent Panel to reform the NDIS and ensure that Australians with disability have access to the supports and services they need. We look forward to engaging further with the Review Panel and any future reforms to the Scheme.

Reference

[1] Christogianni, A., Bibb, R., Davis, S.L., Jay, O., Barnett, M., Evangelou, N. & Filingeri, D. (2018). Temperature sensitivity in multiple sclerosis: An overview of its impact on sensory and cognitive symptoms. *Temperature (Austin)*, 5(3):208-223.

[2] NDIS (30 September 2022). *NDIS Quarterly report to disability ministers: Q1 2022-23*. Retrieved from: https://www.ndis.gov.au/about-us/publications/quarterly-reports

[3] Layton, N., & Brusco, N. (2022*). The Australian assistive technology equity studies: Improving access to assistive technology for people with disability who are not eligible for the NDIS*. Monash University; COTA Victoria.

[4] United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Treaty Series, vol. 2515, 3.

[5] Australian Institute of Health and Welfare (2022). *Younger people in residential aged care: GEN Aged Care Data Factsheet June 2022*. Retrieved from: https://www.gen-agedcaredata.gov.au/Resources/Younger-people-in-residential-aged-care

[6] MS Australia, Menzies Institute for Medical Research & MS Nurses Australasia Inc (2022). *MS Nurse Care in* Australia: Patterns of access and impact on health outcomes. Retrieved from: https://www.msaustralia.org.au/about-us/reports-and-financials/

[7] Layton, N., & Brusco, N. (2022*). The Australian assistive technology equity studies: Improving access to assistive technology for people with disability who are not eligible for the NDIS*. Monash University; COTA Victoria.

[8] United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Treaty Series, vol. 2515, 3.

[9] Australian Institute of Health and Welfare (2022). *People with Disability in Australia 2022*. Retrieved from: https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability

[10] NDIS (30 September 2022). *NDIS Quarterly report to disability ministers: Q1 2022-23*. Retrieved from: https://www.ndis.gov.au/about-us/publications/quarterly-reports

[11] Davidson, P., Saunders, P., Bradbury, B. and Wong, M. (2018), Poverty in Australia, 2018. ACOSS/UNSW Poverty and Inequality Partnership Report No. 2, Sydney: ACOSS.

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