

MS Australia is campaigning for improvements to the National Disability Insurance Scheme (NDIS) to better meet the needs of people living with multiple sclerosis (MS).

To improve the NDIS for the MS community, we believe there are six essential areas for reform:



Improve understanding of neurodegenerative conditions and disorders within the National Disability Insurance Agency (NDIA)



Increased support for people accessing and navigating the NDIS



Improved access to assistive technology and accommodation



Improved access to MS Nurses



Provision of disability supports and services regardless of age



Support for people who are not eligible for the NDIS

The NDIS is Australia's first publicly funded national disability insurance scheme. Legislated in 2013, and in full operation since 2020, the scheme has provided life-changing benefits to many Australians.

However, the NDIS is not without fault or its critics.

Over the last decade and across 28 policy submissions, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

For every positive story of an Australian helped by the Scheme, there are others who have been left behind.

Now with a new Government promising to rebuild trust in the NDIS and implementing a review of the NDIS, there are many reasons for optimism.





HEAR OUR VOICE

UNDERSTAND MS

Australians living with degenerative neurological or neuromuscular conditions deserve to be heard, understood, and effectively represented within the NDIA

The National Disability Insurance Agency (NDIA) can't offer solutions to what it doesn't fully understand

MS Australia has concerns regarding the current understanding of NDIA staff about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. People living 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 participantinformed, 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.

Disability Awareness & Understanding

People living with MS have found that 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 auestions
- 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.

It is crucial that the NDIA implement 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.

The skills and understanding of NDIA staff can be further improved by increasing the number of NDIA staff with lived experience of disability. People with lived experience of disability bring a unique perspective and are better equipped to engage with people with disability and ensure they get the best outcome from the NDIS.

NDIA Neurological Advisory Group

It is estimated that 1 in 6 Australians* live with a neurological or neuromuscular condition or a neurological disorder. The <u>Neurological Alliance Of Australia (NAA)</u>, of which MS Australia is a member, estimates that around 15 per cent 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.

The establishment of a NDIA Neurological Advisory Group will build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA. It 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.

A Neurological Advisory Group could 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

POLICY SOLUTION

MS Australia recommends:

- Improved NDIS understanding of progressive neurogenerative diseases including:
 - » 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

*World Health Organisation (2006). Neurological Disorders: Public Health Challenges. Retrieved from: https://www.who.int/publications/i/item/9789241563369



TIMELY NDIS ACCESS

EARLY INTERVENTION PATHWAYS

People living with MS need improved and early support to access the NDIS

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.

The current NDIS resources do not provide clear and accessible information on accessing the NDIS and present a version of the NDIS that does not match the lived experience of many applicants. 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. There is also no information available on the level and type of detail required in the access request and supporting evidence forms. Additionally, many medical professionals struggle to know

what level of information is required and are overwhelmed by NDIS processes.

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, 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.

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.

Plan Reviews

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.

Support Coordination

For many people living with MS, brain fog, memory and fatigue issues make it difficult to manage their NDIS plan. Support coordination provides crucial support in managing their plan and 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. There is 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.

Early Intervention

MS is an incurable, progressive condition and most people are on a trajectory to meet the Schemes full access criteria within their lifetime. Most people are diagnosed with MS between the ages of 20-40, with 75 per cent 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):

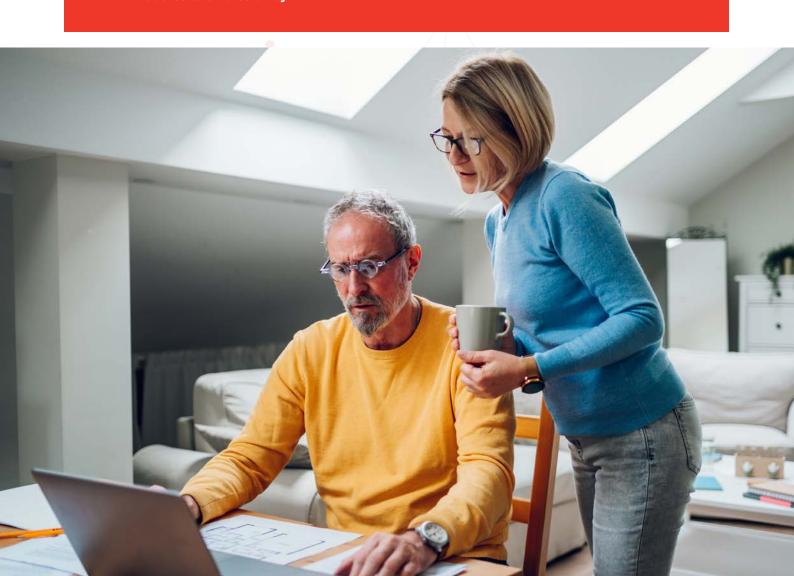
- Allied health services including physiotherapy, occupational therapy, dietetics and exercise physiology to improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time
- Assistive technology 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.

Currently 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.

POLICY SOLUTION

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.
- Participants with progressive, degenerative, neurological and neuromuscular conditions such as MS are only required to have a plan review on an as needs basis
- 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
- An improved, clearly defied and streamlined early intervention pathway for adults with disability





A HELPING HAND

ASSISTIVE TECHNOLOGY AND ACCOMMODATION

Access to Assistive Technology and Accommodation is fundamental to living a good life with MS

All Australians with MS should have access to the assistive technology and accommodation they need

Assistive technology plays 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.

People living with MS also have MS specific assistive technology requirements. Approximately 60-80 per cent 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 symptoms¹. Access to air conditioning and cooling vests/suits can significantly reduce symptoms. 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.

People living with MS struggle to get approved for the assistive technology and supported accommodation they need. Access to these supports is not driven by participant choice and control but by the decisions of NDIS planners and delegates. The focus of assistive technology supports is on disabilities that are immediately obvious to the planner and disregards those with an 'invisible' disability whose needs may not be immediately obvious. 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. These delays can lead to increased costs and the need for new quotes and in the meantime, participants may have to fund items themselves and/or providers carry 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.

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 plans². This means that approximately 70 per cent of Australians living with MS³ do not access NDIS supports, including assistive technology. Their only option is to access supports through a state or territory-based aids and equipment scheme. Many of these schemes are underfunded, have long wait lists and provide a limited range of aids and equipment. Users are often required to pay a large financial contribution towards the cost of items.

A study of assistive technology schemes undertaken by Monash University⁴ 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 <u>Assistive Technology for All (ATFA)</u> 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

Providing equal and affordable access to assistive technology also aligns with Australia's obligations under the Article 20 of the *United* Nations Convention on the Rights of Persons with Disabilities⁵ which requires parties to facilitate:

"...access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost.'

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 data⁶ 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.

POLICY SOLUTION

MS Australia recommends:

- 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





LIFE-CHANGING CARE

MS NURSES

MS Nurse can provide important and costeffective care for people living with MS

All Australians with MS should have access to MS nursing care

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 Report⁷ produced 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,

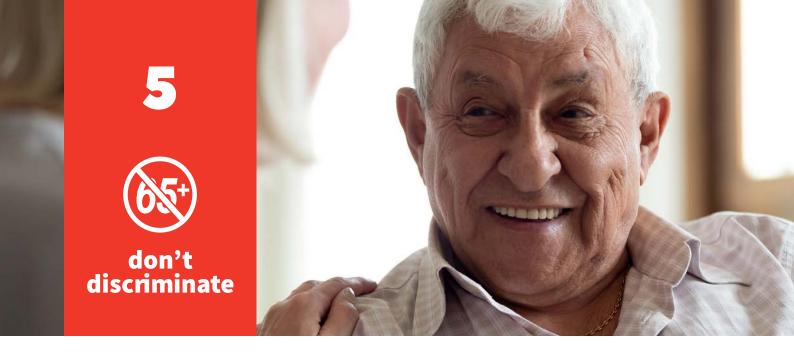
more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions. It is a highly cost-effective model of care.

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 nurse under the *Delivery of Disability Related Health Supports by a Nurse* category. Expanding this category to include MS Nurses would significantly reduce the overall costs of supporting participants living with MS.

POLICY SOLUTION

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



DON'T DISCRIMINATE

AGE SHOULD NOT BE A BARRIFR

Chronic disease doesn't care about your age. Nor should the NDIS!

All Australians with MS should be entitled to support from the NDIS regardless of their age.

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.

The funding cap on home care packages leaves many people receiving only 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, assistive technology 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 selffund 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.

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 Disabilities⁸, 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. 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.

The aged care system must also be reformed to ensure it meets the needs of all older people, including those living with disability. The Royal Commission into Aged Care Quality and Safety (Royal Commission) found that older people with disability receiving aged care do not have access to services and supports at the same level as those provided to people through the NDIS. The Royal Commission recommended the new aged care system include equity for people living with a disability (recommendation 72):

By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions9.

It is crucial that this recommendation is taken into consideration as Australia's aged care system undergoes extensive reform in the coming years.



POLICY SOLUTION

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.
- Implement recommendation 72 of the Aged Care Royal Commission





INCLUSIVE & EQUITABLE DISABILITY CARE

BEYOND THE NDIS

The NDIS does not provide services to the vast majority of Australians with disability

All Australians living with disability are entitled to the supports and services they need to live a full and independent life

Currently there are 4.4. million Australians who have a disability¹⁰ and as of 30 September 2022 there are 554,917 NDIS participants with approved plans¹¹, account for only 12.6 per cent of the disability population. The vast 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. As a result, many people living with disability struggle to access the supports and services they need and must either self-fund or go without. This creates significant economic stress, carer burden, poor mental health and significantly increases the burden of disease and disability.

As the Australian government reviews and reforms the NDIS, this provides a unique opportunity to engage with state and territory governments to address the outstanding

issues in non-NDIS disability programs. Disability programs funded outside the NDIS should be reviewed with an emphasis on streamlining programs and improving access.

Disability and Poverty

Research undertaken by UNSW and ACCOSS¹² 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 true levels of poverty for people with disability are likely to be far higher given the report acknowledges it did not consider the additional living for costs for people with disability.

Further to this, the AIHW¹³ found that 38 per cent of people with disability and 51 per cent of people with severe or profound disability have a low level of personal income, compared to 27 per cent without disability. Government pensions or allowances are the main source of income for 56 per cent of people with disability and up to 76 per cent for people with severe or profound disability. The most common payment type is the Disability Support Pension (DSP) followed by New Start Allowance.

Many people living with MS rely on the DSP or Job Seeker Payment as their main source of income. There are a range of issues with these payments including:

- There is a strong focus on compliance rather that supporting individuals to meet their needs.
 Many people with disability are found not eligible for the DSP and must rely on the Job
 Seeker Payment which comes with job application requirements. In many cases people cannot
 undertake the positions they are applying for but are still required to do so to meet the payment
 obligations.
- The current rates of government payments are not adequate to meet the full costs of people living with MS. In particular, the significantly lower rates of Job Seeker Payment cause considerable economic distress.
- Application processes are difficult and lengthy, and assessment is inconsistent and not undertaken by staff with a good understanding of disability, especially progressive degenerative or 'indivisible' diseases such as MS.
- Wait times for claims vary between 6 and 18 months, placing a significant financial burden on people living with MS, their carers and families. This timeline can be further extended if they appeal a decision.
- There is inadequate flexibility for those undertaking part-time, casual work or intermittent work.

The economic burden faced by those relying on government support directly influences their health and wellbeing and the rate their disease progresses at. Many people have to delay and reduce their specialist appointments, use of allied health services or medications. MS symptoms like fatigue, blurry vision, brain fog and partial paralysis make engaging with government agencies complex and overwhelming. Government payments need to better meet the living costs of those living with disability and be easier to access to navigate.

POLICY SOLUTION

MS Australia recommends:

- A review of disability programs funded outside of the NDIS with an emphasis on streamlining programs and improving access.
- An immediate increase in the rates of the Disability Support Pension and Jobseeker Payment
- A more person-centred focus on the delivery of income payments to people with disability including:
 - » An improved and streamlined application process for the DSP including limiting the application timeframe to three months.
 - » Ensuring a fair and reasonable assessment process undertaken by staff with an understanding of disability, including progressive degenerative or 'invisible' disease such as MS.
 - » Clearer procedures for applicants and health professionals supplying medical evidence
 - » More support and flexibility for those who undertake part-time, casual and intermittent work

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