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The extent and nature of poverty in Australia

Senate Standing Committee on Community Affairs

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SUBMISSION

The extent and nature of poverty in Australia

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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

Multiple Sclerosis (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.

Extent and Nature of Poverty in Australia

MS Australia welcomes the opportunity to make a submission to the Senate Standing Committee on Community Affairs on the extent and nature of poverty in Australia. This submission has a focus on the impact of poverty on people living with disability, in particular people living with multiple sclerosis (MS). This submission outlines the main drivers of poverty for people living with MS and the impacts of poverty, with a particular focus on employment, health outcomes and housing. It also outlines the relationship between poverty and income support for people living with MS.

MS Australia makes the following recommendations:

MS Australia Recommendations

1. A national campaign to improve awareness of the value of employing and retaining people with a disability, including:
    - broader communication on the programs and incentives that can be accessed by employers to support the employment of people with disability
    - resources and training to improve understanding around working with people with disability and creating a positive workplace culture
    - celebrating and building awareness of disability friendly employers across Australia
2. The introduction of a new disability employment service or program that:
    - Has a focus on the needs of people with disability over program compliance and on sustained long-term employment for people with disability
    - Allows for expanded opportunities including volunteering, part-time work, education and training, work experience and career changes
    - Has expanded eligibility to include people currently in the workforce and those undertaking full-time study
3. MS Australia recommends that the new National Housing Accord includes:
    - A commitment to improve access to social and affordable housing for people with disability and their carers
    - A requirement for all new housing builds to meet the *Australian Liveable Housing Design Guidelines* that ensure housing is easier and safer to use for all occupants including people with disability
4. The introduction of a single, nationally consistent assistive technology program to support people with disability who are not eligible for the NDIS
5. Commonwealth Government, state and territory governments and energy regulators work to streamline and unify the energy concessions framework, explore the barriers to accessing energy concessions and find ways to better support Australians to access these concessions including automatic applications, improved communication and reduced administrative burden
6. A review of the cost of healthcare services for people with a disability including access to bulk billing services, eligibility for Pensioner Concession Cards and Health Care Cards and access to private health insurance

7. An immediate increase in the rates of the Disability Support Pension and Jobseeker Payment

8. A more person-centred focus on the delivery of income payments for 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

Disability and Poverty

Over 4.4 million people in Australia live with disability, accounting for 18 per cent of the Australian population. People with disabilities, and their carers, are among the most socially and economically disadvantaged groups in Australia. People with disabilities are more likely to live in poverty, have poor-quality or insecure housing, low levels of workforce participation and education, and be socially excluded or marginalised. They may also face violence and discrimination related to their disability and have difficulty accessing appropriate health care[1].

AIHW data analysis[2] 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. Research undertaken by UNSW and ACCOSS[3] 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 entire population) and that people with disability make up 38 per cent of all people in poverty. 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.

Australians with disability are facing severe economic hardship and this is impacting their health and wellbeing, ability to life safely, access the supports and services they need and engage in their local community. This includes people living with progressive, neurological and neuromuscular conditions such as MS.

Drivers of Poverty

For people living with MS and their families the main drivers of poverty are high living and healthcare care costs and reduced employment and economic opportunities[4]. Analysis of MS Australia’s *Australian MS Longitudinal Study* (AMSLS)[5] shows that the annual cost of a person living with MS is $68,382. This represents a 17 per cent increase in costs from 2010 ($58,652 per person), with many of these being direct costs borne by the person living with MS and their carer. It also includes indirect costs from lost wages, informal care and early retirement. For those with ‘severe disability’, the costs are more than triple at $114,813 compared with those living with low or no disability ($30,561).

Lost wages account for 32 per cent of the economic burden of MS[6]. Many People with MS struggle to work full time hours and face poor workplace attitudes and unsupportive managers. People may have to change careers or take early retirement due to the unsuitability of their profession and/or inability to adapt their work to accommodate their disability. Symptoms can be triggered or made worse by stressful working conditions and requirements to work long hours[7].There are additional economic burdens for carers who may also have to reduce work hours, leave work or retire early to undertake their caring duties.

People living with MS face increased costs of healthcare related to their MS including specialist visits, increased GP visits, allied health services and medications. Many people living with MS have comorbidities including osteoarthritis, migraines, anxiety, depression and allergies which also attract increased healthcare costs. People who are eligible for the National Disability Insurance Scheme (NDIS) may have some of these costs covered by the Scheme, however, those that are not eligible or do not have these services included in their plan must pay for these services directly.

People living with MS also face increased living costs including home and car modifications, assistive technology, transport, energy costs (including air conditioning) and support services such as cleaning, laundry, shopping and gardening. They also face increased costs to undertake social activities and engage in their local community.

Feedback from our Member Organisations indicates that people living with MS can quickly fall below the poverty line through a combination of factors including a rapid decline in health/increase in symptoms, unplanned retirement or job loss, inability to pay a mortgage or rent, sudden increase in need for support services and not gaining timely access to income support.

Impacts of Poverty

Poverty significantly impacts employment outcomes, health outcomes and housing security for people living with MS.

Employment Outcomes

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. MS is a progressive, degenerative, neurological condition, where acquisition of disability often occurs gradually and may vary from person to person.

Being employed has many benefits beyond the financial aspect. It can improve quality of life, contributing to a person's self-worth, independence and belonging, and provides a means of social interaction. The MS International Federation ranks employment as one of their seven principles to improve quality of life for people living with MS[8]. The principles state that equal participation in employment and education:

> *'Empowers and enables people with MS to contribute as valued members of the family and wider society. Participation also enhances visibility and public understanding of MS, which in turn contributes to removing stigma and discrimination.'*

People with MS can contribute a range of skills, talents and qualifications to the workplace. Employing people with a disability can bring diverse and unique perspectives and skills to the workplace including creativity, problem solving, persistence and resilience. People with a disability generally take fewer days off work, stay in jobs longer, build strong connections with customers/clients and boost staff morale[9].

In February 2022, MS Australia undertook a national survey[10] involving 1,748 Australian adults (including 525 people living with MS) to examine workplace attitudes towards those with a physical or mental health condition – including flexible work practices, job prospects, stigma, and disclosure. The findings show that the general community overwhelmingly agree (83 per cent) that people with health conditions in the workplace are 'just as capable' as anyone when it comes to working and eight out of ten (85 per cent) believe workplaces are now more receptive to adapting roles to better fit employees. Importantly, the findings reiterated a widely held belief that meaningful work is a critical part of enjoying a good quality of life – with seven out of ten (70 per cent) Australians feeling more connected to people and community because of their employment. However, the findings also show the reality of the workplace for people living with MS:

- 52 per cent reported missed work opportunities due to their MS
- 28 per cent were uncomfortable in the workplace because they felt people labelled them
- 17 per cent felt the culture of the company they worked at did not make them feel comfortable enough to disclose their condition
- 41 per cent chose not to disclose their condition at work saying it would 'change people's opinion' of them and 25 per cent that it would 'jeopardise career prospects.
- 48 per cent think they will not be seen as a 'long-term team member to invest in and promote'.

Overall, the findings show that there is a disconnect between community attitudes and workplace realities for those with a health condition. Many Australian workplaces are not keeping pace with community expectation towards supporting employees. Improving employment outcomes for people with MS in Australia and keeping more people in the labour market or returning to the workplace has a substantial economic impact. Increased work opportunities for people with MS and their carers significantly reduce the economic burden on both people with MS, their carers and the broader community. Employment can bring financial independence for people living with MS and help to meet MS related costs including home and car modifications, assistive technology, medications and health and community services.

To improve economic opportunities for people with disability and to reduce levels of poverty, the Australian government must commit to improving employment outcomes and opportunities. This should begin with engaging the broader Australian community on the benefit of employing people with disability.

MS Australia recommends a national campaign to improve awareness of the value of employing and retaining people with a disability, including:

- broader communication on the programs and incentives that can be accessed by employers to support the employment of people with disability
- resources and training to improve understanding around working with people with disability and creating a positive workplace culture
- celebrating and building awareness of disability friendly employers across Australia

Many Australians living with Disability Employment Service (DES) to provide support in accessing appropriate employment. MS Australia recognises that the Australia Government has extended the current Disability Employment Service (DES) for two years while a new model is developed. This presents an opportunity to establish a new disability employment service that meets the needs of people with a disability and reflects current Australia workplaces.

The current DES has a strong focus on compliance and reporting over meeting the needs of the person with a disability. For example, people with episodic conditions such as MS often have difficulties attending appointments, job searches, interviews and being able to meet all their DES obligations within the required timeframes. The inflexibility of the DES results in demerits or penalties for these participants rather than a program that adapts to their needs. The DES is focused on the sole outcome of gaining a job rather than a focus on career pathways and sustained long term employment. There is also limited opportunity to use the program to explore other opportunities and pathways including volunteering, part-time work, education and training, work experience and career changes.

Many people living with MS who are already employed need access to employment supports including to access new job opportunities, change to a career/position better suited to their disability and to engage with their employer. Additionally, people living with MS who are engaged in full time study need support to prepare for entry into the workplace. They should not have to wait until they have finished study to access these supports.

MS Australia recommends the introduction of a new disability employment service or program that:

- Has a focus on the needs of people with disability over program compliance and on sustained long-term employment for people with disability
- Allows for expanded opportunities including volunteering, part-time work, education and training, work experience and career changes
- Has expanded eligibility to include people currently in the workforce and those undertaking full-time study.

Housing Security

Access to appropriate and secure housing is crucial to people living with MS maintaining their independence, health and wellbeing. People should be able to choose the living arrangement that best meets their needs and long and short-term goals.

Due to the financial impacts of living with MS, including leaving employment, many people must access housing via the rental market. The current Australian rental market is highly contested and difficult to access for people on a lower income. Many people with disability face discrimination in the private rental sector and most rental properties are not accessible for people with a disability or functional impairment[11]. Owners are unwilling to pay for home modifications such as ramps, rails, widening doorways and modifying bathrooms and kitchens.

Research by the University of Melbourne[12] into housing and people with disability found that 73.6 per cent of respondents live in housing that does not meet or only partly meets their accessibility needs. Inaccessible housing reduces a person’s ability to perform selfcare and domestic duties leading to an increased need for paid and/or unpaid support. Many people also face increased travel costs as the only suitable housing may not be close to their work, family and social activities. There is also an increased risk of injury, decline in health and mental health, social isolation and early entry to an aged care facility or supported accommodation.

MS Australia recognises that the Australian Government has announced a new National Housing Accord to address the supply and affordability of housing. This provides a unique opportunity to ensure that the needs of people with disability are met and that they have access to affordable and secure housing.

MS Australia recommends that the new National Housing Accord includes:

- A commitment to improve access to social and affordable housing for people with disability and their carers
- A requirement for all new housing builds to meet the *Australian Liveable Housing Design Guidelines* that ensure housing is easier and safer to use for all occupants including people with disability

Assistive Technology

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.

There are also supports that are specific to people living with MS. 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 symptoms[13]. 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.

Some people living with MS may be able to access assistive technology through their NDIS plan. However, the NDIS only provides services to a small percentage of people living with disability so many Australians living with MS must access assistive technology 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[14] 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*[15].

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.

Access to Energy Concessions

Living with MS means high energy use, primarily because 90 per cent of people with MS are heat intolerant and run their air conditioners 15 times more than average households[16]. This high energy use, combined with rising energy costs, results in significant energy expenses for people living with MS and their families. Further to this, the 2022 federal budget estimated that electricity prices will increase by an average of 20 percent nationally in late 2022 and a further 30 per cent in 2023-24[17].

A recent report by the Consumer Policy Research Centre (CPRC)[18], Mind the Gap: Identifying the gap between energy concession eligibility and concessions received, estimates that more than 35 per cent of Australians eligible for concessions on their energy bills may not be receiving them. As concessions are not automatically applied to bills, the onus lies with the eligible person to ensure it is applied to their bill. MS Australia supports the recommendations made by the CPRC to streamline and improve access to energy concessions.

MS Australia recommends the Commonwealth Government, state and territory governments and energy regulators work to streamline and unify the energy concessions framework, explore the barriers to accessing energy concessions and find ways to better support Australians to access these concessions including automatic applications, improved communication and reduced administrative burden.

Health outcomes

People living with disability in Australia experience poor health outcomes. According to the AIHW report on *People with disability in Australia*[19] only 24 per cent of people with a disability in Australia rate their heath as excellent or good, compared with 65 per cent of Australians living without a disability. The report also found that cost can be a barrier to accessing healthcare and that for people under 65 years with a disability:

- 1 in 13 (7.6 per cent) will delay or not see a GP when needed, because of cost
- 1 in 22 (4.6 per cent) who need to see a medical specialist do not go mainly because of cost
- 1 in 28 (3.6 per cent) who need to go to hospital delay or do not go because of cost.

The costs of accessing healthcare increase for people with disability who are not eligible for the Disability Support Pension, Pensioner Concession Card and/or Health Care Card and cannot afford to pay for private health insurance. Also, many people who are eligible for health care concessions struggle to access health care services that are bulk billed.

MS Australia's *Living with Multiple Sclerosis in Australia 2019* report[20] surveyed people living with MS and their family members and carers and found that affordability is the biggest barrier to accessing services. The report also found:

- One in four people (27 per cent) had an unmet service need that most often arose from affordability (41 per cent) or accessibility (25 per cent).
- 87 per cent of people living with MS state they have someone (unpaid or informal) who is their main source of support.
- 40 per cent of participants used four or more services within primary and acute health ranging from neurologists, GPs, psychologists, physiotherapists, massage therapists, MS nurses, continence nurses or specialists

People living with MS must access a wide range of health services while relying on unpaid caring support and meeting the other increased costs of living with MS. Not accessing health care in a timely way has lasting consequences on the brain health (brain atrophy) and disability acquisition of people living with multiple sclerosis. Similarly, not filling a prescription because of the fear of how much it will cost continues to have a detrimental impact on people with chronic and progressive neurological conditions. People living with MS can also experience an increase in depression and anxiety related to the unpredictability of MS and concerns over the future, including health and economic stability.

Poverty also significantly affects the health and wellbeing of carers. Carers of people living with MS say that caring impacts their emotional welling, family life and relationships. Caring responsibilities leave carers with little time for themselves, and they are unable to maintain a social life and pursue their own career or other interests.

People with disability, including those living with MS, must have greater financial support to meet the cost of healthcare. Investment in early and appropriate access to healthcare services for people with disability will yield long term results including improved health and wellbeing, reduced disability and less reliance on other government health, disability, aged care and social services.

MS Australia recommends a review of the cost of healthcare services for people with a disability including access to bulk billing services, eligibility for Pensioner Concession Cards and Health Care Cards and access to private health insurance.

Income support and poverty

AIHW data analysis[21] shows that government pensions or allowances are the main source of income for 56 per cent of people with disability and up to 76 per cent of people with severe or profound disability. The most common payment type is the Disability Support Pension (DSP) followed by New Start Allowance/Jobseeker Payment. Research undertaken by UNSW and ACCOSS[22] found that in households whose reference person receives the Disability Support Pension, 36 per cent live below the poverty line.

Many people living with MS rely on the DSP or Job Seeker Payment as their main source of income. Feedback received by MS Australia from our Members Organisations and people living with MS indicate that:

- The current rates of government payments are not adequate to meet the full costs of people living with MS. In particular, for those that are not eligible for DSP, the considerably lower rates of Job Seeker Payment cause considerable economic distress.
- Applications 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' disease 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. The timeline can be further extended if they appeal a decision.
- There is inadequate flexibility for those undertaking part-time, casual work or intermittent work.
- 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, however, they are required to do so to meet the payment requirements.

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.

MS Australia recommends an immediate increase in the rates of the Disability Support Pension and Jobseeker Payment.

MS Australia recommends a more person-centred focus on the delivery of income payments for 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

MS Australia supports the work of the Australian Senate in exploring the extent and nature of poverty in Australia. Australians living with disability are at high risk for falling below the poverty line and it is imperative that action is taken to ensure they are financially secure and have access to secure housing, employment that meets their needs and affordable and accessible health care.

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