

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the National Disability Insurance Scheme's consultation: An Ordinary Life at Home

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Introduction

MS Australia (MSA) is pleased to provide a submission to the National Disability Insurance Scheme's (NDIS) consultation on *An Ordinary Life at Home* and welcomes the National Disability Insurance Agency's (NDIA) efforts to address the operational issues within the National Disability Insurance Scheme (NDIS) towards making the Scheme more consistent, flexible and easier to use.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state members organisations provide services and support. The comments have been provided by representatives of our state organisations who assist people to navigate the Disability Support Pension and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

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

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

Summary of recommendations

Recommendation 1:

That the NDIA partner with MS Australia to develop appropriate information and training materials to improve the Agency's knowledge of MS and its impacts on the person living with the disease and also the impacts on their families, carers and loved ones.

Recommendation 2:

That the early intervention provisions in section 24 and 25 of the NDIS Act (2013) be utilised to make services and supports available for people with relapsing types of MS early on in their disease course.

Recommendation 3:

That sufficient hours of support coordination at the right level from highly skilled, appropriately trained support coordinators be included in a participant's plan to ensure participants with complex accommodation and support needs are able to access the support they need to achieve the goals in their NDIS plans.

Recommendation 4:

That the NDIS underpin any future decisions and assumptions regarding participant co-funding with research specifically into participant budgets and their various income sources.

Recommendation 5:

That specific decision supports be introduced for participants to assist them with the proposed changes to SIL, particularly if they choose to continue receiving housing and support from the same provider. Additionally, that the policy drive of separating support coordination from home and living support provision be allowed to phase in gradually and that opportunity will be given for participant and sector feedback at numerous points during the implementation phase.

Understanding MS

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

There are three courses MS can take. Around 15% of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progress may vary, but the declining neurological progression is constant. Relapsing-remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called exacerbations, relapses, or flares). 70 to 75% of people affected by multiple sclerosis (MS) initially begin with a relapsing-remitting course. Secondary progressive MS (SPMS) is a relapsing-remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years.

There are no medications to cure MS, rather they are used to modify the course of the disease. 64%-79% of people with MS in Australia are using a disease modifying therapy (drug treatments designed to reduce the number and severity of relapses and slow or halt the progression of their MS). These treatments have made a dramatic difference in the lives of people affected by (MS) and other neurological conditions. For others living with progressive forms of MS, the availability of treatment options is more limited.

Acknowledging the diagnosis of MS and maintaining “an ordinary life”

There are distinct differences in the concept of disability between those with an acquired and those with congenital disability. For many, the idea of accessing the Scheme coincides with a public acknowledgement of the functional impacts that MS has on their lives. It is an acknowledgement that they might not be as independent as they once were; a realisation that they have to seek support to maintain or hang on to the “ordinary life” that they have had to date. This is a crucial difference to acknowledge. People affected by MS and other neurological conditions have previously had choice and control. They had a sense of belonging, safety and security. They had opportunities and are making valuable contributions to the society. But their symptoms associated with their experience of MS have caused their own barriers and functional impairments. Most people affected by MS and other neurological conditions will have already utilised informal supports – often exhausting these – before considering access to the NDIS.

Although disease modifying therapies have changed the long-term outcomes for many, there are still people affected by MS and other neurological conditions who have not benefited from these therapies, either because they were diagnosed before these therapies were developed, or because they have a type of MS that has limited therapeutic options.

People with adult-onset conditions or acquired disabilities, such as with MS, have very different expectations of the NDIS. The goal is to keep what they already have at the time of diagnosis - family, employment, income, home, community integration. They have already built “an ordinary life” and want to keep it at all costs.

So, I am not part of the NDIS. I did the prep work to begin to go and start the process and in one of the only times in my professional life, despite being able to talk for myself and advocate for myself, I burst into tears and never went back.

Astrid Edwards, during an episode of Q&A, ABC TV, 22 July, 2021¹

¹ See ABC, Q&A episode Thu 22 Jul 2021, 8:30pm transcript here: <https://www.abc.net.au/qanda/2021-22-07/13447250> and <https://ladywithms.com/>

Improving the NDIA's understanding of MS

This bereavement of loss of function, status, employment, mobility, integration in the community and fundamental changes in roles and responsibilities can often be compounded if those supporting participants within the Agency have little or no understanding of MS and its impacts on the person living with the disease and also the impacts on their families and loved ones. To support people living with MS to improve their experience of the NDIS, MS Australia suggests that Agency staff make full use of the existing internal training materials developed in consultation with people living with MS, prior to any engagement with this cohort. 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. It is essential that NDIA staff are fully briefed **well before** any interactions with participants living with MS.

*Di Pymble-Ward was 35 when she was diagnosed with multiple sclerosis (MS).
Now aged 63, she is in constant pain – in her joints and nerves.*

Numb down the left side of her body, she also experiences sensory problems, which led to a bad fall in October. When she failed to lift her left foot over a speed bump, she "slammed face down on to the road. It was horrible".

Pymble-Ward said she needed help, but didn't have the money for treatment from a physiotherapist and exercise physiologist.

She had been hesitant to apply for support through the National Disability Insurance Scheme because she said "it's hard to admit that you need it". However, once she applied, she felt excited about the support that could help with her pain as well as build strength in her muscles.

When her application was rejected, it was soul destroying, she said. "I filled it in honestly, but apparently when you're filling it in, you have to describe your worst possible day. I was describing my life, which I thought was difficult enough."

She said the application process had been overwhelming and the prospect of having to reapply anew was exhausting. "You do feel a bit worthless when you have to do all that... I feel like we're not respected by the government at all."²

² Michael West Media, article by Tasha May, *Di was in constant pain from her multiple sclerosis, yet still denied by the NDIS*, 8 June 2021 see <https://murrayvalleyonlinenews.com.au/di-was-in-constant-pain-from-her-multiple-sclerosis-yet-still-rejected-by-the-ndis/>

MS Australia is keen to continue to partner with the NDIA to develop similar participant informed training resources. We also welcome feedback about existing resources and ideas on how we could improve these.

Recommendation:

That the NDIA partner with MS Australia to develop appropriate information and training materials to improve the Agency’s knowledge of MS and its impacts on the person living with the disease and also the impacts on their families, carers and loved ones.

NDIS – an insurance scheme

The NDIS was established through extraordinary commitment by governments at all levels, bipartisan support and through consultation with people with disabilities under the *National Disability Insurance Scheme Act 2013 (NDIS Act)*, to replace a state-funded system that was underfunded and fragmented. It was not uncommon for people who accessed state funded disability services to reach crisis points because their (under) funded support and services simply did not cover their day-to-day needs. These crisis points often led to placement/family breakdowns, injury, or periods of hospitalisation.

The NDIS, as its name suggested, was intended to be an insurance-based scheme to replace this broken system, to provide people with disabilities in Australia ‘reasonable and necessary supports and services’ to live like any other Australian who does not have a disability. Having a national system also removed the postcode lottery of service distribution. The UN Convention of the Rights of Persons with Disability (UNCPRD) to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ is indeed enshrined in the NDIS Act.

According to the Productivity Commission, expenditure is factored in over the life of an individual – and scheme sustainability is measured by calculating the total future costs of all those who are insured’.³ Prof Bruce Bonyhady AM, the former NDIA Chairman, suggested that the scheme aims to create an incentive to make short-term investments in participants - aimed at increasing their independence and participation in the community and the workforce in the hope of reducing long-term costs.

What “early intervention” means to the MS community

This idea of an insurance scheme, especially the concept of an early intervention, has always resonated with the MS community. When a person’s functional capacity starts to impact on their ability to undertake a number of everyday activities, and the reliance on informal supports becomes on its own, not enough, the NDIS has been a welcome support to maintain their social

³ See <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf>

and economic participation. The episodic nature of MS, which has some similarities with the psychosocial cohort, makes planning and everyday life unpredictable. The NDIS provides that lifetime safety and security for people living with the impacts of MS, and also for their family and loved ones.

“The NDIS has helped me to achieve my goals to live independently. I have used them to help me coordinate my new kitchen that has a lower bench height and drawers throughout for easy access and lazy Susan’s in corner cupboards”, Paula said.

“I can roll fully under the sink for washing up. It has just made such a big difference to my life and it is now a pleasure to cook again with ease.”

Paula said accessing the NDIS has enabled her to be much more independent and not have to rely on her three children around the house, helping to establish normal mother-child relationships.

“I don't have to have them (my children) doing my household duties when they come to visit. I have more time to just sit back and talk with them,” she said.

“We have family dinners once a week so having my kitchen remodelled gives me the opportunity to cook for them.”

Paula also cooks food such as banana cake and cupcakes to raise money for the MS Society’s bike ride and cake sales. Her love of gardening is also a hobby she can now continue to do independently.⁴

It was therefore heartening to hear the results from a recent ABC national survey, Australia Talks⁵ that showed that 82% of all Australians think we should spend as much as is necessary to ensure people with disabilities have the same opportunities as everyone else. The same survey (representing a majority of our voting population) stated that Australians did not believe that it is unsustainable to spend money to improve the lives of people with a disability.

MS Australia would welcome discussions with NDIA on how we could successfully utilise the Early Intervention provisions in section 24 and 25 of the NDIS Act to make one off services and supports available for people with relapsing types of MS early on in their disease, to support their independence and prolong the period before the need for more specialist supports (as full time participants), if at all avoidable. This type of early intervention in the disease course could have longer term economic benefits to the NDIS and other Australians who will continue to benefit from the social and economic participation of this cohort.

⁴ See <https://carersqld.com.au/paula-exceeds-cooking-and-gardening-goals-with-the-ndis/>

⁵ See <https://australiatalks.abc.net.au/>

Recommendation:

That the early intervention provisions in section 24 and 25 of the NDIS Act (2013) be utilised to make services and supports available for people with relapsing types of MS early on in their disease course.

Working together to improve sector integration

The journey of each person with their own experience of MS invariably starts within the health sector. After initially experiencing symptoms, GPs are often the first port of call. Some however might access support from eye specialists or immediately go to Accident and Emergency due to the severity of their first presentation and symptoms.

The health pathway continues and for some, intersects with the disability sector and the NDIS. For people living with MS, these intersections become very problematic, complex, and hard to navigate.

MS and other progressive, degenerative neurological conditions are hard to plan for. Episodic and degenerative conditions require differences in service utilisation and the need for disease-specific specialisation for optimal outcomes. Health and disability-related systems require flexibility and responsiveness - they must not add stress through administrative complexity.

This lack of clarity and understanding is not only limited to the person living with MS, but also to their family and informal supports. Many formal supports within both sectors and mainstream services struggle to navigate these systems.

The recent Department of Social Services consultation on the National Disability Strategy highlighted that the community of people living with disability and functional impairments required a 'whole of system' reform and approach. MS Australia welcomes the focus of the consultation paper to facilitate an improved collaborative and holistic approach for participants, to ensure that the right support is being provided by the right service at the right time.

MS Australia is however mindful that such negotiations between sectors may often cause distress for those involved in trying to access services and support. More concerningly, this distress is often compounded by additional delays to personalised services and supports.

A fresh approach to ILC funding

Linking people to mainstream supports, negotiating sector intersections and understanding the needs of people affected by MS and other neurological conditions has become a specialised role. Our state member organisations provide MS advisor services, funded through ever

competitive fundraising sources. Innovation in addressing system intersection and complexity on behalf of all people affected by MS and other neurological conditions (all ages, irrespective of their eligibility for the NDIS) could come from a fresh approach to future ILC funding. Specialist Disability Supports from disease specific organisations were previously funded by various state disability budgets for this purpose. There is scope to re-examine this approach to free-up resources and avoid duplication within the current NDIS system, by reconsidering how ILC funding is allocated.

Keeping young people out of residential aged care (RAC)

An additional priority area where sectors overlap, concerns those young people currently living in aged care due to the limitations and availability of suitable specialist disability accommodation. The Government's YPIRAC strategy and targets are very much supported by MS Australia. Whilst we understand that all young people living in RAC have been, or are currently being, contacted by the NDIA, we have identified that there is a need for capacity building activities for the young person, their informal supports, the residential aged care staff and support coordinators to ensure that safe, responsible and sustainable transitions out of aged care are achieved. These cohorts require very specific decision supports and resources to address their information needs. The idea of extending the exploration and design costs to specialist or boutique providers who already have market exposure and the necessary knowledge, skills and experience with this more complex cohort, who are already participants of the Scheme, could potentially achieve improved participant outcomes and experience.

Support co-ordination is essential

MS Australia would also like to reiterate the importance of mandating the inclusion of support coordination in plans as a standard provision for those with complex care needs. The inclusion of support coordination in plans by highly skilled, well trained support co-ordinators, is essential for plan formulation, activation, implementation and monitoring of change of circumstances.

Importance of providing MS specialised support

MS is a complex disease and often requires a complex and specialised response. Participants often recognise the importance of having a greater understanding of the disease and therefore require someone from a specialist MS background to provide support. This should not be seen as a conflict of interest but rather an attempt to engage someone who brings a specialised and expert understanding and approach to the conversation and this approach is usually the choice of the participant. Not all individual advocacy organisations intimately understand MS and a generalised approach should therefore be avoided.

Recommendation:

That sufficient hours of support coordination at the right level from highly skilled, appropriately trained support coordinators be included in a participant’s plan to ensure participants with complex accommodation and support needs are able to access the support they need to achieve the goals in their NDIS plans.

Improved budget flexibility

Living with disability often means living in poverty

As the Scheme is taking the experience of an ‘ordinary life’ as a starting point, a changing conversation should address the fact that many people with disability, including those living with MS, are doing it tough. Poverty and disability go hand in hand.

According to the report, Poverty in Australia 2018, just under 4 of the 10 Australians living in poverty have a disability (739,200 or 38% of the nearly 2 million adults Australians who are living in poverty). 1 in 6 people with disability were living in poverty, compared with just over 1 in 10 Australians without disability. ACOSS/UNSW said, “these numbers are likely to underestimate poverty among people with disability as the poverty line doesn’t take into account the extra costs of disability which many people experience: adjustments to the home, personal support and care, medical and pharmaceutical expenses and additional transport costs such as taxis.”⁶

Economic impact of MS

‘The total costs for all people with MS in Australia in 2017 were \$1.75 billion (2017 Australian dollars), which is an increase of \$0.51 billion compared to the \$1.24 billion (2017 Australian dollars) in 2010. Direct costs now constitute the largest component of the economic impact of MS at 44% of the total costs. Whereas in 2010, lost wages were the largest at 49% of the overall costs, compared to just 32% of the overall costs in 2017. γ. The prescription medications were the largest direct cost component for all disability classes. The costs of MS increased with increasing disability severity. The costs more than tripled in people with severe disability (\$114,813) compared to those with no disability (\$30,561). Lost wages now account for only 32% of the economic burden of MS. The annual per person costs of MS are comparable to those of a person with Parkinson’s disease, or the first year following a stroke and are three times higher than for Type II Diabetes.’⁷

⁶ See <https://www.afdo.org.au/disability-support-pension/poverty-and-disability-fast-facts/>

⁷ See https://msra.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf

Some people with disability, including those living with MS and other neurological conditions, face day to day challenges to actively participating in everyday life. 32% of adults with a disability experience high/very high levels of psychological distress compared to only 8% of those living without a disability⁸. Over 50% of people living with MS will experience a major depression at some point in their lives.⁹ While people with other chronic disorders also have high rates of depression, the rate is higher among people with chronic disorders — such as MS — that are inflammatory in nature.

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person. On average, in 2017, the quality of life of people with MS in Australia is 31% less than that of the overall Australian population. Quality of life for people with MS who are living with severe disability is 41% lower compared to people with MS with no disability.¹⁰

People with MS and other neurological conditions often have to make decisions about home and living based on their income and financial capabilities. Living with a chronic condition or disability have also financial implications for carers, spouses, family and loved ones. Many carers have had to modify their home and living to accommodate their care responsibilities. Some of this cohort have changed their employment patterns to fit their levels of functioning or care requirements. Others have had to resort to attempts to apply for government support such as the Disability Support Pension (DSP). Unfortunately, for those living with episodic conditions, the DSP is not very accessible. The DSP access criteria requires applicants to demonstrate that they have a ‘fully diagnosed, treated and stabilised condition’. The process of application seems deliberately designed to present delays, frustrations, additional costs and barriers to success. This leaves many struggling on financial income support such as JobSeeker.

It is therefore with concern that we read in section 3.3 of the consultation paper the suggestion that participants should ask themselves “would someone without a disability be expected to pay for this?” This statement seems to show a lack of regard and understanding for the participant living with the compounding expenses and financial demands already placed on them. In a time of the COVID-19 pandemic, where people are struggling more than ever to make ends meet, where other government departments are again “sending debt collectors after people who are once again choosing between food and medicine”¹¹, people with disabilities are told they have the same choice and resources as someone without a disability.

⁸ <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/income>

⁹ <https://www.msaustralia.org.au/living-with-ms/expert-blog/multiple-sclerosis-and-depression-%E2%80%93-it-seriously-complicated>

¹⁰ https://msra.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

¹¹ See <https://www.theguardian.com/commentisfree/2021/aug/12/the-government-is-sending-debt-collectors-after-people-who-are-choosing-between-food-and-medicine>

Comments from people with MS via social media:

“If you’re lucky enough to qualify for the pension, I qualified on my second application, the financial support is inadequate. Living expenses continue to increase, but the pension doesn’t.”

“Lack of funds can be very isolating. You are unable to join friends on outings whether that be to dinner, the cinema or even going for a walk.”

The idea therefore that people with disabilities can subsidise NDIS funds with their own personal finances to get the support they want (suggesting a co-payment approach) to home and living is therefore most concerning.

If the NDIA truly supports the concept of personalised budgets, flexibility should be created around the interpretation of who pays for what – especially if it directly relates to a person’s disability. The outcomes of such a flexible approach would be that people with disabilities will ultimately benefit.

Examples of home and living costs unique to MS

Airconditioning

A unique aspect of a diagnosis of MS is the highly prevalent (60–80%) temperature sensitivity. Neurological symptoms can temporarily become exacerbated by environmental or exercise-induced increases (or decreases) in body temperature causing a worsening of symptoms.¹² Flexibility to pay for electricity consumption for i.e. air conditioning appliances or electricity costs can prevent exacerbations and thus stabilise the person’s disability - a cost that can be directly related to the worsening of their disability if not met. In light of the number of financial pressures people with disabilities live with day to day and the choices they have to make i.e. increase electricity bills or paying for another urgent household expense, the NDIS should allow flexibility in personalised budgets for such line items.

Tony Puhakka will be one of the first Australians to receive funding for air conditioning through the National Disability Insurance Scheme (NDIS) after the results of a recent appeal.

Mr Puhakka said he was initially denied funding but argued his requirement for air-conditioning was reasonable and necessary due to his disability.

“Words cannot describe how happy I am with the result, not just for me, but what it could mean for others in my position,” Mr Puhakka said.

¹² Christogianni A, Bibb R, Davis SL, et al. Temperature sensitivity in multiple sclerosis: An overview of its impact on sensory and cognitive symptoms. *Temperature (Austin)*. 2018;5(3):208-223. Published 2018 Sep 5. doi:10.1080/23328940.2018.1475831

“There are a lot of people worse off than me who could really use air conditioning funding, especially in such places with extreme heat like North Queensland.”¹³

Continence

Impairments in bladder function with multiple sclerosis (MS) are common and may affect up to 78 to 90 percent of people living with MS¹⁴. The prevalence of bowel dysfunction in MS is estimated to be about 68 percent of patients. Incontinence products are included in some personalised budgets for those living with MS. The impact for those living with a disability and managing incontinence are however not limited to the use of incontinence products. Often, they must pay for extra laundry costs such as cleaning products, appliance use/maintenance and additional electricity – all costs directly related back to their disability. Flexible budgets should allow for these expenses to be included.

Swallowing disorders

Permanent and transitory swallowing disorders (dysphagia) occur with high frequency (over 50%) in people with MS. As a result, people with swallowing difficulties are often confused about what might be included in their plan i.e. PEG feeding or Home Enteral Nutrition (HEN). Interpretation and guidelines around this area is not clear and is often seen as the responsibility of the participant, as food is seen as an everyday living cost. Participants are not clear about what is funded and what is not? This area gives rise to many inconsistencies for those with NDIA plans. Additional expenses, for those items not covered, could become exorbitant as a direct result of disability. These may include additional dental costs for mouth wash, gum health or other dental products but also more regular dental visits which are not covered by Medicare. Other expenses include purchasing special nutrition/food and supplements to avoid malnutrition. MS Australia has heard of many examples of people unable to afford specialist liquid nutrition and just going without. For those less effected, the purchase of a food processor can assist them in their day-to-day meal schedules by blending food that the rest of the family eat, avoiding the need to make a separate meal. These expenses should be able to be purchased from personalised NDIA budgets.

Symptomatic therapies not available on the Pharmaceutical Benefits Scheme (PBS)

Fampridine (brand name Fampyra®) is a drug used in adult patients with MS to improve walking. Regrettably it is not listed on the PBS, so costs the consumer around \$600 per month. At a recent focus group involving people with MS, a participant described her reliance on

¹³ See <https://www.spinal.com.au/news/tonys-ndis-win-leads-the-way-for-others-with-spinal-cord-injury-and-multiple-sclerosis/>

¹⁴ Browne C, Salmon N, Kehoe M. Bladder dysfunction and quality of life for people with multiple sclerosis. *Disabil Rehabil.* 2015;37(25):2350-8. doi: 10.3109/09638288.2015.1027007. Epub 2015 Mar 24. PMID: 25801920. And

fampridine to keep her walking, essential for managing her young family and allowing her to maintain “an ordinary life”. She said, “it’s the only thing that works for me and keeps me going but it’s expensive”. The family have to make some difficult choices to fund this medication. In this case, subsidy of this medication could be argued to be a “reasonable and necessary” part of this person’s flexible NDIS budget.

Professional financial advice

The consultation document states that “budgets will be flexible, to give more choice and control” and that “you will be supported by NDIA partners (such as LACs), peer networks and other supporters to understand the costs”. MS Australia suggests that people with disabilities, and those living with MS, will benefit from professional financial counselling funded from flexible personalised budgets. LAC partners and peer networks or supporters will not have the knowledge or specialised skills to responsibly guide participants in managing their flexible budgets. MS Australia believes that access to financial planners is directly related to the participant’s disability, due to the complexity of managing the various financial demands, and that the NDIA should allow, and at times encourage, participants to use their flexible budgets to secure financial counselling.

Recommendation:

That the NDIS underpin any future decisions and assumptions regarding participant co-funding with research specifically into participant budgets and their various income sources.

Through this research, we believe that the NDIS can make a valuable contribution to this conversation by providing an evidenced approach that would benefit other areas in government and could inform a more holistic approach to disability in Australia.

Home and living lifecycle

“Home and living” means different things to different people

MS Australia encourages greater flexibility in the interpretation of the concept of Home and Living to particularly include those living with *acquired* disability. The consultation paper and its Appendix seems to focus heavily on examples and speak to an audience of those living with intellectual disability. Changes, transitions and innovation in the operationalisation of Home and Living are *as* important for those of the community living with an acquired neurological disability.

In Australia, we have reached the current state of accommodation supply shortage due to a combination of factors. This has resulted in a lack of options and alternatives.

We need to recognise there is a diversity of need, and that calls for a diversity of solutions. Not all solutions are those that point to the creation of additional housing stock.

There is an urgent need to move people away from thinking people need to move away from home; a change in focus is needed to equip people with more options to stay at home, or, if a move is considered “essential”, for example, to potentially move someone together with their entire family network.

According to a recent study (2021) by Monash University, ‘Problems with existing housing include poor access; unsuitable internal layouts; inadequately designed bathrooms, kitchens and laundries; and a lack of other qualities such as good light and connections to outdoor views and spaces. As well, dwellings may be poorly located in relation to transport, services and amenities, further limiting life choices, particularly around employment. It is up to individual households to make changes to their dwellings – owned or rented – whether through limited government funding pathways if they qualify, or by privately funding them.’¹⁵

Keeping people at home through a preventative and supportive approach will deliver emotional, social and economic outcomes for individuals and families, ensure the sustainability of the NDIS through cost reductions and, in turn, provide benefits to the wider community. This is one area where MS Australia could see benefits in adopting an early intervention approach.

The problems with existing housing stock will continue to remain problematic and will require careful personalised planning and support from the NDIS.

The thing about disability is it usually doesn't only affect the person living it. It changes the lives of children, parents, friends and partners.

*My childhood was spent navigating my father's disability. My brother and I were constantly sent running ahead to see if there were stairs into wherever we were headed. Stairs were everywhere in the 70s. Building codes of the time didn't legislate for ramps or accessibility. More often than not, we'd stand outside with our father waiting until we could coax a couple of strong and willing passers-by to lift him in his wheelchair up the steps. Sometimes we simply gave up and returned home disappointed and, if I'm honest, a bit angry. I'm not proud to say that there were times when I begged that we leave him at home, simply because going out with him was almost always hard. We hardly ever went to restaurants. Stairs were one thing. Accessible bathrooms were decades away. When I moved out of home into my first shared house, the first thing I did before inviting my father to dinner, was to borrow a tape measure from friends so I could size up the doorways.*¹⁶

¹⁵ See https://humanrights.gov.au/sites/default/files/document/publication/monash_-_adaptable_housing_2021_-_digital.pdf

¹⁶ See <https://www.theguardian.com/commentisfree/2021/jan/05/at-home-marks-from-my-fathers-wheelchair-were-everywhere-we-must-improve-accessible-housing#comment-146496472>

At a recent Building Ministers Forum meeting, there appeared to be a majority of ministers that supported the incorporation of minimum accessibility specifications for residential housing and apartments within the 2022 edition of the National Construction Code (NCC).¹⁷ The provision will be inspired by the Silver standards specified in the Liveable Housing Design Guidelines (LHDG) released through Liveable Housing Australia (LHA). These future safeguards will be invaluable for people living with disabilities, though disappointingly several states are yet to adopt these standards.

Australia's housing crisis extends to the disability housing market. This crisis has seen young people living with MS and other neurological conditions, being forced to live in aged care or have extended hospital stays as there is simply nowhere else for them to go.

For 58-year-old Peter Needham, who lives with multiple sclerosis and only has movement in his right arm, seeing his friends and family is the highlight of his day.

After recovering from another illness that almost took his life, his family and friends say visiting him has been made that much harder after he was moved to a regional hospital, more than an hour away. Close friends of Mr Needham said he was in Bunbury Hospital before he was moved to Bridgetown Hospital with two hours' notice.

"He called me one day and said, 'Mate you better come and see me, they're moving me to Bridgetown', "childhood friend Mick Caddy said.

Mr Caddy said the Needham family were told there were not enough beds for him to stay at Bunbury Hospital and no local nursing homes could fit him in.

"His mother is 87 years old this year and how can you expect an 87-year-old to drive to Bridgetown. She can't drive anymore," Mr Caddy said.

Mr Needham recently recovered after a four-week stint in palliative care.

Mr Caddy said he was concerned his friend was in a vulnerable state.

"What happens if Peter died in Bridgetown? What would that do to her mentally if her son died by himself if she couldn't there on time?" he said.

"Surely there's someone within 50 kilometres that can look after Peter, that's all we want."

Mr Needham was receiving care under the National Disability Insurance Scheme (NDIS) until he was told he needed a higher level of care.

The NDIS has come under fire previously for delays on getting patients out of hospitals and onto a care plan.

A spokeswoman from the WA Country Health Service, which manages regional hospitals and patients, said it would always help NDIS patients who come into hospitals.

"We do not turn them away despite the fact they may not require hospital care," the spokeswoman said.

¹⁷ See <https://bdaa.com.au/accessible-housing-to-be-included-in-ncc/>

"While we share in Mr Needham's desire to get him as close to his family as possible, the fact is Bunbury is our biggest and busiest facility and we needed to ensure beds are available for emergency and critical care patients."

The service said it was working with Mr Needham to find him the appropriate care he needs, but said if that failed it would try to find him a hospital bed closer to home.

Mr Needham's mother and close friends have been told he could be moved to a bed in Busselton, which is half an hour closer than Bridgetown.

Mr Caddy said there needed to be more options for vulnerable Australians.

"I think we need more beds everywhere not just Bunbury," he said.¹⁸

Funding models and incentives

MS Australia welcome the NDIS's intention to engage the market to drive innovation through funding alternative models and incentives to shape the market. According to a recent report by Housing Hub and The Summer Foundation (2021) "Despite commencing in 2016, SDA funding is currently only being paid to 54% of the estimated 28,000 NDIS participants who are expected to be eligible for SDA. The over 12,000 remaining people who are eligible for SDA funding are likely to be living in government housing, hostels, residential aged care, or with family. Once the unmet demand and the need to replace old stock with contemporary models of disability housing is taken into account, new housing is needed for an estimated 19,000 NDIS participants over the next 10 years." The continued growth of Specialist Disability Accommodation (SDA) supply is a finding that is sure to be welcomed by MS Australia and people living with MS and other neurological conditions.¹⁹

MS Australia would however like to caution against the constant use of new jargon and acronyms (now introducing for example Individualised Living Options (ILO)) does promote categorisation and a focus on support categories rather than needs. There is a risk that this type of unstructured approach to accommodation might be of concern to people living with MS or other neurological conditions. It would also be interesting to see how this new ILO accommodation option would work within the already contested disability workforce space. Furthermore, people with disabilities are more vulnerable than the rest of the population when it comes to abuse and neglect²⁰. The Quality and Safety monitoring of these types of accommodation options would potentially be fraught with difficulties and might require the introduction of an independent visitor scheme, or something similar.

¹⁸ See <https://www.abc.net.au/news/2021-07-14/friends-are-worried-peter-could-die-alone-in-hospital/100281858>

¹⁹ See

https://assets.ctfassets.net/blhxs4s3wp2f/IPTcZyEQf4OUhAOF2GQnc/f516c1f8b48c5e54f2378769f18f5ba1/SDA_Supply_Survey_Report_-_22_12_2020_small.pdf

²⁰ Australian Institute of Health and Welfare 2020. People with disability in Australia. Cat. no. DIS 72. Canberra: AIHW. Viewed 13 August 2021, <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

Changing the jargon and introducing another accommodation type does not negate or avoid issues such as the lack of capital in the system for providers to scale up, long waiting lists for social housing²¹, and that home modifications and installation of equipment in rental accommodation remains unaddressed.

As many people living with MS and other neurological conditions can also attest, the wait-time for a change of circumstances to allow a participant to access a bed once it becomes available is a major stumbling point for most accommodation. This would be true whatever the size and location of the accommodation.

The reality is that Australians with disabilities have lived with decades of underfunding. The culmination of advocacy, campaigns and lobbying finally resulted in a national disability scheme, that has only really operated nationally for the past three years. NDIS is unlikely to fix the challenges in home and living options in this or the next Federal Budget. The Scheme will have to use market incentives to drive collaboration and partnership across the board of various actors and stakeholders to see real market innovation and improvements. The contested disability dollar requires transparency and greater accountability than ever before to ensure that the need for change does not open the doors for companies who value profit over participant outcomes.

It is important to acknowledge that the concept of supported specialist accommodation might look different for each participant. For example, MS Australia welcomes allowing couples and children to share SDA accommodation, as this makes such a difference to participants living with MS and other neurological conditions.

Models of success

MS Australia's own member organisations provide innovative housing support for people living with high physical support needs so they can live their most independent lives. They are providing innovative ways of navigating the NDIS housing/accommodation pathways, with housing and accommodation designed and built to the highest safety and mobility standards, that includes age-appropriate options for younger people and designed with an understanding of the needs of people living with MS and other neurological conditions. NDIS, as market stewards, should invest more in these providers that are already stepping up to the task.

Links are provided below to the various housing and accommodation options provided by MS Australia's member organisations around Australia:

<https://www.msqld.org.au/services-support/accommodation/sda/>

<https://mswa.org.au/support-services/high-support-accommodation>

<https://www.ms.org.au/support-services/living-arrangements.aspx>

²¹ <https://thenewdaily.com.au/news/national/2019/02/27/years-long-housing-wait-list/>

Supported Independent Living (SIL)

MS Australia has participated in several previous consultations regarding SIL. From these previous submissions it is still worth noting that:

- Many SIL clients are in SIL as it provides the safest option for them, giving them access to 24/7 supports and safety and security - it is not a decision to be made lightly. There are occasions where there may be some improvement in an individual's ability and with an NDIS plan they may be able to seek an individualised living option (ILO) with appropriate levels of funded supports; in many instances SIL providers can work with the participant and their support coordinator and others to facilitate a smooth transition into the new option.
- Having said that, the NDIA must also consider that not every SIL occupant is able to increase their independence and reduce their supports. Those with acquired disability due to trauma or disease, especially those with progressive, degenerative conditions may well require additional supports.
- Some SIL participants may have cognitive impairment that is not obvious to those who do not know them. Our member organisations use a wholistic model of care and support and often have very detailed historical information that enhances individual plan building.

Recommendation:

That specific decision supports be introduced for participants to assist them with the proposed changes to SIL, particularly if they choose to continue receiving housing and support from the same provider. Additionally, that the policy drive of separating support coordination from home and living support provision be allowed to phase in gradually and that opportunity will be given for participant and sector feedback at numerous points during the implementation phase.

A changing conversation

MS Australia welcomes the new approach taken to improve participants' experience and outcomes. It is very important for any future NDIS publications and consultation papers to be more inclusive and mindful of the various types of disabilities and the reasons people become 'disabled'. There cannot be a one fits all approach as the Scheme is at risk of marginalising those living with neurological, acquired or other disability types that are not represented by the content or examples shared during this and any future consultations.

MS Australia also welcomed the Scheme in including families in the changing conversation.

Unfortunately, the NDIS is not available to all – especially for those outside the eligibility of the Scheme. At least 50% of people over 65 years identify as having a disability. And up to 80% of

people over the age of 65 years have at least one or more long-term health condition. It would be amiss of MS Australia not to note this again in this submission and to ask the Scheme to consider broadening the access criteria for all people with disabilities in Australia in any future changes to the NDIS legislation.
