

What we have heard report Submission on Solutions

August 2023





What we have heard report

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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 acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 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.

What we have heard report

MS Australia welcomes the opportunity to make a submission to the NDIS Review on the *What we* have heard report. Over the past seven years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. We have written over 30 submissions relating to the NDIS, including submissions to the NDIS/NDIA, the Joint Standing Committee on the NDIS and the Productivity Commission. We have also provided three submissions to the NDIS Review:

- A <u>submission</u> in December 2022 that provided a broad overview of the issues facing people living with MS and recommended solutions for the NDIS Review Panel.
- A <u>submission</u> in May 2023 on the NDIS Quality and Safeguarding Framework
- A <u>submission</u> in July 2023 on Pricing and Payment Approaches in the NDIS Market

Please find below our responses to the questions on the Review's 10 areas for improvement.

1. Applying and getting a plan

The experience of people living with MS accessing the NDIS is that the NDIA do not have a good understanding of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. They also do not have a good understanding of disability and how to engage with people with disability.

MS Australia recommends the NDIA:

- Commit to educating and training all staff and contractors about people living with progressive generative, neurological and neuromuscular conditions such as MS.
- Establish a resource library of disability materials for use by NDIA staff that includes MS Australia resources. Prior to a planning meeting, staff would use the library to access materials relevant to the participant's disability. MS Australia would be very willing to engage with the NDIS on any further training or education materials required for the resource library.
- Implement 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. The advisory group would seek to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA. The establishment of an advisory group will contribute to ensuring the people living with these conditions gets access to the NDIS supports and services they need at the right time in their disease journey. It will also reduce complaints, improve outcomes measures and ensure this population is treated equitably when accessing the NDIS.

For many people living with MS 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.

The most significant change that can be made to the planning process to support people living with MS is to remove the current requirement for regular plan reviews. Participants should only be required to have a plan review when there are significant changes e.g., when their needs increase or there is a change in their carer/living situation.

MS Australia also recommends:

- Improved and simplified pre-planning resources that better represent the NDIS journey.
- Examples of goals and corresponding services for a range of disability types.
- Planning meetings held over multiple sessions for people who have conditions that may

increase fatigue, pain, 'brain fog' and memory issues, including MS.

- 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. Many health professional struggle to know what level of information is required by the NDIS and are overwhelmed by NDIS processes.

Further to these suggestions, the NDIA needs to improve their current poor communication around decision making and timeframes. This includes failed access request, changes to plans, cutting essential supports, outstanding approvals, internal reviews and complaints.

2. A complete and joined up ecosystem of support

There are currently 33,300 people living with MS in Australia and as of 31 March 2023 there were 10,121 people living with MS who have an approved NDIS plan¹. This means that approximately 70% of people living with MS do not receive NDIS services. For people living with MS who are not receiving NDIS supports, they need access to the following supports and services:

- Assistive technology and home modifications
- Allied health services including physiotherapy, exercise physiology, occupational therapy, dietetics and speech pathology
- Psychological supports and services
- Employment support including finding work, changing careers and making reasonable adjustments in the workplace
- Income support for those that can no longer work
- Respite services

Currently, accessing supports outside of the NDIS are difficult for the following reasons:

- State and territory disability programs are underfunded. In many cases state and territory governments have reduced or removed funding for disability programs on the assumption that people can access these supports via the NDIS.
- Disability programs are inconsistent, complex and difficult to navigate. For example, there are currently 87 government funders administering 108 assistive technology and home modifications schemes outside the NDIS. Eligibility criteria, funding, user contributions and covering the costs of customisation and maintenance vary greatly across the schemes.
- A focus on compliance over the needs of the people living with disability. For example, income support and disability employment programs are driven by compliance rather than supporting individuals to meet their needs.

MS Australia recommends:

- A review of the funding for state and territory disability programs since the introduction of the NDIS to ensure that funding has not been removed or reduced.
- A more streamlined and accessible way for people with disability to access funding and programs, for example a national online portal.
- Streamlining programs that are not disability specific but provide support to vulnerable people such as energy concessions, emergency relief and financial wellbeing.
- The establishment of a national assistive technology program for people who are not eligible for the NDIS.

- An immediate increase in the rates of the Disability Support Pension and New Start Allowance and a more person-centred focus on the delivery of income payments to people with disability.
- 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 and meaningful employment for people with disability.

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

The MS Nurse Care in Australia Report² 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.

MS Australia recommends improved access to MS Nursing care for all Australians living with MS.

3. Defining reasonable and necessary

Currently, the NDIS indicates that access to NDIS supports is driven by whether the supports are effective, beneficial and value for money. They also state that they will consider expert opinion, lived experience, best practice and published and refereed academic research. However, feedback received by MS Australia indicates that the decision to approve supports is undertaken by unqualified staff with little understanding of disability supports and who routinely ignore professional advice and lived experience. There is no evidence that NDIA staff are referencing academic research or even understand how to apply this to approvals. There also appears to be little understanding that people with disability have no control over high disability market prices, especially in relation to equipment and technology. The NDIA needs to bring these prices under better control so that they are value for money and more people can have them approved in their plan.

Further to this the NDIA does not appear to be open to new and emerging supports that might improve the lives of people with disability. There is constant change in this space and the NDIA must keep pace with this change. For example, many people living with MS suffer from temperature sensitivity and struggle to regulate their body temperature. Access to an air conditioner is the best way to manage this. However, it required a participant living with MS taking their <u>case to the AAT</u> to get air conditioning recognised as a reasonable and necessary support for people living with MS. If the NDIA was up to date with currently best practice supports for people with MS and engaged with expert opinion, this would not have been necessary.

To improve decision making around reasonable and necessary supports and make them more consistent and fair, **MS Australia recommends** the NDIA do the following:

- Be guided by the advice and recommendations of health professionals
- Listen to the lived experience of people with disability and their carers
- Ensure there are staffed trained in current best practice in disability supports and can read and interpret relevant academic research
- Establish a library of relevant published and refereed academic research and undertake relevant literature reviews to coordinate relevant research
- Explore new and emerging disability supports
- Introduce more controls over pricing for equipment and technology to reduce high disability

4. Early childhood supports

Early childhood supports are not required for people living with MS. MS Australia has no feedback on this question.

5. The support and service marketplace

The best way to attract and keep workers who have the rights skills, value and attitudes is to professionalise the disability workforce. Currently, the disability workforce is made up overwhelmingly by part-time, untrained and lowly paid support workers. There are high rates of turnover and casualisation across the sector. Professionalising the disability workforce makes it an attractive career prospect and would ensure that people with disability are provided care and services by trained, motivated and experienced professionals.

Ms Australia recommends the following steps to support professionalising the disability support workforce include:

- Mandatory minimum training requirements including undertaking NDIS eLearning units before commencing work and an agreed number of staff having a minimum qualification e.g., Certificate III in Individual Support
- Financial support for people to upskill including undertaking Certificate III, Certificate IV and Diploma qualifications
- Development of a scope of practice for support workers
- A registering body to oversee the profession, provide training and development programs, mentoring and professional support and structured career pathways.

Given the current reforms underway in the aged care sector, joint work could be undertaken to professionalise the support worker roles across the care and support sector

6. Measuring outcomes and performance

Currently, the NDIS is driven by costs rather than participant outcomes. There needs to a greater focus on the participants goals and individual choices.

NDIS participants and their carers should be able to find accessible and publicly available information on the performance and quality of services provided by the NDIS providers in their region. They should be able to easily determine if there are any non-compliance, fraud or service issues with NDIS providers. Access to this type of information is already done in aged care with the <u>aged care star ratings system</u> that uses compliance and quality data and resident feedback to assign a rating to each aged care provider. The introduction of a star ratings system would also reduce fraud and corruption, dishonesty, misuse of funds and abuse of participants. **MS Australia recommends** that the NDIA implement a form of star ratings system with publicly accessible ratings for all providers.

MS Australia recommends that the NDIA gain more regular and detailed feedback from participants on their experiences and any concerns they have with providers. This type of feedback is currently built into the residential aged care sector and could provide a guide for the NDIS:

- Face to face <u>Residents Experience Surveys</u> are undertaken each year by a third-party who survey approximately 20% of aged care residents. The results of these surveys are used to inform star ratings and are collated into a resident experience report for each service.
- As part of the <u>National Aged Care Mandatory Quality Indicator Program</u> all aged care residential services are required to report every quarter on the percentage of care recipients who report 'good' or 'excellent' experience of the service.

7. Achieving long term outcomes

The major barrier to NDIS participants achieving long term outcomes is the current NDIS focus on the cost of supports for participants over the social, emotional and physical outcomes they will provide.

For example, many people living with MS need access to assistive technology such as wheelchairs and mobility aids, home and workplace modifications, car modifications, air conditioning and aids to support with communication, eating/drinking and toileting/showering. However, the feedback received by MS Australia is that access to these supports is focused on the cost of the supports and how long they will be used by the participant. There is no consideration of the improvement they will make to a person's wellbeing and the ability to maintain a social life, employment and living situation. These supports are crucial to allowing people to remain living independently, keep connections with families and friends, be active parents and partners and be an involved and engaged member of their community. They also reduce or delay the need for additional and more costly supports.

MS Australia recommends that the NDIS must move away from the current strong financial focus and return to the original intentions of the NDIS and provide a scheme the supports people to achieve their long-term goals and live the life that they choose.

8. Help accessing supports

The current experience of people living with MS accessing the NDIS is that NDIA Local Area Coordinators (LAC), planners and approvers have inadequate training, high rates of turnover, an inappropriate skill set and attitude for working with people with disability and/or cover too large an area to provide individual support. **MS Australia recommends** that the NDIS improve the recruitment, training and support for these roles to ensure they are fit for purpose.

As outlined at *Question 1: Applying and getting a plan*, **MS Australia recommends** 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. They should also increase the number of NDIA staff who have lived experience of disability. The NDIA also needs a significant culture change to ensure that all staff understand the principles underpinning the establishment of the NDIS and are familiar with United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

For many people living with disability, the best people to provide support in navigating the NDIS and helping them to make informed choices are disability/disease specific providers. MS Australia's state and territory member organisations provide support to people living with MS under the NDIS. Through support coordination and plan management they can provide MS specific support and advocacy. This is especially important as many people living with MS experience brain fog, memory and fatigue issues that make it difficult to manage their plan and coordinate services. These services are especially important for people who have no carer or informal support network.

However, feedback from MS Australia Member Organisations is that currently the delivery of both support coordination and plan management services involves many additional unfunded staffing hours. The coordination of services and management of plans take substantially more time than current NDIS pricing allows for. Plan Managers often spend hours trying to resolve issues with funding and invoices, supporting providers with manual claims and managing problems with uploads. Onboarding new clients also involves additional unfunded hours including setting up service agreements and service bookings and completing compliance tasks such as discussions around emergency planning. They also spend considerable unpaid staffing hours providing increased advocacy and support for clients living with MS. This includes supporting clients to navigate the planning and review process, increased funding for plans and ensuring clients are approved for the services they need, providing additional documentation to the NDIS and supporting clients through appeals. Member Organisations have also reported frequent requests from the NDIA Compliance Team for claim reviews with no offer of additional renumeration or support.

MS Australia recommends that to better support people with disability, the NDIS must recognise the significance of plan management and support coordination services and fund appropriately. They must acknowledge this mostly unfunded and very crucial work and find a way to better fund and support it. This will ensure all people living with disability can have the individualised support they need to navigate the NDIS.

9. Supported living and housing

Access to appropriate housing is crucial to people living with MS maintaining their independence. Feedback received by MS Australia indicates that access to supported accommodation is currently not driven by participant choice and control but by the decisions of planners and NDIS delegates. Planners 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. Supporting people to remain in the housing of their choice will ensure improve social, emotional and physical outcomes and delay their disease progression.

MS Australia recommends the following for people living with MS this includes:

- Living arrangements that best meet their individual needs and long and short-term goals
- Housing modifications that allow them to remain in their own homes as long as possible
- Timely access to home modifications and supported accommodation (as opposed to the currently long delays in planning and approval)
- Supported accommodation options that meet the needs of people with disability
- For older people, alternative options to living in residential aged care

10. Participant safeguards

MS Australia supports policies and processes that protect NDIS participants and ensure high quality support and safe environments. However, the current NDIS regulation arrangements come with a large administrative burden, are difficult to understand and implement and are not focused on the needs of participants.

The NDIS Quality and Safeguarding Framework (Framework) is not well understood by providers and staff, especially front-line disability support workers. As established in the NDIS Review's recent workforce report³, 1 in 4 NDIS workers received less that one day of training in the past year and only 1 in 3 receive the supervision they need (with the rate dropping to 1 in 4 for casual workers). There is clearly a gap in training and supervision for staff and this can have a detrimental impact on participants. Further these untrained staff need to understand what constitutes abuse and inappropriate behaviours in the specific environment they are working in. They also need to understand the difference between their duty of care versus allowing individuals to make informed choices about how they choose to live and undertake day-to-day activities.

MS Australia recommends that the NDIS Quality and Safeguards Commission (Commission) introduce improved training and education materials for the Framework including:

- Clear guidelines for providers on interpretating and implementing the framework in a variety of settings including best practice examples and face-to-face workshops
- Clear measures and reporting requirements for ensuring the Framework is implemented, such as key performance indicators
- Clear definitions of abuse, violence, neglect, exploitation and other important terms
- Compulsory training modules for staff on the Framework including a requirement for providers to report on completion of this training.

As outlined at *Question 6*: *Measuring Outcomes and Performance*, the introduction of a star ratings system would ensure participants have easily accessible information on the performance and quality of services including any non-compliance, fraud or service issues.

Additionally, as outlined in at *Questions 5: The support and service marketplace*, professionalising the disability workforce will attract workers who have the rights skills, value and attitudes. This will improve:

• The quality of services and supports

- Safeguards for participants and reduce and eliminate unsafe and restrictive practices
- Communication and engagement with participants
- Understand dignity of risk and how to support participants to exercise choice and control.

MS Australia understands the need to have a registration system for NDIS providers to ensure that those delivering service have the appropriate skills, expertise and financial and business structures to deliver services and manage government funds ethically and appropriately. However, MS Australia's Member Organisations report several major barriers to registration including cost and time associated with the registration, the costs of adhering to compliance regulations and the lack of information regarding *NDIS Practice Standards* changes. There is a high administrative burden in ensuring registered providers meet all the quality and safeguarding requirements, including regularly updating documentation.

The time spent on administrative/registration tasks has increased in the past 12 months due to changes in the *NDIS Practice Standards* such as the inclusion of emergency planning. There were several new Practice Standard Indicators introduced, however, there was no guidance from the NDIA on how to achieve the indicator. Member Organisation teams spent a significant amount of time trying to decipher the new indicators, developing an action plan and undertaking work to meet the outcomes. This was all unfunded staffing hours.

MS Plus, who provides services in NSW, ACT, Victoria and Tasmania, recently completed a full-term (triannual) NDIS accreditation to continue to be a registered provider. MS Plus estimate it took approximately **834 staffing hours** to complete this process. This includes staff involved in support coordination, plan management and allied health. A full breakdown of these hours is at *Appendix A*. Please note this estimate does not include any time spent by the Quality Team to maintain ongoing accreditation.

MS Australia recommends the NDIA review the NDIS registration process to:

- Recognise the full costs and staffing hours associated with registering as a provider and maintaining the quality and safeguarding requirements
- Reduce the complexity of the process to minimise the administrative burden
- Provide more comprehensive guidelines on changes to the NDIS Practice Standards and best practice examples.

People living with disability are exposed to violence, abuse, neglect and exploitation at much higher rates that the rest of the Australian population. Nearly half (47%) of adults with disability have experienced violence since the aged of 15 and 20% before the age of 15⁴. Women with disability experience high rates of sexual abuse and intimate partner violence, this is particularly concerning since 3 in 4 people living with MS are women. Research undertaken by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) shows that people with disability struggle to report violence, abuse, neglect and exploitation due to a lack of clear definitions, lack of systems, a poor reception when reporting and a reluctance to report⁵. Further, people with disability are at particularly high risk of experiencing violence, abuse, neglect and exploitation if they are not provided with adequate education to identify and recognise such behaviours.

People with disability must be able to identify abuse and inappropriate behaviours and report without fear of retribution. They must feel that they will be listened to and understood, regardless of how they communicate. The Commission must provide a suitable reporting environment and empower people with disability to self-advocate. They must provide appropriate education materials so people can better informed. There should also be materials for carers, family members and informal advocates/supporters so they can support the people in their lives with disability.

MS Australia recommends that the Commission review complaint and reporting processes to ensure that:

- People with disability are provided with a supportive and confidential process that caters to all communication needs
- People with disability, carers and advocates can access information on abuse and unsafe

behaviours, including in easy to read and pictorial formats.

11. Any other information you would like to tell us?

Over the past seven years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. We have written over 30 submissions relating to the NDIS, including submissions to the NDIS/NDIA, the Joint Standing Committee on the NDIS, the Productivity Commission and the NDIS Review. These submissions draw on the experiences of people living with MS and our state and territory Member Organisations.

On 18 July 2022, MS Australia launched a campaign <u>A Better NDIS for People Living with MS</u> to highlight essential areas for reform in the NDIS. The campaign brings together our main ask across our NDIS submissions and advocacy including:

- **Hear our Voice:** Improve the NDIAs understanding of neurological or neuromuscular conditions and disorders including the establishment of a NDIA neurological advisory group
- **Timely NDIS Access:** People living with MS need improved and early support to access the NDIS
- A Helping Hand: People living with MS should have access to the assistive technology and accommodation they need
- Life-changing Care: Access to MS Nursing brings health benefits for people with MS, including lower disability level, slower disease progression, less severe symptoms, lower levels of depression and anxiety, and a higher quality of life.
- **Don't discriminate:** Older Australians living with MS should have access to disability appropriate supports that allow them to remain independent, living in their homes and to have a high quality of life
- Inclusive and Equitable Disability care: Australians with disability who do not have access to NDIS services should be able to access the disability supports and services they need to live a full and independent life

MS Australia has provided the following submissions to the NDIS Review:

- **NDIS Review Major Submission:** The NDIS provides crucial supports and has improved the lives of many people with disability, including those living with MS. However, there are also many outstanding issues in relation to the Scheme that need to be addressed including improving the understanding of disability (including MS), making the NDIS more accessible and easier to navigate, the value of early access and access to the most appropriate supports, and a greater emphasis on participant choice and control.
- NDIS Quality and Safeguarding Framework: MS Australia supports the current NDIS Quality and Safeguarding Framework (Framework), however, we have concerns with how the Framework is currently implemented and recommend further education and training for providers and participants and improved transparency and consumer information and professionalisation of the disability workforce.
- **Pricing and Payment Approaches in the NDIS Market:** MS Australia recommends improvements to the current pricing arrangement including greater transparency in pricing, 'preferred' provider panel arrangements, improved pricing for plan management and support coordination, compulsory publishing of prices and a star ratings system.

Reference

- ¹ NDIS (31 March 2023). NDIS Quarterly report to disability ministers: Q3 2022-23. Retrieved from: <u>https://www.ndis.gov.au/about-us/publications/quarterly-reports</u>
- ² MS Australia, Menzies Institute for Medical Research & MS Nurses Australasia Inc (2022). MS Nurse Care in Australia: Patterns of access and impact on health outcomes. Retrieved from: <u>https://www.msaustralia.org.au/about-us/reports-and-financials/</u>
- ³ NIDS Review (May 2023). *Building a more responsive and supportive workforce*. Retrieved from: <u>https://www.ndisreview.gov.au/sites/default/files/resource/download/building-a-more-responsive-and-supportive-workforce.pdf</u>
- ⁴ Australian Institute of Health and Welfare (2022). *People with disability in Australia 2022*, DIS 72, retrieved from: <u>https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/about</u>
- ⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (August 2021). Rapid Evidence Review: Violence, abuse, neglect and exploitation of people with disability. Retrieved from: <u>https://disability.royalcommission.gov.au/publications/rapid-evidence-review-violence-abuse-neglect-and-exploitation-people-disability</u>



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Appendix A: MS Plus staffing hours for full-term NDIS accreditation

Frontline staff 3-4 hours per client Team of 60 staff = 240 hours Contacting clients to discuss emergency p Contacting clients to complete risk assess Ensuring Service Agreements and Consen Preparing staff for interviews Frontline staff - accreditation briefing groups 4 hours = 3 x 1-hour sessions & 1 hour reviewing documents Team of 12 staff = 40 hours Preparing staff for interviews Leadership Team 4 hours per month Team of 9 staff = 36 hours Completing desktop audits Leadership Team – sample list follow- up 6 hours fortnight prior to audit Team of 5 staff = 30 hours SPP Quality Portal Quality 3 days per week for 5 weeks 10 days = 38 hours SPP Quality Portal Quality 1 day per week for 8 weeks 60 hours Contacting clients not devidence required 60 hours Internal Audit 5 days = 38 hours Review of evidence and report written Team of 3 staff = 36 hours Quality team and executive Three hours per week Team of 8 staff = 24 hours Discerning and following up on changes a requirements (example Emergency and D Uo hours Quality Team 100 hours Engaging quality assessor Completing service description Reviewing schedule Quality Team 1 hour per month (14 meetings) Team of 7 staff = 98 hours Providing assessor with deidentified client Providing assessor with deidentified client Providing assessor in accreditation preparati Propare information sheets	
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