

What We Have Heard report – Emerge Australia submission

Emerge Australia is the national patient organisation for the estimated up to 250,000 Australians living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and their carers. More recently, we have also been supporting people living with Long COVID, due to the strong overlap in symptoms, particularly the presence of post-exertional malaise but importantly the impact these diseases have on quality of life. Both these diseases are invisible but this does not mean they are any less disabling: 25% of people living with ME/CFS are house or bed bound. Recovery to pre-illness functioning is extremely low, at only 5-10%. For the vast majority of people with ME/CFS, the condition is permanent.

It is estimated that ME/CFS costs the Australian economy \$14bn per year, which means that, in addition to the impact of NDIS support on the lives of people with ME/CFS, there is also likely to be a significant economic impact.

1. Applying and getting a plan

You have told us that getting access to the NDIS is not simple or straightforward. Once in, planning processes are complex, confusing and stressful, and that there is little trust or confidence in the way decisions are made.

How can we empower you through the planning process?

People with ME/CFS and Long COVID have enormous difficulty accessing NDIS funding, because the conditions and associated disabilities are not well understood.

1. Lack of knowledge and understanding of ME/CFS and Long COVID

ME/CFS is a disease which causes impairment which is likely to be permanent in the vast majority of cases, as recovery rates are very low (estimated to be 5-10%). The impairment substantially reduces functional capacity and the ability to move around, socialise, undertake self-care and self-management tasks. Most people living with this condition will require support for the rest of their lives.

Lack of specialists with sufficient knowledge of the disease makes it difficult to obtain the necessary evidence required for the application. GP evidence is often not regarded as sufficient to approve NDIS claims, even though they are the centre of patient care for those with ME/CFS and Long COVID.

If the applicant can gather the required documentation, the next obstacle they face is that the disability associated with ME/CFS is often misunderstood by NDIA assessors. With no ME/CFS-specific NDIS assessment guidelines, assessors are not able to understand the disabling impact of post-exertional malaise (PEM) or other disabling impacts of ME/CFS. With Long COVID patients starting to apply for NDIS, it is even more important for NDIA assessors to understand how to assess energy limiting disabilities. Clear assessment guidelines would assist to dispel the belief that ME/CFS is not permanent: recovery to pre-illness functioning is extremely low, at 5-10%.

The result of these obstacles is typically one of two outcomes:

- a) The application is incorrectly rejected, or
- b) Inconsistent assessment decisions are made: one person might get accepted while another with same or even worse level of disability may not.

2. There are no effective treatments for ME/CFS. In requiring specific treatments for access to the scheme, NDIA is coercing people to undergo ineffective treatments without consent and denying them the right to refuse treatments.

Despite medical reports indicating the extensive treatments applicants have undertaken, people with ME/CFS are often required to undertake graded exercise therapy in order to access the NDIS. Medical consensus indicates this treatment is no longer appropriate for everyone with ME/CFS and is unlikely to result in significant improvement in their functional capacity. Graded exercise therapy has been shown to cause harm to people with ME/CFS and is no longer recommended in the US or UK. In Australia, it is not only still recommended but often required for NDIS access, even when medical reports indicate that it is not appropriate.

Coercing patients to undergo treatments which have been deemed medically inappropriate or unlikely to result in significant improvement, or to which the patient has not freely consented, in order to access the NDIS, is a breach of their human rights to informed consent and the right to refuse treatment.

For people with ME/CFS, trying any new treatment carries a risk of harm, due to medication and treatment sensitivities. Coercing people to undergo further treatments beyond what has already been tried and medically recommended, when there is low likelihood of benefit (due to lack of effective treatment options), poses the risk of harm.

3. The application process is incredibly stressful and costly to applicants' health and financial situation.

Due to the energy limiting nature of this disease, many people with ME/CFS report their condition is made permanently worse by the effort and stress involved in the application process. The risk of being left with worsened health and no supports is putting some people off applying for the scheme. For those who do apply, the result is either:

- a) They are accepted onto NDIS, but need more supports than before they applied, adding to the cost of the scheme.
- b) Their application is rejected, their condition has been worsened by the application process and are in even more need of support.

People with ME/CFS pay thousands of dollars to obtain medical reports for NDIS. Not only could this money be better spent elsewhere, such as on supporting their own healthcare, it makes the scheme inaccessible to those on low incomes, like DSP or JobSeeker. In addition, medical practitioners' lack of knowledge about the condition results in inconsistent medical reports, with those fortunate enough to find one of the few practitioners who understand the condition having a much better chance of having their application approved than others, further adding to the inequity of the access process.

Adequate support for those with energy limiting disabilities such as ME/CFS will help prevent people from exacerbating their disease, leading to increase need for disability support. This results in both health and cost savings. Despite the many issues outlined above, some still apply for NDIS, because they feel there are no other avenues for support. For those who are accepted, NDIS is a lifeline and empowers those with ME/CFS to live independent meaningful lives.

Recommendations:

There are several solutions to these problems. Many of these problems could be significantly alleviated through NDIA Assessment Officer education about ME/CFS and Long COVID including low recovery rates and permanence, severity, core symptoms of post-exertional malaise, and the fluctuating nature of energy limiting disabilities. Emerge Australia strongly advocates for:

- i. Co-designed NDIS assessment guidelines for poorly understood conditions like ME/CFS and Long COVID. This will enable NDIS assessors to have a greater understanding of the conditions, and how to appropriately assess impairment in those living with these conditions.
- ii. To make the application process equitable, affordable and inclusive of those with energy limiting disabilities, the application process should be less onerous for applicants with this disability. There are two simple steps which will assist this to occur:
 - a. GP reports, where functional capacity is addressed, should be considered sufficient evidence. Due to the multiple body systems involved in ME/CFS and Long COVID, and a lack of knowledge these conditions among medical specialist groups, applicants who provide a report from their main treating medical professional, including their GP, should be considered for NDIS access.
 - b. When an applicant has gained medical evidence of permanence and disability, this evidence should be accepted by the NDIA. Currently, such evidence is often ignored or overridden by NDIA assessors. This is primarily due to inadequate training and understanding of ME/CFS by NDIA assessors.

2. A complete and joined up ecosystem of support

We have observed that support for Australians with disability is not planned, funded or governed as a whole ecosystem. There is not enough support for people with disability outside the NDIS. This is unfair and is undermining the sustainability of the NDIS. Which results in people falling through the cracks and missing out on much needed support.

What is the best way to provide supports for those not in the NDIS?

When the NDIS was implemented, state and local governments stepped back from providing care and the NDIS became essentially the sole provider of support for people with disabilities. This has meant that some people with ME/CFS who previously had access to supports prior to the NDIS roll out have been unable to access the NDIS, are now worse off.

Common supports which are now difficult to access outside the NDIS include cleaning, gardening, transport, and assistive technology. Some are forced to pay privately for these services but as many living with ME/CFS are also reliant on social security payments, this is often out of reach.

While the NDIS is designed for those with a higher level of need, there are many people with disabilities like ME/CFS and Long COVID who may not require NDIS-level support, but who still require some support in order to function. This lower level of support is also preventative care and a saving to the public health and disability system. Without support, people with energy limiting conditions are at risk of deterioration and some end up requiring more support as their condition declines. With no other supports outside of the NDIS, some with ME/CFS apply for the NDIS, despite only needing a low level of support that could be offered through local streams.

Recommendation:

The NDIS must form part of a suite of coordinated disability support services, both to ensure there is appropriate support for those with low level support needs and to ensure the sustainability of the NDIS. The federal government could establish a “one stop shop” of disability services, and state and local governments should provide basic supports for those with low level needs.

3. Defining reasonable and necessary

Lack of a clear, shared understanding of what is considered ‘reasonable and necessary’ leads to complexity, confusion, conflict and inconsistency.

How would you define reasonable and necessary, and put it into practice?

Being able to define what is “reasonable and necessary” requires that the NDIA understands the participant’s disability and life. Too often decisions about what is “reasonable and necessary” are being made by an NDIA worker who is removed from the life of the participant. To an outsider, these decisions often seem arbitrary and more about cost saving to the NDIA, than about improving lives.

The question that must go along with “reasonable and necessary” is “how will this improve this person’s life?”. Too often that question doesn’t seem to be considered.

For people living with ME/CFS, what is “reasonable and necessary” can be very difficult to demonstrate, given the lack of understanding of the condition within the NDIA. For example, people with ME/CFS have had requests for personal care, carer respite, home adjustments such as motorised blinds, and meal delivery rejected, despite clear explanations of how these are essential and would improve the participants’ life. Others have plans which include components (such as taxi service for someone who is mostly bedbound) which they describe as unhelpful and irrelevant to their lives.

Decisions to approve or reject requests often seem arbitrary and do not reflect the participant’s disability or needs. Many NDIS participants with ME/CFS, who have severe energy limitations, are having to expend significant energy taking their requests to the Australian Administrative Tribunal to fight for necessary supports, rather than living their best lives.

Recommendation:

Decisions around what is reasonable and necessary must be made with an understanding of the participant’s disability and must examine the impact of the request on the participant’s life.

4. Early childhood supports

Early intervention for children is frequently not based on best practice. Not enough support is built around families and helping children to be included in their local community.

What is the best way to support children with disability and those with emerging developmental concerns?

Children with ME/CFS struggle to get access to appropriate supports as their condition is not well understood. There is often a misperception that children with the condition are malingering or school avoidant. But early intervention to provide appropriate support, especially around schooling, can make an enormous difference developmentally and to minimise the consequences of a condition with such severe impairment.

Recommendation:

NDIA should ensure that assessors are educated as to the nature of common energy limiting disabling conditions such as ME/CFS and Long COVID, in order to make appropriate assessments and recommendations.

5. The support and service marketplace

NDIS 'markets' are not yet working for all participants. The current approach to the market relies too much on competition. Not all participants have access to the supports they need.

How can the markets be better designed, structured and supported?

NDIS participants are too often at the mercy of service providers, who hold all the power to determine when and how participants receive required services. Participants must be at the centre of all care and NDIA should help shift power in participants' favour, especially in regards to participants' rights when they have people entering their home.

Providers should not be allowed to charge a different rate for NDIS compared with non-NDIS services. The so-called "NDIS tax" means that plan funds, intended to improve participants' lives, are not stretching as far as they could. Instead, the "NDIS tax" is wasting tax payer money and depriving participants of other supports.

State and local governments being funded to provide NDIS services could help plug gaps in service provision, especially in regional and remote areas.

Recommendation:

Providers should not discriminate between NDIS and non-NDIS clients. Fees for services must be the same for NDIS and non-NDIS services. State and local governments should be funded to provide NDIS services, especially in regional and remote areas, and to improve market competition.

6. Measuring outcomes and performance

Better measurement of outcomes and performance would help participants make informed choices, keep providers and government accountable, and make sure the scheme is sustainable. It would also help the NDIS improve over time.

How should outcomes and performance be measured and shared?

The focus on goals within the NDIS is difficult for people with energy limiting disabilities such as ME/CFS and Long COVID. For many living with ME/CFS (and increasingly Long COVID), NDIS support allows for independence and to avoid institutional care or homelessness. Goals should be relevant to the type of disability and for those with an energy limiting disability focus should be on quality of life and maintain independence.

NDIS outcomes should focus on measuring a range of factors to demonstrate how the scheme has improved the life and wellbeing of participants. There are many ways the NDIA could measure this, including physical and mental health, quality of life, engagement in work (both paid and unpaid), independence and inclusion.

Evaluation of the impact of the NDIS should also include evaluation of service provision, NDIA's performance and participant satisfaction with the scheme.

Recommendation:

The federal government has adopted a Wellbeing Budget to ensure that a broad range of outcomes are used to assess economic performance. The NDIA should take a similar approach and adopt a Wellbeing focus on measuring outcomes of the NDIS. The outcomes should include both reduction in negative factors such as social isolation, poverty, anxiety about maintaining independence, as well as positive factors such as improved wellbeing, independence and inclusion.

7. Achieving long term outcomes

We have observed that there is a lack of focus on achieving long term outcomes relating to participation, inclusion in communities and employment. A good life is one enriched by connections to family, friends and community. These need to be nurtured by the scheme.

How would you like to build better outcomes into your plans?

NDIS supports, focusing on individual's needs, may improve community participation for some. However, people with ME/CFS and Long COVID face significant obstacles to greater participation in community as these conditions limit energy expenditure, a limit which is not improved with supports. Emerge Australia frequently hears reports of participants feeling pressure to increase participation even though this is not realistic for the level of disability they experience. The NDIA would benefit from incorporating a better understanding of disease and disability severity when focusing on participation goals.

Other obstacles to greater community involvement arise from a lack of understanding of the condition (eg: a need to lie down, or to minimise or avoid exposure to fragrance or loud noise). Reducing these obstacles requires broader societal change, beyond the scope of the NDIS.

The pandemic increased community participation for many people with disability, including many with ME/CFS, through access to online services and events. It would be useful for the NDIA, as an organisation with significant influence, to consider ways to foster national online services that make services accessible for those with disabilities who have limited access to face-to-face communities.

Recommendation:

Greater community participation is an admirable outcome for the NDIS, though this will not be possible for all people with disabilities. Long term outcomes should be relevant and achievable for the individual, rather than a one-size fits all approach. NDIA should advocate for mainstream services such as theatres or cinemas to provide online services to increase accessibility for those for whom access to face-to-face events is limited.

8. Help accessing supports

The roles of 'intermediaries' such as local area coordinators, early childhood partners, remote community connectors, support coordinators and plan managers overlap, leave gaps and are confusing.

What does good service from someone helping you navigate the NDIS look like?

It is very difficult for NDIS applicants and participants to find accurate information about and navigate the scheme.

NDIS applicants struggle to know exactly what is required for an application. The information is complex and difficult to parse, especially for those with cognitive difficulties, or for whom English is not their first language.

NDIS participants report struggling even more to understand the rules around what can be claimed, how to log expenses, and which bucket of funding expenses belongs to. The system was established assuming that most participants would be agency managed, but with participants increasingly self-managed, it can be very complex for participants to understand. Participants report wanting to do the right thing, and spending an enormous amount of energy trying to navigate this complexity and carrying anxiety that they may have gotten it wrong.

Recommendation:

NDIA should provide a service to help both applicants and participants navigate the system. Rules should be simpler and clearer. Applicants and participants could be assigned a case manager who can learn about their disability, explain the NDIS clearly, and interpret the rules fairly.

9. Supported living and housing

Many participants with housing and living supports in their plans still have limited choice in where, how or with whom they live. There has been little innovation in housing and living supports. The supply of specialist disability accommodation is not always meeting the needs of participants.

How should housing and living options be improved to build a good life?

People living with ME/CFS have specific needs which are different to those with other disabilities. For example, often they need a very quiet environment which is not conducive to living with others. However NDIA often rejects requests to live alone. Housing decisions must reflect the best interests of the individual and their choice. Forcing people to live with others is a throw back to the old model of disability group housing.

Recommendation:

NDIS participants should be allowed to live alone if that is their wish. NDIS participants should not be forced to live with others and should have the dignity of housing that meets their needs.

10. Participant safeguards

We are concerned to learn that the NDIS may not have worked well enough to safeguard all participants, while making sure they can still have choice and control. More can be done to empower participants to keep themselves safe, and ensure systems are working together to improve safety and outcomes.

How should the safeguarding system be improved for a better NDIS?**Recommendation:**

We suggest that the NDIS safeguarding mechanism should:

1. Be user-friendly

The current Safeguarding Framework is too complex and impossible to navigate for many participants with invisible illnesses, who live with cognitive impairment.

The new framework should come with resources which are accessible for self-managing participants to help keep themselves safe.

2. Empower participants

NDIS participants have support workers come into their home to deliver services, which makes them vulnerable. We hear stories of support workers being disparaging or abusive towards participants. The new Safeguarding Framework must facilitate empowering participants to maintain agency, dignity and control over their home environment and ensure their safety.

Empowering participants should include making it easier for participants to file complaints against providers whose services are inadequate, unprofessional or abusive.

3. Support participants & providers

The new Safeguarding Framework should outline how the NDIA will support participants & providers to use the Framework.

Given NDIA has fewer staff managing participant plans, more support should be provided to helping participants self-manage safely.

4. Encompass non-registered providers

All NDIS providers must be required to follow any Safeguarding Framework, and participants empowered to ensure compliance.

There needs to be a mechanism by which non-registered providers agree to the requirements of the new Safeguarding Framework.

5. Focus on prevention

The ultimate goal of the new Safeguarding Framework should be to prevent issues from arising. This helps people with disability to focus more on living their lives to the fullest, rather than managing the NDIA and service providers.

6. Be flexible

Safeguarding should not be at the expense of flexibility. The new Framework should not impinge on participants' ability to live their best lives on their terms.