National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024

Consultation on draft lists of NDIS Supports

August 2024

Emerge Australia is the national patient organisation providing services and evidence-based education about myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Increasingly, Emerge Australia works with those impacted by post-acute sequelae of COVID-19, known as long COVID, because of the striking symptom similarities. Research suggests up to 45% of all people with long COVID meet the diagnostic criteria for ME/CFS.[1]

An estimated 25% of the 250,000 Australians estimated to be living with ME/CFS are house or bedbound. However, few people with ME/CFS have access to NDIS support due to poor understanding of the disease, most notably poor understanding of the core symptom, post-exertional malaise. Accessing the NDIS based on ME/CFS as a primary disability is so difficult that some people opt to apply for access based on one of their comorbidities instead, even if these are less significantly disabling than their ME/CFS.

In addition to the lack of understanding of ME/CFS and other energy-limiting diseases, there is a similar lack of understanding about the reasonable and necessary supports required to assist people who live with ME/CFS. Emerge Australia appreciates this opportunity to provide feedback on the proposed included and excluded supports, and their relevance to our community.

Emerge Australia recognises the significant amount of work that is being undertaken to reform the NDIS. We also subscribe to the principles of co-design, which will help the NDIS better serve people with disability. However, **there are a few matters that have made it difficult for us to provide more considered** feedback in this submission:

- Consultation period is too short.
- The way the lists of inclusions/exclusions is confusing, it is not easy to read or compare.
- We note the ‘easy read’ version of the document was released on 14/8/24, only 4 days before the consultation period ended and did not address the inclusion/exclusion list. It simply referred the reader to the original version, which, as already stated, is not easy to read.

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[1] C. Kedor, et al (2022). ‘A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity’. *Nature communications*, 13:1.

1. Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included? If not, what changes would you suggest?

Emerge Australia is concerned that in the process of creating the proposed list of inclusions/exclusions for NDIS Supports, not all types of disabilities have been considered.

People living with severe ME/CFS and long COVID are limited by the amount of energy they have. With limited energy, they often need to choose between everyday tasks. For example, it may be a choice between washing their hair or making a meal. If the person uses more energy than they have available, they will experience post exertional malaise (PEM).

PEM is the most disabling aspect of ME/CFS, and those with long COVID who experience PEM. PEM is the exacerbation of symptoms following physical or mental exertion, usually when a person has gone beyond their energy threshold.

When a person is experiencing PEM, there are items not included in the draft supports list that can help people with ME/CFS to manage and reduce the intensity and duration of this exacerbation in symptoms. Such items include amino acids, heat packs and ice packs. These are not treatments, rather, they act as supports. Thermoregulation is also an issue for many people with ME/CFS, which means air conditioning/heating are important supports to maintaining and managing health, particularly when experiencing PEM.

When such disability supports are in place, the person is assisted to return to baseline functional capacity as soon as possible. In addition, if the person is experiencing severe PEM and is not supported to resolve this quickly, this PEM can result in a reduction of baseline capacity. This will mean that the person will require more, ongoing support. Such reduction in baseline capacity can be permanent.

2. Are there goods or services on the draft exclusion list that you think shouldn't be there? If yes, please list in order of importance.

Like our response to the previous question, many of the goods and services on the draft exclusion list do not consider the reality for many people with energy limiting diseases like ME/CFS and long COVID, or others who are house or bedbound. People who are house or bedbound require a high level of support in their homes. What may seem like ordinary tasks or appliances, are often crucial supports or assistive technology (AT) for these individuals. They are reasonable and necessary disability supports

Moreover, we believe that blanket exclusions should not exist, as they make it very difficult for people with ME/CFS and long COVID, and others on the NDIS, to access the reasonable and necessary supports they need. Most people with ME/CFS already fight for their reasonable and necessary supports, because the disease is so poorly understood.

While the draft list includes the disclaimer that, *Additional living costs that are incurred by a participant solely and directly as a result of their disability support needs*, this is insufficient. The decision for funding such 'excluded' supports then becomes subjective, up to the individual

NDIA worker. Participants are then required to fight for what they need, and the individual NDIA worker's interpretation and knowledge about the disease, both highly variable, will be how decisions are made.

Goods or services on the draft exclusion list that should be funded are listed below. While we have attempted to list in order of importance, this is difficult as each individual is different, and therefore will have different priorities.

- **Evidence-based therapy supports:** There is currently no evidence-based treatment for ME/CFS. There are some common management approaches with strong anecdotal evidence (such as pacing – see below) but these currently lack the published research required for them to be considered "evidence-based". For disabilities with few or no evidence-based therapies, there must be flexibility to allow funding for supports for which the individual gains benefit. This benefit can be defined as supporting or maintaining stability of function. For people with ME/CFS and long COVID, this includes therapeutic approaches which may be considered alternative, such as general massage, Chinese medicine or acupuncture. A possible solution is to allow therapies that require AHPRA registration.

  Exclusion based on having a recent medical event is also not helpful for people with ME/CFS. If person has had a recent medical event, it is highly likely that this will cause them to experience PEM due to the physical and/or emotional stress such events cause. For example, if a person requires hospital admission, this is highly likely to cause PEM, and a decline in baseline. As mentioned previously, this decline can be permanent.

- **Internet and phone services:** Many people who are housebound or bedbound are reliant on the internet, phone and tablet devices for social and community connection. For many, phones are essential as laptops and computers are too heavy to lift. These supports help people maintain a connection to the outside world, which helps reduce the mental health toll of such an isolated life. These should be funded where they serve such a crucial function.

- **General home maintenance:** Where the individual is unable to complete these tasks due to their disability, these should be funded by the NDIS. For example, if the individual is unable to take their own bins out or do their own laundry, the NDIS will fund someone to undertake these tasks. This individual will also be unable to mow the lawn, paint a wall or undertake any other minor home repairs or maintenance. Such home repairs and maintenance should be funded supports for such individuals. While the inclusion list includes home and yard maintenance, the exclusion list includes "General home repairs, general renovation and maintenance", which is confusing.

- **Standard household items:** Home appliances should not be automatically excluded. They should be funded where it is clearly a support for someone's disability because, for some people with disabilities, these items are assistive technology. For example, someone may be unable to wash their own dishes but may be able to stack and unload a dishwasher. Or, they may have a support worker to stack and unload their dishwasher, which would cost the NDIS less than a support worker to wash their dishes. Similarly, as mentioned in the previous question, air conditioning is a necessary support for people whose disability includes difficulty with thermoregulation.

- **Smart watches:** Pacing using the heart rate monitoring function available on smart watches is a common self-management technique to assist individuals to maintain functional capacity and is a vital disability support.

- **Hair and beauty services:** Where an individual is unable to attend a hair salon due to being housebound or bedbound, in-home haircuts, or the difference between attending a salon and an in-home haircut, should be funded. Some people with ME/CFS are unable to wash and dry their own hair, so use in-home hairdressers once a week for this support.

- **Water filters:** Many people with ME/CFS also have comorbid multiple chemical sensitive (MCA), which requires water filters and other adaptations to reduce the chemicals in their water. In such cases, water filters and similar devices should be funded.

- **Regarding "Mainstream – School Education" and "Mainstream – Higher Education and Vocational Education and Training":**
    - "Educational supports associated with home schooling" should be funded for people where home schooling is not a choice. This is the case for people who are house/bedbound. Home schooling, in this situation, is directly related to their disability.
    - "Textbooks and teaching aids" should be funded for students with sensory processing difficulties. For example, someone with visual sensory processing issues is unable to watch lectures, so requires a transcription service.

3. Do you have any further feedback or concerns with the draft NDIS support lists?

Some of the exclusions appear to assume not that those supports shouldn't be funded, but that they shouldn't be funded by the NDIS. Instead, we interpret the assumption is that such supports should be funded by the school, workplace or local/state government. For example, amendments to public housing to accommodate someone's disability is a specific exclusion because it is assumed the state government will pay for those amendments.

Such assumptions do not address if the state government will actually provide that support, and in some cases to date they haven't been. The Federal Government should not be required to pay for all supports, the states need to share responsibility, but this should not come at the expense of people with a disability. What safeguards or other measures are in place to assist those people with disability if the states don't fund areas the federal government think they should?

Finally, we note that these lists are part of a "transitional rule", which will stay in place until the Commonwealth, States and Territories agree on a rule to replace it. As this timeframe is unknown, we would like to know:

- Will there be any further opportunity for input or review of these “transitional rules”?
- When agreement has been reached on a new rule, what mechanisms will be put in place to review how this “transitional rule” has operated, particularly in relation to what has not been funded?