National Disability Insurance Scheme Rules 2021

Proposed NDIS legislative improvements and the Participant Service Guarantee

SUBMISSION

ME/CFS Australia Ltd

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1. Plan variation without consultation

For conditions that are poorly understood by staff, the lack of consultation holds a high risk of resulting in inappropriate plans.

It is evident from participant experience that Energy Limiting Chronic Illnesses (ELCI) are not understood by the NDIA or staff of the NDIS. Even with consultation, plans rarely acknowledge that for people with ELCI, effort in one domain may render activity in other domains impossible, and that effort on one day may incapacitate the participant on the following days or weeks.

In particular, there is often an incorrect assumption, that is expressed in letters from the NDIS to people with ME/CFS, that they *… may complete tasks more slowly or in a different way to other people… .* When people with ME/CFS cannot manage a task, the speed, or the way in which it is done, even with assistive technology, will not change the fact that the person cannot manage the task. This false assumption demonstrates that functional limitations associated with ME/CFS have not been understood.

In addition, the experience of participants has demonstrated that ME/CFS is poorly understood by NDIS staff, who often refer to this complex neuroimmune condition as 'chronic fatigue'. 'Chronic fatigue' is experienced by many Australians, with or without a disability. This overlooks the key characteristics of functional limitations experienced by people with ME/CFS.

This lack of understanding is a clear indication that **staff of the NDIS lack the knowledge required to make appropriate plan variations without consultation.**

2. Changes to the 'Becoming a Participant' Rules

It is a concern that **staff of the NDIS have made,** and will continue to make under the changes to the law, **medical decisions on behalf of participants**. Participant experience has shown that NDIS staff have required intending participants to undertake medical treatments, where medical specialists have clearly indicated in their reports to the NDIS, that the treatment would worsen the person's condition and thus further reduce their functional capacity.

NDIS law must recognise the professional boundaries in Australia for the practice of medicine which is legally restricted to registered health professionals who have been in direct consultation with their client.

Appropriate treatment

The term 'appropriate treatment' needs guidance in the Rules, as to who determines what is 'appropriate', and on what basis. Within the healthcare system it is required that 'appropriate' treatments are determined by the treating health professional in consultation

with their patient. Will this be the case, or will NDIS staff continue to demand treatments as a precondition for accepting a participant into the Scheme?

Will participation in the NDIS remain contingent upon undergoing treatments required by the NDIS, irrespective of medical advice to the intending participant regarding suitability and potential harm?

Substantial improvement

What is the basis for determining whether or not an improvement is substantial?

For the purposes of establishing eligibility for participation in the NDIS, **defining 'substantial' as an improvement that would remove severe impairment to functioning, across all domains,** is the only definition that is meaningful. Anything less substantial might influence a participant's plan, but would not change their eligibility, which only requires severe impairment in at least one domain.

The term 'substantial improvement' requires qualification by the word **sustained**. Long-term functional capacity will not be affected by improvements which are not sustained and therefore will not influence eligibility for participation in the NDIS.

Rule 9(2)(b)

> (2) The impairment may be considered permanent, or likely to be permanent, only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.

Available

'Available' has not been defined. For psychosocial disabilities, the term used is 'reasonably available', but even there, no clarification of what is considered 'reasonable' is stated.

Relevant concerns include: accessible within both geographic constraints and functional capacity; affordability; risk of harm including side effects which might reduce functional capacity or quality of life; availability of treating health professionals who have both knowledge and experience in the application of that treatment and an understanding of the potential participant's particular disabling condition(s).

Appropriate

The health system requires that 'appropriate' medical treatments are determined by a treating health professional in consultation with the participant. Current experience of intending participants is that staff of the NDIS require medical treatments as a precondition for participation without consulting the treating health professional.

Evidence-based

The evidence-base must be current.

For example, people with ME/CFS report being asked to undertake treatments from a 2002 clinical guideline. The NHMRC has acknowledged that the 2002 Australian Clinical Guidelines for ME/CFS are outdated.

Recent evidence has shown that the NDIS-mandated treatments are not only ineffective, not providing substantial improvement, but also carry significant risk of harm.

Rule 9 (2) i, ii, iii 'unable to perform tasks/participate'

'Unable to perform tasks' requires qualification in each of 9 (2) i, ii and iii that includes: effectively, completely, safely and in a manner that maintains the person's dignity.

Fluctuating Conditions

People with disabilities-other than psychosocial disability- may also have fluctuating conditions.

The permanence of the condition remains compatible with the fluctuation. The nature and the severity of impairment can be substantial even during the least disabling phases of the fluctuations. Further, in Energy Limiting Chronic Illnesses (ELCI), the degree of fluctuation may be directly impacted by the quantity, quality and types of support provided by the NDIS. Appropriate supports may allow better management of the demands on limited energy reserves and reduce the frequency, length of time and degree of impairment associated with the fluctuations. It is worth noting that in ME/CFS when energy reserves become depleted, the decline in functional capacity is substantial and may even impact on the functioning of organs and bodily systems.

The current NDIS framework discriminates against people with Energy Limiting Chronic Illnesses (ELCI). The NDIS framework does not allow consideration of energy limitations in assessing intending participants for whom **impairment in every domain is worsened, when the support needs for any one domain are not met.**

For example, an intending participant may be able to shower independently if, and when, all their other support needs are met. However, if they are required to expend energy on other ADLs, then this may make showering impossible.

If a person is able to perform a task on one occasion, then the NDIS framework assumes that they will always be able to carry out that task.

There is no recognition that undertaking one task prohibits the ability to perform other tasks.

Letters from the NDIS consistently claim that people with ELCI can work, "..more slowly or in a different way to other people.." , when energy reserves are depleted. This is impossible.

Energy Limitation is not 'fatigue'

Experience has demonstrated consistently that NDIS assessors interpret medical reports and participants statements of lived experience that describe energy limitation as 'fatigue'. The fact that the person has **no functional capacity beyond the limits of their energy reserves** is not recognised even when it is explicit in the medical reports.

Energy limitation is a medical characteristic that defines functional limitation. This is not 'fatigue'. Functional incapacity due to depleted energy reserves does not allow a performance of a task.

3. Changes to Plan Management and Payment of Supports

Unreasonable risk needs to differentiate between risk, when the participant is without support, and risk when the participant has appropriate supports to facilitate independence in decision-making.

For example, in Energy Limiting Chronic Illnesses (ELCI) the participant may have the necessary energy for cognitive tasks to manage their decision-making and finances, if they receive adequate support in other domains.

4. Decisions Section 100 (1B) and (1C) of the Act.

We welcome reasons for decisions being available on request. However, given that NDIS participants are by definition severely impaired, all decisions should be automatically accompanied by a statement of reasons.

The legislation needs to include that the AAT consider all decisions made by the NDIS concerning a participant's plan. .

5. Additional Considerations

The complexity of the Rules, and the multiple places in which they are found, is a significant barrier for participants. As an adjunct to the changes to the Rules, we request provision of a simplified application process that is accessible to people with disabilities and their carers, many of whom are currently excluded from the NDIS, because they cannot negotiate the administrative requirements.