Submission to National Disability Review

Firstly, my apologies for this late submission as I only have become aware of the review. Accordingly, I will only focus on a specific aspect of concern.

This submission focuses on why a medical condition such as ME(FM)/CFS should not matter in whether a person qualifies for NDIA/NDIS support or not.

This is an important question to answer as current policy is setting unjustified discrimination as to who can access the scheme and does not appear to be in line with the legislation as enacted. Also, such individuals are not the only ones affected, so are the carer(s) who must live the same life to large extent.

Proper access will invariable affect the lives of at least 2 individuals, the affected person and the carer.

The NDIA/NDIS scheme as intended and as my reading seems to confirm, was to be based on a person's disability without regard to how the disability arose. It's intention was to provide support for the most disadvantaged members in our society who through other government schemes or lack of, cannot adequately meet such needs for whatever reasons.

In fact, information required to be submitted to NDIA/NDIS on standard Forms and the legislation as part quoted below, both look at the nature of the disability in determining a person's eligibility. The legislation does not discriminate on the basis of a label of the illness.

The ACT says:

NATIONAL DISABILITY INSURANCE SCHEME ACT 2013 - SECT 24

Disability requirements

(1) A person ***meets the disability requirements*** if:

(a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

(b) the impairment or impairments are, or are likely to be, permanent; and

(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self-care;

(vi) self-management; and

(d) the impairment or impairments affect the person's capacity for social or economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the variation.

In our case as an example, the focus by NDIA/NDIS was on the medical label of the disability and not on the nature of the disability and whether you met the requirements as noted above which in our case we believe we can easily demonstrate.

Again in our case, I have been a full time carer for 21 years and find it difficult to understand how the claim that my spouse does not have a disability worthy of NDIA/NDIS support even though the person is house bound, in a wheel chair and has many other special needs. The long term nature in my spouses case must surely be indicative of the permanent nature of the condition and that the resulting disability will have created significant impact upon our quality of life.

The lists of medical conditions as noted in the legislation was included to avoid such individuals having to go through the above legislation tests, that is, they would have automatic admission to the scheme. It was not a list of the only conditions that qualifies for admission to the scheme. It was done to simply access for many individuals.

For those not on those lists, they would need to satisfy the above tests to get onto the scheme, as not all conditions could be defined.

Current government policy is automatically ruling out anyone who claims ME/CFS without any regards to the extent of the disability which is not the intent and spirit of the legislation.

In fact, we have met other NDIA/NDIS participants who qualify and they are not half as disabled as my spouse is, so something is clearly wrong with the way the scheme is being applied if its purpose is to supposedly help the disadvantaged in our society.

I believe that just as the legislation intended, it is not the label of the illness that led to the disability is what should determine whether one is entitled to support under NDIA/NDIS, but what is the extent of the disability as per the criteria as noted above under ACT 24.

As a final point, whilst alternative schemes may exists, only NDIA/NDIS was setup with the resources needed to meet the high costs that such disabled individuals need. To push them onto another scheme on the basis that it’s the more appropriate scheme is to deny them the help they need and as was the intention of NDIA/NDIS legislation.

This needs to be addressed ASAP as many are missing out when help is sorely needed for both the affected person and the carer as well.