

5th October 2022

Personal Submission - NDIS General Issues Inquiry

I am a thirty-one-year-old female, I have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and this year I applied for access to the NDIA, five years after I became disabled by this illness. ME/CFS is a complex neurological illness and not the same as having general chronic fatigue as is commonly misunderstood.

I have recently had my first access request rejected by the NDIA and am drawing on that experience to highlight some of the issues relevant to this inquiry. These issues have made my first access request an unnecessarily lengthy, onerous, and quite frankly emotionally unbearable process, which is doubly significant given that I am a disabled person in need of support.

Please note, I have already highlighted some of these issues in the Parliamentary Inquiry into the Culture and Capacity of the NDIA however have elaborated on some issues and included new ones given the broader scope of this inquiry.

Issues:

1. Repeated (incorrect) advice across NDIA that a psychologist or psychiatrist is a relevant professional in the context of treating my disability (ME)

- I contacted my Local Area Coordinator for assistance with applying as I have a cognitive impairment and was struggling with the paperwork, to be informed:

"I did some research in Chronic Fatigue Syndrome and found that one of the specialists to treat it is psychologist. Therefore, I would strongly encourage you to obtain a Psychology report to show the agency how your disability have permanently impacts on your daily functional capacity." (NB: this is a direct copy and paste, the spelling/grammatical errors were included).
- These words (identically written but I believe without the grammatical errors) were also written to me later by the NDIS assessor who rejected my access request.
- This indicates that guidelines within the NDIA on ME/CFS are wrong - a psychologist is not the relevant professional to treat the impairments caused by ME and is certainly not going to be able to provide an insight as to the permanency of my physical illness nor loss of functional impairment in regard to the physical disability side of ME. I worry that this stems from outdated (twenty-year-old) Australian guidelines that Cognitive Behavioural Therapy can assist with managing ME/CFS – information which is sorely outdated and no longer considered best practice.
- The impact of these errors is that I did not pursue getting help from the LAC, not only for this error in information but also because they didn't outline how they could be

of assistance (for example, can they assist me in filling out my access request form because I have a cognitive impairment? I don't know as they never advised me).

- Not having help with filling out paperwork is one of the main reasons why a year after I've started learning about the NDIS, I, as someone with cognitive impairment, still hasn't been able to put together a successful application in the extremely specific language that the NDIA requires.

2. Not providing detailed reasons for rejection in access request process.

- The NDIA assessors **do not have to provide any details or evidence to substantiate their decision to reject access requests.** For example (as in my case), I was rejected on the grounds of 'permanency' for 'not having tried all available treatments' in the context of an illness that doesn't have any effective treatments available to it or it's impairments. I had no way of knowing what treatment(s), for which impairment(s) they expected me to have completed to gain access, or really whether they have any sound foundation for the rejection at all.
- I asked the assessor for particulars about my decision so that so that I might address it at the review stage. In their first correspondence, the assessor merely said that I could request a review and restated what was in the original 'access not met' template email. This response to requests for further information is common NDIA practice.
- This practice wastes both the agencies and applicants' resources and time. It also means that an applicant doesn't have the information required to improve their evidence/application when applying for a review, potentially leading to another 'access not met' decision.
- **This is neither a fair nor transparent process.**

3. NDIS assessor belief that they can override a medical practitioner's opinion of what treatments are safe/suitable for the applicant.

- After sending a second email to the assessor to try and obtain specific information about my rejection (and therefore improve my evidence for a review), I was informed that there was:

"Identified potential for me to benefit from further therapy interventions, (i.e., further psychosocial therapy, psychiatric and neuro-rehabilitative support and physiotherapy)."

- My medical practitioner had already addressed that neither psychological and physiotherapy-based treatments were going to be inappropriate or ineffective in my case, and psychiatric and neuro-rehabilitative support are completely irrelevant to my condition.
- **This indicates that the assessor was ‘guessing’ at ways to deny my access request (based on no guidelines or foundation) and that he had also rejected the detailed medical opinion provided to him and presumed to know better.**
- How is this lack of process and reasoning even possible from a government agency?
- A second reason for denying my request was given, however for the sake of brevity I will only say that it was a conclusion that was not open to him to draw from the evidence my doctor had submitted, and in fact completely contravened explicit statements from my doctor that confirmed my illness was stable/didn’t fluctuate.

4. Based on constant reports from within the ME/CFS community and my own experience, assessors are untrained to deal with complex / health-based disability access requests and are inclined to outright reject them.

- My access request was initially rejected because the two criteria (permanency and substantially reduced functional capacity) were not met. **It is considered the norm, and in fact highly likely, to be rejected from the NDIA when you have ME/CFS** – and this is despite the ME community putting in significant prior effort to educate themselves about the complexities of applying for the NDIS with a health-based disability.
- Ultimately, after two emails to the first assessor (trying to get further details) and then two complaint emails being sent, the Technical Advisory Board within the NDIA advised that **I had in fact met the ‘Permanency’ criteria**.
- It took about two months from my initial ‘access not met’ decision for me to achieve this outcome, which is a correction on one criteria of the original assessor’s decision – indicating that assessors make errors/don’t take the initiative to get the right advice from TAB when reviewing access requests based on health-based disability and automatically reject them (with the pretty atrocious internal reasoning aforementioned).
- If I had not filed two complaints, at the informal advice of a lawyer, then who knows when or if this incorrect finding as to the permanency of my condition would have been corrected during my first access request process. It may have been corrected at the review stage if the reviewer formed a different opinion, or it may not have unless I’d filed these complaints – thus sending the issue to TAB. Not having a ‘permanent’ illness is one of the most challenging things to establish to the NDIA when you have

ME/CFS and one of the primary reasons for rejection – so it seems that I got ‘lucky’ in this regard, whereas many others within my illness community wind up at the Administrative Appeals Tribunal trying to establish this criterion. The lack of consistency is concerning (although I do note, everyone’s case and impairments and ‘treatments’ will be different, however, given there are really no treatments that can substantially improve any of the ME symptoms, this overall point can still be made).

- It also wasn’t until the ‘review’ stage that I was finally informed that I needed to supply more information, and from whom (**specifically an allied health professional, not a psychologist after all**). This was the **first time** I was informed that I needed allied health input, and I’m not sure why this couldn’t have been stated at any time sooner in the process (or from the LAC I first contacted). Because ME/CFS falls under ‘other’ conditions on the ‘providing evidence of your disability’ NDIA webpage, this information was not clear to me at the outset.
- The impact of this was to draw out the process significantly and delay my entire review – as I could have placed myself on occupational therapy waiting lists sooner had I known this was needed.
- There is also confusion within the NDIA as to whether input from an allied health professional is necessary for an access request for those with ME. I initially applied without allied health input, as I know people with my condition who have been accepted without it. I have since heard that the rules around this have changed. The reviewer insisted that allied health input was essential, and that certain information could not be provided by my GP (despite the fact that they’ll still use evidence from your GP to reject you as not having substantial functional impairment). If I had known that allied health input was a must-have from the outset – I would have worked to include this in my original access request.

5. A culture and processes that deny chronic illness-based disability as true disability

- The NDIS is not set up to understand or accept applications from people who experience disability because of health-based conditions like mine. **This is the first thing that advocacy bodies for disabling illnesses will say when they are presenting a seminar on how to apply to the NDIS.**
- **25% of patients with ME/CFS are either housebound or bedbound** – they are some of the people in this country that are most urgently in need of support, as their condition can deteriorate rapidly and permanently without it.
- The fact that applying to the NDIS is significantly more challenging for ME/CFS applicants is unjust. The NDIA will say that it looks at impairments, not the overall disability and of course at an initial level all of that is true, **however the accuracy of its internal guidelines, and its understanding disability as not including health based disability, its exclusion of chronic illness based language (i.e. ‘symptoms’)**

instead of impairments), and even potential assessor biases, all have an impact on why applying with ME/CFS is an arduous and sometimes impossible journey.

- I have read (and re-read) at **least 200 documents** related to applying for the NDIS and I'm still in the process of preparing for my second access request. A large part of what I've read is not information about the NDIS from advocacy bodies or from the NDIA itself, but from **others with ME/CFS** who have successfully prepared primers on applying to the NDIS successfully with my condition (ME) and how to specifically address each criterion, knowing that it is a challenge to get on the NDIS with illness-based disability.
- The challenge goes beyond just having to convert a chronic illness into disability, **it is incredibly technical to prove that ME/CFS is a permanent disability – and specialist knowledge of how to do this to satisfy the NDIS is required before in order to gain access** (if you have a successful access request at all).
- **The burden of translating a health-based disability into the 'black and white' view of disability that a NDIS assessor understands is unbearably burdensome** to the applicant and a barrier to access, especially when the applicant also has cognitive impairments.
- **If I had not received the advice of people with my condition who have previously navigated NDIS access, and especially how to translate my entire illness into 'disability language' that the NDIS finds acceptable, then I genuinely believe that I would have zero chance of getting onto the NDIS.** And despite the overwhelming research I put into preparing a successful application - I was still rejected at the outset, and that I still failed to establish one final criterion at the review stage.
- I have a law degree and used to work in media. Yes, I also have cognitive impairments, however if it's this hard for me – then how hard it is for someone who hasn't got a higher education degree to apply?
- My doctor's letter had to be about 6 pages- mostly trying to tackle why my illness/impairments are 'permanent'.
- I commonly see in ME support groups that people want or need to apply for the NDIS, but they 'don't have it in them', 'don't have the energy/capacity' or 'can't bear to reapply' after failing to gain access the first time. Why is it so hard?

6. Assessors look for any reason to deny your access request, not to look at the totality of evidence and accept it.

- My occupational therapy report recommended complex assistive technology for me, including a power chair. At present, I don't have my own power chair because you need extensive occupational therapy advice prior to purchasing one and I figured that I may as well wait until I am on the actual NDIS (because I would also need a

hoist for the car, house modifications, training in how to safely operate one etc). I have seriously considered buying one (as the length of time it has taken to get on the NDIS has blown out far longer than I anticipated) but as mentioned, it's not simply a question of buying one – as I need all the other stuff to go with it too!

- I presently use a rollator (wheeled walker) around the house, but even such can barely walk with that, and only for very short distances (as stated in my OT report).
- The fact that I did not currently have, or use, 'prescribed' technology was used against me, with the NDIA saying that a **rollator (as well as other assistive technology that I use such as a shower stool) was considered a 'common household item'** and using a rollator in itself didn't show that I had substantially reduced functional capacity. I am thirty-one years old. I also believe that there is legal authority that says that a rollator is not a 'common household item', however perhaps it's the fact that it wasn't prescribed to me that was the issue – it remains unclear. Nevertheless, why is this even relevant when the report has recommended that I be in a power chair and that I can't even safely walk with a rollator?
- It seems almost a 'trick' or 'catch 22' that the NDIA will play – insisting that you provide 'detailed information as to how you get through a day' and then for the many of us who don't have adequate equipment or disability support, or who confess the adjustments that we have made to our lives in order to meet (or still not meet) our most basic daily needs – this information serves only as fuel for the assessor to reject you.

7. High level of errors in communications from NDIA staff

(NB: I have only gone through the access request process once – so these examples are all from only one attempt to access the NDIS and all occurred PRIOR to the review stage)

- Frequent spelling errors including in important information (like my address)
- Incomplete/incorrect changing of details/ filling out of template emails
- Incorrect email attachments sent to me (e.g. sent the wrong form to sign to request a review)
- A blank email was sent to me.
- Simple errors in my initial access request rejection letter – e.g. saying that a letter wasn't dated (when it clearly was, in the top right of the letter, where one would expect to find the date written).
- The assessor for my review was only able to find two out of the five pages of my GP's letter on my file and had to request that I send through the missing pages – how is this situation possible when I sent the document through as a single PDF?
- Having to assist the NDIA in doing its job - just adds to the 'load' of the disabled person in a process that's already been too unnecessarily onerous, confused and lengthy by this point.

The impact of this – creates confusion and further mental work for the applicant and adds to the burden of applying, even more so for those with cognitive impairments. It is also stressful, because for example, if I receive a blank email – I will wonder, was it supposed to contain something important? Or if the assessor thought that my report wasn't dated, did he discount it – or give it less weight?

8. The process of “attempting to contact people” by telephone

- In my access request rejection letter, the assessor stated: “I attempted to contact you to discuss this decision, but I was unable to reach you.”
- My application letter clearly states that I’m not able to use the telephone and that I request my correspondence in writing. This was ignored. Does this mean I missed out on receiving detailed information regarding the decision? I will never know.
- According to members in the ME community the NDIA routinely does this. Clearly unacceptable from a government body that deals specifically with disabled people.

Potential Solutions

- Have a primer/guideline on ME/CFS and other health-based disabilities so that assessors and LACs don’t simply do ‘internet research’ (or however they get the wrong information) and provide incorrect answers/access request denials based on that.
- Direct health-based disabilities to specialist staff in the first instance so that we don’t get guaranteed rejections and then have to ‘fight’ to escalate the issue to the Technical Advisory Board ourselves.
- Provide further information as to why an access request was not met as opposed to template letters that don’t provide the participant with any level of detail to improve their access request when requesting a review. This wastes everyone’s time and resources – including the NDIA’s.
- Commit to hiring competent professionals with basic spelling and administrative skills and training them adequately. Make them subject to performance reviews based on the quality of their work, which should benefit the public and not create unnecessary confusion and add to the cognitive load of disabled people in the access request process.

I appreciate your time in considering my submission,