

**Submission
No 171**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Ms Miriam de Vries

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Dear Committee Members,

Please accept below my submission to the Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.

Regards,
Miriam de Vries

The NDIS application process isn't flexible enough to accept clients who clearly are disabled and need help but don't fit into their specific categories.

I have had ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) since 2006. This is a poorly understood illness involving the immune and nervous systems and severely impacting the ability of my mitochondria to produce energy for my cells. For me it causes extreme exhaustion that is not relieved by rest, muscle pain, major cognitive defects, tinnitus, temperature regulation issues, postural orthostatic tachycardia syndrome (POTS), bladder incontinence, and a very poorly controlled immune system (I either over- or under-react to any disease going past).

I recently had to resign my job, since it was just too exhausting to continue, and spend 20+ hours per day in bed. I personally fund home help for 3-4 hours per week, and an electric wheelchair when I go out, although I'm unsure how I'll continue to fund these needs now I'm no longer working. My limitations have been recognised by Centrelink and the NSW RMS, who provide me with a mobility allowance, health care card, and a disabled parking permit.

The severity of the symptoms of this disease have been researched to be far worse than most other chronic illnesses <https://www.healthrising.org/blog/2015/08/05/chronic-fatigue-syndrome-worse-multiple-sclerosis-cancer/> - indeed my 82 year old mum had more energy than I did, almost right up until her death from emphysema.

I self-administered the WHODAS 36 item complex scoring that the NDIS uses (once accepted into the scheme) to determine how much help you need, and scored an overall 48.96%, with some domain scores up as high as 84.38%. My scores make it clear that I'm significantly disabled in many ways and once admitted to the NDIS would be eligible for considerable support.

My doctors agree that my condition has been largely unchanged in the last 10 years.

And yet despite the above I'd be very unlikely to be accepted for the NDIS. I personally have not (yet) applied, but I've watched my fellow patients, many of whom are more disabled than I am, try and fail to be accepted, even on appeal, unless they have some co-existing illness that is in itself severe enough to allow for support.

The NDIS is sticking closely to its definition of clients needing to be fully treated and stable, as defined by specialists, not GPs. On the face of it, this is reasonable, and there certainly should be controls ensuring that only people who really need it has access.

However there are patients like us who fall between the cracks. ME/CFS has historically been a difficult to define disease, because most if not all currently available tests come back normal. Patients generally look healthy. Our test results look healthy. And yet we claim to be ill and unable to function. So we're often accused of malingering, or that our disease is psychosomatic. Indeed,

our one major recommended treatment protocol (see PACE trial mentioned below) is based on that idea.

We don't fit neatly into one speciality, and are therefore shunted from one specialist to another, in an attempt to treat various symptoms. Personally I've seen a psychologist, a rheumatologist, a gynaecologist, an optometrist and a cardiologist, none of whom found much that they could treat even within their speciality since I don't react "normally" to their treatments, although all did agree that I was clearly physically unwell. Fellow patients also see gastroenterologists, endocrinologists and pain specialists. But none of these specialists can deal with all our issues, and none are prepared to sign off that we're "fully treated and stable" because they don't cover the whole disease.

Historically research funding has been ludicrously low over the years compared to other diseases (<http://www.oatext.com/Estimating-the-disease-burden-of-MECFS-in-the-United-States-and-its-relation-to-research-funding.php#Article>), and as a result there is no commercially available test for us to confirm our diagnosis, although there have been strides made in this direction just recently <https://app.secure.griffith.edu.au/news/2016/03/01/screening-test-for-chronic-fatigue-syndrome-on-its-way/>.

There is also only one recommended treatment (as promoted on the RACGP website) <https://www.racgp.org.au/your-practice/guidelines/handi/interventions/other/graded-exercise-therapy-for-chronic-fatigue-syndrome/> which has been exploded in recent years as being based on faulty statistics <https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/>. I and many of my fellow patients refuse to undertake this "treatment" since it's been shown to make this illness much more severe – which aligns with my own experience any time I've tried to exercise a little, or even just do a few more daily activities, I'm back on full bedrest, sometimes for weeks.

So the NDIS requires us to be fully treated and stable. Both my general GP and my integrative GP who specialises in CFS agree that this is indeed the case. Yet I cannot "prove" this to the satisfaction of the NDIS because there is no specialist to deal with my illness, there's been insufficient research to establish which speciality should treat us, to find a test to confirm the diagnosis, or any useful treatment protocol.

The NDIS vision statement (as per their website) is: **Optimising social and economic independence and full participation for people with disability.** I clearly fit into that category, as do many of my fellow ME/CFS patients, and need help. Why are we being excluded from receiving support by an overly bureaucratic process that is applying rules that are too strict for our specific case?