

ME/CFS: and the disability hurdle

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Conflict of Interests

The author declares his conflicts as follows:

- * Chair – ME/CFS Australia Ltd
- * President – FNC ME/CFS Assoc.
- * Member of various advocacy groups
 - * Person with ME/CFS



Identifying the Problem

- A review of the AAT caselaw reveals no cases have been decided with respect to ME/CFS presently;
- The current grey-literature evidence identifies that ME/CFS applicants are not succeeding in their claims ((ME/CFS Legal Resources, 2017; Reilly & Buchanan, 2018; Emerge, 2018a; Hutchinson, 2018; Ludlam, 2018).

Type of Literature?

- Review of Literature databases – no literature on NDIS and ME/CFS (ME or CFS);
- Review of NDIS framework:
 - Legislation;
 - Rules;
 - Guidelines;
 - Case Law;
- Direct correspondence from NDIS and Ministers;
- Review of Grey Literature (Google, Bing, Google Scholar) inclusive of
 - Commentary;
 - Parliamentary submissions from ME/CFS patients, interest groups, advocates, organisations;
 - Hansard;
 - Popular Media (Television, Newspaper, Other);
 - Correspondence of Ministers;
 - NDIA correspondence.

What is the NDIS?

- The National Disability Insurance Scheme ('NDIS') is a social insurance scheme created by *National Disability Insurance Scheme Act 2013 (Cth)* ('NDIS Act');
- NDIS is the Commonwealth's response to disability sector's call for the creation a new mechanism of funding support for disability (Buckmaster, 2014);
- Rudd Labor Government requested the Productivity Commission investigate new approaches, including a social insurance model of long term disability care and support;
- The Productivity Commission (2011) found:

The current disability support system is underfunded, unfair, fragmented and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in community. (at p. 2)

- NDIS was proposed to support some 410,000 people with significant and ongoing disability with long-term care and support (Buckmaster, 2014);
- National Disability Insurance Agency (NDIA) was created to administer the NDIS;
- Gillard Labor Government rolled out the program via pilot sites and now, with funding agreements from the States, Liberal National Government has fully rolled it out.

What is the Purpose of the NDIS?

- The NDIS (2017) claim it is designed to:

*... support a better life for hundreds of thousands of Australians with a **significant and permanent disability** and their families and carers. The NDIS will mean peace of mind for every Australian - **for anyone who has, or might acquire, a disability.***

- The NDIS assist people with a disability by providing supports to “participate in and contribute to social and economic life to the extent of their disability” (Section 4(2), *NDIS Act*).
- Reasonable and necessary supports should:
 - a. Support people with disability to pursue their goals and maximise their independence,
 - b. Support people with disability to live independently and to be included in the community as fully participating citizens, and
 - c. Develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment. (Section 4(11), *NDIS Act*);
- Plans are individualised, directed by the participant, consider family, carers and significant others.
- Aims to build capacity to increase participation and inclusion in community with the aim of achieving individual aspirations.

What is the Criteria for Access?

- There are two main pathways to access the scheme – via Disability requirements of Section 24, or the early intervention requirements of section 25 of the *NDIS Act*.
- Section 24 requires that:
 - the claimant's disability is attributable to one or more **intellectual, cognitive, neurological, sensory or physical impairments** or to one or more impairments attributable to a psychiatric condition (S. 24(a)); and
 - the **impairment or impairments are, or are likely to be, permanent** (S. 24(b)); and
 - the impairment or impairments result in **substantially reduced functional capacity to undertake, or psychosocial functioning** in undertaking, **one or more** of the following activities; communication; social interaction; learning; mobility; self care; self management (S. 24(c)); and
 - the impairment or impairments **affect the person's capacity for social and economic participation** (S. 24(d)); and
 - the person is **likely to require support** under the national disability insurance scheme for the person's **lifetime** (S. 24(e)).
- 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** (S. 24(2)).

What is the Criteria for Access? (cont'd)

- The second pathway is the early intervention's under Section 25, and its key components are that:
 - Impairment(s) are, or are likely to be **permanent**; and
 - Supports likely benefit the person by reducing future support needs for the disability;
 - Early intervention supports likely benefits the person by:
 - Reducing the person's future needs for supports in relation to the disability; and
 - Mitigate or alleviate impact of impairment on functional capacity; or
 - Prevent deterioration of such functional capacity; or
 - Strengthens sustainability of informal supports, including carer capacity building; and
 - Degenerative conditions can potentially meet requirements.
 - The NDIA can reject early intervention if it believes support is more appropriately funded or provided through **other general systems** of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered (eg Medicare, Public Health System).

Other Considerations

- Accompanying the legislative framework are:
 - *National Disability Insurance Scheme (Becoming a Participant) Rules 2016 (Cth) ('the Rules');*
 - *Explanatory Statement to Becoming a Participant Rules 2014 ('Explanatory Statement');*
 - *Operational Guidelines of the National Disability Insurance Agency ('Operational Guidelines').*
- NDIS Case Law from the Administrative Appeals Tribunal, Federal Court or High Court.
- Significant Cases:
 - *Mulligan and NDIA* [2014] AATA 374 per Toohey and McCallum not disability is not defined:

A person may have a disability without necessarily meeting all, or even any, of the disability requirements in s 24(1)(b), (c), (d) and (e). For example, a person might have a temporary disability, or a permanent disability that has only minimal effect on functioning, or no effect on his or her social or economic participation. The fact that s 13(1) states that the NDIA may provide support to people with disability who are not participants tends to support this view.
 - *Fear by his mother Vanda Fear and NDIA* [2015] AATA 706 at [51], affirmed the scope of the term 'disability' stating:

...there may be little obvious distinction between disability and chronic illness or medical conditions.

Other Considerations (cont'd)

- The NDIS takes a “functional definition of disability” and is based on Article 1 of the 2008 *United Nations Convention on the Rights of Persons with Disabilities*.
- The *Explanatory Statement*, however, focuses on disability being a loss of ability to perform an activity that results in impairment – that being “results in a substantially reduced functional capacity” (*Mulligan v NDIS* [2014]).
- In *Mulligan v National Disability Insurance Agency* [2015] FCA 544, [17]-[18] per Mortimer J affirmed that:

the NDIS was not intended to provide funded supports (as opposed to general supports) for every person with a disability” hence it is “intended to cover a subset of those affected by disability

- *Mortimer J affirmed his view at [56], stating*

*That being the case, **no arbitrary limits are placed on access to the NDIS**. No decision-maker need be satisfied a person’s impairment is “serious”, or more serious than another person’s. No qualitative judgments in that sense are called for. Rather, the legislative scheme is **based on a functional, practical assessment of what a person can and cannot do**. Critically, the scheme makes detailed provision for that assessment, and it is sufficient for a person to have **substantially reduced functional capacity in relation to one activity**. That, in my opinion, recognises the spectrum of impairments which can be experienced by persons with disabilities, and accommodates different abilities within one person in terms of her or his daily activities. **That is why a detailed functional assessment is so important.***

What Does Permanent Mean?

- Rule 5.4 of the *Rules* states that an impairment:

*... is, or is 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**.*

- In *Mulligan v NDIA* [2014], the AAT echoed the substance of Rule 5.4, stating that it:

*... provides that an impairment is, or is 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 it**.*

What is the Minister's Position on ME/CFS?

- Dan Tehan, Commonwealth Minister for Social Services, advised Tanya Davies (MP) on 3 July 2018 that:

*The [NDIA] ... is currently consulting with **Specialist Practitioners** in the ME/CFS field to obtain **accurate and up to date information** relating to **current research and best practice** in the field of ME/CFS. This information is being used to inform consistent and current practices within the NDIA*

*When reviewing ME and CFS, available research indicates that **due to the natural progress of the condition a majority of individuals recover without intervention**. for example, on Australian study followed 253 patients diagnoses with chronic fatigue, and found that only approximately 11 per cent continued to meet diagnostic criteria at six months.*

*The NDIA **cannot consider that every person diagnosed with ME or CFS will go on to have permanent and lifelong impairment**, and therefore it would not be accurate or appropriate to include ME or CFS on List B.*

- **Key points** - The four key points are that the Minister (briefed by the NDIA):
 - believes **multiple specialist practitioners** are being consulted;
 - believes that the NDIA is relying on **current, accurate research and best practice**;
 - **misconstrues** the findings of 2006 Dubbo study (Hickie, et al, 2016);
 - **equates** ME and CFS to **mere “chronic fatigue” including fatigue of less than 6 months duration**.

What is NDIA's Position on ME/CFS?

- On 21 June 2018, Ms. Christine Faulkner, General Manager, Operations, NDIS, when responding on behalf of the Minister, Dan Tehan, to a patient advocate inquiry, states:

*The current understanding of the NDIA is that while the Centres for Disease Control and Prevention (CDC) ...**no longer recommends graded exercise therapy for CFS**, this is due to the CDC regarding that there was **insufficient evidence available to confirm it was beneficial**, not that it was proven to be **ineffective**. By contrast, a comparable agency in the UK, the National Institute of Health and Care Excellence, **recommends graded exercise therapy**, as do the current Australian Clinical Practice Guidelines.*

- Ms. Faulkner repeats the points made by Mr. Tehan, that:
 - The NDIA is consulting with multiple specialist practitioners;
 - Has obtained “accurate and up to date information relating to current research and best practice”;
 - ME/CFS is not a list B condition and that:

*... available research indicates that due to the **natural progression of the condition a great majority of individuals recover without intervention**. it cannot be considered that every person diagnosed with ME or CFS will go on to have a permanent and lifelong impairment, and therefore **it would not be accurate or appropriate to include ME or CFS on List B**.*

What is NDIA's Position on ME/CFS? (cont'd)

- On 15 August 2018, Ms. Kate Argus, Director A/g, Advisory Team, Technical Advisory and Complaints Branch, National Office, NDIA, when responding to a peak patient organisation. Ms Argus confirms:
 - that “the NDIS **does not have any policy/guidelines**” for ME/CFS on NDIS applications;
 - that contrary to previous representations, only Professor Andrew Lloyd was advising the NDIS - “because of [his] credentials and experience”:

*Prof Lloyd has advised that there is **conflicting evidence regarding permanency** of ME/Chronic Fatigue Syndrome Information indicates that **MANY INDIVIDUALS RECOVER without intervention over weeks to months**, but approximately **10% will meet diagnostic criteria for ME/chronic fatigue syndrome at six months**. Of these, **a small subset may go on to suffer from both severely disabling and very prolonged (greater than 5 years) ME/chronic fatigue syndrome – these patients may be housebound or even bed-bound** as a result of the illness and despite best available evidence-based management.*

- Ms. Argus addresses permanency, stating when it will be considered:

*Information received by Prof. Andrew Lloyd indicates when the ME/chronic fatigue syndrome has been present in a **stable, non-improving pattern, despite evidence-based management** (such as ... CBT, ... GET and cognitive remediation) **for 5 years**, the Australian expert guidelines indicate that the condition should be regarded as permanent for medico-legal purposes.*

What is NDIA's Position on ME/CFS? (cont'd)

- Ms. Argus states with respect to CBT and GET, that her advice was that:

*The current understanding of the NDIA is that while the Centres for Disease Control and Prevention (CDC) ...**no longer recommends graded exercise therapy for CFS**, this is due to the CDC regarding that there was **insufficient evidence available to confirm it was beneficial**, not that it was proven to be **ineffective**. By contrast, a comparable agency in the UK, the National Institute of Health and Care Excellence, **recommends graded exercise therapy**, as do the current Australian Clinical Practice Guidelines.*

- Ms. Argus concluded that Professor Lloyd further provided advice on:

... The aetiology of ME/CFS, medical and allied health specialities involved in diagnosis and treatment, treatment options clinically indicated for the condition, likelihood of permanency, and prevalence of being diagnosed as a stand-alone condition as opposed to being diagnosed as part of a co-morbidity. He has further provided information regarding the evidence and research regarding ... GET and ... CBT.

What is the Evidence Base?

- Ms. Argus provided the references from Professor Lloyd;
 - 19 papers referenced;
 - 8 recent papers were from 2015 to 2017;
 - Criteria include - 1994 CDC Criteria, 2003 ME/CFS Criteria, 2011 ICC Criteria and 2015 P2P ;
 - 2006 Dubbo Study included;
 - 2017 Cochrane review of exercise therapy (recently criticised by Vink and Vink-Neise, (2018)).
- Observations of Evidence Base:
 - There is no rigour and very limited diversity in the scope of the evidence base;
 - Only one opinion utilised – Prof. Lloyd’s preference is for CBT/GET hence a biased view;
 - A significant number of review papers relied upon;
 - A significant body of **relevant and current research** has been **omitted** despite the Minister’s assertion that information is “accurate and up to date”;
 - Primarily biopsychosocial rather than pathophysiological research focus;
 - Treatment focus upon CBT and GET – conflicting evidence questions them as ‘best practice’;
 - No deference to United Kingdom’s NICE Guidelines by Lloyd BUT NDIA do defer to it (despite the fact that the criteria is not an internationally accepted criteria diagnosed in Australia).

Misconceptions of NDIA Position?

- The NDIA engages in conflation of terms:
 - The agency refers to chronic fatigue and CFS as though they are one and the same. Chronic Fatigue is a single symptom. CFS includes multiple symptoms (Fukuda et al, 1994);
 - CFS, ME and ME/CFS are all conflated into one term, despite the fact that they have different diagnostic criteria;
 - NICE's CFS/ME as defined under the United Kingdom's NICE Guidelines is not an international criteria, and is not used here in Australia – yet the guideline is relied upon by NDIA;
 - Studies using the **Oxford criteria** for CFS (ie fatigue only) are equated to Fukuda CFS – they are not the same (with Oxford effectively being chronic fatigue only – omitting the additional symptoms).
- The NDIA asserts “chronic fatigue” is referred to in the Dubbo study (Hickie et. Al, 2006):
 - The term ‘chronic fatigue’ is utilised in Dubbo study at all. The term Post-Infective Fatigue is.
- Dubbo Study has been misconstrued:
 - The study examined acute IgM positive Epstein Barr Virus, Q-Fever and Ross River Fever patients;
 - 89% of patients recovered from their fatigue symptoms **before 6 month point (hence no CFS)**;
 - NDIA confuses the “provisional cases of post-infective cases” with CFS (which the study states is “termed here **confirmed ‘post-infective fatigue syndrome’**”) at 6 months (the 11% of participants);
 - This recovered 89% were **never cases of CFS** at any point in the study – they were provisional;
 - The NDIA is clearly in error in their position.

Misconceptions of NDIA Position? (cont'd)

- The NDIA's contention that "many individuals recover without intervention" (hence not permanent) is entirely and overtly erroneous;
 - The assumption is **based on an erroneous understanding of the Dubbo study**;
 - The evidence on 'recovery' is variable, inaccurate, limited and often more accurately described as 'improvement' (Adamowicz, 2014);
 - Recovery research has not been based on objective criteria (Twisk, 2014);
 - There are **no proven, effective treatments** or management that effects recovery or cure (Lloyd, 2018);
 - **Recovery is rare**, and 1 in 5 patients worsen over time (Baraniuk, 2017, p. 53);
 - RACP Guidelines assert "**complete recovery was uncommon (6%)**": (Loblay et al, 2002, p. S41);
 - 2002 Guidelines state - Prognosis "more severe end of clinical spectrum ... for recovery is poor" (Loblay et al, 2002, pp. S41-S42, S 47);
 - 2002 Guidelines state - Patients with CFS for 10 years or more "are more disabled ... and have significantly more severe symptoms (particularly cognitive impairment) ..." (Loblay et al, 2002, pp. S41-S42, S 47);

Misconceptions of NDIA Position? (cont'd)

- The NDIA does not identify that **there are no known or proven cures** for ME/CFS, ME, nor CFS (Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 259; Carruthers, et al., 2003, p. 50; Zinn, et al, 2016a, p. 2; Dantzer, et al, 2014, p. 44; Blease, et al, 2017, p. 553; Green, et al, 2015, p. 861; Centres for Disease Control, 2017; Green et al, 2014, p. 1; Gibson, et al., 2006, p. 8.)
- The NDIA asserts that the 2002 Australian Guidelines are the current accepted guideline:
 - Professor Lloyd was the primary contributor to the construction of the 2002 guidelines and does not appear to have declared an apparent conflict of interest – being a bias with respect to those guidelines;
 - There is **no foundation** for the position that the Australian Guidelines are the current guideline of reference – to the exclusion of all others;
 - The 2003 ME/CFS Guidelines are utilised heavily throughout Australia and are specifically clinical in nature. Emerge (2018b) indicate that 36% are diagnosed with ME/CFS – the term used and criteria set out by Carruthers, et al (2003);
 - Professor Lloyd sits on the NHMRC ME/CFS panel currently;
 - The NHMRC is considering a guidelines revision (which the NDIA acknowledge);
 - The NHMRC panel is deferring to the 2003 ME/CFS Guidelines;

Does ME/CFS meet the NDIS Disability Criteria? (cont'd)

- The List B conditions include Neurological Conditions:
 - ME is classified as a neurological condition by the WHO, and CFS is indexed under ME;
 - ME/CFS, like Multiple Sclerosis ('MS'), is a fluctuating condition of varying severity;
 - List B conditions do not require claimants to establish the condition as a disability;
 - Both are neurological conditions – yet MS is included under List B conditions and not ME/CFS;
 - The NDIS Act specifically caters for conditions that vary in intensity (S. 24(2));
 - There is a strong argument for inclusion on List B.
- The Australian Institute of Health and Welfare's identified the Disability-Adjusted Life Years (DALY) for various conditions, including CFS. In comparison to MS, **the DALY's for CFS are greater at the more severe end**, but higher in the moderate group than early phase MS:

Table 1 - Disability Categories and Weights – CFS v MS (Mathers, 1999: 201)

Disease Category, Subcategory or Sequelae	Weight CFS	Weight MS	Disease Category, Subcategory or Sequelae
Mild Handicap	0.127	0.330	Relapsing-Remitting Phase
Moderate Handicap	0.449	0.670	Progressive Phase
Severe or Profound Handicap	0.760	0.670	End-Stage

Does ME/CFS meet the NDIS Disability Criteria? (Cont'd)

- Clearly on the basis of DALY's, ME/CFS is on par with MS and arguably deserves List B status:
- ME/CFS arguably fulfills the requirements of a disability under Section 24(1) of the NDIS Act on the following grounds:
 - The evidence base demonstrates ME/CFS results in intellectual, neurological, cognitive, sensory, physical impairments, and psychiatric: (S. 24(1)(a):
 - ❖ Intellectual – eg: Carruthers, et al, 2013, p. 15;
 - ❖ Neurological – eg: WHO, 1969; Ferrero, et al, 2017, p. 1; Twisk, 2015, p. 72; Zinn et al, 2016a, pp. 7-8; Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 97; Carruthers et al, 2003, p. 17; Carruthers et al, 2011, pp. 17, 50; Natelson, 2017; Ferrero et al, 2017, pp. 1-2;
 - ❖ Cognitive – eg: Twisk, 2015, p. 72; Carruthers et al, 2003, p. 97; De Luca, et al, 1995, p. 39; DeLuca, et al, 1997, p. 154; Ickmans, et al., 2013, p. 1476; Ickmans, et al., 2015, pp. E843-E844; Nijhof, et al., 2016, pp. 247-250; Zinn et al 2016a; Zinn et al, 2016b; Zinn et al, 2016c;
 - ❖ Sensory – eg: Carruthers et al, pp. 11, 73; Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 78;
 - ❖ Physical – eg: Jason & Richman, 2007, p. 86; Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, 2015, p. 76; Twisk, 2005, pp. 72-74; Blease, et al, 2017, p. 550; Fukuda, et al, 1994;
 - ❖ Psychiatric – eg: Natelson, et al, 2017, 413; Jason, et al, 2007, pp. 86-87; Daniels, et al, 2017, pp. 1, 5; Johnson, et al, 2016, p. 98; Williams, et al, 2016, pp. 5-7; Carruthers, et al, 2003, p. 29.

Does ME/CFS meet the NDIS Disability Criteria? (cont'd)

- The evidence base for ME/CFS holds no study to demonstrate actual recovery (ie ordinary meaning, nor cure) – hence no evidence that establishes that the condition is other **permanent** or **likely to be permanent**: (S. 24(1)(b));
- The evidence base demonstrates that ME/CFS creates **impairments** (communication; social interaction; learning; mobility; self care; self management): (S. 24(1)(c));
- The evidence base demonstrates that ME/CFS impairment or impairments **affect the person's capacity for social and economic participation**: (S. 24(d))
- The evidence base for ME/CFS holds no study to demonstrate that a person would not **likely require support** under the NDIS for their **lifetime**: (S. 24(e));

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