

Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into Independent Assessments

SUBMISSION

ME/CFS Australia Ltd



31 March 2021

Contents

Executive Summary.....	1
Summary of Recommendations.....	2
About ME/CFS Australia.....	1
About ME/CFS.....	1
Our Experience.....	2
Terms of Reference.....	2
Preamble.....	3
Scheme Ethos.....	3
Issues Inherent to ME/CFS.....	3
Submissions.....	4
Reasons for Introduction of Independent Assessments.....	4
Potential Bias.....	5
Inappropriateness of IAs.....	6
Consumer View.....	8
Recommendations.....	8
Impact of IAs in Other Jurisdictions.....	9
Experience of IMEs.....	9
The Victorian Workers Compensation Experience.....	9
ME/CFS Australia’s Concerns.....	12
Consumer View.....	14
Recommendations.....	15
Human and Financial Resources.....	15
Appropriately Qualified Person.....	15
Historical Challenges.....	16
Human Resources.....	18
Funding.....	20
Tune Review.....	22
Consumer View.....	22
Recommendations.....	23
Assessor Requirements.....	23
Limitations of the Independent Assessors.....	24
Options.....	24
Independence.....	24

Qualifications	25
Training	25
Expertise.....	25
Quality Assurance	25
Consumer View	27
Recommendations	27
Appropriateness of Assessment Tools.....	27
Inappropriate Tools.....	27
Perception of Others.....	29
Illustrating the Issue.....	30
Individual Patient Needs	31
Consumer View	32
Recommendations	32
Implications for Access and Eligibility	33
Implications for Access	33
Implications for Eligibility.....	33
ME/CFS Australia’s Concerns	41
Potential Beneficial Application	42
Consumer View	43
Recommendations	43
Implications for Planning	44
Deficient Plans	44
Weighting of Evidence	45
Consumer View	45
Recommendations	46
Review and Challenges to Outcomes.....	46
Fairness	46
Appeal Mechanism	47
Funding the Process.....	47
Reviewable Decisions.....	48
False Economies.....	48
Consumer View	49
Recommendations	50
Appropriateness for Particular Disability Cohorts	50

ME/CFS Australia’s Position	50
Optional Use	50
Recommendations	51
Appropriateness for Particular Disability Types.....	51
Recommendations	51
Any Other Matters	52
Assessment Duration	52
Physical Issues	52
Neurocognitive Issues	52
Opt Out Option	53
Recommendations	54
Homebound/Bedbound	54
Recommendations	54
Adverse Reports	54
Recommendations	57
Assessment Fatigue	57
Recommendations	59
Budgeting	59
Recommendations	59
Funding For AAT	59
Recommendations	60

Executive Summary

It is well established that the legislatively mandated objects and principles of the National Disability Insurance Scheme (NDIS) are centred on providing participants with choice, control, independence and opportunity.

It is the position of ME/CFS Australia that the proposed Independent Assessment concept is inconsistent to achieving these objects and principles and the intention of the scheme.

ME/CFS Australia's main points are:

- Independent Assessments are not, at their core, independent;
- The system of Independent Assessments is open to the inappropriate management of applicants and participants to their detriment;
- The knowledge base with respect to ME/CFS among the medical and health practitioners across Australia is poor to non-existent, hence Independent Assessments are unlikely to be performed by appropriately qualified people who have the knowledge and experience to do so appropriately;
- The use of certain standardised assessments with ME/CFS will not provide an accurate or valid assessment because of the inherent nature of the impairments and delayed onset of post-exertional symptoms;
- The use of optional independent assessments by appropriately qualified persons could allow some with ME/CFS to have assessments where no other option exists.

We therefore submit that the current intended implementation of independent assessments should be set aside. ME/CFS Australia has enclosed 32 key recommendations below and relies upon those submissions.

Kind regards



Geoffrey Hallmann *BBus(Hons), LLB(Hons), DipLegPrac, DipFinPlan*
Chair - ME/CFS Australia



ME/CFS Australia Ltd

ABN: 23 088 896 299
ACN: 088 896 299
Ph: 0414 014 365 (Chair)

Postal: PO Box 6176, Upper Mount Gravatt QLD 4122
Registered Office: 13 Forestoak Way Goonellabah NSW 2480
Email: info@mecfs.org.au Website: www.mecfs.org.au

Summary of Recommendations

ME/CFS Australia make the following recommendations:

- (1) **Recommendation 1** – The NDIA and DSS engage with people with a disability and associated stakeholders to collaboratively design the NDIS reforms;
- (2) **Recommendation 2** – IAs should be an option available for those seeking access to the NDIS. IAs should not be compulsory;
- (3) **Recommendation 3** – NDIS or Medicare funded access to treating or self-nominated health practitioners should be made available to allow an individual sufficient funding to access an appropriate assessment or assessments and report(s) for the purposes of an access request;
- (4) **Recommendation 4** – The NDIA and DSS, in consultation with the peak body and associated ME/CFS entities, work towards the appointment of appropriate assessors and an appropriate co-designed training program for such assessors for IA purposes;
- (5) **Recommendation 5** – The NDIS has presented no investigation of the process of using IAs. The NDIS have not taking into account any adverse use of IAs. One pilot study has yet to complete. The NDIS needs to conduct an independent assessment of the recipients of IAs, especially across complex conditions, especially ME/CFS, and obtain feedback on the quality of the assessments/reports.
- (6) **Recommendation 6** – For the purposes of transparency, accuracy, and accountability, all IAs should be recorded, with a copy being provided to all the parties involved;
- (7) **Recommendation 7** – For the purposes of transparency, the NDIS should make all policies and guidelines that are provided to, and communications with, assessors for the assessment, available to all the parties involved;
- (8) **Recommendation 8** – For the purposes of accountability and the integrity of the scheme, the NDIS should provide a formal complaints process, with oversight by the AAT, to allow those subjected to an IA, to bring forth genuine complaints, with the expectation of genuine investigation and outcomes;

- (9) **Recommendation 9** – The NDIS and DSS should collaborate with people with ME/CFS, the peak body and relevant stakeholders to establish the expertise required to conduct an IA of ME/CFS;
- (10) **Recommendation 10** – Practitioners should have specific expertise in ME/CFS and have sufficient knowledge of the individual’s impairments;
- (11) **Recommendation 11** – Assessors should be required to undergo rigorous ME/CFS specific training for accreditation and reaccreditation, including adopting a trauma-informed approach;
- (12) **Recommendation 12** – Assessors should conduct themselves in a manner that accounts for the personal circumstances of the person with ME/CFS, including geographic location, illness severity, communication ability, ethnicity, cultural background, gender, age and other issues;
- (13) **Recommendation 13** – Recommendations 9 to 11 are reaffirmed;
- (14) **Recommendation 14** – The NDIS should have a rigorous complaints mechanism that is transparent and allows for an appeal to the AAT, with the option of rehearing;
- (15) **Recommendation 15** – The NDIS should implement multiple safeguards in place before the IA’s are introduced to oversee the quality and rigour of IA’s;
- (16) **Recommendation 16** – The use of instruments should not be applied on a uniform basis. Validated instruments for certain diagnosed conditions may be suitable. In ME/CFS, consultation with the peak body should be conducted to establish validated instruments, if any, that might be appropriate;
- (17) **Recommendation 17** – The weight of evidence demonstrates that the NDIA should remove ME/CFS from their list of conditions that have “clinical, medical or other treatments that would likely reduce or eliminate” the functional impact of ME/CFS.
- (18) **Recommendation 18** – There is a place for an optional assessment with an ME/CFS competent IA with a genuinely knowledge of ME/CFS, who clinically and scientifically understands the condition (and its many nuances), has proper guidance on the condition, and is able to provide a genuine and properly constructed assessment.

- (19) **Recommendation 19** – The use of an IA that works on a standardised approach will not meet the support needs of people with ME/CFS. The process should remain individualised.
- (20) **Recommendation 20** – The NDIA should accord weight to the evidence of the participants' treating practitioners ahead of the IA, in the absence of there be an exceptional reason to do so.
- (21) **Recommendation 21** – ME/CFS Australia recommends that there be an appeals system available to people so that they can dispute an IA.
- (22) **Recommendation 22** – ME/CFS Australia recommends that there be funding available for people to appeal both tiers of the AAT.
- (23) **Recommendation 23** – The fact that ME/CFS is accompanied by multiple disabilities means that the use of inappropriately qualified persons to conduct IA's will lead to the overlooking of such disabilities.
- (24) **Recommendation 24** – The fact that ME/CFS is accompanied by multiple disabilities means that the use of inappropriately qualified persons to conduct IA's will lead to the overlooking of such disabilities.
- (25) **Recommendation 25** – The vulnerability of people who have ME/CFS and the high risk that IAs represent to their health, should be justification for allowing such persons to opt out of participating in an IA.
- (26) **Recommendation 26** – Given the existence of persons who are housebound or bedbound with ME/CFS, they should be given the option to opt out of the IAs to protect their health, or to opt in provided an appropriately qualified person is available with knowledge and experience of ME/CFS, who will visit the residence and allow for individual sensitivities.
- (27) **Recommendation 27** – ME/CFS Australia recommends as a matter of fairness, that the NDIA provide adverse IA reports to applicant's/participants so that they have the ability to respond with evidence and have that response considered in the final decision.
- (28) **Recommendation 28** – ME/CFS recommends that funding be provided to applicants/participants to provide a report in response to an adverse IA.

- (29) **Recommendation 29** – Recommendation 29 – ME/CFS Australia submits that LAC"s should not be permitted to arbitrarily and capriciously report changes in circumstances without corroborating evidence from a treating health professional.
- (30) **Recommendation 30** – ME/CFS Australia submits that any LAC or other report of an alleged change in circumstances should be a matter that can be subject to internal and external review.
- (31) **Recommendation 31** – ME/CFS Australia recommend that plans remain centred around the individual needs of the participant and not be determined by way of a fixed budget.
- (32) **Recommendation 32** – ME/CFS Australia recommend that the Government should allow legal aid funding for disputes in the AAT in Tier 1 and Tier 2 disputes.

About ME/CFS Australia

ME/CFS Australia is the peak body representing all people in Australia living with or affected by ME/CFS. One of our key goals is to influence national healthcare decision makers to improve the care, disability services and treatment of people with ME/CFS.

Our members are ME/CFS organisations in Australia, primarily comprising the state ME/CFS organisations.

Every state and territory ME/CFS association has a director seat on the board open to them to participate in the decision-making of the national body. ME/CFS Australia works with these organisations in moving the national agenda forward.

ME/CFS Australia Ltd is a not-for-profit organisation, a registered charity and has Deductible Gift Recipient (DGR) status. We were formally incorporated in 1999.

Our current member organisations are as follows.

- ME/CFS & FM Association NSW, Inc. – state member organisation for New South Wales
- ME/CFS/FM Support Association Qld, Inc. – state member organisation for Queensland
- ME/CFS South Australia, Inc. – state member organisation for South Australia
- ME/CFS and Lyme Association of WA, Inc. – state member organisation for Western Australia
- Bridges & Pathways Institute – located in South Australia
- Far North Coast ME/CFS Association – located in New South Wales

About ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ('ME/CFS') is a severe, complex, acquired illness with numerous symptoms related mainly to the dysfunction of the brain, gastro-intestinal, immune, endocrine and cardiac systems. ME has been classified as a neurological disorder in the World Health Organisation's International Classification of Diseases since 1969 (ICD 10 G93.3).

Symptoms include overwhelming post-exertional malaise from mental or physical activity; dysfunctional sleep; pain; neurocognitive dysfunction; problems with memory; visual issues; sensitivity to touch and sound; problems with standing and balance; problems with body temperature and weight; problems with circulation; neurological dysfunction; and recurrent flu-like symptoms;

The condition impacts children and adults.

ME/CFS affects up to 1% of the Australian population. The condition is permanent.

Our Experience

Our organisation and members have received numerous complaints from, and been involved in discussions with, applicants in the NDIS system. There are some distinct patterns of concerns about the approach of the NDIS to ME/CFS during the process of the access request, determination of support and review processes.

We draw upon that experience in providing this submission. We draw upon skills-based knowledge of the system and various investigations into the specifics of the scheme.

Terms of Reference

ME/CFS Australia acknowledge the terms of reference are as follows:

1. The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;
2. The impact of similar policies in other jurisdictions and in the provision of other government services;
3. The human and financial resources needed to effectively implement independent assessments;
4. The independence, qualifications, training, expertise and quality assurance of assessors;
5. The appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;
6. The implications of independent assessments for access to and eligibility for the NDIS;
7. The implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;
8. The circumstances in which a person may not be required to complete an independent assessment;
9. Opportunities to review or challenge the outcomes of independent assessments;
10. The appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander

peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;

11. The appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and
12. Any other related matters

Preamble

Scheme Ethos

ME/CFS Australia understand the NDIS is a social insurance scheme based on the social model of disability. This is reflected in sections 3 and 4 of the *National Disability Insurance Scheme Act 2013* (Cth) ('NDIS Act').

The scheme therefore responds to the needs and goals of the individual. Presently the participant is required to gather the medical and other evidence in order to demonstrate their entitlement to access to the scheme, and to establish the supports that they require to allow them to live their best life.

The NDIA assesses the participant's support needs against the standard of what is 'reasonable and necessary'. The determination of the funding is then determined against the participant's needs to achieve their individual goals.

Issues Inherent to ME/CFS

ME/CFS Australia represents people who have a variety of challenges and symptoms that drive complex needs. This has created inherent barriers to the diagnosis and treatment of ME/CFS and exposed a void of medical knowledge surrounding the condition.

In 2019 the NHMRC ME/CFS Advisory Committee noted:

Patient perspectives are critical to understanding the complexity of ME/CFS and patient interactions with health care services. Patients have, however, described feeling dismissed, negatively stereotyped and stigmatised after attending health care services. This was affirmed by many public consultation submissions. These attitudes can affect patients receiving a timely and accurate diagnosis and effective clinical care. Other barriers to accessing clinical care raised during public consultation included hypersensitivities to light, sound and smell, and difficulty finding

a place to lie down to help manage orthostatic intolerance during a clinical appointment. Housebound, bedbound and rural patients have reported difficulties in accessing healthcare services, further impeding effective care.

Poor clinician-patient interaction can be seen as a form of epistemic injustice in which the patient experience is given little credibility, leading to delayed diagnosis or misdiagnosis and further harm. The IOM reports that approximately 84% of those afflicted with ME/CFS remain undiagnosed and that those diagnosed waited six years or more to receive a diagnosis.

A 2005 UK survey indicated that only half of General Practitioner (GP) respondents believed that ME/CFS was a real condition. These results are similar to those of an Australian survey of GPs conducted in 2000, indicating medical education and training is a key priority in addressing barriers to effective health care.¹

Compounding this issue, the committee further acknowledged ‘the lack of understanding of the condition by National Disability Insurance Agency (NDIA) assessors, and the rejection of claims of people who are significantly impaired’.²

It is submitted that an Independent Assessment system will draw upon a medical and health practitioner base that is known to have a severe deficiency with respect to the ability to recognise, diagnose and manage the condition. Moreover, the knowledge base is so deficient that there are less than 20 specialist physicians and general practitioners in Australia that could profess to have a firm grasp of the full extent of the illness, including the full range of symptoms and comorbid conditions.

In the absence of any intention to accurately and thoroughly train Independent Assessors on the complexities of the condition, there are unlikely to be Independent Examiners who can appropriately evaluate the support needs of the condition for NDIS purposes.

Submissions

Reasons for Introduction of Independent Assessments

The former Minister, the Honourable Mr. Stuart Roberts, MP, has expressed on many occasions that the government’s objectives are to:

¹ Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee, ‘Report to the NHMRC Chief Executive Officer’, NHMRC (Report, 30 April 2019) <<https://www.nhmrc.gov.au/file/14332/download?token=qKIBRFLf>> 12 (‘NHMRC’).

² Ibid.

- ensure that the scheme is financially sustainable³ (despite having recorded surpluses for many years);
- make the scheme ‘simpler, faster and fairer approach for determining a person’s eligibility’;⁴
- conduct assessments using standardised tools.

The joint submission of the DSS and NDIS makes the point that independent assessments (‘IA’) are a solution to ‘reduce the potential for ‘sympathy bias’’⁵ This is a position that has been expressed across multiple statements by the Government across the past decade. It has been stated by the NDIS more recently in a recent review report.⁶ It is a cornerstone to the justification of the introduction of IAs.

Potential Bias

ME/CFS Australia submits “potential” bias is not evidence of actual bias. It is a supposition. There is no evidence base for the assertion. There has been no attempt to assess the existence of this issue within the scheme since 2013.

ME/CFS Australia notes the statement in the paragraphs of the Productivity Commission which immediately follow the ‘sympathy bias’ assertion:

Participants expressed some concerns about the independence of assessors, preferring to have someone with knowledge of the individual undertaking the assessment.

... in my view, taking the assessment process too far away from experts who have the best view of the needs of the person who is living with the disability. *I think it would be wrong to completely remove treating doctors from the assessment process. I would suggest that any assessment should be made **taking careful consideration of the expert advice provided by any treating doctors.** (Paul Petrie-Repar, sub. DR988, p.4)*

³ NDIS ‘ Minister Reveals Plan to Improve NDIS’, NDIS, (News, 14 November 2019)

<<https://www.ndis.gov.au/news/4016-minister-reveals-plan-improve-ndis>>.

⁴ Stuart Robert, ‘Landmark reforms to deliver on the promise of Australia’s National Disability Insurance Scheme (NDIS)’, *Department of Social Security* (Media Release, 28 August 2020)

<<https://ministers.dss.gov.au/media-releases/6156>>.

⁵ Productivity Commission, ‘Disability Care and Support: Productivity Commission Inquiry Report, Volume 1’ (Report No. 54, 31 July 2011), <<https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf>> 327.

⁶ National Disability Insurance Agency, ‘Assessment of Functional Capacity for NDIS – Development and Framework’, *NDIS* (Document, August 2020), <<https://www.ndis.gov.au/media/2640/download>> 7, 26 and 27.

As noted elsewhere in this chapter, while the individual undertaking assessments would be independent, it would be important to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include family members, carers and direct support professionals. Moreover, the assessment process would draw upon existing medical reports.

ME/CFS Australia questions the wisdom of making Independent Assessments based upon potential risk without any empirical data to support its existence in the scheme, particularly when the Productivity Commission itself identified the value of the treating practitioner(s) and their familiarity with their patients.

Below, ME/CFS Australia outlines its submissions with respect to Jurisdiction. Central to those concerns are the experiences of the Victorian Workers Compensation system (an experience we would submit is universal throughout Australia's Workers Compensation schemes and insurance industry).

The Victorian Ombudsman issued reports in 2016 and 2009 that demonstrated the broadscale misuse of IAs by agents to terminate claims, as well as significant assessor bias. This, in our submission, raises more concern, particularly given the access process within the NDIA already represents a check to any potential overstatement issues during the access assessment and the rigorous assessment of support requirements.

As identified above, former Minister Roberts was on the record as having expressed the intention to manage financial sustainability of the scheme using IAs.

Our concern is that independent assessments will be used as a restrictive tool as they have been in various Workers Compensation schemes, to justify the:

- denial of access of applicants to the scheme;
- reduction of plan funding;
- removal of participants from the scheme.

Inappropriateness of IAs

ME/CFS Australia acknowledges that within the ME/CFS cohort, there are individuals who cannot obtain an assessment because:

1. They do not have a current treating specialist or GP because due to various reasons including, but not limited to:

-
- (a) The exceptionally small number of experienced ME/CFS practitioners (particularly knowledgeable specialists);
 - (b) The inability to develop an ongoing relationship with a medical practitioner (e.g. disbelief in the condition, limited knowledge, rotating GPs at clinic, differing home visiting practitioners, unavailability, remote location, etc);
 - (c) Being housebound/bedbound and unable attend medical appointments;
 - (d) Distrust of medical profession after being dismissed/traumatised.
2. They do not have the funds to travel to and/or obtain an assessment and report from an ME/CFS specific medical practitioner with a genuine understanding of the condition.

In limited circumstances, the availability of an option to attend an assessment with a genuinely knowledgeable⁷ ME/CFS practitioner would be appropriate, in order to allow people with no alternative the ability to access the scheme. The *Tune Review* covered this specific issue:

4.38. Notwithstanding this, it may not always be possible to source an appropriate provider, or there may be particular individual circumstances where it is more appropriate for non-NDIA approved providers to undertake the assessments. In addition, functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable.

4.39. Therefore, it is reasonable that the NDIS Act is amended to enable the NDIA to require the provision of a functional capacity assessment by a NDIA-approved provider, but that this power be discretionary. To support this, the NDIA will need to develop clear operational guidelines for decision makers in exercising this discretion.⁸

ME/CFS Australia is, however, of the view that the NDIA's current assessment parameters for ME/CFS are inappropriate and operating on an outdated evidence

⁷ NHMRC (n 1) vi, 15 - ME/CFS Australia makes it clear that "knowledgeable" means more than merely aware of a particular view or ideology. ME/CFS is not a functional disorder. ME/CFS is not a psychological disorder. ME/CFS is a multisystemic biomedical disorder that is diagnosed by way of the criteria recommended by the NHMRC. This is essential to conducting an appropriate evaluation of the whole of the condition as properly understood.

⁸ David Tune, 'Review of the National Disability Insurance Scheme: Removing Red Tape and Implementing the NDIS Participant Service Agreement', *Department of Social Security* (Report, December 2019) <https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf>, 67 ('Tune').

base, particularly with respect to the permanency of the condition. Any assessor engaged for the purposes of an IA would need appropriate training, with such training designed with the input of the peak body.

Consumer View

The process of putting together an access request for the NDIS was a difficult and demanding process – particularly with a disability impacting cognitive function and physical function. My situation is complex. It takes weeks to bring together the documents. It takes months to summarise. Even when that was done, I could not fund the specialist report.

I could not attend personally. I could not fund a local alternative because they don't have the knowledge. I could not fund a neuropsychological assessment of the cognitive function issues. I could not fund an occupational therapist assessment. In short, I was being excluded from even applying because the disability prevented me earning the money that I needed to fund the application process. It was a perpetual catch-22.

Recommendations

Recommendation 1 – The NDIA and DSS engage with people with a disability and associated stakeholders to collaboratively design the NDIS reforms;

Recommendation 2 – IAs should be an option available for those seeking access to the NDIS. IA's should not be compulsory;

Recommendation 3 – NDIS or Medicare funded access to treating or self-nominated health practitioners should be made available to allow an individual sufficient funding to access an appropriate assessment or assessments and report(s) for the purposes of an access request;

Recommendation 4 – The NDIA and DSS, in consultation with the peak body and associated ME/CFS entities, work towards the appointment of appropriate assessors and an appropriate co-designed training program for such assessors for IA purposes;

Impact of IAs in Other Jurisdictions

Experience of IMEs

ME/CFS Australia's experience of Independent Assessments extends into other jurisdictions. ME/CFS results in a multitude of legal issues whereby the condition is reviewed by way of independent assessments. Often such examinations will involve two or more assessors.

This can occur in situations such as:

- Family law disputes (where the other spouse contests to the diagnosis and/or functional limitations in order to avoid meeting the correct spousal entitlements to their partner);
- Estate disputes (where family provision claims can see a person left out of a will because the disbelief of the condition created estrangement or the other beneficiaries contest the entitlement to additional provisions because they disbelieve the extent of disability);
- Insurance claims (such as income protection and TPD, where the insurer sends the claimant to an assessment to review the function and/or disability of the individual in order to establish their entitlement to the claim within the context of specific wording);
- Workers Compensation (whereby the worker is sent an independent assessor by the insurer, and at times, by the Commission itself);
- Disability Support Pensions (whereby Centrelink assess the claimant's disability and assess the impairment in accordance with the relevant tables).

Unfortunately, the general consensus of such 'independent assessments' is that there is an overwhelming misconception of ME/CFS, a disbelief, inappropriate assessment methodologies, and report content not reflective of the actual history or discussions within the consultation. For the majority, the report was adverse and not reflective of the reality of the condition, thereby resulting in a legal contest.

The Victorian Workers Compensation Experience

The NDIS is, by way of its construction, an insurance scheme. The most appropriate comparative is therefore a State-run insurance scheme – Victoria's WorkCover. It is noted that such a scheme is a model litigant and subject to the *Victorian Model Litigant Guidelines*⁹ with respect to its conduct and integrity.

The Guidelines require, among other things:

⁹ Victoria State Government, 'Victorian Model Litigant Guidelines', Justice and Community Safety (Guideline, 5 May 2020) <<https://www.justice.vic.gov.au/justice-system/laws-and-regulation/victorian-model-litigant-guidelines>>.

7. In essence, being a model litigant requires that the State and its agencies, as parties to litigation, act with complete propriety, fairly and in accordance with the highest professional standards. The expectation that the State and its agencies will act as a model litigant has been recognised by the courts...

8. The obligation to act as a model litigant may require more than merely acting honestly and in accordance with the law and court rules. It also goes beyond the requirement for lawyers to act in accordance with their ethical obligations.

An illustration of the issues that can arise were revealed by the Victorian Ombudsman in her 2016 report on WorkCover Victoria.¹⁰ To illustrate, we quote the following:

*Contrary to the key principles [of the Workcover Scheme], my investigation found numerous examples of **agents selectively using evidence to reject or terminate a claim**, while disregarding other available evidence. This occurred even where the weight of evidence in support of the worker's claim was considerable. One former agent employee said that for claims staff, 'it was a matter of just finding something to terminate on'.*

- ***failed to provide crucial background information about injured workers to IMEs** when they were forming their opinion, which agents then relied on to reject or terminate workers' entitlements*
- *requested multiple supplementary reports from IMEs in **an attempt to influence or change their opinion**, which some witnesses described as a 'fishing exercise'*
- ***engaged in 'doctor shopping'** for an IME opinion that would support a rejection or termination of entitlements.*
- *One former agent executive said agents **'tend to send the worker to a whole host of Independent Medical Examiners** until they find a doctor who is prepared to say, "yes this person has work capacity"*
- ***posed leading questions to IMEs** in an attempt to **receive an opinion** that would support a rejection or termination...¹¹*

¹⁰ Deborah Glass, 'Investigation into the management of complex workers compensation claims and WorkSafe oversight', *Victorian Ombudsman* (Report, September 2016)
<<https://assets.ombudsman.vic.gov.au/assets/Reports/Parliamentary-Reports/1-PDF-Report-Files/Investigation-into-the-management-of-complex-workers-compensation-claims-and-WorkSafe-oversight.PDF?mtime=20191218114504>>.

¹¹ Ibid 7.

189. In some cases, the evidence suggested that agents' choice of IMEs may have been **motivated by the opportunity to obtain an opinion from an IME who was considered to hold particular views.**

190. Agent email data shows examples where agents sent injured workers to **certain IMEs** based on a belief that those IMEs were '**good for terminations**'.¹²

195. Witness evidence shows that agents sometimes selectively use IMEs, with the ACCS stating that many matters that go to conciliation **rely 'on a small pool of heavily used IMEs, many of whom are largely removed from current clinical practice'**

196. At interview, a former agent executive said that agents have **preferred lists of IMEs** from whom they are more likely to get a report that would **support a termination or rejection.**

197. At interview, a psychologist who treats injured workers said that agents often send workers to the same IMEs, noting that 'there's a **great incentive** for them [IMEs] **not to have an independent opinion,** so they **get repeat business**'.

198. A worker representative also said they had observed agents **overusing certain IMEs** and suggested that agents should have less control over which IME a worker is sent to.

199. An analysis of the costs paid by each agent to individual IMEs in 2014-15 **confirmed that some IMEs are favoured** and frequently used by particular agents...

200. Evidence indicates that availability is a key consideration in agents' choice of IMEs. As such, some agents have 'block bookings' with specific IMEs. Comments were made at interview by both WorkSafe and agent executives that **agents may 'favour' or frequently use certain IMEs** based on the reliability and quality of their reports.¹³

¹² Ibid 50.

¹³ Ibid 51-52.

A follow up report was conducted at the end of 2019 by the Ombudsman.¹⁴ Despite her first report and alleged reforms, the Ombudsman concluded:

Agents are still unreasonably terminating complex claims: cherry picking evidence, doctor shopping, relying on Independent Medical Examiners (IMEs) over treating doctors even when evidence is unclear, contradictory or inconclusive – or ignoring it if it didn't support termination.

If anything, the evidence strongly suggests that much of the impact of my 2016 report has been to drive these practices underground. Agent staff were told to be careful what they put in writing – in case the Ombudsman sees it. Staff were advised to use words like 'entitlement reviews' in their emails rather than 'termination'.¹⁵

ME/CFS Australia's Concerns

ME/CFS Australia makes the point that within a state-run agency that was created for the benefit of injured workers and required to operate as a model litigant (i.e. with 'complete propriety, fairly and in accordance with the highest possible standards'), the various agent insurers used their right to call for independent assessments to the detriment of claimants by employing it as a method of terminating the claims of vulnerable workers, especially complex claims.

Compounding this issue is the fact that when they were exposed, the agencies continued to flout their model litigation obligations with respect to independent assessments and even sought to hide their behaviour.¹⁶

It is the concern of ME/CFS Australia that given former Minister Robert's expressed intention to ensure the financial sustainability of the scheme, the independent assessment will be utilised as a tool to justify the:

- denial of access of applicants to the scheme;
- reduction of plan funding;
- removal of participants from the scheme.

¹⁴ Deborah Glass, 'WorkSafe 2: Follow-up investigation into the management of complex workers compensation claims', *Victorian Ombudsman* (Report, December 2019) <<https://assets.ombudsman.vic.gov.au/assets/Reports/Parliamentary-Reports/1-PDF-Report-Files/WorkSafe-2-final-report.PDF?mtime=20191216121840>>.

¹⁵ Ibid 4.

¹⁶ Ibid.

The joint submission of the DSS and NDIS makes that point that independent assessments are a solution to ‘reduce the potential for sympathy bias’¹⁷

ME/CFS Australia submits “potential” is not evidence of actual. In contrast, the Victorian Ombudsman’s report demonstrates that the misuse of IAs to terminate claims and the bias of assessors is significant. This, in our submission, raises more concern, particularly given the access process within the NDIA is quite rigorous, accompanied by a rigorous assessment of support requirements.

ME/CFS Australia notes the following paragraphs of the Productivity Commission which very clearly state:

Participants expressed some concerns about the independence of assessors, preferring to have someone with knowledge of the individual undertaking the assessment.

*... **in my view, taking the assessment process too far away from experts who have the best view of the needs of the person who is living with the disability.** I think it would be wrong to completely remove treating doctors from the assessment process. I would suggest that any assessment should be made **taking careful consideration of the expert advice provided by any treating doctors.** (Paul Petrie-Repar, sub. DR988, p.4)*

As noted elsewhere in this chapter, while the individual undertaking assessments would be independent, it would be important to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include family members, carers and direct support professionals. Moreover, the assessment process would draw upon existing medical reports.

ME/CFS like many of the disabled participants are some of the most vulnerable people in the population.

Below ME/CFS Australia makes submissions with respect to the impact of such a system on people who have ME/CFS. Subjecting them to unqualified assessors

¹⁷ Productivity Commission, ‘Disability Care and Support: Productivity Commission Inquiry Report, Volume 1’ (Report No. 54, 31 July 2011), <<https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf>> 327; National Disability Insurance Agency, ‘Assessment of Functional Capacity for NDIS – Development and Framework’, NDIS (Document, August 2020), <<https://www.ndis.gov.au/media/2640/download>> 7)

who are not independent (because of their financial dependence on the repeat business of the NDIS), who do not understand the condition will cause trauma.

Consumer View

I've been involved in a Workers Compensation process for many years. I have been sent to 10 Insurer IME doctors and 4 Insurer Allied Health IMEs, in addition to three insurer IME paper reviews and 10 Approved Medical Specialists for the Workers Compensation Commission. Not one IME found that I was disabled. Only 1 IME had an inkling, with limited experience in CFS. Only two found I had CFS – and they ignored all the other issues. They denied I required treatment, investigations, or management. Most tried to diagnose a psychological issue – which led me having about 6 different diagnoses across the years. All but two AMSs found I have impairment – and those left out most of the issues I have because they rushed me in and out and allowed nothing for memory issues. You couldn't argue against what happened in the appointment because they were presumed to be correct. If I had video, I could have demonstrated what they misconstrued, what they twisted and what they left out.

When the insurer didn't like what my doctors said, they sought out a doctor who would provide an opinion to deny. When I saw what was written, their facts were incorrect (or curated via omissions), gave leading questions and suggestions, and misrepresented key points.

The whole process was a joke. It wasn't independent at any point. The insurer use of IMEs was punitive. It was amazingly dishonest and disgraceful.

Time and time again, they lost in the Commission. Time and time again, they would use another IME to deny the claim. It was systematic and deliberate.

The process cost me health and tens of thousands of dollars. It was unethical and traumatic. In the end they changed the legislation and threw me off anyway.

Recommendations

Recommendation 5 – The NDIS has presented no investigation of the process of using IAs. The NDIS have not taking into account any adverse use of IAs. One pilot study has yet to complete. The NDIS needs to conduct an independent assessment of the recipients of IAs, especially across complex conditions, especially ME/CFS and obtain feedback on the quality of the assessments/reports.

Recommendation 6 – For the purposes of transparency, accuracy, and accountability, all IAs should be recorded, with a copy being provided to all the parties involved;

Recommendation 7 – For the purposes of transparency, the NDIS should make all policies and guidelines that are provided to, and communications with, assessors for the assessment, available to all the parties involved;

Recommendation 8 – For the purposes of accountability and the integrity of the scheme, the NDIS should provide a formal complaints process, with oversight by the AAT, to allow those subject to an IA, to bring forth genuine complaints, with the expectation of genuine investigation and outcomes;

Human and Financial Resources

Appropriately Qualified Person

Section 26 of NDIS Act allows the CEO of the NDIA to refer an applicant to an “appropriately qualified person” for an examination. The same term is used in Section 36 and 50, whenever the CEO requires information to assess the participant for a specific purpose.

The NDIS does not define the term. ME/CFS Australia submit that guidance can be found in the words of Senior Member Fice in *Natoli and Secretary, Department of Social Services (Social Services Second Review)* [2015] AATA 495 at [30]:

*The expression appropriately qualified medical practitioner is a defined term in the Impairment Tables and it means a medical practitioner whose **qualifications and practice are relevant to diagnosing a particular condition.***

When considering the definition from a dictionary perspective the term means:

... a person who has professional qualifications, training, skills or experience relevant to the nominated subject matter and can give authoritative assessment, advice and analysis on performance

*relating to the subject matter using the relevant protocols, standards, methods or literature.*¹⁸

In the context of the NDIS, the requirement for relevant experience to the conditions, and knowledge of the evidence base, forms the basis of the term. ME/CFS Australia submits that ME/CFS, like many of the conditions that come before the NDIS, cannot be assessed by way of a generalist approach. Clinical knowledge and experience are imperatives to properly understanding the functional impairments, circumstances, support needs and nuances of ME/CFS.

Historical Challenges

ME/CFS Australia submits that persons with ME/CFS are some of the most vulnerable in Australian Society and are among some of the most disabled. The problem in Australia, however, is the lack of genuine knowledge of the condition. This knowledge vacuum is derived from a number of factors:

- poor funding of research across nearly four decades in Australia and overseas;
- an absence of training on the condition within Australia's medical schools;
- an absence of professional development of medical practitioners;
- poor quality, long outdated Australian guidelines which are not fit for purpose (due to having failed to take on board consumer input during their creation);
- the adverse influence of flawed and now rescinded overseas policy such as the UK 2007 NICE Guidelines, US CDC Advisory or the UK PACE trial.¹⁹

In recent years, the quality of research has improved significantly. Whilst Australia has made no headway with respect to providing up to date guidelines, the NHMRC ME/CFS Advisory Committee has advised that three criteria be selected for use in Australia.²⁰ The Committee recommended that the NHMRC formulate new guidelines at some point in the future. In 2015, the US released the Institute of Medicine review of the literature and made recommendations for ME/CFS.²¹ The US CDC amended its advice on ME/CFS across 2019 and 2021 to reflect the IOM findings and updated developments in the area, including removing Graded Exercise

¹⁸ Law Insider, 'Appropriately Qualified Person Definition' (Website, 2013-2021)

<<https://www.lawinsider.com/dictionary/appropriately-qualified-person#:~:text=appropriately%20qualified%20person%20means%20a,relevant%20protocols%2C%20standards%2C%20methods%20or>>.

¹⁹ NHMRC (n 1) 6, 10-11

²⁰ Ibid 15.

²¹ Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations and Institute of Medicine, *National Academic Press* (Report, 28 January 2015) 'Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness' <http://www.nap.edu/catalog.php?record_id=19012> ('IOM').

Therapy (GET) and Cognitive Behavioural Therapy (CBT) as treatment recommendations.²²

The UK produced a draft update of the UK NICE Guidelines in late 2020 which reflect more contemporary views on some aspects the condition, particularly acknowledging the poor quality of research with respect to graded exercise and cognitive behavioural therapy. Most relevant to the NDIS, the draft UK 2020 NICE Guideline corrected a long-held misconception by the NDIA that the majority of people recover. The draft states that ME/CFS:

- *varies in long-term outlook from person to person – **although a small proportion of people recover or have a long period of remission**, many will need to adapt to living with ME/CFS*
- *can have a major impact on people's lives, including their daily activities, family and social life, and work or education, so they may need to adjust how they live²³*

Despite these improvements in research and guidance globally, Australia still has inappropriate treatment recommendations being recommended by the RACGP, despite representations from the peak body and other patient organisations, requesting their removal.²⁴

In 2019, the NHMRC ME/CFS Advisory Committee outlined the issues facing people with ME/CFS when interacting with medical and health practitioners:

*A review and meta-synthesis of qualitative studies on ME/CFS patients **identified a disparity in views between patients, clinicians and researchers on the diagnosis and treatment of ME/CFS.***

*Patient perspectives are critical to understanding the complexity of ME/CFS and patient interactions with health care services. Patients have, however, **described feeling dismissed, negatively stereotyped and stigmatised after attending health care services.** This was affirmed by many public consultation submissions. These attitudes can **affect patients receiving a timely and accurate diagnosis and effective***

²² CDC, 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' Centres for Disease Control and Prevention (Website, 2021) <<https://www.cdc.gov/me-cfs/index.html>>.

²³ NICE, 'Guideline: Myalgic Encephalomyelitis (or Ecenphalopathy)/Chronic Fatigue Syndrome Diagnosis and Management: Draft for Consultation" *National Institute for Health and Care Excellence* (Document, November 2020) <<https://www.nice.org.uk/guidance/GID-NG10091/documents/draft-guideline>> 14.

²⁴ RACGP, 'Graded Exercise Therapy; Chronic Fatigue Syndrome', Royal Australian College of General Practitioners (Website, March 2015) <<https://www.racgp.org.au/clinical-resources/clinical-guidelines/handi/handi-interventions/exercise/graded-exercise-therapy-chronic-fatigue-syndrome>>.

clinical care. Other barriers to accessing clinical care raised during public consultation included hypersensitivities to light, sound and smell, and difficulty finding a place to lie down to help manage orthostatic intolerance during a clinical appointment. **Housebound, bedbound and rural patients have reported difficulties in accessing healthcare services, further impeding effective care.**

Poor clinician-patient interaction can be seen as a form of epistemic injustice in which the patient experience is given little credibility, leading to delayed diagnosis or misdiagnosis and further harm. The IOM reports that **approximately 84% of those afflicted with ME/CFS remain undiagnosed and that those diagnosed waited six years or more to receive a diagnosis.**

A 2005 UK survey indicated that only half of General Practitioner (GP) respondents believed that ME/CFS was a real condition. These results are similar to those of an Australian survey of GPs conducted in 2000, indicating **medical education and training is a key priority in addressing barriers to effective health care.** (Footnotes Omitted)²⁵

The net impact of the historical underpinnings of ME/CFS in Australia means that there are many practitioners who do not know, nor understand ME/CFS, many who know the name but not how to address it, too many that still believe this condition does not exist, and a pool of practitioners who have been guided by outdated information to address the condition in a certain way that has been shown to be inappropriate. Only a small number of practitioners (number well less than 50) have what can be described as an up to date, comprehensive understanding of the condition.

ME/CFS Australia submits that these issues have left people with ME/CFS vulnerable to ignorant and even biased practitioners whose opinion will cause detriment.

Human Resources

ME/CFS Australia is of the view that contrary to what the Independent Assessment Toolkit states, the practitioner undertaking an IA cannot be 'disability neutral' when

²⁵ NHMRC (n 1) 12.

undertaking an assessment of ME/CFS.²⁶ The foundation for that assertion is set out in the historical context above.

ME/CFS submits that the human resources required to carry out Independent Assessments for NDIS requires high-level ME/CFS-specific expertise in order to comprehend the extent, nature and needs of the condition, including:

- The significance of the history of onset;
- The significance of the severity of onset;
- The significance of the duration since onset;
- The comorbid conditions that arise with the ME/CFS;
- The triggers, breadth, fluctuations, predictability, intensity and duration of symptoms;
- The biological impact of the condition and scientific foundation for it;
- The impact of activity and the resulting post-exertional consequences, including triggers, onset, symptoms, fluctuation, intensity, predictability, and duration, as well as cumulative impact of activity over a period of time;
- The neurocognitive and memory issues that accompany the condition, including triggers, onset, symptoms, fluctuation, intensity, predictability, and duration, as well as cumulative impact of activity over a period of time;
- The treatment and management options including the inappropriateness of GET and CBT as treatment options;
- The course of the condition, including potential fluctuations, remissions, plateaus, and deterioration that can occur;
- The severity types, including mild, moderate, severe and very severe, comprehension of the spectrum of severity changes that can occur, and existence of housebound and bedbound patients;²⁷
- The relevant currently accepted international criteria for ME/CFS including the multitude of issues and investigations that are relevant;
- Appropriate instruments that can assist in the identification of actual functional impairments;

²⁶ NDIS, 'Independent Assessment Selection of Assessment Tools' *NDIS* (Document, September 2020) <<https://www.ndis.gov.au/media/2683/download>>, 7.

²⁷ B. M. Carruthers, M. I. van de Sande, K. L. DeMeirleir, et al 'Myalgic Encephalomyelitis: International Consensus Criteria' (2011) 270 *Journal of Internal Medicine* 327, 329 ('Carruthers').

- The inappropriateness of Functional Capacity Assessments for ME/CFS because they are “demonstrably false and invalid” with “no support in the scientific literature” with respect to ME/CFS;²⁸
- Understanding how to deal with persons with ME/CFS and their families/advocates, across the spectrum of illness severity, including comprehending that such persons may be unable to communicate or engage in the process at all, or to a limited degree across multiple appointments;
- Other relevant matters.

ME/CFS is a complex, multisystem disorder. It is not a condition that a practitioner can casually ‘wing’ for the purposes of an independent assessment. For those who have a genuine need for the supports that come with access to the NDIS, they deserve a fair and knowledgeable assessment of their condition.

Funding

ME/CFS Australia submits that there has never been any proper funding of this condition. The historical public sector funding of ME/CFS has been exceptionally poor²⁹ and at times, funding has been redirected to ‘chronic fatigue’ projects, when funding was ear-marked for ME/CFS projects. Some non-government funding has flowed into the area.³⁰

To place the issue into context, we direct you to the recent 2020 study of Mirin, Dimmock and Jason which compared the position of ME/CFS in terms of funding relative to other underfunded conditions (see: Figure 1).

This graphic representation of US funding of ME/CFS highlights the degree of the problem relative to other funded conditions. ME/CFS is at the bottom of funding.

MS Australia, the peak body for multiple sclerosis, a similar condition in terms of symptoms, impact and disability, records on their website the various government funding avenues for MS research. On NHMRC funding across the past 10 years, the

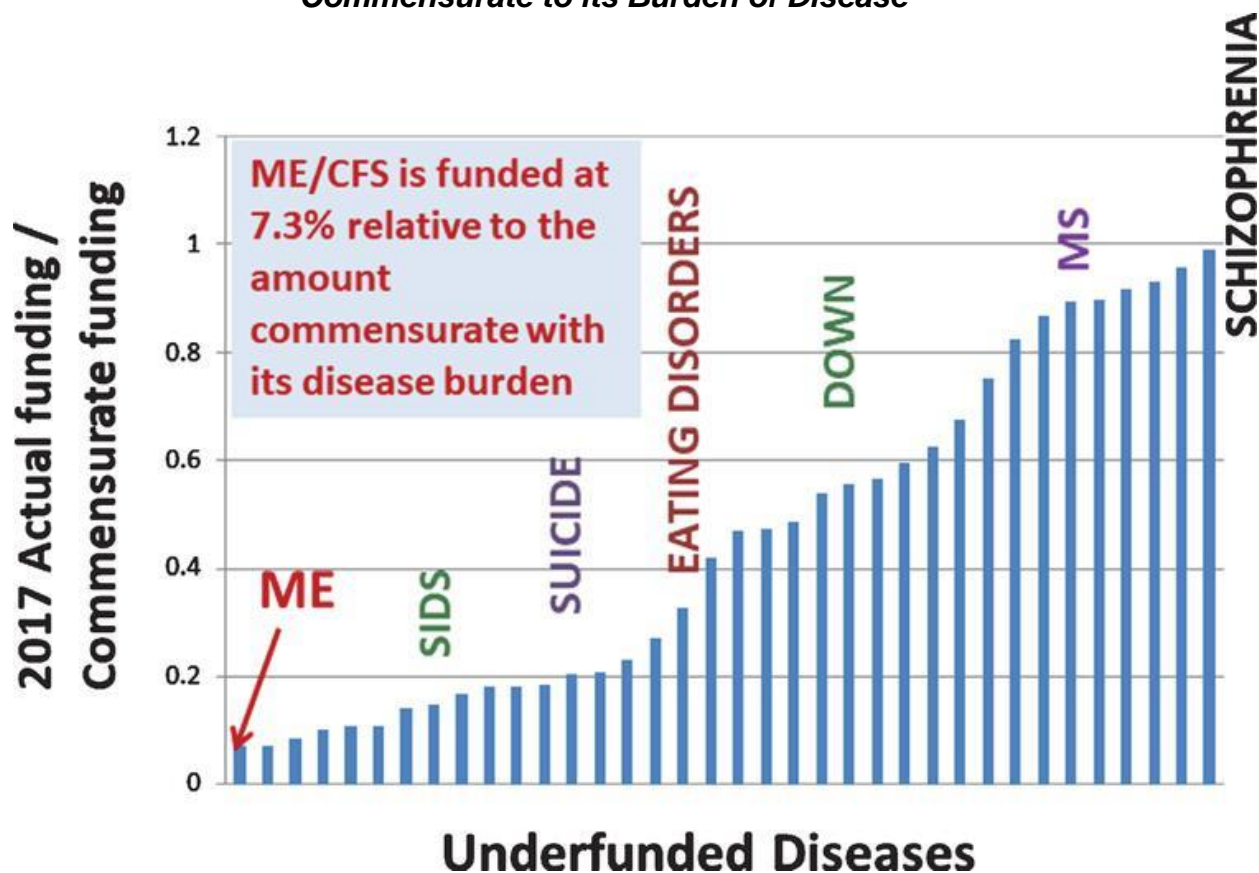
²⁸ Barbara B. Comerford and Richard Podell, ‘Are Functional Capacity Evaluations an Accurate Measure of Work Ability in Chronic Fatigue Syndrome and Fibromyalgia Disability Cases?’ *Tristate Disability* (Article, 2014) <<https://www.tristatedisabilitylaw.com/articles/>> - “*Much of the research on the use of FCE testing has demonstrated that, in many contexts, it is of questionable value, at best. When we limit our focus to the so-called subjective conditions – chronic fatigue syndrome and fibromyalgia, the evidence justifies a much more negative view. For chronic fatigue syndrome and fibromyalgia the FCE is a demonstrably false and invalid test, with no credible support whatsoever in the medical and scientific literature. In short, it is ‘junk science’.*”

²⁹ NHRMC (n 1) v, 2.

³⁰ Ibid 3.

condition received over \$ 40 million to MS researchers.³¹ The NHMRC ME/CFS Committee reported funding just \$ 1.63 million from 2000 to 2019.³²

Figure 1 – US Funding Levels Comparison of Underfunded Conditions Commensurate to its Burden of Disease³³



It is this disparity across all forms of government funding that has contributed to the knowledge vacuum and practitioner ignorance/misconceptions that exist.

It is the submission of ME/CFS Australia that the NDIS would need to co-design education programs for practitioners, in collaborations with persons with ME/CFS and the stakeholders in order to create knowledge within the medical community and within appointed NDIS assessors.

Funding for this task will need to reflect the needs of the condition and the degree of the problem. It will need cover appropriate professional training designers, as well

³¹ MS Australia, 'Government Funders' MS Australia (Website, 2021) <<https://msra.org.au/research-report/funding-avenues/government-funders/#:~:text=The%20Australian%20Government%27s%20Endeavour%20Scholarships,the%20rest%20of%20the%20world.&text=In%20the%20past%20ten%20years,to%20MS%20researchers%20around%20Australia.>>

³² NHRMC (n 1) 2.

³³ Arthur Mirin, Mary E Dimmock and Leonard Jason, 'Special Section: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)' (2020) 66(2) *Work* 277, 280.

as researchers and other staff and the process of bringing together the parties to reach a consensus. Ongoing funding would be needed for monitoring performance of the training and outcomes, in addition to updates.

The funding should also cover:

- The cost of assessments and reports of a person with ME/CFS who elects to use their own treating or appointed practitioners to carry out an assessment and provide a report for the NDIS;
- The cost of in-home assessments for house-bound or bed-bound persons;
- Have flexibility for multiple appointments where persons with ME/CFS can only interact for limited time periods;
- Include telehealth appointments;
- Include remote area coverage;
- Allow for other ME/CFS specific needs.

Tune Review

ME/CFS Australia does note that the *Tune Review* did contemplate a condition such as ME/CFS, where the expertise was lacking. In such circumstances it recommended the following:

*4.38. Notwithstanding this, it may not always be possible to source an appropriate provider, or **there may be particular individual circumstances where it is more appropriate for non-NDIA approved providers to undertake the assessments.** In addition, functional capacity assessments would not always be required, for instance if a participant's functional capacity is stable.³⁴*

Given the specific resource issues facing ME/CFS, an optional IA approach to ME/CFS falls within the contemplation of the recommendations to the NDIA from the *Tune Review*.

Consumer View

I have had ME/CFS for over 25 years.

It took a number of years to obtain a diagnosis and longer to find a GP with any knowledge of the condition. It took 15 years

³⁴ Tune (n 8) 67.

before I found a specialist that had a detailed understanding of the condition and who could investigate it and identify areas that were treatable in order to improve quality of life.

This is a reflection of the fact there is no training out there and a narrative of misconception surrounding the condition.

I have also experienced medical practitioners who do not believe the condition. They can be abusive and damaging. I have been told I have psychological issues, diagnoses with multiple (conflicting) psychiatric conditions simply because they did not believe in ME/CFS. I've had practitioners refuse to see me. I've been neglected and dismissed. I have had significant treatable diagnoses missed because of ignorance and poor attitudes.

Access to the safety net revolves around an accurate diagnosis and a knowledgeable practitioner. Without them, you are left financially devastated.

Recommendations

Recommendation 9 – The NDIS and DSS should collaborate with people with ME/CFS, the peak body and relevant stakeholders to establish the expertise required to conduct an IA of ME/CFS;

Recommendation 10 – Practitioners should have specific expertise in ME/CFS and have sufficient knowledge of their impairments;

Recommendation 11 – Assessors should be required to undergo rigorous ME/CFS specific training for accreditation and reaccreditation, including adopting a trauma-informed approach;

Recommendation 12 – Assessors should conduct themselves in a manner that accounts for the personal circumstances of the person with ME/CFS, including geographic location, illness severity, communication ability, ethnicity, cultural background, gender, age and other issues;

Assessor Requirements

ME/CFS Australia has outlined above the need for an appropriate qualified person to demonstrate independence, qualifications, training, expertise and quality. ME/CFS Australia reiterates that position as follows.

Limitations of the Independent Assessors

ME/CFS Australia submit that in the context of ME/CFS specifically, the approach of independent assessments is counter-intuitive for the following reasons:

- It is well acknowledged that the medical and health fraternity are unaware of the condition, its symptoms, impairments, and needs;
- Many have an attitude that the condition does not exist (which is offensive and scientifically wrong);
- Many of those who have a treating practitioner are likely to have the most knowledgeable person to assist them in their application and to explain their needs;
- Those who lack the knowledge of the condition can be offensive, miss the essential components of the condition, not comprehend the complex nuances, fail to comprehend the broad spectrum of illness severity, and not comprehend the variability (and triggers) that occur throughout a day, week or month;
- Lack the knowledge to apply appropriate measures and instruments to comprehend the impairments of the condition.

Options

ME/CFS Australia is firmly of the view that the individual should have the ability to select their own assessor, whether they are a treating practitioner or otherwise.

Independence

ME/CFS Australia have outlined the issues that have arisen in other jurisdictions with respect to Workers Compensation and IMEs. Wherever an assessor is dependent upon the NDIS for remuneration for the performance of specific tasks, there can be no independence. Moreover, there is room for bias, financial conflicts, inappropriate relationships/familiarities, and collusion.

By giving the participant control over the selection of the assessor, this conflict of interest can be managed. More importantly, there is an opportunity for a full and fair assessment to be conducted.

This is consistent with the objectives of the NDIS.

Qualifications

ME/CFS Australia submits that in terms of the type of health practitioner that meets the definition of an appropriately qualified person, there are certain types of physicians/practitioners that have a strength in their speciality that assist in the assessment of ME/CFS. Occupational Therapists and certain select allied health practitioners can hold value when assessing impairment in an ME/CFS specific manner, using appropriate instruments that assess the actual functional impairments of ME/CFS and not that which a mismatched instrument claims to demonstrate.

Training

Assessors, in order to be an appropriately qualified person, should be required to demonstrate competency and proficiency in the understanding and assessment of ME/CFS.

Sampling of reports could be undertaken to ensure quality control (see below). Where deficiencies arise, additional training could be required in order to retain accreditation. Such training program will require a collaborative approach with the ME/CFS community representatives to construct appropriate programs.

Practitioners attending to ME/CFS persons will need to be trauma-informed, have specific awareness of the issues related to ME/CFS (particularly in terms of avoiding certain behaviours, comments, judgements, body language, deodorants/chemicals, etc) that might trigger the individual.

Expertise

ME/CFS Australia has submitted the degree of expertise required for ME/CFS. This submission demonstrated the historical influences that have caused misconceptions and attitudes that are adverse to the proper and appropriate assessment of ME/CFS.

Any practitioner who is a proponent of GET/CBT or holds views that ME/CFS is a functional disorder, not real, or psychological, would not be appropriate.

Quality Assurance

ME/CFS Australia submits that the NDIA needs to ensure there is a genuine quality assurance program in place, including an internal complaints process for the review of IAs. The NDIA should:

- Note that Independent Assessors operate under the AHPRA or peak body Code of Conduct;

- Have its own enforceable Code of Conduct for Independent Assessors in the same way that NSW Personal Injury Commission has an Approved Medical Specialists Code of Conduct, for example;³⁵
- Consider that the existing complaints mechanism against Independent Assessor are either AHPRA or the Independent Examiner's peak body, and the outcomes of such complaints are more often than not, not acted upon. (Experience with such complaints processes have not yielded outcomes unless the complaints represent a serious breach, or they have a series of similar complaints, hence the process is not effective);
- Include a separate process within the NDIA that handles complaints about alleged Independent Assessor Code of Conduct breaches or other complaints;
- Include a process for assessing an Assessor where multiple complaints are raised against a specific assessor;

Such a process can assist in ensuring there is a genuine integrity to the process and oversee the performance of Independent Assessors in a way that no other Government Agency currently does. The integrity of the NDIS should be paramount and that requires appropriate oversight.

Quality assurance is therefore essential to the maintenance of a fair and appropriate assessment in ME/CFS. Quality Assurance will also require:

- Regular auditing of IAs and of complaint decisions by independent third parties;
- Measurement of applicants' and participants' satisfaction surveys of the assessor, outcomes and IA process;
- A reassessment mechanism where required;
- Transparent public reporting of complaint statistical data;
- Recording of IAs for the purpose of transparency and accountability.

³⁵ Personal Injury Commission, 'Approved Medical Specialist Code of Conduct', *Personal Injury Commission*, (Code, November 2009) <<https://pi.nsw.gov.au/resources/archive/workers-compensation-division/policy/ams-code-of-conduct-november-2009>>.

Consumer View

In the context of workers compensation, I have not been seen by any IMEs who understood the condition for the most, and the rare one that did, had a very narrow understanding of the condition that would cause me detriment.

On two occasions I had permission to record an assessment. When the report was not accurate, I was able to have it corrected. This ensured the accuracy of history, treatments, medications and other significant factors where accuracy was imperative.

On another occasion the IME forgot he was being recorded. When he provided an outline of the conduct of the interview following a complaint, he subsequently made assertions that certain things had happened or did not happen, when the exact opposite was true. The recording demonstrated he was not forthcoming with the true circumstances.

In a situation of power imbalance like that, the IME was presumed to be correct – until I provided a transcript and showed otherwise.

Recommendations

Recommendation 13 – Recommendations 9 to 11 are reaffirmed;

Recommendation 14 – The NDIS should have a rigorous complaints mechanism that is transparent and allows for an appeal to the AAT, with the option of rehearing;

Recommendation 15 – The NDIS should implement multiple safeguards in place before the IAs are introduced to oversee the quality and rigour of IAs;

Appropriateness of Assessment Tools

Inappropriate Tools

ME/CFS Australia submit that the current proposed assessment tools are not sufficient to measure impairment in ME/CFS.

The key issue with respect to ME/CFS are:

- The condition ebbs and wanes, hence the fluctuations are almost never captured by standardised testing;

- The process of testing ME/CFS can require subjecting to person to testing over a prolonged period of time (many hours or even across days), which will often result in exacerbation of the underlying condition (which is traumatic and may not be recoverable);
- ME/CFS involves a number of systems including:
 - Energy systems
 - Orthostatic intolerance
 - Neurocognitive dysfunction
 - Gastrointestinal disturbance
 - Cardiac dysfunction
 - Visual system
 - Endocrinological system
 - Neurological dysfunction;
- The onset of impairment/dysfunction issues often not apparent until the system is challenged and/or the individual enters a post-exertional state (onset 24/48 hours later). That effect can also manifest in the hours following activity, with changes across the following days to weeks. Standardised instruments do not capture this type of longitudinal impairment.

The recent US Institute of Medicine report into ME/CFS addressed the issue of Post-Exertional Malaise for example:

Standardized symptom questionnaires with self-report items used to assess PEM include the CFS Medical Questionnaire (Komaroff et al., 1996c), CFS Screening Questionnaire (Jason et al., 1997), Centers for Disease Control and Prevention (CDC) Symptom Inventory (SI) (CDC, 2005), ME/CFS Fatigue Types Questionnaire (MFTQ) (Jason et al., 2009), and DePaul Symptom Questionnaire (DePaul Research Team, 2010). These questionnaires, which include items designed to measure the presence, duration, frequency, or severity of PEM, were developed from patient input to query specifically about PEM, and some were tested for psychometric properties (Hawk et al., 2006b; Wagner et al., 2005). However, they have been used primarily for subject recruitment in research, for comparison of diagnoses in research protocols, or for epidemiological assessments.

Use of a standardized instrument is critical to measuring PEM accurately because slight differences in wording on various self-report items have been shown to change the prevalence of PEM in the same group of patients (Jason et al., in press); thus, how one asks about PEM can influence the responses. As indicated

earlier in this chapter, individual experiences of PEM may vary widely in terms of triggers, onset, duration, severity, impairment, and symptoms that are exacerbated. For example, patients for whom normal daily activities, such as unloading the dishwasher, trigger PEM, may not engage in exercise. Thus, an item that asks about fatigue after exercise will not capture these patients' experiences with PEM. Similarly, responses to this item will not indicate PEM in patients who experience symptom exacerbation after cognitive exertion (Jason et al., in press). Thus, development of a sufficiently inclusive but probing clinical instrument is essential.³⁶

The IOM report addresses much of the literature with respect to some of the instruments used and identified some of the inherent flaws that exist.

What is notable is the absence of any research where the Vineland, CANS or WHODAS 2.0, for example, are used as a measure of functional impairment in ME/CFS. There is, therefore, no evidence base to indicate validity in the assessment of this for impairment in ME/CFS.

ME/CFS Australia submit that in a condition such as ME/CFS, where a significant percentage of the cohort have fluctuating symptoms that can take them in and out of functional impairment (like Multiple Sclerosis for example), the NDIS has no instrument to assess this fluctuation.

Perception of Others

With regards to the specific instrument, being the Vineland-3, ME/CFS Australia expresses specific concern because of common issue of misperception. With ME/CFS, family and caregivers can be unsupportive and even hostile towards an individual with ME/CFS. Given that there exist unequal power dynamics that arise from Medical Practitioners and lay people (e.g. carers and family members), it is not uncommon for family members to believe the misconceptions of ill-informed practitioners who assert the condition is not real, or can be cured with graded exercise. This can cause issues of disbelief, resentment and stigmatisation.

Bourlazreg and Rokach recently affirmed this specific issue in the context of discussing the stigma and isolation of the condition:

³⁶ IOM (n 21), 82.

... the stigmatization of this illness results in dismissiveness and scepticism from peers, from authority figures (e.g., teachers and employers), and sometimes even from family members.³⁷

McManimen et al affirmed a similar issue and the extension across the spectrum of social interactions including family:

Lack of a clear-cut biological cause has increased scepticism about this illness, and patients report the legitimacy of their illness is frequently questioned by family, friends, and even their physicians.³⁸

Nehrke, Fox and Jason outlined the extent of the problem from a familial perspective:

Previous research discovered that 95% of patients felt alienated from those around them whereas 70% of patients' families or friends believed that their symptoms were a result of mental disorder.³⁹

Whilst some individuals have supportive family members and carers, it is self-evident that the majority experience significant issues with respect to belief and support. In such circumstances the perception of a family member or carer can be heavily tainted to the detriment of the individual with ME/CFS. In such circumstances the Vinelands would likely result in an inappropriate response being obtained that would be more reflective of the belief and bias of the family member/carers, than it would be of the applicant's actual issues. In such circumstances such an instrument simply will not work.

Illustrating the Issue

The recent AAT case of *Caine and Secretary, Department of Social Services (Social Services Second Review)* [2020] AATA 2089 involving ME/CFS and an application for the Disability Support Pension, illustrates a perfect example of an assessment of disability that failed to appropriately assess what it takes an individual to engage in a short activity such as shopping:

³⁷ Samir Boulazreg and Ami Rokach 'The Lonely, Isolating, and Alienating Implications of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' (2020) 8 *Healthcare* 413, 425.

³⁸ S.L. McManimen, D. McClellan, J. Stoothoff, and L.A. Jason, 'Effects of Unsupportive Social Interactions, Stigma, and Symptoms on Patients with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome' (2018) 46(8) *Journal of Community Psychology* 959, 961.

³⁹ P.I. Nehrke, P.A. Fox, and L.A. Jason, 'Research Volunteers' Attitudes Toward Chronic Fatigue Syndrome and Myalgic Encephalomyelitis' (2017) 7(4) *Neurology (E-Cronicon)* 172

55. Having regard to Ms Caine's evidence and Ms Steele's reports, the reasonable conclusion is that the arbitrary but prescriptive activities required for 20 points in Table 1 **could at most be repetitively performed over a sustainable period once every three days**. Ms Caine has given evidence that she has **learnt to carefully manage her activities to balance her physical limitations** with the requirement to perform essential tasks such as shopping. There is **no evidence to suggest that there is capacity or ability to increase the physical demands** she places on herself.

56. Having reached this conclusion, it is not reasonable or accepted by the Tribunal that **an activity which consumes 45 minutes but requires three days almost entirely dedicated to the preparation, performance and recovery** should be described as being habitual or regular. **It is more accurately classed as one which can be performed once or rarely**. Having reached this conclusion, it is appropriate to award Ms Caine 20 points under Table 1 of the Impairment Tables.

In the context of the NDIS, multiple applications for access have been denied because the decision maker focused on the fact the applicant indicated they could perform an activity within the Section 24(1)(c) of the NDIS Act, when in fact the activity was performed for a disproportionately small amount of time compared to the substantial reduction in functional capacity that occurs during the subsequent days of Post-Exertional Malaise.

The purpose of the NDIS assessment is to capture the reality of the condition, not a misconception of the condition.

Individual Patient Needs

ME/CFS Australia submits that the purpose of the assessment is to assess the needs of the individual participant. The use of assessment tools, as proposed, lack specificity, and are not likely to capture the substantial reduction in functional capacity experienced by an individual, as experienced in day-to-day life. Moreover, the agencies the NDIA intend to use to complete the assessments lack the disability-specific expertise such that applicants and those already eligible for the scheme, stand to be denied eligibility.

Consumer View

My day-to-day experience of ME/CFS is consistently inconsistent. Often there is no rhyme or reason for the decline or fluctuation in the function I experience. Then there are activities that I know will result in a period of being lounge-bound due to post-exertional malaise for days to weeks.

I've experienced attempts to measure the effect of my condition via a variety of instruments in a number of settings, including as a research participant. They capture a snap-shot in time – that reflects either a point in time, or an average across a time period (e.g. four weeks).

I haven't been given a questionnaire yet that measures the ebb and flow throughout a day – or through a week.

I can have a week of 2 good days and 5 days in bed with severe symptoms because I spent a weekend with my family doing some low impact activities. Another week I can have moderate symptoms that have minor fluctuations, because I don't do anything. The first week I might report that I did activity – and that looks great (when in fact I had no function for 5 days) because that's all I am asked about. The next week looks poor because I did minimal activity – yet that looks poor because I am not doing anything.

When I diarise activity, it is more accurate – but still doesn't capture the experience accurately.

When I participated an objective measure like a 2-day Cardiopulmonary Exercise Test to prove the impact of post-exertional malaise, the cost of exertion was clear – but the price was to make me housebound for weeks, with no recovery of the function I had before the test, until 6 months later.

That's too high a price to pay to prove what is known as the cardinal symptom of the condition, and I have reported as having.

Recommendations

Recommendation 16 – The use of instruments should not be applied on a uniform basis. Validated instruments for certain diagnosed conditions may be suitable. In ME/CFS consultation with the peak body should be conducted to establish validated instrument, if any, that might be appropriate;

Implications for Access and Eligibility

Implications for Access

ME/CFS Australia submit that use of IAs will be of detriment to the majority of people with ME/CFS in terms of access. As the scheme currently stands there are already inherent barriers that have been precluding applicants with ME/CFS from entering the scheme. Such barriers, we submit, are the result of the NDIA not having a full grasp of the permanent nature of the condition, and misconceptions as to the belief that certain treatments represent a cure.

In terms of IAs ME/CFS Australia holds concern from a number of perspectives:

- The overwhelming lack of knowledgeable ME/CFS practitioners;
- The potential for the NDIS to provide inappropriate and misleading guidance on the requirements for ME/CFS applicants to demonstrate (in a similar manner to that used in the assessment stage);
- The fundamental misconception of permanency in ME/CFS;
- The use of flawed instruments and/or FCE tools, that will not capture the functional impairment in ME/CFS.

It is ME/CFS Australia's view that a compulsory IA system will create a substantial barrier to eligibility and therefore block access.

An IA, improperly done, will simply render the most vulnerable ineligible to access what their actual permanent condition with genuine substantial impairment, requires them to have.

This is not congruent with the objectives of the scheme.

Implications for Eligibility

ME/CFS Australia submit that use of IAs will be of detriment to the majority of people with ME/CFS in terms of eligibility. Entry into the scheme has been heavily vetted to date, particularly with respect to ME/CFS.

The scheme is very clearly set up for those people who are likely to be affected throughout their life. Section 24 of the NDIS Act states as much:

Disability requirements

(1) A person meets the disability requirements if:

...

(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**.

ME/CFS Australia has been involved in referring a number of individual eligibility reviews directly to the NDIA to question their validity. After affected individuals conducted Freedom of Information Inquiries, a copy of the *Eligibility Reassessment Checklist Age: 7+ years* the following section appears with respect to permanency:

Disability – Permanency	Details	Yes/No
<p>Section 24(1)(b), NDIS Act 2013</p> <p>An impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence based treatments that would be likely to remedy (i.e. cure or substantially relieve) the impairment.</p> <p>If there is a potential treatment which may reduce, or eliminate, disability related functional impacts this must be explored before the impacts are considered permanent.</p>		
<p>7. Is there evidence the person has a disability on List B?</p> <ul style="list-style-type: none"> Disabilities on List B are considered permanent. 	<p>Yes, go to question 9</p> <p>No, go to question 8</p>	
<p>8. Are there any clinical, medical or other treatments that would likely reduce, or eliminate, disability related functional impact?</p> <ul style="list-style-type: none"> E.g. Surgery, rehabilitation, medication. <ul style="list-style-type: none"> Conditions such as Fibromyalgia, Chronic Fatigue Syndrome, Chronic Pain, Depression, Anxiety, PTSD, Obesity, Osteoarthritis would be unlikely to meet this criteria. 	<p>Yes, Refer to National Access for Reassessment – Revocation</p> <p>If yes, do not complete remainder of checklist</p> <p>No, go to question 9</p>	

ME/CFS Australia makes the following submissions on this specific point:

- Firstly, as can be gleaned from the above checklist, it is an absolute given the ME/CFS will be **always by reassessed for eligibility and access revoked**.

The NDIA have expressly targeted ME/CFS with a number of other conditions that the NDIA views as not permanent;

2. Secondly, the NDIA have wrongly concluded that ME/CFS is not inherently a permanent condition, hence it specifically identifies the condition as reviewable for permanency. There is no “clinical, medical or other treatments that would **likely reduce or eliminate**” the functional impact of ME/CFS. The key word, likely. There is nothing in the evidence base that reaches the threshold of likely. Despite this fact, the NDIA have repeatedly and persistently required that ME/CFS applicants and participants demonstrate a treatment that is “likely” to reduce or eliminate the functional impact. ME/CFS Australia has presented evidence to the contrary. Recent evidence supports the position of the peak body:

- (a) *Position of the NDIS* – The position of the NDIA was expressed to ME/CFS Australia as based on the following.

Professor Lloyd had provided information on the aetiology of ME/CFS, medical and allied health specialities involved in diagnosis and treatment, treatment options clinically indicated for the condition, ... He has further provided information regarding evidence and research regarding Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT)...

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 cognitive behavioural therapy (CBT), graded exercise therapy (GET) and cognitive remediation) for 5 years, the Australian expert guidelines indicate that the condition should be regarded as permanent for medico-legal purposes.⁴⁰

ME/CFS applicants continue to report that they are being required to provide evidence that they have undertaken CBT and GET and evidence of the outcome (or provided acceptable reasons as to why not);

⁴⁰ Letter Under Cover of Email from Kate Agus, NDIA, to Geoffrey Hallmann, ME/CFS Australia, 15 August 2018.

(b) *UK NICE Draft Guidelines* – One of the documents the NDIA rely upon is the long outdated 2007 NICE Guidelines.⁴¹ The draft of the latest iteration has adopted a completed opposite approach to the evidence base and their views:

(i) The NICE Draft makes some very clear statements on the use of physical therapy that contradicts the position of the NDIA:

Do not offer people with ME/CFS:

- **any therapy based on physical activity or exercise as a treatment or cure for ME/CFS**
- *generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses*
- *any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy*
- *structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS*
- *therapies derived from osteopathy, life coaching and neurolinguistic programming (for example the Lightning Process).⁴²*

Respectfully – there is no grey area here. It is the complete opposite of the view expressed by the NDIA

(ii) The NICE Draft was unequivocal:

The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS.

*In developing more specific recommendations on the content, approach and delivery of physical activity management, **the committee considered the benefits and harms associated with graded exercise therapy that had been identified in the***

⁴¹ Ibid.

⁴² National Institute for Health and Care Excellence, Guideline', *NDIS* (Document, November 2020), 27-28 <<https://www.nice.org.uk/guidance/gid-ng10091/documents/draft-guideline>>.

***qualitative evidence** and their own experiences of these types of interventions. They recommended **not to offer any programme based on fixed incremental physical activity or exercise**, for example graded exercise therapy or structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS.⁴³*

- (iii) With respect to CBT, the NICE Draft makes some very clear statements on the use of this therapy that contradicts the position of the NDIA:

*Do not offer CBT as a treatment or cure for ME/CFS...
Explain that CBT for people with ME/CFS:*

- is not curative*
- is designed to improve wellbeing and quality of life.⁴⁴*

- (iv) The NICE Draft clarifies their position and makes clear the evidence base is poor and CBT should not be a treatment:

***The quantitative and qualitative evidence was mixed**, and this reflected the committee's experience. Based on **criticisms in the qualitative evidence of CBT being used as a 'treatment' for ME/CFS**, the committee considered it was important to highlight that CBT is not a cure for ME/CFS and should not be offered as such, but that it is a type of supportive psychological therapy which aims to improve wellbeing and quality of life and may be useful in supporting people who live with ME/CFS to manage their symptoms. It should therefore only be offered in this context...*

None of the clinical evidence included or reflected the needs of people with severe ME/CFS, and the qualitative evidence was mixed, with some people reporting benefit and others harm.⁴⁵

⁴³ Ibid, 63.

⁴⁴ Ibid, 34.

⁴⁵ Ibid, 68.

(c) *Cochrane Review* – Another of the documents the NDIS relied upon was produced by the Cochrane Review.⁴⁶ The draft of the latest iteration has adopted a completed opposite approach to the evidence base and their views:

- (i) With respect to CBT (and other psychotherapies) and functional syndromes (including CFS), the Cochrane Review authors identified multiple methodological concerns in psychotherapy trials, including the high drop-out rates and the selection bias in sampling.⁴⁷ This accords to the findings of the NICE ME/CFS Guideline panel. Despite being a 2014 review, the NDIA had no regard to this review.

More recently, the Cochrane editor issued a more definitive statement in regard to the 2008 CBT review – the most recent review conducted. The editor noted the “2008 review predates the mandatory use of GRADE methodology to assess the strength of evidence and the review is **no longer current.**” Most importantly, the editorial note states “It **should not be used for clinical decision making**”.⁴⁸

This is most significant because it directly contradicts NDIS policy based on the evidence base provided to it. There is, therefore, clearly no basis for the NDIS or the DSS to rely upon such evidence on CBT;

- (ii) With respect to GET, the NDIA relied upon the 2017 Cochrane Review of ME/CFS and GET.⁴⁹ Following multiple representations to Cochrane about the methodological flaws of this review, the authors released an amended 2019 Review that acknowledged many of the flaws of the studies.⁵⁰ The key amendments included:

- *Bias* – The Cochrane authors identified a high risk of performance and detection bias in every study included;

⁴⁶ Ibid.

⁴⁷ N. Van Dessel, M. den Boeft, J.C. van der Wouden, ‘Non-pharmacological interventions for somatoform disorders and medically unexplained physical symptoms (MUPS) in adults’ *Cochrane Database of Systematic Reviews* 2014; 11: CD011142.

⁴⁸ Cochrane, ‘Editorial Note: Cognitive Behavioural therapy for chronic fatigue syndrome’ *Cochrane*, (Article, 2021) <https://www.cochrane.org/CD001027/DEPRESSN_cognitive-behaviour-therapy-chronic-fatigue-syndrome?fbclid=IwAR2G212oY5QONk4B_IFLyXkyYcKPso-oyi913mKUUO24BMYldSOsk-7IIYNc>.

⁴⁹ L. Larun, K.G. Bruberg, J. Odgaard-Jensen, and J.R. Price, ‘Exercise Therapy for Chronic Fatigue Syndrome’, (2017) 4 *Cochrane Database Sys Rev* 1, 6

⁵⁰ L. Larun, K.G. Bruberg, J. Odgaard-Jensen, and J.R. Price, ‘Exercise Therapy for Chronic Fatigue Syndrome’, (2019) 4 *Cochrane Database Sys Rev* 1.

- *Adverse Effects* – The Cochrane authors acknowledged that the evidence in regard to serious adverse reactions caused by GET was uncertain due to the fact that the certainty of evidence was very low;
- *CBT* – The authors admitted that the evidence with respect to CBT did make the drawing of conclusions as to the comparative effectiveness of CBT, with respect to GET, impossible;
- *Criteria* – The authors acknowledged that the primary studies were drawn from the 1991 Oxford Criteria and 1994 Fukuda criteria (outdated and flawed criteria). The authors admitted that if a patient was diagnosed by way of another criteria (such as the 1988 Ramsay ME Criteria, 2011 ME Criteria or 2003 Consensus Criteria) the impact of GET may well be different;
- *Certainty of Evidence* – The authors acknowledged that the grades for each study with respect to certainty of evidence, was low to very low across the papers.

Taking account of the evidence base – as opposed to the evidence base provided by a proponent of the CBT/GET approach – it is submitted that the NDIS requirements are patently incorrect and outdated. Even if the evidence base was to be taken into account, there has never been a research paper that established CBT or GET was “likely to reduce or eliminate” the substantial impairment of ME/CFS. Despite this fact the NDIA was still requiring CBT/GET and denying access to the scheme;

3. Thirdly, the NDIA’s requirement to do CBT/GET was and still is, placing people with ME/CFS in harm’s way. One of the significant issues that surrounded the evidence base, which NICE found to be of low to very low quality, was the failure of studies to report harms.

(a) *UK Survey for NICE on CBT* – In responding to a request for evidence from the NICE Guidelines Review Committee⁵¹, the patient organisations collected data and a report was produced by Oxford Brookes University.⁵²

⁵¹ Forward ME Group, ‘CBT and GET Survey Results Published by Forward-ME Group’, (3 April 2019) <<https://www.meaction.net/2019/04/03/cbt-and-get-survey-results-published-by-forward-me-group/?fbclid=IwAR3sEJmAbYjfnOW0acxDTQ0gVYxOjLBbDAuyFIIDLxnLp1bsXB2fyfXUFOQ>> (‘Forward ME’).

⁵² H. Dawes, ‘Evaluation of a survey exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programmes’ (27 February 2019) <<http://www.meaction.net/wp-content/uploads/2019/04/NICE-Patient-Survey-Outcomes-CBT-and-GET-Oxford-Brookes-Full-Report-03.04.19.pdf>> (‘Dawes’).

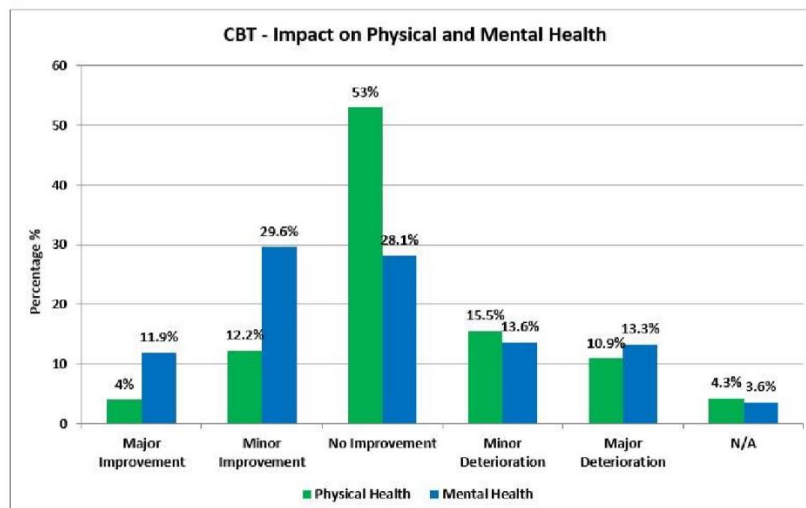


Figure 7. Impact of CBT treatment on physical and mental health

The large survey of patients (n = 670) reveal with respect to CBT that 53% experienced no change in the physical or mental health. 24.6% experienced deterioration in their physical health. With respect to mental health, 41.5% reported improvement in mental health, 28.1% experienced no change and 26.9% experienced deterioration.⁵³

- (b) *UK Survey for NICE on CBT* – A recent survey in the UK conducted by Oxford Brookes University⁵⁴ at the request of NICE Guidelines Review Committee⁵⁵ demonstrate that GET is associated with significant harms:

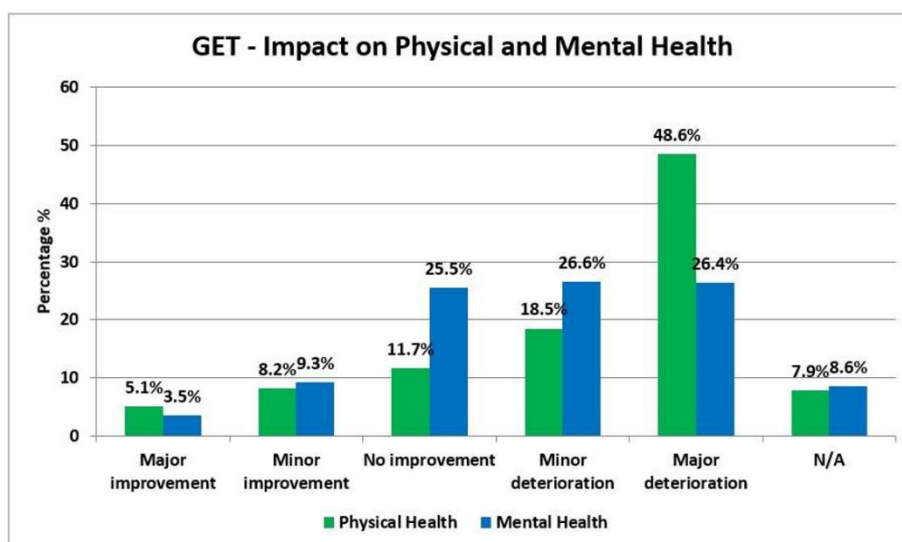


Figure 13. Impact of GET treatment on physical and mental health

⁵³ Ibid, pp. 6-7.

⁵⁴ Forward ME (n 51) 11.

⁵⁵ Dawes (n 52).

Of the respondents, some 67% reported deterioration in physical health following GET, 11.7% reported no improvement. GET also caused the mental health of 53% of respondents to deteriorate, whilst 25.5% reported no improvement and 12.8% reported improvement.⁵⁶

When CBT and GET were combined (see over), 48.4% reported that CBT did not improve physical health, whilst 11.8% reported an improvement in physical health. 35.5% of respondents reported that their physical health deteriorated with CBT. Mental health improved in 29.4% of respondents, whilst 32.7% reported no improvement and 34.3% reported deterioration. The report also found that some 58.4% reported a worsening of symptoms.⁵⁷

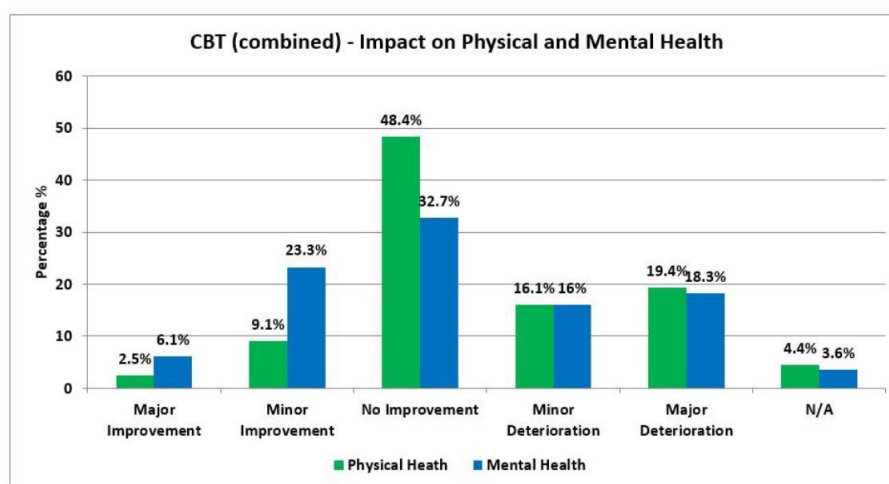


Figure 19. Impact of CBT (combined with GET) on physical and mental health

ME/CFS Australia submits that it is simply inappropriate for the NDIA to require patients to engage in treatments where the evidence base does not support their position, and moreover, the vast majority of people who engage in such treatment, will experience no benefit or a deterioration in their mental and physical health.

This is fundamentally unfair and against the intent of the scheme.

ME/CFS Australia's Concerns

ME/CFS Australia submits that arbitrary assessments with respect to access and eligibility by inappropriately qualified, inexperienced and unknowledgeable assessors

⁵⁶ Forward ME (n 51) 11.

⁵⁷ Ibid, 13.

holds the potential to unfairly and unjustly deny access to the scheme or remove people with ME/CFS from the scheme.

Moreover, given the widespread existence of practitioners who hold various irrational and unfounded beliefs that the condition is not real, not biological, temporary, treatable, recoverable or otherwise, there is a very real potential for arbitrary and capricious reporting adverse to the interests of the person with ME/CFS and fairness.

Additionally, like a condition such as Multiple Sclerosis, the symptoms and experience of ME/CFS can fluctuate over time, variably and unpredictably. In MS, flares and pseudoflares are common. MS is a condition that falls under the neurological conditions identified under the List B permanent condition of the *NDIS Operational Guideline*.⁵⁸ ME/CFS, which is also a neurological condition, does not appear under List B.

ME/CFS is largely ignored within Community Supports and the health care system. For this reason, the only opportunity to progress or improve capacity, is the NDIS. Removal from the NDIS will cause any progress to decline. Those who are forced to do those activities they had support for, will suffer the post-exertional repercussions and harm that is inherent to the condition. For those who are incapable of any form of function, they will be left without supports, or to the care of their family/caregivers.

For some who were living in Aged Care facilities despite their youth, they will be forced to return to this inappropriate option after serving the long waiting periods that exist for re-entry. Aged Care facilities often require co-payments and are staffed by health practitioners with absolutely no understanding of the condition. This often means inappropriate rooms with food, light, noise and odour exposure, and attempts to engage people in activities that they simply cannot do.

Such outcomes are the very antithesis of the Scheme's purpose and objectives.

Potential Beneficial Application

ME/CFS Australia do submit that if the NDIS were to provide optional access to an appropriately qualified person, with genuine clinical and research knowledge of the condition, appropriate guidelines that reflect the actual reality of the condition, and knowledge and tools to appropriately ascertain functional impairment, the IA may have value.

For many who do not have an established relationship with a medical practitioner, for those who are isolated, or remotely located, and for those who are financially unable

⁵⁸ NDIS, 'Operational Guidelines', *National Disability Insurance Schemes* (Website, 20 April 2021) <<https://www.ndis.gov.au/about-us/operational-guidelines>>.

to fund their own reports, and for those whose medical practitioners have not willingness and/or confidence to navigate the paperwork, an IA holds potential.

A properly constructed assessment has the potential to open up access where such people could not obtain a report.

Consumer View

Obtaining a report from my Doctor or from an Occupational Therapist is beyond my budget. My situation is complex. My documents are detailed. My tests are extensive. Other than the original treating doctors, no one is willing to even bother to read the documents, let alone understand them, or treat me.

I don't have a regular local doctor. When I have regular, non-ME/CFS issues, I have to visit the local super clinic where I get to see a locum. The appointments are short. They don't care about ME/CFS. I've even had one doctor refuse to read a report because it was "too long" and he doesn't "want to know about that".

The ability to access a genuine assessment from someone who knows ME/CFS and the issues, to genuinely sit down and pay attention, and provide an accurate, genuine report – that would be invaluable. I couldn't afford it otherwise.

However, if they don't know ME/CFS or they cannot be bothered to review the tests – no assessment would be of help.

Recommendations

Recommendation 17 – The weight of evidence demonstrates that the NDIA should remove ME/CFS from their list of conditions that have “clinical, medical or other treatments that would likely reduce or eliminate” the functional impact of ME/CFS.

Recommendation 18 – There is a place for an optional assessment with an ME/CFS competent IA with a genuinely knowledge of ME/CFS, who clinically and scientifically understands the condition and its many nuances, has proper guidance on the condition, and is able to provide a genuine and properly constructed assessment.

Implications for Planning

Deficient Plans

The joint submission No. 13 by the NDIS and DSS made clear that IAs will be used as a “key source of information the NDIA delegate will consider in making decisions about a person’s ... plan”.

ME/CFS Australia submits that the use of IAs to determine reasonable and necessary supports will result in participants receiving deficient or inappropriate assistance, as opposed to the supports they require, based upon the merits of their needs.

Supports are designed to “assist the participant to pursue the goals, objectives and aspirations” of the participant.⁵⁹

As a part of this process of considering supports the participant’s plan takes account of the goals, objectives and aspirations of the participant, the environmental and personal context of the participant’s living, that participant’s statement.⁶⁰

IAs are able to be commissioned as a part of this process currently.⁶¹

As the process exists presently, it is the participant that has a major voice in the identification and selection of the proposed supports.

ME/CFS Australia submit that participants who are subjected to IA selected supports, there is a significant danger that they will not be fit for purpose. The rationale for this position is grounded in our prior submissions about the deficiencies of assessors with knowledge of ME/CFS. We again submit:

- There is currently an overwhelming lack of knowledgeable ME/CFS practitioners;
- The proposed instruments do not capture the loss of function in ME/CFS;
- There is a potential for the NDIS to provide inappropriate and misleading guidance on the requirements for ME/CFS applicants to demonstrate (in a similar manner to that used in the assessment stage);
- There is a fundamental misconception of the nature and functional impairments in ME/CFS.

The use of IAs that are not conducted properly will not assist in a proper planning process for persons with ME/CFS.

⁵⁹ *National Disability Insurance Scheme Act 2013* (Cth), s 34.

⁶⁰ *Ibid*, s 33.

⁶¹ *Ibid*, ss. 33, 36.

Weighting of Evidence

The joint submission No. 13 by the NDIS and DSS made clear that the NDIA delegate will take account of other evidence provided by the participant, when making the planning decision.

ME/CFS Australia submit that it is common practice within the Workers Compensation jurisdiction to give weight to the treating doctor over an IME. The logic behind such an approach is simply because the treating practitioner knows and understands their patient, having interviewed them on multiple occasions, experienced the variations in the condition, reviewed and internalised the tests and results, and garnered a full picture of the condition and its challenges.

An independent assessor cannot, in the space of a 3-hour appointment, ever hope to obtain anything other than a superficial view of the participant. An IA may, however, cover gaps in the reporting of the treating practitioners, and such gaps may be addressed by way of the Independent Assessor's report.

For this reason, weight should be accorded to those who are in the best position to provide an opinion, notwithstanding the IA demonstrating something so different from the treating practitioner's report that it should render it unreliable.

Consumer View

The planning stage requires appropriate information about ME/CFS. In preparing evidence, I had to go to great lengths to establish functional impairments. The supports centred around the evidence.

Without that evidence, it was not possible to establish things were reasonable and necessary. My supports were unique to my situation and essential to enabling me to meet my goals and objectives. My doctors knew me and knew my situation.

This allowed them to articulate my needs based on their experience of having observed me and spoken to me across dozens of appointments over the years.

Recommendations

Recommendation 19 – The use of an IA that works on a standardised approach will not meet the support needs of people with ME/CFS. The process should remain individualised.

Recommendation 20 – The NDIA should accord weight to the evidence of the participant’s treating practitioners ahead of the IA, in the absence of there being an exceptional reason to do so.

Review and Challenges to Outcomes

Fairness

The objective of the NDIS is to provide eligible persons with a disability, with access to the reasonable and necessary supports they require in order to lead an ordinary life.

It is not the objective of the NDIS to throw up barriers to people with a disability, in order to prevent them from obtaining entry to the Scheme. It is not there to favour those who have a greater support network, or lobbying voice, or financial means.

The Scheme is there to operate fairly.

ME/CFS Australia directs you to its submissions with respect to IME assessments in the Workers Compensation jurisdiction. The reality of insurance frameworks is the IAs that are produced are rarely supportive, rarely accurate and often adverse to the interests of the person examined.

Whilst there are assertions that IAs will improve assessments, the scheme needs to provide a mechanism of fairness to allow for the reality in which an IA does not accord fairness.

ME/CFS Australia reiterate that the NDIS is a model litigant that must act beyond its obligations of honest, truthfulness and fairness. Moreover, it must always be mindful that those with disabilities who have the ability to meet the criteria of disability, have an entitlement to enter the Scheme, or remain there. It is not there to take advantage of a deficient IA that allows it to deny an individual access to the Scheme. It should always remain paramount that a genuine applicant should have the right to prove that eligibility.

This is fairness.

Appeal Mechanism

For those with ME/CFS the NDIS has proven to be a daunting institution to deal with. For most who apply, the NDIS has applied a covert assessment process in which it has acted upon the views of a single advisor whose put forth materials and views that the vast majority of the ME/CFS community and patient organisations disagree and that with the passing of time are being shown to be inappropriate.

For those who are on the Scheme, the NDIS have on a significant number of occasions triggered eligibility reviews on the basis of spurious assertions of changed circumstances where none existed, then applied a checklist (see above on p. 36) that automatically refers the participant for reassessment merely because of the misconception that they condition can be treated, when the evidence base shows it will never be likely to improve functional impairment.

It is in the context of that tension that ME/CFS Australia submits that IAs should always a reviewable decision/document within the internal review mechanism, as well as the external review mechanism.

Aside from the various biases that arise from misconceptions and erroneous views that are held by some practitioners with respect to the nature of ME/CFS, there are the same potential errors that all other people face in the NDIS system. Factual errors or omissions are always a possibility within a complex institution such as the NDIA. There are also procedural errors that can arise in the course of any administrative process.

Internal reviews based on merit are imperative, as are appeals to the AAT on merit. Such a mechanism instils confidence in the integrity of the system. An internal review, being less formal in nature, presents an opportunity to the parties to identify and correct the majority of errors without causing disputes to escalate in costs and complexities by moving them to the AAT.

Funding the Process

ME/CFS Australia knows from its interactions with member organisations and consumers that people with ME/CFS do not, as a matter of course, have the financial resources, nor the health or cognitive function, necessary to construct, apply and present their case in the AAT.

ME/CFS Australia again reiterate that the Scheme is designed to ensure fairness.

Fairness is not throwing up barriers to justice. It is not subjecting a lay-person with a disability up against a qualified legal practitioner. It is not forcing them into a situation where they lose their health and function further. Self-representation slows down the process and escalates costs for the NDIS. Self-representative is contrary

to the objective of fairness when the NDIA abuses its financial and resource powers to intimidate a disabled lay person who is fighting for a right to receive assistance.

In the *Tune Review*, the following was recommended:

participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment

ME/CFS Australia submit that these recommendations are appropriate as well.

Reviewable Decisions

ME/CFS Australia submits that the reviewable decisions should extend beyond the IA to include:

- Review of access decisions relying upon an IA;
- Review of planning decisions relying upon an IA;
- Code of Conduct breaches by assessors;
- Procedural decisions.

False Economies

Any system that prevents the review of an IA creates a false economy.

Forcing potential and existing participants to suffer while they do not have access can result in lost income, lost revenue to the community, and increased use of health resources to counter the effect of decline.

Forcing these people to engage in waiting periods, and the costs of evidence gathering in to counter an error, represents a cost to society.

A review system allows many of these costs to be avoided and an early resolution to be achieved on the simpler cases where obvious errors occur.

Funding AAT disputes allows matters to be resolved at an earlier point by way of negotiation and clarification of facts and obvious errors. Faster conduct of cases through legal representation lowers the cost of disputes to society, by freeing up scarce legal resources faster, with less cost.

A refusal to review creates the perception of costs prevented, when in fact it is deferring costs to other parts of society, that can often be more expensive.

Aside from meeting the objectives of the scheme, their model litigant objectives a review system accords fairness.

Consumer View

I have had ME/CFS for 25 years. For 24 of those years I have been engaged in some form of dispute or litigation with insurers. For almost all of that I have been self-represented.

Conflict arises solely because those who are assessing ME/CFS do not understand the condition. I have been subject to over 20 IME assessments and they have NEVER been accurate, never been supportive, and never caused anything other than future conflict.

I have expended tens of thousands of dollars for investigations and reports that are a waste of time, money and energy.

Every dispute causes me decline. Many times I have not been able to appropriately represent myself. There is little to no funding available to assist you.

You have barriers to representation. You have barriers to obtaining medical evidence and opinions. You have barriers to being able to verbalise your own case before a decision maker.

It's hurdle after hurdle.

I applied for NDIA. Their decision was atrocious and obviously so. My only option was to appeal to the AAT – but I did not have the energy to do so at that time, nor the resources to pay someone to assist me.

Despite being patently eligible, I missed out. If there was funding to appeal, I firstly get assistance to be heard, and secondly, get the assistance I required. Instead – I declined and I am a bigger financial burden on the state than I would have been had I been accepted.

It's backwards decision making.

Recommendations

Recommendation 21 – ME/CFS Australia recommends that there be an appeals system available to people so that they can dispute an IA.

Recommendation 22 – ME/CFS Australia recommends that there be funding available for people to appeal both tiers of the AAT.

Appropriateness for Particular Disability Cohorts

ME/CFS Australia's Position

ME/CFS Australia is of the view that the IAs, as they are currently proposed, using the standardised instruments proposed, without appointing appropriately qualified persons with an education and clinical expertise in ME/CFS, will not be appropriate to conduct a full and fair assessment. Moreover, the presentation of a person to an IA is not a representation of that person in their day-to-day environment. Indeed, for those people who fluctuate, and the majority who experience Post-Exertional Malaise or exacerbation of orthostatic intolerance after an activity, their presentation would be anything other than representative.

ME/CFS Australia submit that this particular disability does not fit the mould of a standardised assessment. In our submission, there is a high probability that the ME/CFS, despite its high degree of disability, will be left off the Scheme, as it has been with health funding, community supports and research funding.

Optional Use

As ME/CFS Australia submitted above, there should be an option for people with ME/CFS to opt into an IA. ME/CFS Australia recognises that there are barriers to obtaining an assessment that include, but are not limited to:

- Inability to obtain a regular treating practitioner;
- Remoteness of location;
- Isolation;
- Inability to fund other reports.

ME/CFS Australia reinforces its submission that the access to an IA should be optional and should include the ability for the individual to select their own assessors.

Recommendations

Recommendation 23 – The fact that ME/CFS is accompanied by multiple disabilities means that the use of inappropriately qualified persons to conduct IAs will lead to the overlooking of such disabilities.

Appropriateness for Particular Disability Types

ME/CFS Australia is only in a position to comment on the issue of ME/CFS. To that end, the submissions made above have been very clearly ventilated. ME/CFS is a condition that is accompanied by various comorbid disabilities (e.g. POTS, NMH, Sleep Apnoea, Fibromyalgia, etc).

ME/CFS Australia is of the view that the IAs will not provide a fair and equitable assessment for ME/CFS as they are currently proposed.

The legislation requires an appropriately qualified person to conduct such assessments, and such person must not only have an appropriate qualification, but also experience and an understanding of the evidence base for ME/CFS. They must know, for example, that these other disabilities accompany ME/CFS. That is rarely the case. Even among some doctors who consider themselves to be knowledgeable, these comorbidities are missed.

Appropriately qualified persons must have an approach to the condition that is congruent with the NHMRC's views on the condition, and not be drawn from the psychological or functional disorder school of thought. They should not be drawn from persons who do not believe the condition, or those who are proponents of the CBT/GET school of thought, which has been shown to be inappropriate.

The NDIA must recognise that ME/CFS, like a number of conditions, has specific knowledge and needs, hence the appropriate persons must be appointed to assess them.

Recommendations

Recommendation 24 – The fact that ME/CFS is accompanied by multiple disabilities means that the use of inappropriately qualified persons to conduct IAs will lead to the overlooking of such disabilities.

Any Other Matters

Assessment Duration

ME/CFS is a condition that is highly sensitive to activity. The duration of the NDIS assessment process is intended to last 3 hours.

Physical Issues

For the severe, mere minutes is enough to create a prolonged crash. For those who are moderate, 3 hours may simply be beyond them.

For all categories, participation in an assessment comes with an element of PEM. That means that there will be an adverse physical and mental harm that results merely from participation. If the individual has to travel, then the degree of that harm escalates. For many, they live in social isolation – they have no personal vehicles, nor someone to assist them.

Public transport is prohibitive because of the exposure to sounds, smell and light, as well as the energy expelled. For those with orthostatic intolerance (be it Postural Orthostatic Tachycardia Syndrome or Neurally Mediated Hypotension), there is likely to be no ability to travel, or indeed stand.

If people with ME/CFS are forced to attend, then there are a large percentage who may simply be unable to participate due to having exhausted all their function just in the process of travel.

Neurocognitive Issues

One of the key symptoms within ME/CFS are the neurocognitive issues that arise. Exacerbating the condition with activity such as an interview, travel, walking, etc, can impact upon the following:

- Mental sharpness;
- Concentration;
- Short term memory;
- Long term memory;
- Working memory;
- Ability to make and consolidate memories;
- Task organisation;
- Speed of task completion;
- Verbal cognitive processing;
- Auditory sequencing

- Comprehension of social cues;
- Executive function;
- Linguistic function;
- Word finding,
- Receptive language.⁶²

Aside from the inherent neurocognitive symptoms, exacerbation can render the person non-communicative and/or unable to comprehend the questions being asked of them.

Opt Out Option

ME/CFS Australia notes submission No. 13, being the joint submission the NDIS and DSS in which these organisations make specific representations. At point 6 in particular, they state they “acknowledge there may be exceptional circumstances where it may not be appropriate to request an individual undertaken an independent assessment”. Such circumstances included

- *risk and safety: where the process is likely to do more harm than benefit to the individual, and may pose a safety risk to the individual or assessor, or*
- *the assessment is inaccessible or invalid, or where there may be concerns about the process of producing valid information, and other sources and/or forms of information are better suited.*

If IAs are to be introduced, ME/CFS Australia is of the view that there are a significant percentage of people with the condition who will be severely impacted by attending such assessment. Stressors, be they physical or psychological, are an exacerbator to the condition. It is well established that exacerbation causes a decline in the condition.

The IA should not cause harm to participants. The decline arising from harms is often not reversible. Causing participants’ decline is counter to the objectives of the Scheme and inappropriate.

ME/CFS Australia submits that there should be an option for participants to opt out of IAs by way of the exceptional circumstances option to prevent harms.

⁶² Carruthers (n 27) 34, 73.

Recommendations

Recommendation 25 – The vulnerability of people who have ME/CFS and the high risk that IAs represent to their health, should be justification for allowing such persons to opt out of participating in an IA.

Homebound/Bedbound

For a significant percentage of the ME/CFS population, there are those who are substantially or permanently bound to their residence.

For those who are homebound, or those that have adverse travel reactions, they cannot leave the residence. If an IA is arranged these accommodations will need to be made. For many, with sensitivities to chemicals, odours, light and sound, a visit from an external party can cause significant harm. IAs would require knowledge of such issues, and an adjustment to their physical presentation and conduct (e.g. no deodorant, low voice, assessment in low light). If an IA was to be conducted over a Telehealth modality, there is a potential for light and electromagnetic sensitivity that may prevent or modify the approach.

For those who are bedbound with acute sensitivities, or even a complete inability to communicate, the process is likely to be impossible. Any reasonable assessor would automatically conclude from such a presentation, that there is a substantial functional impairment of the relevant activities.

In a Covid-19 environment, there is a strong reluctance on the behalf of people with ME/CFS to venture out into the community. With comorbidities as a risk factor, and immunocompromised bodies, the need for IAs to be conducted at home or via a device, will be an imperative.

Recommendations

Recommendation 26 – Given the existence of persons who are housebound or bedbound with ME/CFS, they should be given the option to opt out of the IAs to protect their health, or to opt in if provided with an appropriately qualified person with knowledge and experience of ME/CFS, who will visit their residence and allow for individual sensitivities.

Adverse Reports

In the eventuality that the submissions of the various consumers, advocates and support organisations are not heeded, ME/CFS Australia submits that participants

should be accorded fairness, good faith and reasonable conduct from the NDIA, and applicants/participants accorded an opportunity to address such adverse Independent Assessments BEFORE a decision is made – at the expense of the NDIS.

Within context of insurance, it is submitted that the concept of fairness, good faith and reasonable conduct involves a specific process.

In *Beverley v Tyndall Life*,⁶³ Ipp J outlined this concept in his decision with respect to a Total and Permanent Disability policy:

*93 What did fairness, good faith and reasonable conduct require of the respondent after it had obtained the reports of Dr Salmon and Dr Silbert? On the respondent's view of those reports they contained material adverse to the appellant involving matters not previously raised. The reports had been obtained by the respondent in the course of investigating the appellant's contentions, that is, by exercising its right under condition 7.7 to obtain confirmation of the "diagnosis" by a specialist medical practitioner of its choice. **The reports were perceived by the respondent to refute rather than confirm the diagnosis, and to refute it on novel grounds.** In my opinion, **fairness required the appellant to be given the opportunity of answering the new material before the respondent made its decision.** Were that not to be so, the respondent, in its capacity as a party in an adversarial position to the appellant, would be entitled to obtain evidence adverse to the appellant's contentions, not reveal that evidence to the appellant, assume its adjudicatory role, and determine the issue against the appellant by reason of the evidence that had not been disclosed. **In my view fairness would not tolerate such a transmogrification from adversary to adjudicator while concealing crucial material.***

*94 In my view, **it would be prejudicial to the insured if the insurer were only to be required to disclose the new material after deciding to reject the claim.** If disclosure were to be made before the final decision, **the insured would be given an opportunity to answer the new material on its merits.** But if disclosure were to be made thereafter, the insured, ordinarily, would only be able to have the decision set aside by demonstrating, in subsequent litigation, that the decision itself was unreasonable.*

⁶³ *Beverley v Tyndall Life Insurance Co Ltd* [1999] WASCA 198

The decision in *Beverley* established that a claimant be provided an adverse report **BEFORE** a final decision is made, for the purposes of enabling a response. The rationale, aside from fairness, was one of allowing a response before forcing it to litigation.

Presently the NDIS does not accord such an opportunity when an independent assessment is obtained, and it appears there is no intent in the currently released draft proposed amendments to the NDIS.

Presently the NDIS does not provide funding to applicants/participants to allow them to obtain specific reports to address specific issues such as access and supports. This burden falls on the individual – who often lacks the financial resources to produce such reports.

ME/CFS Australia puts forth the following submissions for its recommendations below:

- (1) There is a significant power and resource imbalance between the NDIS and the applicants/participants;
- (2) It has been well recognised with the case law of the AAT, as indeed it has in the context of other insurance law, that the observations of a treating health practitioner over an extended period carry greater weight and reliability than a three-hour interview of an independent assessor;⁶⁴
- (3) The current system has seen a significant burden placed upon the applicant/participant to self-represent when navigating the NDIS system;
- (4) The financial capacity of people with disabilities is exceptionally limited (if not non-existent) because of employment limitations and being on various social security benefits;
- (5) The functional and intellectual capacity of people with disability is limited (and sometimes extremely limited) hence there are those who have no to limited ability to respond to an adverse decision;
- (6) The NDIS legislation, rules, guidelines and participant charter do not guarantee fairness, good faith or reasonable conduct in the assessment processes, although procedural fairness and natural justice are ever present requirements in such administrative decisions;
- (7) There is no funding for the first-tier dispute in the AAT, and limited funding available for a second-tier dispute. This places the applicant/participant in a

⁶⁴ *Ray and National Disability Insurance Agency* [2020] AATA 3452 [61] (Parker K).

significant disadvantage that can prevent access to the AAT, or appropriate representation before the AAT;

- (8) The provision of adverse reports to people BEFORE a decision can allow matters of contention to be addressed before a termination occurs, hence reduce costs to the system and individuals that arise from unnecessary disputes;
- (9) The provision of funding to conduct a review of an adverse report by a treating practitioner or a participant/applicant nominated Independent Assessor (external to the NDIS), will assist in overcoming areas contention without the need for litigation;
- (10) Fairness, good faith and reasonableness should form the cornerstone of the NDIA assessment process.

Recommendations

Recommendation 27 – ME/CFS Australia recommends as a matter of fairness, that the NDIA provide adverse IA reports to applicant's/participants so that they have the ability to respond with evidence and have that response considered in the final decision.

Recommendation 28 – ME/CFS recommends that funding be provided to applicants/participants to provide a report in response to an adverse IA.

Assessment Fatigue

Under the NDIS proposal, a participant with ME/CFS can be assessed when an event occurs that triggers a review. On a number of occasions to date, an LAC has caused the triggering of a review. If the LAC forms a view, for whatever reason, that there has been a change (as has occurred – erroneously and arbitrarily) or simply makes an error, the participant can be reviewed.

ME/CFS Australia submit that assessment fatigue is a potential issue that can arise under the proposed system.

In ME/CFS there are limited practitioners. Those who have the condition have for the most, very limited resources. The medical evidence in the NDIS needs to be recent.

If a participant is forced to go through the process of proving their eligibility, yet again, there is an inherent danger that they cannot afford to obtain the assessments that they require because:

- The medical practitioner is unavailable or not available due to waiting lists;
- The process of gathering evidence is expensive (including multiple tests) or prohibitively expensive;
- The waiting times for using public health resources and the process of review and reappointments can very well take months or years – especially if the costs cause inherent delays;
- Certain tests are not funded by the health system (eg Neurocognitive testing, Cardiopulmonary Exercise Testing, etc);
- Certain tests (eg Cardiopulmonary Exercise Testing) can result in a permanent decline in health and function;

In addition to the practical issues of bringing together the evidence, there is the issue of assessment fatigue. The process of constantly subjecting a participant to an eligibility assessment can and will lead to adverse impacts upon the individual, particularly in ME/CFS (where they are particularly vulnerable). This can:

- Increase stress and anxiety levels;
- Cause adverse impacts such as permanent or prolonged ‘crashes’;
- Cause people to fall off the system when they would otherwise be entitled, simply because they are too unwell and/or financially compromised hence cannot provide the required evidence;
- Cause undue pressure that increases risk of suicide;

Within the Workers Compensation sphere there has been ample examples of insurers applying pressure to claimants by forcing them to repeat IME examinations for the purpose of making them prove each and every claim is reasonably necessary. Additionally, there are examples of insurers forcing claimants of the system to force them back to work. Constant disputes lead to constant litigation, all of which only serves to adversely impede the health of the claimant.

In a scheme where the participants are the most vulnerable, the NDIA’s current intended approach will place undue stress and strain on participants, their carers and their families – often unnecessarily.

Recommendations

Recommendation 29 – ME/CFS Australia submits that LAC’s should not be permitted to arbitrarily and capriciously report changes in circumstances without corroborating evidence from a treating health professional.

Recommendation 30 – ME/CFS Australia submits that any LAC or other report of an alleged change in circumstances should be a matter that can be subject to internal and external review.

Budgeting

ME/CFS Australia has become increasingly aware that the proposed changes are directed towards reducing budgets. ME/CFS Australia expresses its concern that plans will be required to fit within a set budget, as opposed to a budget based around the reasonable and necessary supports that a person requires.

In ME/CFS that has the potential to be devastating and counter to the objectives of the Scheme. ME/CFS Australia is aware of the variety of supports that individuals with ME/CFS have been provided. Some people who have not been able to mobilise are better able to participate in the community because of their wheelchair. Some who have been forced to live in residential aged care, now have an opportunity to engage in independent living, with significant assistance to meet their specific needs.

ME/CFS Australia submits that any move toward a fixed budget approach or even a points based standardised assessment will lead to the needs of people with ME/CFS, being unmet, to their detriment.

Recommendations

Recommendation 31 – ME/CFS Australia recommends that plans remain centred around the individual needs of the participant, and not be determined by way of a fixed budget.

Funding For AAT

The NDIS is a complex and convoluted system for any able bodied, non-legal person to navigate. Indeed, for many legally qualified people, the system is still a significant challenge.

As it currently stands those who wish to be a part of the scheme, or remain in the scheme, or those who wish to challenge decisions made with respect to their funding and supports, the AAT is their only option. Despite the fact that these people have

disabilities, they are being expected to go up against the legally represented and fully funded NDIA legal team and argue their case in a purely legal framework.

ME/CFS Australia submits that this inequality of power is the antithesis of the scheme. The inability to put forth their case on a level playing field with the NDIS is completely at odds with the intention of the NDIS in terms of allowing people with a disability to fully participate in society.

ME/CFS Australia submits that for the sake of equity, fairness and consistency with the scheme itself, people should be allowed to access legal aid in order to obtain assistance to argue their case before the AAT where such case has a reasonable prospect of success.

Recommendations

<p>Recommendation 31 – ME/CFS Australia recommend that the Government should allow legal aid funding for disputes in the AAT in Tier 1 and Tier 2 disputes.</p>
