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PURPOSE, INTENT AND ADEQUACY OF THE DISABILITY SUPPORT PENSION: SENATE INQUIRY

Joint submission from
the Brisbane ME/CFS Support Group and
the Fibromyalgia, ME/CFS Gold Coast Support Group Inc.

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Introduction

Thank-you for the opportunity to provide a submission into this inquiry by the Senate Standing Committees on Community Affairs References Committee regarding the Purpose, Adequacy and Intent of the Disability Support Pension.
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/DisabilitySupportPensio

This submission has been prepared by and on behalf of over 530 people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and their carers residing in the Brisbane and Gold Coast.

Contributing organisations

- Brisbane ME/Chronic Fatigue Syndrome Support Group: https://www.facebook.com/groups/Brisbane.CFS.Support
- Fibromyalgia, ME/CFS Gold Coast Support Group: https://www.facebook.com/groups/goldcoast.fibromyalgia.cfs" https://www.facebook.com/groups/goldcoast.fibromyalgia.cfs

Erica Eele had worked in several senior and executive director-level policy and strategy roles across a variety of Queensland and Australian government organisations, including Queensland Health. She has been living with ME/CFS for over 5 years.

Kathy Dallest has 21 years of lived experience of ME/CFS and had a major relapse 5 years ago, forcing her to withdraw from her PhD studies in the School of Medicine at the University of Queensland. Her background is in nursing, community and public health, digital health informatics and research. She has worked in Australia and overseas in clinical, policy and program delivery roles including Scottish Government and NEHTA (now called the Australian Digital Health Agency. She also cares for an adult child with ME/CFS.

About ME/CFS and lack of DSP access

- ME/CFS is a severe, highly debilitating, complex, chronic illness that affects most bodily systems, particularly the nervous, immune, cardiac, gastrointestinal and endocrine systems (British Medical Journal, 2021; Carruthers & van de Sande, 2012; Carruthers & van de Sande, 2005; Health Council of the Netherlands, 2018; Institute of Medicine, 2015; Johnston, Staines, & Marshall-Gradisnik, 2016).
- It has been classified as a neurological disease by the World Health Organization (WHO) since 1969 (World Health Organization, 2010).
- Up to an estimated **250,000** Australian residents live with ME/CFS. **25 per cent** are so severe, they are housebound or bedbound (Institute of Medicine, 2015; Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019).
- Some are so severe that they, similar to the estimated **600,000** frail, housebound or bedbound people, are unable to leave home even to see a doctor (Alejandra Pinero de Plaza, 2021).
- Less than 6 percent of ME/CFS patients recover their full, pre-morbid health (Carruthers & van de Sande, 2012, p. 1).
- There is no cure for ME/CFS – only treatments for symptom management (Carruthers & van de Sande, 2012; Centers for Disease Control and Prevention, 2021).

Lack of access to the DSP poses serious risks to both ME/CFS patients and in turn, the Australian economy. Many ME/CFS patients are unable to maintain an adequate standard of living and afford appropriate medical care. Consequently, many ME/CFS experience prolonged, highly debilitating symptoms which may become permanent and/or result in early deaths.

- The NCNED estimates ME/CFS costs the national economy **$14.5 billion** per year (Close et al., 2020).
- Many people with ME/CFS die far earlier from suicide, cancer or heart disease than the general population (Johnson, Cotler, Terman, & Jason, 2020; McManimen et al., 2016).

Inquiry Terms of Reference

(b) the DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal

Many of the key issues outlined below reflect those outlined in the 2016 Submission 37, jointly submitted by several ME/CFS support organisations to the Joint Committee of Public Accounts and Audit's inquiry based on Auditor-General's report Number 18 (2015-16) Qualifying for the Disability Support Pension (ME Action Network Australia, ME/CFS Australia (South Australia) Inc., & ME/CFS and Lyme Association of Western Australia, 2016).

Lack of knowledgeable, training doctors

The first and foremost issue facing many ME/CFS patients in meeting the DSP's Impairment Tables is finding appropriate doctors and specialists who are also willing and able to write the often lengthy, detailed and specifically-worded reports required for DSP evidence (Joint Standing Committee on the National Disability Insurance Scheme, 2021, p. 14). Few doctors or specialists are sufficiently knowledgeable about ME/CFS' multi-system complexities (Institute of Medicine, 2015; Steven et al., 2000; Thomas & Smith, 2005. This lack of adequate training is despite ME/CFS being classified as a neurological disease by the World Health Organization since 1969 and the existence of internationally-accepted diagnosis criteria, such as the International Consensus Criteria and the Canadian Consensus Criteria (Carruthers & van de Sande, 2012; Carruthers & van de Sande, 2005; Carruthers et al., 2011). Indeed, the National Health and Medical Research Council's report on ME/CFS states:

> "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" (Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019, p. 12).

Outdated clinical guidelines and research

The dearth of knowledgeable and trained doctors is underpinned by the fact that many medical practitioners rely upon Australian CFS guidelines that are nearly twenty years out-of-date and fail to reflect internationally renowned biomedical research (Larkins & Molesworth, 2002).

Not only are the guidelines outdated, much of the recent, high-quality research is still not being adequately adopted by government agencies such as the NDIA and Centrelink. As the Chair of ME/CFS Australia Ltd., the national peak organization for ME/CFS, had testified regarding the NDIA at a recent NDIS Independent Assessments public hearing:

"…they're working off the bat of something that's three to four years old. I've obtained an outline. They did not provide me the actual advice they received, but the outline that they provided me had 19 references in a condition where there are 10,000 papers. There were 19 references, one of which was already outdated by the time I got it." (Joint Standing Committee on the National Disability Insurance Scheme, 2021, pp. 15-16)

No ME/CFS specialist field

Furthermore, unlike other serious, chronic illnesses such as cancer, no specialist medical field has claimed ME/CFS. The multi-systemic nature of ME/CFS therefore results in ME/CFS patients having to navigate and consult with multiple specialists and thereby endure substantial costs to try to meet the DSP Impairment Tables' requirement that the patient has been 'fully diagnosed, fully treated and fully stabilised.' Since currently no 'treatment' exists, doctors can only advise on symptom management.

PEM and fluctuating symptoms and severity

Another key barrier for ME/CFS patients is the fact that they suffer from 'post-exertional malaise'(PEM), the hallmark symptom of the illness, and few DSP assessors and clinicians understand it. PEM can fluctuate substantially in both symptoms and severity. The patient may be able to do a seemingly simple task or activity one day, such as talking for a few seconds or minutes, raising their arms or sitting up, but be totally unable to repeat it the next day. Or if they do attempt to repeat it, their health may worsen and/or they may take days, weeks or even longer to recover.

As outlined in the ME/CFS and the NDIS Group Submission regarding the Inquiry into Independent Assessments under the NDIS:

"PEM is a cardinal feature of ME/CFS. It is a pathological inability to produce sufficient energy on demand with prominent symptoms primarily in the neuroimmune regions (Carruthers et al., 2011).

The level of exertion involved in triggering PEM will vary depending on the severity of the individual. The more severe the ME/CFS, the less exertion it takes to trigger PEM. In severe cases, the exertion that triggers PEM may be as simple as taking a shower or walking. In very severe cases it can be as simple as having a conversation or brushing teeth.

Persistent or repeated exertion may lead to a deterioration of health and greater functional decline. Acute exercise can negatively impact neurophysiological processes in ME/CFS contributing to an exacerbation in symptoms including severe fatigue, headaches, muscle aches, cognitive deficits, insomnia, and swollen lymph nodes.

ME/CFS is often a relapsing-remitting disease with new symptoms occurring either in discrete relapses (or "crashes") or accruing over time (Tucker, 2016). The National Organization for Rare Disorders (NORD) states: "Symptoms and their severity can fluctuate over the course of the illness, even from hour to hour." (National Organization for Rare Disorders (NORD) The US National Institutes of Health notes that sensitivity to noise, light and chemicals may force patients to withdraw from society" (National Institutes of Health, 2016) (Reilly & Nelson, 2021).

The fluctuating and often delayed nature of PEM poses further challenges for ME/CFS patients in securing the requisite evidence to meet the DSP Impairment Tables. Often functional impairment tests such as neurocognition or exercise-related tests only record the functional capacity exhibited on the examination date but do not include the post-test PEM, which can render the patient incapacitated for days, weeks or even months.

GET/CBT: extremely harmful treatment

Furthermore, a key concern is that often DSP assessors require ME/CFS patients to do Graded Exercise Therapy/Cognitive Behavioural Therapy (GET/CBT), as recommended by the Australian clinical guidelines, to help demonstrate that the patients have been ‘fully treated’ (Larkins & Molesworth, 2002). Consequently, often ME/CFS patients face huge costs and endure enormous distress in seeking adequate medical diagnosis and ‘treatment’, they face a terrifying dilemma of risking significant worsening of their health via GET/CBT in order to secure DSP income.

This is despite the fact that in 2016 over 100 internationally renowned expert researchers of ME/CFS documented major flaws in the research on GET/CBT and called for reanalysis of the study data. Unfortunately, the findings from this flawed study has influenced clinical guidelines in many countries including Australia (Tuller, 2018). Research from Australia’s National Centre for Neuroimmunology and Emerging Diseases (NCNED) does not support GET/CBT as a treatment for ME/CFS (Marshall-Gradisnik & Staines, 2019.). The call to remove GET/CBT as a mandatory ‘treatment’ is reflected in the fact that the USA’s Centers for Disease Control no longer recommends GET/CBT (Centers for Disease Control and Prevention, 2021) and that the November 2020 UK NICE’s draft updated guidelines also removed GET/CBT as mandatory treatment recommendations for ME/CFS patients (National Institute for Health and Care Excellence, 2021). Final NICE guidelines are expected later this year. Furthermore, the Health Council of the Netherlands has also explicitly stated that social security medical disability assessors not make GET/CBT mandatory for social disability insurance.

“Medical disability assessors within the context of private and social disability insurance, the Social Support and Provision Act and the Long-term Care Act should recognise that ME/CFS is a serious disease that is accompanied by substantial functional limitations, and they should not regard a patient’s decision to forgo CBT or GET as inadequate recovery behaviour” (Health Council of the Netherlands, 2018, p. 4).

Implications for DSP assessment

DSP assessment-related problems arising from the above-mentioned hurdles include:

- Misconception that ME/CFS is a psychiatric, not a biophysical, disorder and therefore requires cognitive behavioural therapy and other psychological counselling. In particular, often clinicians believe that depression is a cause of ME/CFS therefore not a secondary symptom, due to the debilitating presence of severe multi-system symptoms including severe and unrelenting fatigue.

- Misconception that on the surface, people with ME/CFS ‘look well’ when sitting during a consultation or assessment and therefore do not have significant impairment. Consequently, the assessors overlook symptoms such as PEM which often arise after the meeting. Again, as the Chair of ME/CFS Australia Ltd testified at the NDIS Independent Assessment hearing:

  “It [ME/CFS] still requires appropriate assessments with knowledge of the condition and the nuances of the condition. You can’t take an individual based on one particular day, because, if you look at me today, your not going to put me on the scheme. Now, if I go home today and I’m in bed for the next five, then you have a substantial impairment.” (Joint Standing Committee on the National Disability Insurance Scheme, 2021, p. 14)

  “When you get to the bottom of what’s going on and you start to explore, beyond looking at an individual – and this is the problem: unfortunately, it doesn’t matter who it is, whether they’re disability-neutral or independent; they look at the individual and they make an assessment on what they see on the day…It depends on the day, the hour, the minute. The instruments that are being proposed do not capture that, cannot capture it, because, when you assess someone, do you assess them when they’ve done their two hours of preparation to go shopping, or do you assess them when they’ve come home after four hours, immediately hit the lounge and don’t appear outside for

another week?.. The fact that somebody gets to an office doesn't mean that they're capable of getting to the office; it means that they got to the office in order to be there for the assessment. It may have taken a week of rest in order to get there. They've got adrenaline running. The assessment itself is not a representation." (Joint Standing Committee on the National Disability Insurance Scheme, 2021, p. 15)

- Misunderstanding that since an ME/CFS patients can perform a task one day, e.g. they can speak coherently, that they may be fine the next and/or can perform other similar tasks. In other words, lack of awareness of the PEM that may follow a particular task. In actual fact, often ME/CFS patients engage with others, including doctors, when they are their best (but temporary) functional capacity and must spend days, weeks or longer recovering from even brief contact.

- Misunderstanding of why certain medications are prescribed to ME/CFS patients. For example, some patients use opioid addiction-related medications, such as Low-Dose Naltrexone, to manage chronic pain and inflammation.
- Overlooking the severity, multitude and diversity of ME/CFS symptoms due to the misleading term 'fatigue'. As outlined by the above-mentioned diagnostic criteria, ME/CFS is a multi-system chronic illness which has multiple symptoms. Furthermore, often ME/CFS patients have other co-morbidities such as fibromyalgia, irritable bowel syndrome, metabolic syndrome, sleep disorders, and depression (Institute of Medicine, 2015, p. 224).

(e) the capacity of the DSP to support persons with disabilities, chronic conditions and ill health, including its capacity to facilitate and support labour market participation where appropriate

DSP review processes harm and hinder labour market participation

Furthermore, the DSP assessment and review processes are so onerous, they tend to hinder, not facilitate, labour market participation among ME/CFS patients. Similar to the points listed above, many ME/CFS patients must endure an exceedingly distressing and often traumatising DSP assessment and review process. The constant doubt by assessors, the ongoing search for doctors and highly onerous and expensive task of evidencing 'fully treating' an illness that is actually 'untreatable,' often worsens their health and depletes their wallets. As a result, many ME/CFS patients remain too unwell to look for work or retain a job.

Indeed, recent ME/CFS patient studies have found that employment rates among ME/CFS patients are substantially lower than even the general population with disabilities.

- According to a survey by Emerge Australia, a national ME/CFS patient advocacy and support organisation, 53 per cent of survey respondents were not in work, training or education. Only 22 per cent were in part-time paid work (Emerge Australia, 2018, p. 35).
- By comparison, the employment rate of working-age people with disability in Australia was 48 per cent, with 60 per cent employed full-time and 41 per cent employed part-time (Australian Institute of Health and Welfare, 2020, p. 20).

(g). the adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations

DSP traps ME/CFS patients in poverty and disability

High medical costs

The DSP is not enough to live on and pay for high medical costs. Given the complexities of ME/CFS, many ME/CFS patients must undergo a substantial number of tests and medical consultations to manage their symptoms as well as meet DSP review assessments. According to recent research, on average, Australians with ME/CFS' out-of-pocket medical expenses exceed $18,000 per annum (Close et al., 2020). In particular, many ME/CFS patients are prescribed and use supplements, medications and complementary medicine, many of which are not reimbursable via Medicare, the Pharmaceutical Benefits Scheme or private health insurance.

High housing costs

People on low incomes, including DSP recipients, are unable to afford rental accommodation. In March 2021, only 1.2 per cent of private rentals were found to be affordable (defined as 30 per cent or less of overall income), according to Anglicare Australia's 2021 Rental Affordability Survey (Anglicare Australia, 2021).

Stigma and lack of support result in greater living costs for ME/CFS patients

Furthermore, many people with ME/CFS lack adequate supports due to widespread stigma and disbelief by family, friends, and clinicians (Cromby et al., 2015; de Carvalho Leite et al., 2011). While many people with more recognised chronic illnesses such as cancer or MS also face challenges in accessing support, ME/CFS patients face challenges of societal stigma, disbelief and neglect, similar to many other chronic invisible illnesses (Hale, Benstead, Lyus, Odell, & Ruddock, 2020). However, with ME/CFS, the situation is often likely to be substantially worse due to ME/CFS' lower recognition in society and the medical field, resulting in significantly high risks of isolation, family estrangement and functional impairment (Kingdon, Bowman, Curran, Nacul, & Lacerda, 2018; Nacul et al., 2011). As a result, people with ME/CFS are likely to rely even more heavily upon the DSP for daily living and medical costs due to lack of informal and formal supports from others to assist them with basics such as transport and accommodation. Consequently, their ability to maintain an acceptable standard of living in line with community expectations is often severely compromised.

DSP additional income test costs outweigh benefits

The DSP fortnightly income received by single persons on the DSP starts to decrease after just $178 per fortnight of additional income. The DSP is reduced by 50 cents for every additional dollar earned above the $178 per fortnight.[1]

Similar to other people with chronic illnesses, for many ME/CFS patients, working exacerbates fatigue, pain, cognitive impairment and many other symptoms. Therefore, the DSP additional income test actually disincentivises many ME/CFS patients to work. This is due to the fact that the reduced DSP income plus the

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[1] For example, the current situation for a single person on the DSP means that if, in one fortnight, the person earns a about $46/hour in paid work and works 13 hours, they would receive a total of $607.50 in job-related gross income. Consequently, they would receive a reduced DSP income of fortnightly $584.62. Therefore, in total, the person would end up with **$1192.12 per fortnight**. Given high housing and medical costs, this amount is still insufficient to allow for an acceptable standard of living in line with community expectations. The situation would be even worse for DSP recipients earning a lower hourly wage.

costs of further physical and mental debilitation often far outweigh the additional income earned from paid work, unless the paid work is exceptionally highly remunerated.

Impacts: ongoing poverty traps, suicide ideation and risks of early death

The inadequacy of the DSP, combined with the above-mentioned hurdles, results in many ME/CFS patients remaining too unwell to return to work, even part-time, due to the constant struggle and suffering from living below the poverty line and unaffordable medical care. Ultimately, many ME/CFS patients remain trapped in a never-ending cycle of poverty and debilitated health. Even more alarming is that the downward spiral of disability and destitution pose serious risks of suicidal ideation and early death (Devendorf, McManimen, & Jason, 2018; Jason, Corradi, Gress, Williams, & Torres-Harding, 2006; Johnson et al., 2020).

(j) the relative merits of alternative investments in other programs to improve the standard of living of persons with disabilities

Investment in research

Past government inquiries pertaining to the DSP appear to focus primarily on the costs of the DSP. However, it is pertinent to consider the relative merits of accelerated research investments into disabilities such as ME/CFS. Such research could make significant contributions for outcomes that matter to consumers, finding appropriate diagnostic methods and treatments and thereby reducing the, impact and severity and thereby enormous socio-economic costs of such debilitating chronic conditions.

For example, although the National Health and Medical Resource Council (NHMRC) committed in 2019 $3 million in research funding to ME/CFS (Australian Department of Health, 2019), the actual per capita amount is insufficient for gaining an adequate understanding of ME/CFS. Given the over 250,000 ME/CFS patients in Australia, that funding only equates to $12 per patient, which is a tiny fraction of research received by other, serious chronic illnesses. Furthermore, past research funding has been highly lacking (Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019, pp. v, 2), resulting in the current dearth of expert knowledge among both clinicians and DSP assessors.

Recommendations

Assessment

- Until the pathophysiology of ME/CFS is clearly understood and is captured in clinical and policy guidelines then all levels of medicine will have challenges in understanding the illness and providing appropriate care. Hence the research being undertaken at NCNED is vital in solving these aspects of the illness to better inform all levels of clinical management and policy making.
- Given the scarcity of ME/CFS-knowledgeable specialists, DSP assessments should not require a specialist report. A medical report outlining the individual's diagnosis, functional impairment and symptom management treatment from the ME/CFS patient's treating GP should suffice.

- GET/CBT should not be a required 'treatment' for ME/CFS since, as outlined above, there is no evidence for it . It has been resoundingly denounced by expert researchers into ME/CFS as it has been found to cause significant harm to ME/CFS patients.

- Expert clinicians in ME/CFS and allied health practitioners should be central to developing guidelines for DSP assessment of people with ME/CFS against the DSP Impairment Tables. The International Clinical Criteria (ICC) and the Canadian Consensus Criteria (CCC) are widely accepted for identification of functional impairments.
- Provide ME/CFS education for all DSP assessors, including Job Capacity Assessors and Centrelink-employed medical practitioners. The education materials should include an overview of the current, biomedical scientific literature about ME/CFS and co-developed with ME/CFS patients and research experts of ME/CFS.
- The DSP assessment process and assessors, particularly the DSP impairment tables, should be more flexible to allow for fluctuating conditions and severity.

DSP income and cost of living

- The level of DSP income received by DSP recipients should be substantially increased to enable patients with ME/CFS to afford housing, other essential costs and at least the above-mentioned estimate of $18,000 per annum, per person, in out-of-pocket medical expenses. The annual income amount should increase to be commensurate with Australia's Consumer Price Index increases.
- The DSP additional income test should have a higher threshold beyond the current $178 per fortnight and deduct less than the 50 cents per each dollar earned. Ultimately, the threshold and deductions should be calculated based upon an assumption that the combined a) DSP adjusted income and b) the paid work income equate to a sufficient amount to afford housing, medical costs and other essential cost of living expense.

- For spouse income-related calculations, enable the system to cater for monthly calendar salary reporting to ensure consistent fortnightly income is received by the DSP recipient. Alternatively, maintain the same annual salary level calculation when the salary remains unchanged.

ME/CFS patient quotes

1. “I didn’t apply for DSP as I was a single Mum, struggling along as it was and couldn’t afford for my health to go down any further due to the stress of applying and having to attend more appointments than I already was. I weighed it up and it was just too much for me personally. I needed to concentrate on my health foremost to ensure I could still function for my children. I really don’t think I could’ve coped with it mentally at that time either. So yes, I agree with number 4 re the process negatively impacting me.” Anonymous

2. “I've been on dsp [sic] for years always reported my husbands [sic] salary annually. So got fortnightly payments the same all year. Since dec [sic] we have to report fortnightly. I spent over three months and over 15 hours on the phones with them trying to sort it out. Everyone i [sic] spoke to changed the coding and what the previous [sic] person had done. I went to management [sic] they couldn't understand either. My husband gets paid last day of the month for period 1st to last day. Hes [sic] annual salary no ot etc.

   But they are working it out incorrectly. So now my dsp [sic] is very small one fortnight and then my normal payment next fortnight. How can the payments be so much less than previous [sic] years?

   My Mp [sic] tried to sort it as well but cant. [sic] The algorithms are incorrect for annual salary income.

   Eg [sic] last year I got $238 a fortnight. This year $90 one fortnight $250 next fortnight. How can the one fortnight payment be so much less when his income has not increased. [sic]

   I'm now reporting $0 one fortnight and whole monthly [sic] payment the next fortnight. But next month because of the reporting days I have two reporting days of $0 because they fall before the end of the month. Its [sic] going be another nightmare sorting it out:(

   Let annual salary do it the same as before. Its [sic] made it more complicated and their system is not catered for monthly calender [sic] month salary eg [sic] 1st to 30 th [sic]. Especially when its [sic] salary and doesn't change , no overtime or anything.” Anonymous

3. “I have Me/Cfs [sic] and found applying for DSP a very long and difficult process negatively impacting my health contributing to making my condition worse. I also found the whole process upsetting, stressful and traumatic. On many occasions, Centrelink would not accept my medical certificate even though I was unfit for work. Many times I was not up to attending appointments resulting in my then Newstart payment being cancelled and having to wait on hold for lengthy periods to try to sort it out. I was told I had to look for work or my payment could be suspended. I had knots in my stomach each time I made a job contact for work I was not able to do. On top of having debilitating chronic illness, I felt intimidated and very much abused. I was told by Centrelink in order to meet “fully stabilized and treated” requirements, I had to undertake GET again and if it made my condition worse, then they would look at the Tables (when Centrelink already had evidence that GET had made my condition worse). I never would have put myself through that again if I did not need DSP. I felt that I was abused.” Anonymous

4. “The process of making a claim for DSP was traumatizing. Not only did my GP not understand what needed to be done, I had no idea and no-one at Centrelink would give me any clear advice or guidance. The whole experience was deskilling, devaluing and demoralizing. After many specialist appointments and pulling information together at the same time as being extremely impaired and

hardly able to function [sic] I submitted my claim. After a job capacity assessment [sic] I was rejected and when I finally got access to the outcome of the JCA there were many misrepresentations of the facts and of the information I gave in the interview. My health and wellbeing deteriorated. I felt I wasn't listened to, was misunderstood, discarded and I gave up." Anonymous

5.

a. **the purpose of the DSP;**

The purpose should be to provide full and adequate financial support required to achieve daily living standards re accommodation, food, medical/health/ disability expenses.

b. **the DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal;**

The eligibility, assessments and evidence are appropriate, however how a person demonstrates this is far too complicated. Medical practitioners flatly refuse to support a person's application because it's too complicated for them to navigate and they are not paid adequately for their time to support a patient. Saying that a report by a medical practitioner isn't required but to instead provide current medical records if [sic] the first instance, allows for non-medically trained persons to make judgement calls. Then if the application moves forward, the Job Capacity Assessor (JCA) may also lack necessary medical understanding based on medical documents they've never been trained to analyse. Finally, if the JCA accepted the applicant is fully diagnosed, treated and stable with incapacity to work more than 15 hours per week, the final stage is a contracted medical practitioner who only purpose is to confirm decisions made by non-medically trained people. It's rare that an applicant gets through to the contracted (Sonic) medical assessment and is then denied as being 'not' eligible.

It was my experience to make it through to the JCA where the assessor made the arbitrary decision my condition was not permanent. However, the guidelines clearly state ME/CFS is a condition deemed permanent for disability support. The JCA also determined I was not fully treated as I had not tried what is currently deemed 'evidence based' treatment. That the JCA was an exercise physiologist (EP), it was apparent in our interview that he 'personally' felt I hadn't 'tried hard enough' to get past the deconditioning he considered to be the problem. He disregarded recent medical research evidence and continued to follow the outdated and harmful stance of Graduated Exercise Therapy used for those with fibromyalgia, MS and other such conditions which typically do improve with such treatments. But do they significantly improve disability to allow a person to work more than 15 hours per week? That was the question which this EP did not consider in my application. He failed to apply my work capacity.

On rejection, I was also informed that I was not eligible because I had not provided a copy of a specialist letter confirming diagnoses. This was an error on my part where I had inadvertently up-loaded two copies on the same report, instead of the specialist's letter as necessary. Once I realised it was a simple matter to upload the documents and add even further documents subsequently acquired for the review. Much to my shock, the reviewer up-held the decision. And, even worse, the so called 'independent' reviewer had simply copied and pasted paragraphs from the JCA report. This to me, begs the question: did I get an independent review as required? Or did the JCA do the review maintaining his professional prejudices to the condition involved?

On Administrative Appeal Tribunal (AAT) the member over-turned the decision providing I had supplied 'substantial' evidence of being fully diagnosed, fully treated and stable; I had provided a confirmation of diagnosis by an appropriate specialist; and I met 20 points on table 1 and 30 points on table 7; plus evidenced my incapacity to work more than 15 hours per week. The member's 32-page decision was filled with the evidence I had initially submitted and on which she made her decision to award me the DSP.

c. **the impact of geography, age and other characteristics on the number of people receiving the DSP;**

I live in a rural area (MMM5), which with being mostly housebound made updating medical records to submit difficult. As my condition had been stable for over a decade, I was not currently seeing a specialist and only seeing my GP for basic health care and management (regular bloods and scans as recommended to healthy patients). I was not able to apply for DSP earlier due to my husband working full-time to pay for my extraordinary medical bills and living expenses.

d. **the impact of the DSP on a disabled person's ability to find long term, sustainable and appropriate, employment within the h she made her decision open labour market;**
e. **the capacity of the DSP to support persons with disabilities, chronic conditions and ill health, including its capacity to facilitate and support labour market participation where appropriate;**
f. **discrimination within the labour market and its impact on employment, unemployment and underemployment of persons with disabilities and their support networks;**
g. **the adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations;**

Those with disability spend more on medical/disability costs including household goods and food. Without an income or suitable funding, they are unable to receive the basic care afforded to everyone else in the community. Government and pensioner rebates do help, but that does not cover expensive specialist foods and supplements or off-label medications prescribed. I found applying for electrical medical rebate for medical equipment from either state or federal difficult as a person who is mostly housebound very difficult. Being able to supply forms signed by a doctor in order to access rebates meant I did access rebates. Having to make an appointment and likely incur cancellation fees for a specialist to sign a piece of paper is so out of touch with the needs of severely disabled housebound/bedbound people. There are expenses for special pillows and supports, toothbrushes, and more which NDIS do not cover as they're are not for functional disability but my health condition. (So even if I have NDIS funding which I could use, I'm not allowed to and face being liable to refund and also risk future funding).

h. **the appropriateness of current arrangements for supporting disabled people experiencing insecure employment, inconsistent employment, precarious hours in the workforce; and inequitable workplace practices;**
i. **the economic benefits of improved income support payments and supports for persons with disabilities, their immediate households and broader support services and networks;**

The benefits that are seen from NDIS supports in social, community and economic participation should also be recognised as occurring with DSP. With a suitable pension, it allows spending in local shops and businesses, improving social and family relationships as affordability is no longer a barrier. Those who are not eligible for taxi rebates, or face community supports which have a co-payment and that don't allow the transport of walkie wheelers or don't help carry bags, literally are just to drive the vehicle without any support. This prohibits access to the community. Having adequate funding will improve spending in the community but also improve access. It will stop disability being hidden behind closed doors, being ignored and unseen. Acceptance of the LGBTQI after the referendum has allowed that section of the community to live free and openly, while disability is still looked upon as failure, disgrace and unworthy of being seen in the community and even if possible, employed in workplaces.

j. the relative merits of alternative investments in other programs to improve the standard of living of persons with disabilities; and

The NDIS is an invaluable investment to improve the standard of living for persons with disability. It is not a replacement to income and will not cover typical daily living expenses. But when both areas are appropriately funded for the individual's needs, the outcome to society and the community and for the individual is massive. And much closer to the expectations of the community in caring for those who are suffering and unable to live to the standard every human has a right too. It's a travesty seeing the number of 'Go Fund Me' being necessary so that people can get a necessary item or food, e.g. parents needing to buy a specific vehicle in order to transport their wheel-bound child (NDIS will cover the modifications etc., but the parents are not able to be sufficiently employed to save or borrow for a $70-90k vehicle).

k. any related matters.

Eligibility - even though the DSP and NDIS criteria are different, there is enough of an over-lap in eligibility which should allow for reduced information being needed to gain access to DSP.

NDIS requires the person have permanent severely functional disability or psychosocial disability, have been appropriately diagnosed, tried all evidenced based treatments and have attempted any known treatment which may significantly improve the disability.

Should a person have met this eligibility and therefore are an NDIS participant when applying for DSP, then it's a matter of incapacity to work more than 15 hours per week that is the qualifying factor i.e. meeting 20 points on a single table and confirming diagnoses by a specialist doctor. This would reduce the cost of the same details being provided, as currently doctors are asked to re-rewrite the same details with different emphasis and wording. The NDIS and Australian Services already ask that information be shared regarding eligibility in being an Australian citizen etc. So, this confirmation that the applicant is an NDIS participant which requires 'lifelong support' (not only the next 2 years) is just a tick in the box." R

List of acronyms

AIHW – Australian Institute of Health and Welfare

CCC – Canadian Consensus Criteria

CFS - Chronic Fatigue Syndrome

DSP – Disability Support Pension

EP – Exercise Physiologist

ICD – International Classification of Diseases

JCA – Job Capacity Assessment

ME - Myalgic Encephalomyelitis

NCNED - National Centre for Neuroimmunology and Emerging Diseases

NHMRC – National Health and Medical Research Council

NDIS - National Disability Insurance Scheme

PEM – Post-exertional Malaise

WHO – World Health Organization

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