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SUBMISSION TO THE REVIEW OF QUEENSLAND'S ANTI-DISCRIMINATION ACT 1991

Joint submission by Fibromyalgia ME/CFS
Gold Coast Support Group, Inc. and
individuals with ME/CFS

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2. Introduction

Thank-you for the opportunity to provide feedback regarding the Queensland government's review of the Anti-Discrimination Act (ADA) 1991. This document is to augment Erica Eele's feedback provided during the QLD Human Rights Commission's (HRC) online focus group co-organised with Queenslanders with Disability Network (QDN) on 4 February 2022. The following input is from people in Queensland and other Australian states with Myalgic Encephalomyelitis (ME), also sometimes known as Chronic Fatigue Syndrome (CFS).¹ (Carruthers & van de Sande, 2012; Carruthers & van de Sande, 2005)

Erica Eele has nearly 6 years of lived experience of ME/CFS. As the founder and member of the Brisbane ME/CFS Support Group, she is a prominent advocate in the Australian and Queensland ME/CFS community as well as a member of QDN, Women with Disabilities Australia. Erica has also worked on collaborative, disability-inclusion-related research projects and programs of the University of Sydney's Centre for Disability Research and Policy and QDN. Furthermore, Erica has conducted academic research on international/United Nations Convention-related human rights. Additionally, she has worked in several senior and executive director-level strategy and policy roles across a variety of Queensland and Australian government organisations.

Kathy Dallest has 22 years of lived experience of ME/CFS and experienced 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.

Contributing organisations

- National Advisory Advocacy Council for ME/CFS Research Ltd.
<https://www.naac-mecfs.org>
- Fibromyalgia, ME/CFS Gold Coast Support Group, Inc.
<https://www.facebook.com/groups/goldcoast.fibromyalgia.cfs>

Human rights and socio-economic significance of strengthening the Anti-Discrimination Act

As per the findings of Australia's Disability Royal Commission, people with disability (PWD) comprise some of Australia's most vulnerable members and therefore the ADA is key to Australia meeting its commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Furthermore, as the Australian population ages, PWD will comprise a growing proportion of the nation's total population. Consequently, the socio-economic and human rights imperatives of developing a robust and comprehensive Anti-Discrimination Act in Queensland will also increase.

¹ In research literature and government documents there are a variety of names used for ME/CFS, due the debates regarding definitions and diagnostic criteria.

3. Summary of ADA recommendations

The following are the recommendations for the revised ADA:

Recommendation 1: conduct further study of the epistemic situations in the healthcare of people living with ME/CFS.

Recommendation 2: use both the terms ‘disability’ and ‘impairment’ to define disability-related discrimination.

Recommendation 3: protect people from discrimination if they have an assistance animal.

Recommendation 4: protect people who have assistance animals other than hearing, guide, or assistance dogs.

Recommendation 5: protect people from discrimination because of their physical features.

Recommendation 6: recognise ‘intersectional discrimination’ whereby people often experience discrimination because of the combined effect of more than one of the sixteen ‘attributes’, such as sex, age, impairment, or race.

Recommendation 7: weaken the ‘unjustifiable hardship’ loophole and reduce the number of ‘unjustifiable hardship’ exemptions.

Recommendation 8: replace the term ‘equality’ with ‘equity’ since equity explicitly recognises the fundamental disadvantage faced by PWD.

Recommendation 9: the review of the ADA engage academics who have expertise in both economics and disability to develop cost-benefit analyses methodologies used in ascertaining ‘unjustifiable hardship’, ‘reasonable accommodations’ and ‘reasonable adjustments.’

Recommendation 10: include positive duty for all organisations, landlords and employers to make reasonable adjustments or reasonable accommodations.

Recommendation 11: the positive duty requirement should apply not only to the current areas of goods and services, work, education, and accommodation but also to *all areas*, including medical research.

Recommendation 12: the QLD Human Rights Commission (HRC), Community Legal Centres and Legal Aid must be fully resourced to enable PWD to easily lodge and pursue complaints. Sufficient financial, logistical, and social supports and easier complaints processes must be provided to enable PWD to lodge and pursue complaints. ‘Unconscious bias’ must be explicitly recognised and addressed in the ADA.

Recommendation 13: extend the ADA’s current scope to also include explicitly:

1. Medical research
2. AI – for example, the needs of PWD must be embedded in the algorithms that inform AI.
3. Domestic and family violence
4. Disaster preparedness, response, and recovery planning
5. Representation and portrayal of PWD in both non-digital and digital media.

Recommendation 14: QLD HRC or another specialist body should have the powers to set guidelines and require compliance. Such powers should complement and strengthen, rather than confuse or weaken, current national legislation, such as the Disability Discrimination Act, in providing preventative ways to proactively end systemic discrimination.

Recommendation 15: other state and national legislation must not weaken/compromise the ADA

Recommendation 16: Queensland should have a specialist Anti-Discrimination Tribunal, not the more generalist bodies such as the Queensland Civil and Administrative Tribunal (QCAT) and the Queensland Industrial Relations Commission (QIRC), to deal specifically with anti-discrimination matters, particularly those involving disability-related discrimination.

Recommendation 17: PWD complainants should not be forced into signing non-disclosure agreements.

4. Discrimination

An estimated 250,000 Australians, including over 45,000 Queensland residents, have ME/CFS.²(Carruthers & van de Sande, 2012; Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019) Due to the multiple types of functional impairment, people with ME/CFS face substantial disability-related stigma and therefore discrimination. (#MEAction, 2022; Hallmann et al., 2014) Some areas of discrimination include:

1. Built environment/infrastructure, transport, and employment:

- 1.1. **Wheelchair access** – no/insufficient wheelchair access at workplaces, schools, cafes, and other public places. Scooters obstruct sidewalks. Many neighbourhoods do not have footpaths at all, resulting in extreme difficulty for wheelchair access. Taxis and other public transport lack sufficient wheelchair access.
- 1.2. **Noise** – most shops, buildings and public transport lack noise-minimisation solutions (e.g., carpets, thick walls, insulated floors to minimise noise). For people with hyperacusis, this results in inaccessibility to such facilities and venues.
- 1.3. **Smells/Fragrance** – no bans exist on fragrances, including fragrances embedded in products, e.g., liquid soap. The diesel smell from buses also worsens symptoms. Yet about 20% of Australians have Multiple Chemical Sensitivities (MCS). (Steinemann, 2018)

“Over my lifetime the discrimination that’s been most difficult is the one from medical and allied health practitioners.

I can’t tell you the number if [sic] doctors [sic] offices/suites or clinics I’m unable to access due to the building access - no ramps, small door ways [sic], no suitable toilet facilities [sic]. And, due to chemicals - safe accessible spaces to wait. I’m forever sitting on footpaths waiting so as to reduce exposure and harm.

These things have caused me and my care great anxiety anytime I leave home to attend new places. Website details and signage at the properties are very poor. The receptionist lack [sic] training to even know about good access and needing low chemical safety spaces. It’s a case of “suck it and see” approach which is not how everybody else approaches access to the community and health needs.”
(Anonymous person with ME/CFS)

² This is based upon a 1% prevalence rate, as per the ME International Consensus Criteria.

- 1.4. **Light** – light-sensitive people are unable to tolerate bright/flickering light. Yet most public areas, such as shops, schools and offices use bright lighting. Similarly, many websites and mobile applications are inaccessible due to the usage of high contrasting colours and image enhancements, such as flickering .gifs, blurring and many more.
- 1.5. **Sight** – not all websites and apps support Web Content Accessibility Guidelines (WCAG). Furthermore, even the current WCAG does not adequately address the above-mentioned accessibility issues of light-sensitive people.
- 1.6. **Touch** – pain sensitive-people are unable to tolerate hard seating in public areas. Furthermore, risks of bumping into people in crowded areas, such as peak-hour trains, pose significant accessibility issues.
- 1.7. **Extreme temperatures intolerance** – areas with no heat reduction (e.g., insulation, ceiling fans, A/C and blinds) are intolerable to PWD who have impaired body temperature regulation capabilities. (Bruno & Summers, 2014; Summers & Simmons, 2009)
- 1.8. **Reach/mobility/lifting** – many facilities (e.g., shelves) are out-of-reach for people with limited carrying and/or lifting capacity.
- 1.9. **Insufficient toilet facilities** – many public areas, including cafes, lack sufficient toilet facilities. This negatively impacts people with urinary issues, such as incontinence.
2. **Disaster planning** - the above considerations are rarely, if at all, included in disaster planning and social services.
3. **Media representation** – PWD remain disproportionately under-represented in media and advertising.
4. **Health research** – PWD, particularly women with auto-immune diseases and ME/CFS, are often seen by medical professionals as just being hysterical when in distress and/or discussing symptoms. Consequently, such health conditions remain heavily under-researched despite their high prevalence. (Brea, 2017; A. A. Mirin et al., 2020)
5. **Welfare and social services** – many people with invisible, energy-limiting chronic illnesses (ELCI), particularly conditions that are less recognised, miss out on welfare and social services such as the NDIS and the Disability Support Pension. (Hallmann, 2018; ME/CFS Australia Ltd, 2021a, 2021b)
6. **IT and Artificial Intelligence (AI)** - emerging algorithms that impact artificial intelligence often omit the needs of PWD. For example, the timing of crosswalk lights is too short and negatively affects people with limited mobility. Similarly, some voice-recognition technologies often malfunction if a person has a speech impairment.

Additional discrimination experienced by ‘invisible’, energy-limiting, chronic illnesses

Similar to other people with energy-limiting chronic illnesses (ELCIs), such as back pain and Multiple Sclerosis, many people with ME/CFS endure additional discrimination due to the seemingly ‘invisible’ nature of their symptoms. Often, ME/CFS is not seen as a valid ‘disability.’ Consequently, despite missing out on access

“I have faced discrimination from other disabled people because they did not acknowledge or appreciate my disability because it's invisible, while calling for their rights as disabled people to be enforced (not considered but enforce, as if privileged over ‘every’ other person).” (Anonymous person with ME/CFS)

to ADA-related areas such as employment³, transport and housing, people with ME/CFS face added discrimination in areas such as access to the NDIS and the Disability Support Pension, compared to other people with more well-recognised disabilities.

Medical discrimination and neglect

People with ME/CFS experience substantial medical discrimination and neglect which stems from ME/CFS' stigma as 'just being in a patient's head' and not a real medical condition. (#MEAction, 2022; Froehlich et al., 2021) Despite the high prevalence of ME/CFS, over half of health practitioners receive little or no medical training regarding ME/CFS. (Institute of Medicine, 2015; Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019)

Furthermore, despite the large, high quality and growing body of biophysical research, Australia's current ME/CFS clinical guidelines are nearly twenty years old and reflect highly harmful, outdated practices such as Graded Exercise Therapy/Cognitive Behavioural Therapy (GET/CBT) (Larkins & Molesworth, 2002), despite over 100 internationally renowned ME/CFS researchers denouncing GET/CBT (Tuller, 2018) and both the USA's Centers for Disease Control and Prevention (USA Centers for Disease Control and Prevention, 2022) and the UK's 2021 National Institute for Health and Care Excellence (NICE) ME/CFS Guidelines have softened their stances in recommending GET/CBT as a mandatory approach to managing ME/CFS. (National Institute for Health and Care Excellence & Royal College of Physicians, 2021) Consequently, many practitioners believe that ME/CFS is a psycho-social condition that just exists within the patient's head and prescribe harmful treatments such as GET/CBT. Many people with ME/CFS have reported their doctors and other medical authorities disregarding, disbelieving or, even worse, laughing at them. This lack of medical validation and stigma creates enormous additional discriminatory barriers for people with ME/CFS in

"Being young and double vaxxed [sic], no doctor or person I've tried to talk to about it has believed I'll have ongoing symptoms.

I tried to see one doctor who was very dismissive, disbelieved and questioned pretty much everything about my medical history and didn't listen or help at all. It was awful. Normally if I have to see other doctors I don't even mention chronic health issues because it's so hard. But now I have to, and I have no idea what to do. I've been putting it off as long as possible! I feel like GPs want you to go in with one easy straightforward problem and then they send you off.

How do you bring up all your issues without being overwhelming, especially if you look young and healthy? How do you get brave enough to go?

I'm so exhausted I'm worried I won't be able to string a coherent sentence together let alone make them believe me about both me/cfs [sic] and ongoing covid complications in one go!"

(Anonymous person with ME/CFS)

³ For example, the Australian Institute of Health and Welfare states that 10% of working-age people with disability are unemployed. However, ME/CFS patient organisation Emerge Australia's 2018 research found that 53% of their survey respondents with ME/CFS were unemployed. (Ref: *Health and Wellbeing Survey of Australians with ME/CFS: Report of key findings*, Emerge Australia. 2018)

obtaining vital supports and services and seriously worsens their health. (Cromby et al., 2015; Devendorf et al., 2018; Hallmann et al., 2021)

Epistemic injustice in healthcare

Patients and health practitioners exchange and interpret knowledge in clinical settings. Many people with ME/CFS complain about not being listened to, believed or trusted as first-hand ‘knowers’ of their experiences and have difficulties in trying to make themselves understood. Negative stereotypes of ME/CFS have existed in Australia and overseas for decades, reinforced by out of date clinical guidelines and evidence based practice (EBP) practice ideals which are not relevant to the lived experience. This bias and tension is often reported by people with ME/CFS as a marginalisation of their knowledge and experience resulting in a reluctance to engage with healthcare and a consequential diminishing quality of life and health status, until they find the energy and courage to engage once more. Additionally, efforts to examine how contemporary healthcare reform could minimise epistemic injustice and open a pathway to improving quality of life for people with ME/CFS would be most welcome. This perspective sits well within the remit of the review of the ADA.

Recommendation 1: Conduct further study of the epistemic situations in the healthcare of people living with ME/CFS

Under-funding of ME/CFS bio-medical research

ME/CFS-related discrimination is also exacerbated by the chronic under-funding of ME/CFS bio-medical research. According to data received by ME/CFS South Australia Inc. from the National Health and Medical Research Council (NHMRC), until 2019, ME/CFS-related funding was approximately 1/179th of the amount of NHMRC funding devoted to MS, despite the higher prevalence of ME/CFS and research that has found that ME/CFS functional impairment far exceeds that of MS. (Kingdon et al., 2018) Furthermore, the NHMRC research funding from 2000 to 2016 that was supposed to be devoted to ME/CFS was instead used for more general psychological/psychiatric research or other focus areas such as Gulf War Syndrome. ⁴

Table 1: Prevalence and NHMRC Funding of ME/CFS and 6 Other Diseases

<u>Disease</u>	<u>Prevalence 2018</u>	<u>NHMRC Funding 2018</u>	<u>Per Person</u>
Dementia, ALL	436,366	\$62,216,184	\$142
Breast Cancer	68,824	\$22,731,167	\$330
HIV/AIDS	(2017) 27, 545	\$15,739,945	\$571
Parkinson's	81,000	\$9,264,582	\$114
MS	25,600	\$4,585,224	\$179
ME/CFS	Conservative 101,000	\$0*	Previous years \$1

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Similar under-funding trends have been reported in the USA. Recent research found that “the disease burden of ME/CFS is double that of HIV/AIDS and over half that of breast cancer. We also find that ME/CFS is more underfunded with respect to burden than any disease in NIH’s analysis of

⁴ Source: spreadsheet received by Erica Eele on 12 March 2019 from: Richard Tooth, Data Architect, Data Analytics and Reporting Section, Corporate Operations and Information, National Health and Medical Research Council

⁵ Source: *Briefing Notes on ME/CFS*, ME/CFS South Australia. Statistics included in email from NHMRC to ME/CFS Australia (SA) on 25 February 2019

funding and disease burden, with ME/CFS receiving roughly 7% of that commensurate with disease burden.” (Arthur A. Mirin et al., 2020, p. 1)

Gender discrimination in health research

Much of the above-mentioned medical neglect has been attributed to underlying gender discrimination in the medical field (Mirin, 2021): the fact that the majority (80%) of ME/CFS patients are women and that, as mentioned above, many doctors trivialise women’s health symptoms as simply due to ‘hysteria.’ (Brea, 2017)

5. Impacts of discrimination on people with ME/CFS

- **National economic losses** - The National Centre for Neuroimmunology and Emerging Diseases estimates ME/CFS costs the national economy \$14.5 billion per year. Most of the costs, 94% are born by the patient. (Close et al., 2020) Furthermore, since most ME/CFS patients are between 29 and their 30’s at ME/CFS onset (Johnston et al., 2016) and since many end up permanently unemployed, the economic losses are even greater when calculated over an ME/CFS patient’s lifetime.
- **Poverty** - Many people with ME/CFS become trapped in severe poverty. According to a 2018 survey of people with ME/CFS, the majority receive no income, not even Centrelink welfare benefits. (Emerge Australia, 2018, p. 36)
- **Domestic and family violence** – The above-mentioned poverty trap, high levels of isolation and heavy reliance upon others leave many people with ME/CFS vulnerable to domestic and family violence, including abuse, gaslighting and neglect.
- **Worsening health** - Less than 10 percent of ME/CFS patients recover their full health (Carruthers & van de Sande, 2012) and many end up with worsened health, including permanent disability. (Devendorf et al., 2018)
- **Early death** - Many people with ME/CFS die far earlier from suicide, cancer, or heart disease than the general population. (Devendorf et al., 2018; Johnson et al., 2020; McManimen et al., 2016)

6. Definition of ‘impairment’ vs. ‘disability’

Recommendation 2: Use both the terms ‘disability’ and ‘impairment’ in the ADA.

Disability

I recommend using the UNCRPD definition of disability since it recognises both functional impairment as well as the social model of disability:

“Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” (United Nations, 2006)

Impairment

To further define the meaning of ‘impairment’, I support continuing to use the ADA’s current term ‘impairment’ with the following modifications:

- ‘Disability’ and ‘impairment’ should include not just the more commonly recognised, visible and/or well-known conditions e.g., people using a wheelchair, blind and deaf people, people with autism and Down syndrome. These terms should also include ELCIs, such as the over 50 conditions listed in the International Classification of Diseases. (Hale et al., 2020)

- Evidencing ‘impairment’ should not rely entirely upon official medical diagnosis and testing. This is because many chronic conditions, such as ME/CFS, do not yet have a single test and as mentioned above, many doctors are insufficiently trained to properly diagnosis and thereby verify and validate the impairment.
- ‘Bodily’ functions should be changed to ‘body’ functions because ‘bodily’ is often subconsciously inferred to only mean incontinence-related issues.
- ‘Malfunction’ should be more explicitly defined to include non-function, inappropriate function, deficiency, or over-reaction, e.g., an over-reactive and under-reactive thyroid. It should also include ‘immune impairment,’ ‘immuno-compromised,’ ‘immune dysfunction,’ and ‘immune dysregulation,’ since apparently these terms entail different medical nuances.

7. Assistance animals

People with disability who have a guide, hearing, or assistance dog are currently protected from discrimination. But the law does not protect people who have assistance animals other than dogs.

Recommendation 3: Protect people from discrimination if they have an assistance animal.

Recommendation 4: Protect people who have assistance animals, including pets used for mental health assistance, other than hearing, guide, or assistance dogs. Many PWD who have mental health conditions, such as depression and anxiety, rely upon other pets to help manage their mental health.

8. Physical features discrimination

The law does not currently protect people from discrimination because of their physical features, which includes a person’s height, weight, size, or other features of their bodies or faces. For example, the media often omits including portrayal of people with different physical features. This invisibility exacerbates ‘unconscious bias’ towards and devaluing of people with different physical features.

Recommendation 5: Protect people from discrimination because of their physical features.

9. Discrimination on combined grounds

Recommendation 6: Recognise ‘intersectional discrimination’ whereby people often experience discrimination because of the combined effect of more than one of the sixteen ‘attributes’, such as sex, age, impairment, or race.

The fact that First Nations peoples experience disproportionately higher prevalence and severity levels of disability (Australian Institute of Health and Welfare, 2021) exemplifies intersectional discrimination. Furthermore, First Nations peoples, many with severe mental and/or intellectual disabilities, are disproportionately incarcerated, a terrible consequence of their combined discrimination. Similarly, the extremely high rates of poverty and increasing homelessness among older women with disability illustrate the consequences of intersectional discrimination. (Faulkner & Lester, 2020)

10. Unjustifiable hardship

Recommendation 7: The ‘unjustifiable hardship’ loophole must be weakened and exemptions reduced. We recognise that the ADA Discussion Paper states that determining unjustifiable hardship involves trying to “strike the right balance between the rights of people with disability and the competing interests of employers, schools, accommodation providers and others, having regard to the overarching goal of promoting equality and inclusion.” (Page 39) However, ‘unjustifiable’ and

'reasonable' adjustments are likely to often be skewed in favour of able-bodied people's norms, particularly since they currently comprise the socially and numerically dominant part of the population.

For example, the Australian Human Rights Commission granted Queensland Government and Queensland Rail temporary exemptions under the Disability Discrimination Act regarding Queensland's New Generation Rolling (NGR) Train Project which entailed a new fleet of trains. This exemption enabled the project to significantly dilute transportation accessibility for people with disability. These sorts of exemptions must stop to avoid further undermining of the DDA and the ADA. (Australian Human Rights Commission, 2018)

Equity principle

Recommendation 8: The term 'equality' should be replaced with 'equity' since equity explicitly recognises the fundamental disadvantage faced by PWD. Whereas 'equality' simply sets the same standard bar against which the two parties must try to reach, regardless of pre-existing disadvantage. Consequently, PWD will often end up losing out to the able-bodied majority.

Cost-benefits analysis methodologies

We are unable to provide a well-informed opinion pertaining to the more technical details of ascertaining unjustifiable hardship, its exemptions, and associated cost-benefits calculations, including the compliance costs for business and organisations, as it is not my area of expertise.

Recommendation 9: the Review of the ADA should engage academics who have expertise with both economics and disability to develop relevant cost-benefit analysis methodologies.

11. Reasonable accommodations and 'positive duty'

Apply positive duty to all areas of life

Recommendation 10: adopt a positive duty for organisations, employers, and landlords to make reasonable adjustments or reasonable accommodations.

"When applying for jobs and in employment etc you can ask for 'reasonable adjustments', who determines what is reasonable? It's to [sic] easy for able bodied people to not understand what is 'reasonable' for disabilities that can affect an individual very differently.

In education for example my daughter is dyslexic so extra time was granted for tests/exams etc [sic] but it didn't really help her. She could have better educational success if her assessments were verbal. Trying to fit people into boxes and generic criteria doesn't always work." (Anonymous person with ME/CFS)

Recommendation 11: Furthermore, the positive duty requirement it should apply not only to the current areas of goods and services, work, education, and accommodation but to *all areas*, including medical research.

Equity principle and human rights

Similar to my above-mentioned points, determining what constitutes ‘reasonable’ should be based upon the principle of equity to recognise the socially constructed, disadvantaged position of PWD in being able to achieve the same outcomes and fully enjoy the same human rights as able-bodied people, unless appropriate supports or adjustments are provided.

“Employers are generally sneakier than this. They are smart enough not to directly decline accommodation requests & instead find more banal reasons to end someone’s employment. Also, few employees are confident enough to advocate for themselves for accommodations.

In my experience, more complex accommodations (beyond new office chairs & ergonomic mice etc) only really happened successfully when a skilled advocate was involved (eg [sic] Vision Australia or Spinal Injury Association). The only other time I saw it happen successfully was when people were employed in family businesses.” (Anonymous person with ME/CFS who has worked in the vocational counseling industry)

12. Enforcement barriers

Recommendation 12: The following barriers must also be addressed to strengthen enforcement of the ADA.

1. **Under-resourced HRC** – The QLD HRC faces continual and chronic under-resourcing and therefore is hampered in its ability to execute its duties. The QLD HRC or other compliance-related body must be adequately resourced to be able to fully enforce the ADA.
2. **Under-resourcing of Community Legal Centres/Legal Aid** – Similarly, Community Legal Centres/Legal Aid must also be adequately resourced to support PWD. This includes:
 - 2.1. ensuring that both the Legal Aid services are fully accessible to all PWD. ‘Accessibility’ especially includes accommodating the needs of frail, homebound and bedbound PWD, of which there are over 600,000 (approximately 2.4% of the total population) Australian residents in this cohort. (Pinero de Plaza, 2021)
 - 2.2. all Legal Aid staff are trained on how to effectively engage with PWD, adequately equipped and appropriately rewarded to do so.
 - 2.3. all Legal Aid lawyers and paralegal staff are remunerated as per the median remuneration of other similarly practicing lawyers and paralegal staff. As stated on Community Legal Centres Queensland’s website, “good laws need good lawyers to make sure they achieve what they are intended to do.” (Community Legal Centres Queensland, 2022)
3. **High costs of complaints** – PWD, including people with ME/CFS, face enormously high financial, physical, and emotional costs of lodging and pursuing a complaint. Many PWD are too financially impoverished⁶ and lack sufficient or any social support to lodge a complaint. Sufficient financial, logistical, and social supports and easier complaints processes must be provided to enable PWD to lodge and pursue complaints.

⁶ For example, ¼ of the former Newstart program’s recipients were people with disability. (Ref: Economic Justice Australia. (2017, 2 January 2017). *1-in-4 on Newstart has a Significant Disability*. Economic Justice Australia. Retrieved 11 May from <https://www.ejaustralia.org.au/wp/social-security-rights-review/1-in-4-on-newstart-has-a-significant-disability/>)

“Laws need enforcement, and I wonder how many PWD are equipped to pursue complaints (which is one way things change, when orgs see penalties happening to others when they’ve fallen foul of a law). There’s a power issue. There might be a law in place, but if you’re poor, unsupported etc, you might not have the resources to take action to get the law to support you.

if it’s a workplace which is discriminating, it’s very hard to get things addressed because you risk losing your job. And having lodged a complaint (eg: [sic] with HR or whatever) will make it hard to get a good reference and get another job. There are systemic obstacles to PWD making the law work for them.

So I think that reforming the law without addressing those obstacles probably won’t make much difference?” (Anonymous person with ME/CFS)

4. **Unconscious bias** – Many PWD face enormous difficulties in proving of ‘unconscious bias.’ For example, both employers and landlords unconsciously assume that PWD are incapable and use other, more subtle tactics to deny PWD equitable access and opportunities. Such unconscious bias results in both direct and indirect discrimination. Unconscious bias must be explicitly recognised and addressed in the ADA.

13. Preventing systemic discrimination

We agree with the ADA Discussion Paper’s point that the current system lacks a preventative focus and that “more subtle and less visible forms of discrimination are commonly experienced by some groups, and these are often linked to attitudes, biases, and stigma.” (ADA Discussion Paper, page 16)

Extend scope of Anti-Discrimination Act

We also think the ADA’s current scope is too narrow in that it focuses primarily on areas such as goods and services, employment, education, and accommodation.

Recommendation 13: The ADA’s reach should extend beyond its current scope to also include explicitly:

1. Medical research
2. AI – for example, the needs of PWD must be embedded in the algorithms that inform AI.
3. Domestic and family violence
4. Disaster preparedness, response, and recovery planning
5. Representation in both non-digital and digital media.

Linkages with Disability Discrimination Act and other related legislation

Recommendation 14: the QLD HRC or other specialist body should have the powers to set guidelines and require compliance. Such powers should complement and strengthen, rather than confuse or weaken, current national legislation, such as Australia’s Disability Discrimination Act (DDA), in providing preventative ways to proactively end systemic discrimination.

Supposedly the DDA is meant to address systemic disability discrimination. However, the disproportionately high numbers of disability-related complaints and the findings of the Disability Royal Commission show that clearly both the DDA and the ADA are failing to adequately protect

PWD from discrimination. Consequently, further investigation of and remedies for the DDA must also be undertaken.

Recommendation 15: Furthermore, other state and national legislation must not weaken/compromise the ADA. For example, the QLD Residential and Tenancies Act must omit ‘no-grounds evictions’ and employment law should not allow unfair dismissal.

Specialist anti-discrimination tribunal

Recommendation 16: We also support Community Legal Centres Queensland’s recommendation that Queensland needs to have a specialist Anti-Discrimination Tribunal, not the more generalist bodies such as the Queensland Civil and Administrative Tribunal (QCAT) and the Queensland Industrial Relations Commission (QIRC), to deal specifically with anti-discrimination matters, particularly those involving disability-related discrimination. A specialist Anti-Discrimination Tribunal needs to have anti-discrimination law experts, particularly ones who are familiar with disability-related legal matters. A specialist tribunal is needed since:

- Legal concepts such as ‘unconscious bias’ often involve “difficult medical questions, including psychiatric assessments, to digest, understand and apply as part of the decision-making process. Not all generalist decision makers deal well with these complexities and sensitivities.” (Community Legal Centres Queensland, 2022)
- A specialist tribunal could better ensure more consistent approaches to foundational anti-discrimination law concepts and thereby make it easier to predict outcomes. Apparently, QCAT and QIRC approaches are often inconsistent, and this may be because both bodies are not anti-discrimination specialists, particularly disability-related ones.

Remove non-disclosure agreements

Often many personal case settlements result in PWD being required to sign non-disclosure agreements. Consequently, this hampers opportunities for improving measures to end systemic discrimination due to the wider community’s lack of knowledge of case details and outcomes.

Recommendation 17: We recommend that PWD complainants not be forced into signing non-disclosure agreements.

14. About ME/CFS

Approximately 250,000 Australian residents currently live with ME/CFS, a severe, highly debilitating, complex, chronic illness that affects most bodily systems, particularly the nervous, immune, cardiac, gastrointestinal, and endocrine systems. (Carruthers & van de Sande, 2012; Johnston et al., 2016)

- It has been classified as a neurological disease by the World Health Organisation (WHO) since 1969. (World Health Organization, 2010)
- Of the over 50 identified symptoms, ME/CFS-related functional impairment includes things such as severe fatigue; mobility, cognitive and visual impairment; extreme sensitivity and/or intolerance to even faint noise, light and smells, slight temperature changes and many more. (Johnston et al., 2016)
- The chief hallmark of ME/CFS is post-exertional malaise (PEM), whereby even seemingly light activity, such as briefly talking, sitting up or lifting a coffee cup, can re-trigger symptoms and result in hours, days, weeks and even months of having to lie in bed. (Carruthers & van de Sande, 2005; USA Centers for Disease Control and Prevention, 2022)

- Many people with ME/CFS have co-morbidities such as Postural Orthostatic Tachycardia Syndrome (POTS), fibromyalgia, migraines and Irritable Bowel Syndrome. (Carruthers & van de Sande, 2012)
- ME/CFS can cause profound disability and affects many aspects of life, possibly for one’s entire life. Approximately 25% of people with ME/CFS are so severely impaired that they are homebound or bedbound. (Institute of Medicine, 2015)
- There is no cure for ME/CFS – only treatments for symptom management. (Carruthers & van de Sande, 2012)
- Many people with ME/CFS die far earlier from suicide, cancer, or heart disease than the general population. (Johnson et al., 2020; McManimen et al., 2016)

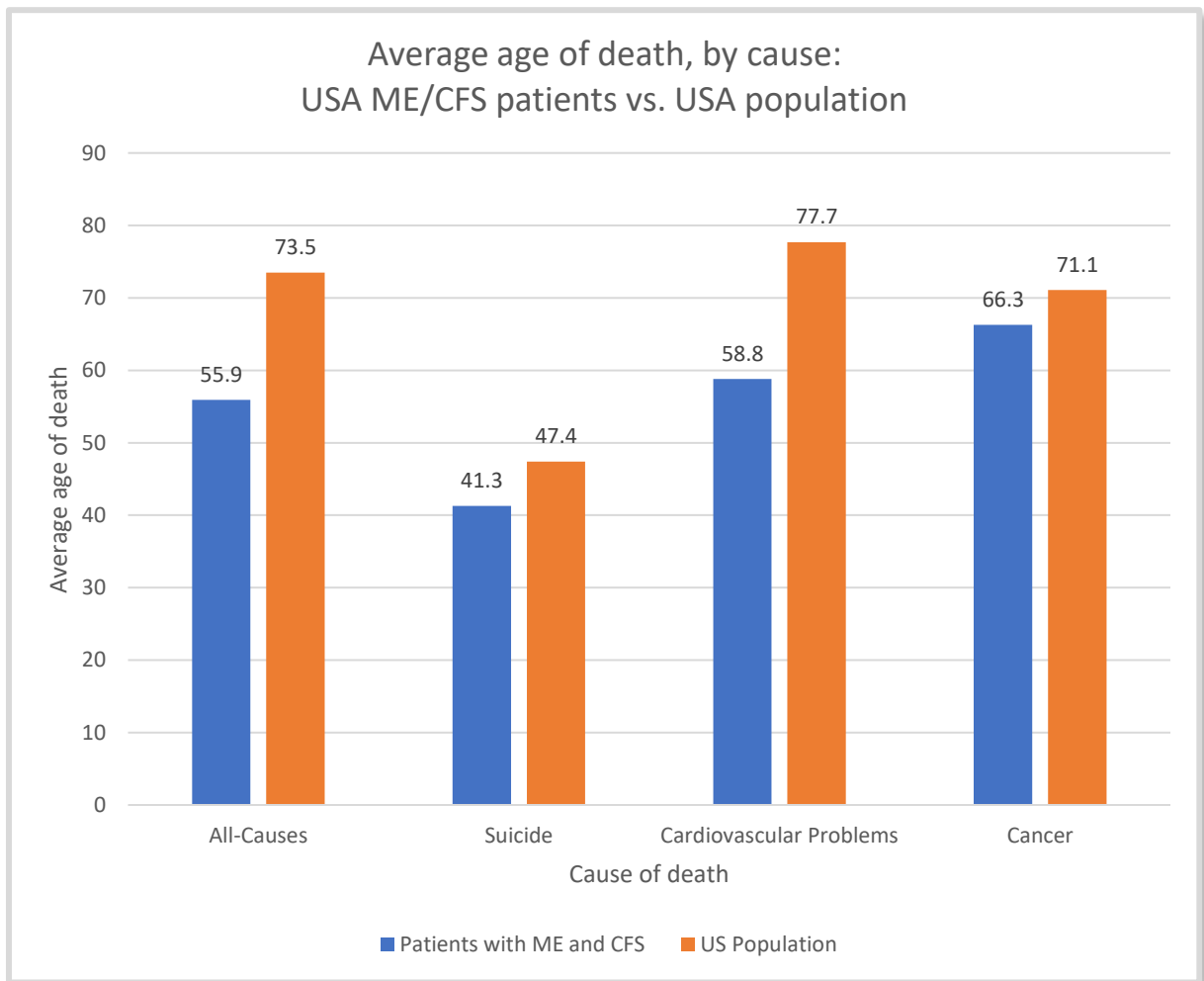


Figure 1: Average age of death, by cause: ME/CFS patients vs. US population.

(Ref: McManimen et al., 2016)

15. Acronyms

ADA – Anti-Discrimination Act

AI – Artificial Intelligence

CBT – Cognitive Behavioural Therapy

CFS – chronic fatigue syndrome

DDA - Disability Discrimination Act

DSAPT - Disability Standards Accessible Public Transport

DSP – Disability Support Pension

EBP – evidence based practice

ELCI – Energy-Limiting Chronic Illness

GET – Graded Exercise Therapy

HRC – Human Rights Commission

ME – myalgic encephalomyelitis

MCS – multiple chemical sensitivity

NDIS – National Disability Insurance Scheme

NHMRC – National Health and Medical Research Council

NICE - National Institute for Health and Care Excellence

PWD – people with disability

QCAT – Queensland Civil and Administrative Tribunal

QDN – Queenslanders with Disability Network

QIRC – Queensland Industry Relations Commission

POTS - Postural Orthostatic Tachycardia Syndrome

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