

# SUBMISSION TO THE DRAFT NATIONAL DISABILITY ADVOCACY FRAMEWORK 2022-2025

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## Introduction

Thank-you for the opportunity to provide feedback regarding the National Disability Advocacy Framework 2022-2025. This document is to augment our feedback provided during the webinar co-organised by The Social Deck and the Australian Department of Social Services on 12 July 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) (Carruthers & van de Sande, 2005; Carruthers et al., 2011; Institute of Medicine, 2015).

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. She now has Long COVID. 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>
- Brisbane ME/CFS Support Group  
<https://www.facebook.com/groups/brisbane.me.cfs.supportgroup>

## Recommendations

### Equitable access

#### Homebound/bedbound access

Often current advocacy requires people with disability to travel to a government agency or access via online video. Little, if any, engagement is available in the home. However, over 2.4% of people in Australia (over 600,000) are frail, homebound and/or bedbound (Alejandra Pinero de Plaza, 2021). Many such people are too unwell to see a doctor, let alone participate online to access disability, systemic or individual advocacy activities.

**Recommendation 1:** Therefore, to provide equitable access for this cohort, disability advocacy processes should include options for in-person/in-home engagement. If the representative from the government agency is unfamiliar with the homebound/bedbound person with a disability's actual disability, then a health consumer who understands the homebound/bedbound person's disability should accompany the government representative.

### Funding transparency, equity and accountability

Funding for disability advocacy should be transparent and funding details should be publicly listed. Furthermore, both the funding recipient and the funding provider should be held accountable for their respective roles in the funding arrangements. Funding should be commensurate with the burden of disease to ensure equity. Furthermore, equitable funding requires:

a. **'Disability' definition** – the definition of 'disability' is often too narrowly defined to mean the more visible, more 'high-profile', well-recognised conditions such as people in wheelchairs, deaf, blind or chronic illnesses such as cancer.

**Recommendation 2:** Following on from the UN Convention on the Rights of People with Disability's definition of disability, which recognises 'functional impairment' and the social model of disability, 'disability' should also include more invisible, chronic illnesses, particularly the over 50 energy-limiting chronic illnesses such as ME/CFS, Multiple Chemical Sensitivity (Steinmann, 2018, 2019) and endometriosis (Hale et al., 2020).

b. **Data** - Our government agencies frequently only use the 18% disability prevalence statistic from the Australian Institute of Health and Welfare (Australian institute of Health and Welfare, 2020, p. 2), which has many data gaps and therefore far under-estimates the extent of disability.

**Recommendation 3:** funding should not just rely upon existing 'known' data but also include the many as yet missing cohorts, particularly people with chronic illnesses. Data collection, monitoring and reporting must be transparent, consistent, based upon robust methodologies and sufficiently funded and resourced.

#### c. Intersectionality prioritised

**Recommendation 4:** Equity should prioritise groups facing intersectionality/multiple disadvantage (e.g. disability + LGBTIQI, First Nations, people who are homebound/bedbound, youths, etc;) and reflect the burden of disease.

## Co-design principles

Too many consultations involving people with disability do not actually involve full-fledged co-design but rather tokenistic, tick-the-box exercises whereby people with disability's voices often end up being diluted or ignored. Some, but not all, barriers include:

1. Lack of access
2. Lack of understanding by the project managers
3. Under-resourcing of advocacy services
4. Lack of transparency of feedback from participants
5. Late engagement
6. 'Rubber stamp syndrome' - pre-determined outcomes were already largely decided prior to the engagement
7. Poor role definition and/or unclear processes
8. Predominance of vested, non-independent interests

**Recommendation 5:** Co-design should adhere to Queenslanders with Disability Network's published principles on co-design. Co-design should be meaningful and involve people with disabilities not just as external, ad-hoc commenters/advisors but as decision-makers, planners and implementers. Co-design processes should be fully and adequately funded.

## Governance

Currently, three main federal ministries have direct relevance to disability issues:

1. Ministry for the NDIS and Government Services
2. Ministry for Social Services
3. Ministry for Health

This tri-partite arrangements creates significant hurdles for achieving a consistent, integrated approach to disability issues. 'Disability' spans all parts of life and government departments. We need an integrated holistic, whole-of-government approach, not be sidelined into just social services.

**Recommendation:** Disability policy and the National Disability Advocacy Framework should be governed by the Australian Department of Prime Minister and Cabinet, not the Ministry for Social Services. Alternatively, it should be its own Ministry, similar to the Ministry for Women.

In the absence of such a Ministry, greater collaboration and integration between the above-mentioned Ministries should be fostered. Furthermore, all other Ministries, state and local government agencies should also collaborate on disability-related issues as well as have disability advocacy embedded within their respective organisations, policies and programs.

## Implications of lack of disability advocacy

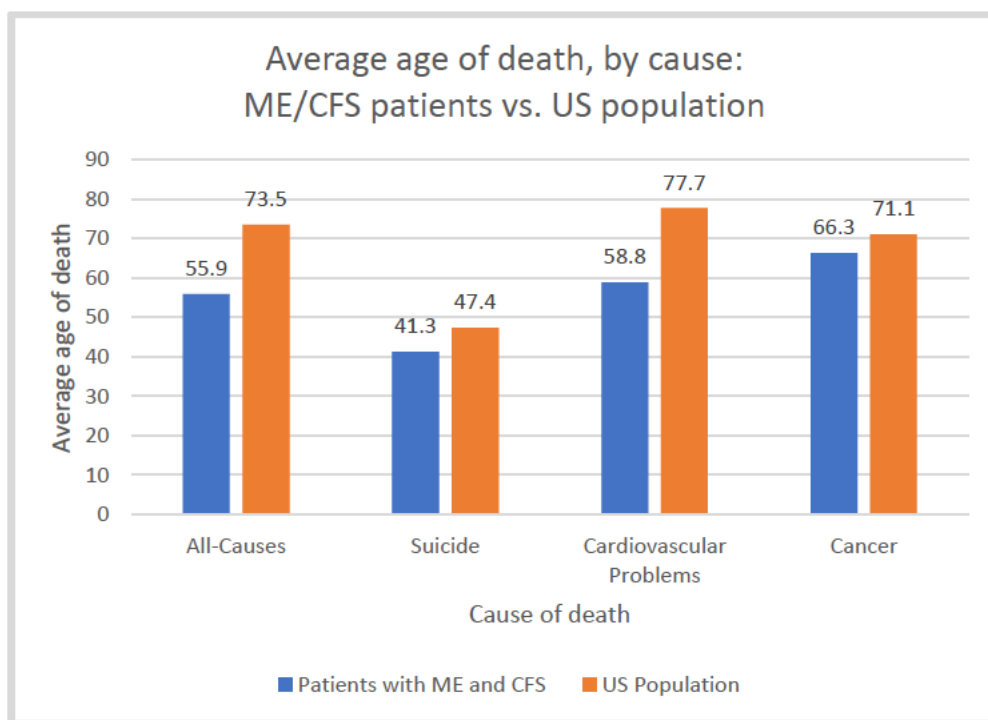
In order to further the progress of the proposed National Disability Advocacy Framework, it is recommended that the forthcoming report highlights the economic and political drivers behind improving disability advocacy. Although we recognise that much of the draft Framework focuses on the importance human rights, we are also aware that the current predominant discourse and drivers of change are primarily economic and political, especially in the current global and domestic economic and geo-political climate.

## Economic implications

**Recommendation:** Emphasise the cost-benefits of having a robust National Disability Advocacy Framework. The ongoing neglect of advocacy for people with disability is likely to result in exponentially increased economic costs. In contrast, the benefits of advocacy can yield greater economic, social and political participation among people with disability.

For example, the lack of adequate disability advocacy for people with ME/CFS in Australia perpetuates enormous national economic and personal costs for them and their families.

- **National economic impact** - Research findings of the National Centre for Neuroimmunology and Emerging Diseases (NCNED) estimate that the annual economic cost of ME/CFS is over \$14.5 billion (Close et al., 2020, p. 1).
- **Poverty** - An Australian patient survey research by Emerge Australia Inc. found that 53% of survey respondents with ME/CFS were not in any work, training or education. Furthermore, the majority (39%) of survey respondents reported they receive no income and more than 2/3 live below the poverty line (Emerge Australia, 2020, p. 48).
- **Worsening health and early death** - According to USA research, people with ME/CFS are at higher risk of early death due to cancer, heart disease or suicide compared to the general population (McManimen et al., 2016, p. 15).



(Ref: McManaman et al., 2016)

## Political implications

**Recommendation:** Emphasise that Australia's disability communities are a growing voter block. The AIHW estimates that the disability population is approximately 18%. However, if one considers the AIHW's own disability collective data gaps, the large cohorts of people with chronic health conditions and the many as yet undiagnosed or misdiagnosed cohorts who remain disabled despite medical recognition, disability prevalence in Australia is likely to be far larger than the mere 18% official statistic. The fact that the NDIS and disability issues rose to such prominence in the 2022 federal elections is no mere coincidence but a sign of the growing political influence of voters with disabilities and their families.

## About ME/CFS

- ME/CFS is a severe, highly debilitating, complex, chronic illness that affects most bodily systems, particularly the nervous, immune, cardiac, gastrointestinal and endocrine systems.
- It has been classified as a neurological disease by the World Health Organisation (WHO) since 1969. (World Health Organization, 2010)
- Up to an estimated 260,000 Australian residents live with ME/CFS. 25 percent are housebound or bedbound. Conservative estimates from Deakin University suggest that the ME/CFS population will more than double by the next year, due to many Long COVID cases ending up with ME/CFS (Emerge Australia, 2022). In an international review of the science, NCNED identified the significant overlap of Long-COVID symptoms with ME/CFS and recommend longitudinal monitoring (Sukocheva et al., 2021).
- Australia's clinical guidelines for ME/CFS are twenty years out-of-date and do not reflect current, internationally-renowned biomedical research (Larkins & Molesworth, 2002).
- Less than 1/3 of doctors receive training regarding ME/CFS (Institute of Medicine, 2015, p. 2; Myalgic Encephalomyelitis Chronic Fatigue Syndrome Advisory Committee, 2019)
- The US National Academy of Medicine estimates 90% of people with ME/CFS are undiagnosed (Institute of Medicine, 2015, p. 1).
- Less than 10 percent of ME/CFS patients recover their full health (Carruthers & van de Sande, 2012, p. 1).
- There is no cure for ME/CFS – only symptom management. (Carruthers & van de Sande, 2012)

"I sure hope that the giant chasm in services available & serious illness is discussed. I've been stuck in bed & at home for 18 months now with only my husband to look after me. I'm very lucky, there are many who don't have anyone....

I consider my self [sic] gap filler. Too sick to work, not disabled enough on paper for a pension, lost sickness benefits because my condition is permanent, can't get home help because I'm married, the gaps, knock backs, set backs, ridiculously high hurdles have been endless & the biggest thing of all is there isn't a place that can provide assistance navigating through all the crap or advocating for the gap fillers, so as sick as I am, I struggle, stumble, bumble & force myself to keep trying, when I should really be resting so I don't keep getting worse.... It's an awful system that is getting worse & they throw money at to make it better & research & survey & advertise etc, but it just gets worse. Put the funds in the faces of the chronically ill [sic] people & ask, "How can we best help you?" I don't [sic] sympathy, ridiculously over priced [sic] therapies that won't help, aids that I won't use as I'm too exhausted to get out of bed most days. If I get a cleaner once a week for two hours, that lift [sic] such a huge burden off our lives, on one basic wage we're struggling to keep up with rent, so finding another \$70/week to fund a cleaner ourselves isn't possible..... it really wouldn't be a huge difference to help so many more people....

Im [sic] sick of hearing about funded activities for groups who fit within the criteria, just cut them back marginally & share funding more equitably. Certainly would improve my QOL." (Anonymous person with ME/CFS, 11 July 2022)

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