Review of Australia’s Disability Strategy

September 2024

Emerge Australia is the national patient organisation providing services and evidence-based clinical education about myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Increasingly, Emerge Australia works with those impacted by post-acute sequelae of COVID-19, known as long COVID, because of the striking symptom similarities. Research suggests up to 45% of all people with long COVID meet the diagnostic criteria for ME/CFS.

An estimated 25% of the 250,000 Australians estimated to be living with ME/CFS are house or bedbound. However, few people with ME/CFS have access to the support they need due to poor understanding of the disease and the key symptoms that contribute to impairment or disability. These include, but are not limited to, post-exertional malaise (PEM)[1], fatigue, cognitive dysfunction, pain, sleep disturbance, orthostatic intolerance[2] and secondary depression or anxiety. The degree of impairment exceeds that of other well-known diseases such as rheumatoid arthritis, multiple sclerosis, depression, heart disease, cancer and lung disease.[3, 4, 5] Despite the severity of their disability, people with ME/CFS and, increasingly, long COVID, face stigma and disbelief, abuse and medical neglect.

Emerge Australia welcomes this opportunity to provide feedback on the Australian Disability Strategy (ADS) and its Outcome Areas. We recognise that the ADS is an aspirational document, and reviews such as this are critical to improving the implementation of the Strategy.

A note about the Social Model of Disability

We note that the ADS is based on the social model of disability, which sees disability as largely a social construct, and puts the onus on society to adjust and accommodate to an individual’s disability. This is in contrast with the medical model of disability, in which disability is seen as a pathology requiring treatment. For Australians who live with ME/CFS and long COVID, their disability straddles the divide between these two models, for their disability is caused by a disease for which there are no effective treatments, but for which these are much needed, and also exacerbated by social systems which discriminate against and stigmatise them.

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[1] PEM is a delayed worsening of symptoms that occurs after minimal physical or mental activity. Extreme fatigue and other symptoms experienced are not in proportion to the amount of activity that has been done.

[2] Problems with sitting or standing, that may include dizziness, sweating, nausea and reduce or resolve when lying down

[3] C. Kingdon, et al. ‘Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls’ *PharmacoEconomics- Open,* 2:4 (2018).

[4] L. Nacul, et al. ‘The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers’ *BMC Public Health,* 11 (2011).

[5] M. Núñez, et al. ‘Health-related quality of life in chronic fatigue syndrome versus rheumatoid arthritis as control group’ *Journal of Chronic Fatigue Syndrome,* 14 (2008).

Implementation mechanisms

Guiding principles

Emerge Australia supports the ADS’ guiding principles. We note, however, that there continue to be many instances in which these principles are not applied to people living with energy-limiting conditions such as ME/CFS or long COVID. For example, people with these conditions are often denied the right to make their own choices about types of medical treatment, instead they are required to undergo certain treatments in order to substantiate applications for supports such as the NDIS or DSP.

Recommendation: ADS guiding principles must be applied consistently to people with all disabilities and should be embedded in disability systems such as NDIS and DSP, which regularly exclude people with energy-limiting conditions such as ME/CFS and long COVID.

ADS Outcome Areas

The ADS Outcome Areas ensure that the ADS is implemented across all aspects of the lives of people with disabilities. Emerge Australia has identified several aspects in which the implementation of the ADS Outcome Areas could be improved.

Employment and Financial Security

1. Working from home (WFH)

WFH removes a barrier to employment for many people disabilities, especially those living with ME/CFS and long COVID, as it removes the need for energy-consuming commuting and allows people to lie down when they work and more easily have regular rest breaks. The current trend away from working from home is reinstating this barrier to employment but this issue is not addressed by the ADS.

Recommendation: That working from home is explicitly described in the Employment Targeted Action Plan as a disability employment support strategy that leads to increased workforce participation for people with disabilities like ME/CFS and long COVID.

2. Financial independence

Policy Priority 3 (Strengthen the financial independence of people with disability) states that,

“*Adequate income provides increased financial security, economic independence and an appropriate standard of living, giving people more choice and control over their lives, and enabling their participation in community life. The income support system provides an important safety net for people with disability who are unable to work or cannot find employment*.”

Despite this, social security payments have not kept pace with the cost of living, the pressures of which are especially severe for people with serious medical conditions like ME/CFS and long COVID, which bring significant out-of-pocket medical expenses.

Recommendation: The rate of all social security payments should be raised to ensure that Australians with disabilities can live with financial independence and dignity, in keeping with ADS Policy Priority 3.

Inclusive Homes and Communities

1. Affordable housing

Housing insecurity and lack of affordable housing is an issue across the Australian community, and a source of incredible stress for many. This is even more so for people with disabilities like ME/CFS and long COVID, who are more likely to be on low incomes and face higher medical expenses than the average Australian. Access to safe and secure housing is a basic human right. Despite affordable housing being Policy Priority 1 for this Outcome Area, there has been very little tangible change in the availability of affordable housing in Australia since the beginning of the ADS.

Recommendation: The Government must increase the rate at which affordable housing is becoming available, utilising a wide range of means, to ensure that the right of all Australians to safe and secure housing is delivered.

2. Choice and control

Policy Priority 2 for this Outcome Area is that people with disabilities should have “choice and control about where they live, who they live with and who comes into their home”, however the implementation of the NDIS is working counter to this policy. Many people with ME/CFS who have applied for Specialist Disability Accommodation under the NDIS have found they have little or no choice and control over their home environment.

Recommendation: The implementation of the NDIS must reflect this policy priority and ensure that Australians with disability must have choice and control over where they live, who they live with and who comes into their home.

Safety, Rights and Justice

1. Medical abuse and neglect

The lack of understanding of ME/CFS, and now also long COVID, has resulted in people living with these conditions experiencing widespread medical abuse and neglect. People living with these conditions are routinely recommended harmful treatments which are not supported by evidence and, when they report having experienced harm from these treatments, their concerns are often dismissed and disbelieved. People living with ME/CFS are often required by their medical practitioner to undertake harmful treatments such as graded exercise therapy or cognitive behaviour therapy, to fulfil NDIS application requirements.

Recommendation: Clinical education about energy-limiting conditions like ME/CFS and long COVID must be a priority to ensure safe healthcare, as future COVID-19 infections will continue to see an increase in their prevalence. There must also be a mechanism for reporting harm from non-pharmaceutical treatments so that these adverse effects can be documented and addressed.

2. Right to refuse treatment

The right to refuse medical treatment is an important component of informed consent. Only the individual themselves (or a legal proxy) can provide or refuse consent to a medical treatment. However, people with ME/CFS and long COVID are often denied the right to refuse inappropriate or harmful treatment when applying to access government supports like the NDIS or DSP. People feel they must comply with medical practitioner prescribed graded exercise therapy, a treatment which contemporary evidence shows can be harmful to people with energy-limiting disease. Participating in these treatments is still required, even in cases where they have been deemed inappropriate by their treating doctor. Accessing government support should not be contingent upon having undergone a treatment that the individual has not freely consented to.

Recommendation: All government support systems should uphold the individual's right to refuse medical treatment, especially where a treatment is potentially harmful or has been deemed inappropriate for that individual.

Personal and Community Support

1. Equitable access to the NDIS

The focus of this Outcome Area is that people with disability can access the supports they need, and that "eligible people with permanent and significant disability" can obtain necessary supports through the NDIS. However, despite often having severe disabilities, people with ME/CFS and long COVID routinely have NDIS applications rejected, because NDIA assessors do not understand these conditions and the nature of the disability they cause. While the introduction of specialist navigators to the NDIS system is intended to address this issue, this situation will only improve when organisations with specialist knowledge of these conditions are involved.

Recommendation: Access to the NDIS must be equitable, to ensure that all Australians living with disability can access the supports they need. There must be greater education about the disabling nature of energy-limiting conditions like ME/CFS and long COVID, and how to appropriately assess functional capacity in people living with these conditions. The government must make greater use of organisations with specialist knowledge of specific disabilities, such as Emerge Australia, to ensure this help ensure access decisions are equitable. Training of NDIS and DSP assessors by organisations such as Emerge Australia, would ensure a consistent assessment approach is afforded to each applicant.

2. Access to assistive technology (AT)

Policy Priority 4 requires that people with disability are supported to access assistive technology (AT). AT is crucial to the lives of many people with disability and can take many forms. Not all AT utilises disability-specific tools. Many forms of AT are ordinary appliances or tools which help make the lives of people living with disability easier. The changes to the NDIS will exclude many tools which are currently being used as AT, such as smart watches and dishwashers. Someone with ME/CFS or long COVID may not be able to wash their own dishes, but they may be able to load dishes in a dishwasher. While a support worker could wash their dishes, a dishwasher would allow the individual to retain some independence and would be more cost effective than the ongoing cost of a support worker salary. However, these ordinary appliances will be excluded from the NDIS.

Recommendation: What may for many appear to be an everyday appliance, may be an essential support for others. Access to AT should be based on the usefulness and appropriateness of the specific tool for that individual.

Education and Learning

1. Equitable access to education

People with ME/CFS and long COVID face unique challenges with education, which are compounded by the lack of awareness of these conditions. Too often young people with ME/CFS and long COVID are considered to have school refusal by their teachers and schools, and are chastised for not attending school and denied the supports they need to access education.

Recommendation: That a consistent approach, articulated in a national strategy across the education system, to support students experiencing energy-limiting conditions and those that reduce physical and cognitive capacity to equitably participate in education should be developed.

Health and Wellbeing

1. Access to telehealth

Medicare rebates for telehealth services were transformative for the healthcare of people living with ME/CFS and long COVID, for whom travelling to a clinic for an in-person consultation may not be possible. Unfortunately, changes to the eligibility requirements for accessing rebates for telehealth services have meant that these same people, who most need telehealth, have lost access and once again have fallen through the cracks of the healthcare system.

Recommendation: People with chronic illnesses like ME/CFS and long COVID should be exempt from the requirement of a face-to-face appointment with their GP (or GP clinic) in the previous 12 months in order to be eligible for telehealth rebates.

2. Healthcare providers

Policy Priority 1 is for all healthcare providers to have the capability to meet the needs of people with disability. However, many healthcare providers continue to refer to Australia's outdated ME/CFS clinical guidelines (which are being updated over the next three years) and long COVID treatment which are not informed by current evidence. This has adverse impacts on the care patients receive. Emerge Australia is working to educate clinicians about this growing patient cohort, but more must be done and quickly.

Recommendation: There must be greater investment in clinical education about energy-limiting conditions like ME/CFS and long COVID to ensure that healthcare providers can meet the needs of this patient cohort.

3. Disaster preparedness

Policy Priority 4 is that disaster preparedness plans be inclusive of people with disabilities. People with energy-limiting conditions like ME/CFS and long COVID have specific needs during disasters that may be different to those of other people with disabilities. Inclusion and consultation on the development of disaster preparedness must include a diverse range of disabilities to ensure that these differing needs are addressed by disaster preparedness plans.

Recommendation: Disaster preparedness plans should include consultation with people with a range of disabilities, including those with conditions like ME/CFS and long COVID which, though common, are not well understood.

Community Attitudes

1. Stigma and discrimination

People living with ME/CFS and long COVID face significant stigma and discrimination from across the community, including the medical system, government systems and support, and even from within the disability community itself. Lack of understanding of these conditions often results in a de-legitimisation of the individual's disability, compounding the other systemic issues faced by people with disabilities.

Recommendation: Greater education about energy-limiting conditions such as ME/CFS and long COVID is needed across the community, including for all disability support systems.

2. Safe healthcare & education

Policy Priority 2 is for key professional workforces to be able to confidently and positively respond to people with disabilities. These professions include but are not limited to healthcare and education, two professions from whom people living with ME/CFS and long COVID routinely experience stigma, neglect and abuse. Emerge Australia provides clinical education to health professionals, but more is needed to shift attitudes and ensure that people living with these conditions receive healthcare that is safe and have equitable access to education.

Recommendation: More education is needed for the healthcare and education systems about the nature of invisible disabilities like ME/CFS and long COVID.

Conclusion

Emerge Australia believes that the ADS provides a roadmap to a better future for all Australians living with disability. We hope that the implementation will include more attention to the needs of Australians with invisible disabilities like ME/CFS and long COVID in the future. We look forward to continuing to work with all levels of government to ensure that the implementation of the ADS reflects the needs of our ME/CFS and long COVID community.