



Emerge Australia's response to: Consultation Paper: A New Act to Replace the Disability Services Act 1986

The Department of Social Services

QUESTION 1: Do you agree with the proposed objects for the new Act? What other objects should be included in the new Act?

Emerge Australia fully agrees with the proposed objects for the new Act. We do not have any objects to add.

QUESTION 2: Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

Emerge Australia would like to raise a few points regarding the proposed definition and approach to the target group.

We acknowledge the Department's decision to adopt the social model of disability, which generally is less stigmatising of people with disabilities than the medical model. The social model of disabilities has two distinct benefits of relevance here: it doesn't pathologise people with disabilities, and assumes they don't inherently need support. In addition, it places the emphasis on the barriers which create issues, rather than the disability.

However, we are concerned that, by defining the Act's target groups by the barriers they face, it is the barriers, rather than the people living with the disability, which are centred. Barriers are important and need to be addressed, but people with disabilities must always be centred.

In addition, while the social model of disability is less pathologising for many people with disabilities, it can also exclude people whose disability is caused by a medical condition/s. This is because there is an implied assumption in the model that if all barriers are removed, people with disabilities will be free to fully participate in society. While this may be the case in some situations, it is not true for all people with disabilities. For the patient groups we represent and advocate for, people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and, most recently, people with Long COVID, even with all barriers removed, our patient cohort will still have limited energy and associated symptoms that impair their ability to go about their everyday lives. The Act should be supporting all people with disabilities, whether caused by medical condition/s or otherwise, who need support.

We encourage the Department to be mindful that the language adopted centres people with disabilities and is inclusive of all people with disabilities, including those whose disability is caused by medical conditions.

QUESTION 3: Do you agree with our suggested principles for avoiding duplication and requiring coordination? What other principles do you think should apply?



Emerge Australia supports the idea of avoiding duplication and requiring coordination of services. Such measures should improve efficiency, save money and allow those using the system to have a more positive and straightforward experience.

However, we are concerned that in the desire to avoid duplication and require coordination, the central point of this Act is lost. The focus of the Disability Services Act should be on those people who fall through the cracks, and who currently do not receive support, due to other problems with the system. As Labor promised during the election campaign, this Act should ensure that there is *No One Left Behind*.

We raise this issue because many people with ME/CFS do not have access to NDIS, often due to a lack of understanding of the illness by assessors. Although there is mention that the Act is supposed to cover people not covered by NDIS, we believe this needs to be more explicit. We are concerned, and have seen many times over in our patient community, that people who cannot obtain support to manage their disability are left behind.

We believe this Act should be most concerned with ensuring that all people with disability who need support, get that support. How will the government, and the new Act, ensure *No One Left Behind*? How will it ensure services reach those who need them? How will the Act assist the federal government to coordinate with other levels of government and identify gaps in services? These questions must be addressed to in the new Act to avoid repeating mistakes of the past and leaving some of those in most need of support with nothing.

While we acknowledge the importance of avoiding duplication, we strongly recommend that the Act has greater focus on ensuring that there is *No One Left Behind*, by identifying service gaps and mechanisms for service delivery.

QUESTION 4: Do you think the new Act should include a definition for disability? Do you have any additional comments?

Emerge Australia supports the inclusion of a definition for disability in the Act. We believe it is important for all to have a shared understanding of the people served by this Act.

We do not believe a 'legal' definition, like the example provided from the NDIS, should be used. This definition is not suitable because it is exclusive, rather than inclusive. We understand this is because it is written for a different context, where it defines eligibility criteria for the program.

Given the purpose of this Act is to cover people with disabilities who are not eligible for NDIS, the definition for disability should be broad enough to encompass all people with disabilities. In particular, the definition should include those whose disability is caused by a medical condition/s, like those with ME/CFS and Long COVID. For this reason, we support a broad, inclusive definition like the UN example, provided that the definition covers all people with disabilities, including those with medical conditions.

QUESTION 5: How do you think quality and safeguarding arrangements should be managed by the new Act?

First, we would like to acknowledge the Department for raising this issue. Many in our patient community have struggled to find support workers. There are a number of reasons for this shortage,



with over-regulation and a complicated compliance system exacerbating this issue. Safety and safeguarding are important measures which we hope will only be strengthened by streamlining and simplifying the system. We also hope that simplifying the system will allow new people to join the field, and new businesses to open who can be confident of ongoing work because they can employ workers across disability and aged care sectors.

For Emerge Australia, the most important consideration should be how to make it as easy as possible for service providers to do their work, while maintaining the highest quality and safety. To achieve this, we support the creation of a single piece of legislation that covers all people working with vulnerable people. In addition, creation of a one-stop-shop to provide support and information to service providers may assist with the implementation of the legislation, and ongoing monitoring.

QUESTION 6: Do you agree with the supports and services listed above? What other kinds of supports and services should be included in the new Act?

Emerge Australia agrees with the list of types of services funded under the new Act, and would like to take this opportunity to clarify how these supports and services will assist those with chronic illnesses like ME/CFS and Long COVID.

- Accessibility:

As discussed in Question 2, the medical versus social model of disability means that accessibility is often thought of as ramps or closed captions. For other people living with disability, like those with ME/CFS and Long COVID, telehealth rebates and access to online services are the kind of supports needed to make even basic things like healthcare accessible. Many of these supports have been wound back since the acute phase of the pandemic. How will the Act support accessibility services for people with disability due to chronic illness?

- Accommodation support:

Social security payments have not kept pace with rises in cost of living, including rent. For those who do not receive government support, these issues are even more pressing, with homelessness a common issue for people with ME/CFS, and increasingly for those with Long COVID. What sort of housing support or assurances would the new Act provide?

- Advocacy:

People with ME/CFS who apply for NDIS have enormous difficulty accessing advocacy support to assist with their application. ME/CFS is an energy limiting disease that also leaves most with cognitive difficulties. People with ME/CFS, particularly those without the support of a carer, often relapse during the application process due to the energy required to complete the paperwork and assessments. Would this Act cover people who have not yet been accepted onto NDIS, but who going through the application process? What sort of advocacy support would the Act provide? For those not eligible for NDIS, what kind of advocacy support will the Act provide for other matters?

- Employment and training:

Most people with ME/CFS and Long COVID require accommodations in order to participate in work and education. These accommodations can be particularly difficult for people with a stigmatised, invisible illness to obtain. How will the new Act assist people with invisible illnesses like ME/CFS and



Long COVID to obtain the required accommodations to continue participating in the workforce and education?

- Independent living:

Living independently can be a significant challenge for people with ME/CFS and Long COVID, especially those who are house- or bed-bound. Daily activities like cooking, shopping and cleaning all require energy that many people don't have. How will the Act support those with ME/CFS who do and do not have access to NDIS to maintain living independently?

- Information and education:

ME/CFS and Long COVID are poorly understood, stigmatised conditions. The lack of understanding about how these invisible conditions affect those living with them creates additional barriers to both accessing necessary services and engaging with life. How will the Act facilitate greater awareness of what constitutes disability, in particular greater understanding of invisibility disabilities like ME/CFS and Long COVID?

Research estimates 90% of people with ME/CFS have not been diagnosed and GPs often lack knowledge and confidence in diagnosing the disease. We urgently need community awareness programs and education for health providers and government support assessors. How will the Act support the development and implementation of such information and education programs?

- Recreation:

Social isolation is a significant issue for people with ME/CFS and Long COVID, 25% of whom are house- or bed-bound. Due to the energy limiting nature of the disease, participating in common recreational activities is not suitable for most. How will the Act ensure that recreational programs are inclusive of all people with disabilities, including those with invisible disabilities, for whom the key barrier is an intrinsic lack of cellular energy, rather than an extrinsic social barrier?

- Respite care:

ME/CFS and Long COVID also have a profound impact on carers, particularly those who provide support to the 25% of patients who are house- or bed-bound. Emerge Australia's 2019 health and wellbeing survey reported 90% of carers were financially unsupported in their role as carer. Further, despite indicating that they require support for certain activities, only 16% cent of respondents reported that they received help from professional carers.

This indicates a large proportion of carers for people with ME/CFS are family, friends or others who are not paid/subsidised for their work. How will the Act ensure carers who do not otherwise receive government support can still access respite care services?

- Research, development and data collection:

Despite its prevalence, severity and permanent nature for most patients, there is inadequate data, research or development about ME/CFS and, more recently, Long COVID in Australia. For example, the Australian Burden of Disease Study (ABDS), conducted by the Australian Institute of Health and Welfare (AIHW), has not listed ME/CFS as a separate disease since 2003. In the 2011 ABDS study, ME/CFS was excluded as a separate disease due to outdated prevalence estimates used in 2003. How will the Act ensure that the impact of high disabling, invisible diseases like ME/CFS and Long COVID are adequately monitored and accurate data collected?



We strongly encourage the Department to ensure that all research and data collection related to people with disabilities centres people with disabilities. A vital measure to ensure this is the inclusion of people with disabilities at all steps of research. Including this as a requirement in the Act will help ensure that any research on people with disabilities is done *with*, not *to*, people with disabilities.

QUESTION 7: Do you consider it necessary to retain separate provisions for employment services and rehabilitation employment program, or could they be combined?

Emerge Australia does not consider it necessary to retain separate provisions for employment services and rehabilitation employment programs. Similar to Question 3, combining these services should enable better use of resources.

We are most concerned with how streamlining these services will better enable the Department to provide equity of access. Many people with ME/CFS, and now those in the early stages of Long COVID, have difficulty accessing these services even though they need them. There are two main reasons for this: diagnosis and permanence.

GPs struggle to diagnose ME/CFS within the first two years of symptom presentation, most often due to lack of understanding of the condition. It takes, on average, 2 to 5 years to be diagnosed with ME/CFS. Even though ME/CFS has a recovery rate of less than 10% to pre-illness function, many people with ME/CFS struggle to have their illness classified as permanent, and this often comes down to the doctor's knowledge of the condition. This can lead to inequitable access to services under the current system. For example, person A living with ME/CFS may have the same level of functioning as person B, but not yet have a diagnosis. Person A would be covered under employment services, whereas person B, who has a diagnosis and label of permanence, would be covered by rehabilitation employment programs.

Long COVID presents an additional cohort of post-infection patients who will also struggle with these issues. Many of these people have been unwell for 1-2 years, and are starting to engage with disability services. However, it is incredibly difficult for these people to demonstrate permanence when the disease has yet not been around long enough.

The current system sees people allocated to services based not on need but inconsistent and inadequate knowledge in the medical field. People with inadequate knowledge determine whether or not an individual has been able to have their condition deemed permanent.

Combining services for this patient cohort would also be of benefit but, once again, ensuring equitable access is equally as important. However, we also raise the issue of service access for those who have yet to receive a diagnosis or permanency, but who require support. Often, early service intervention can help reduce the severity of long-term disability. We encourage the Department to ensure that every person with a disability who needs support has access to this support, regardless of diagnosis. This Act should ensure that there is *No One Left Behind*.

COMMENTS: If you have any other comments, suggestions, concerns, or thoughts about our plans for the new Act, please let us know.

We would like to thank the Department for the opportunity to provide feedback on these questions about the new Act. As the national patient body for people with ME/CFS and Long COVID, which are both invisible and disabling illnesses, we would welcome the opportunity to provide more



information about how our patient cohort, and how the Act could be tailored to assist those living with chronic, complex illness.