

NDIS Safeguarding Framework

Emerge Australia

Emerge Australia is the national patient organisation for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). More recently, we have also been supporting people living with Long COVID, due to the strong overlap in symptoms, particularly the presence of post-exertional malaise. Both these diseases are invisible illnesses because their symptoms are often invisible, unless you know what to look for. But this does not mean they are any less disabling: 25% of people living with ME/CFS are house or bed bound. Recovery to pre-illness functioning is extremely low, at only 5-10%.

Emerge Australia acknowledges the work completed to date reviewing the successes and failures of the NDIS. This submission brings attention to specific issues facing those living with invisible illnesses like ME/CFS, raising awareness of how the NDIS can better serve people living with such disabling, but often overlooked, conditions. We have chosen to respond to two of the proposed questions to highlight these specific issues.

Q. What is working well, or not working well, to keep people with disability safe and their supports good quality?

Keeping people with disability safe, and their supports good quality, has been an ongoing issue for people living with invisible illnesses like ME/CFS and Long COVID. There are a number of factors which have contributed to the framework not working well for these participants:

- Participants do not have rights to services delivered how they want and need them. Needing to fit into the service providers' needs, rather than their own, means that people are not getting appropriate care.
- Current NDIA rules and regulations make the NDIS anything but person-centred. Participants live in fear that their cost claims will be rejected as incorrect, that they have to argue (even lodge claims with AAT) to get their needs met and plan fulfilled.
- They are not "sage and fit for purpose". For example, participant requests for providers to wear masks to protect from COVID are refused, or participants are told to supply the masks themselves.

For participants "to live free from abuse, violence, neglect and exploitation", a number of changes should be made to assist those living with invisible illnesses. The underlying issue is the lack of understanding about invisible illnesses and the level of disability these participants face: participants report service providers who are patronising, dismissive, disbelieving of their disability. Consequently, the following issues have arisen:

- There is a strong need for effective monitoring and responses to emerging issues to occur as the NDIS develops. In the current arrangement, participants feel more like the NDIA is monitoring participants more than service providers.
- Participants feel they receive little support or protection while managing both the NDIA and service providers. For people with energy limiting, poorly understood diseases, this often results in unnecessary symptom exacerbation, and sometimes deterioration.

- When issues with their care arise, particularly when receiving services from an agency, participants feel they have little recourse. This adds to their feelings of powerlessness, isolation and sense of disbelief about the disabling nature of their illness.

Q. What could a new Framework look like and what should its role be?

A new framework should focus on providing all people with a disability the support they need to lead a fulfilling life. This framework should look beyond the NDIS, to wider systems that also work to keep people with disability safe.

All people with disability should be protected and guided by the new framework, to ensure consistency regardless of whether the person is a NDIS participant, or not.

The current Safeguarding Framework is complex and was developed on the assumption that most participants would have their plans managed and would obtain services through agencies. The NDIA has acknowledged this is increasingly not the case, as more participants choose to self-manage, and obtain services privately through unregistered providers. This increases the challenges of safeguarding participants, and puts the onus on participants to be across the Safeguarding Framework. We suggest the new Safeguarding Framework should:

1. Be user-friendly

The current Safeguarding Framework is too complex and impossible to navigate for many participants with invisible illnesses, who live with cognitive impairment.

The new framework should come with resources which are accessible for self-managing participants to help keep themselves safe.

2. Empower participants

NDIS participants have support workers come into their home to deliver services, which makes them vulnerable. We hear stories of support workers being disparaging or abusive towards participants. The new Safeguarding Framework must facilitate empowering participants to maintain agency, dignity and control over their home environment and ensure their safety.

Empowering participants should include making it easier for participants to file complaints against providers whose services are inadequate, unprofessional or abusive.

3. Support participants & providers

The new Safeguarding Framework should outline how the NDIA will support participants & providers to use the Framework.

Given NDIA has fewer staff managing participant plans, more support should be provided to helping participants self-manage safely.

4. Encompass non-registered providers

All NDIS providers must be required to follow any Safeguarding Framework, and participants empowered to ensure compliance.

There needs to be a mechanism by which non-registered providers agree to the requirements of the new Safeguarding Framework.

5. Focus on prevention

The ultimate goal of the new Safeguarding Framework should be to prevent issues from arising. This helps people with disability to focus more on living their lives to the fullest, rather than managing the NDIA and service providers.

6. Be flexible

*Safeguarding should not be at the expense of flexibility. The new Framework should not impinge on participants' ability to live their best lives *on their terms*.*