



A submission by **COVERSE** to the
*Australian Senate inquiry into the
National Disability Insurance Scheme Amendment
(Getting the NDIS Back on Track No. 1) Bill 2024¹*

About **COVERSE**

We are the national peak body representing Australians who have been adversely impacted by the COVID-19 vaccines. We are 100% controlled and operated by COVID-19 vaccine-injured Australians and are a charity registered with the Australian Charities and Not-for-profits Commission (ACNC). We collect information and data directly from impacted patients, and as patients ourselves we are embedded in the COVID-19 vaccine-injured community. Full details of our organisation and activities can be found on our website at coverse.org.au. We have no conflicts of interests and have not accepted any funds from government, medical groups, pharmaceutical corporations, or political campaigns.

Summary

As the NDIS seeks to make adjustments to the Scheme over the coming years, it is our belief that we, as COVID-19 vaccine-injured Australians, can provide a unique and valuable insight. We are a cohort of newly disabled people. We invite you to involve us in the development of assessment tools, and research our progress through the NDIS to ensure the changes implemented are achieving targeted goals. Recommendation 1 addresses this.

COVID-19 vaccine injured people are currently attempting to access the NDIS. Our attempts are thwarted with some of the same issues of misunderstanding that have dogged our experiences to date with attempting to seek medical and government assistance for a medical condition, and now disability, that is poorly recognised and understood. The proposed changes to the way in which people are able to access the NDIS and, are then assessed for need, is of significant concern to **COVERSE** in light of our community's recent and ongoing experience of failed access to assistance due to unnecessary roadblocks. While we see some advantages to a functional capacity, rather than diagnostic assessment, forming the basis for assessing eligibility for the NDIS, we have a number of concerns regarding the proposed legislative changes. These are addressed in Recommendations 2 and 3.

Recommendations:

1. COVID-19 vaccine injured people are included as part of the co-design, consultation and implementation process for the NDIS Bill.
2. Functional capacity assessment
 - 2.1. Functional capacity assessment tools are co-designed with people with lived experience of a broad range of disability, including vaccine injuries.
 - 2.2. Functional capacity assessors receive education about vaccine disability from people with lived experience.
 - 2.3. When someone is being assessed with a new and emerging disability, special provision can be made for additional information to be provided by external sources, to assist in providing fair functional capacity assessments.

¹ www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/NDISAmendment2024

3. Needs assessment
 - 3.1. Needs assessment tools are co-designed with people with lived experience of a broad range of disability, including vaccine injuries.
 - 3.2. Needs assessors receive education about vaccine disability from people with lived experience.
 - 3.3. When someone is being assessed with a new and emerging disability, special provision can be made for additional information to be provided by external sources, to assist in providing fair needs assessments.
 - 3.4. An appeals process must be included in the needs assessment process.

Finally, we refer to the submission by Emerge Australia, in that they specifically include people with Long Covid in their submission. People with Long Covid and COVID-19 vaccine injury share many overlapping conditions, including many having a diagnosis of ME/CFS, indeed many people known to **COVERSE** engage assistance from Emerge Australia. As such, the recommendations and concerns raised by Emerge Australia are echoed by our community.

The newly disabled - a collective experience of COVID-19 vaccine-injured Australians

In the many submissions that **COVERSE** has made to other Parliamentary and government inquiries we have detailed the negative experiences of Australians who have been harmed by the COVID-19 vaccines.² This includes worrying levels of medical gaslighting, lack of medical and scientific investigations, zero follow-up from pharmacovigilance agencies, the censorship of these patients and their doctors, and many other matters that all contribute to an enormous shortfall in the acknowledgement and statistical appreciation of harms caused by the COVID-19 vaccines. References for many of the statements we make in this current submission can be found in our prior submissions should our Senators wish to explore these issues further.

With many of the COVID-19 vaccine injured community now passing 3 years of disability, having exhausted rehabilitation and medical solutions to their various conditions, they are now being advised by their medical and allied health professionals to apply for NDIS support, as their conditions are considered chronic. To date, the COVID-19 vaccine injured community has faced the same difficulties accessing support through the NDIS as they have with finding support through medical services. **COVERSE** has no record of anyone in the COVID-19 vaccine injured community who has been successful in their application for access to the NDIS.

What kinds of disability?

Analysis of VAERS³ reports from December 2020 to July 2022 showed 770 different types of adverse events of statistical significance due to the COVID-19 vaccines.⁴ While not all of these result in lifelong disability, many do, or the combination of symptoms create a cluster effect resulting in chronic disability. Some of the adverse reactions being experienced by our community are able to be described within known diagnostic criteria, for example:⁵

- Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP);
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS);
- Dysautonomia
- Pericarditis
- Myocarditis
- Postural Orthostatic Tachycardia Syndrome (POTS)

² coverse.org.au/submissions

³ Vaccine Adverse Event Reporting System (VAERS) in the USA (vaers.hhs.gov). Our equivalent in Australia is the TGA's Database of Adverse Event Notifications (DAEN) (daen.tga.gov.au).

⁴ As far as we know neither this data, or its analysis, have been published by the CDC in any peer reviewed scientific journal. However, others have attempted to explain the data, such as: researchrebel.substack.com/p/cdc-finally-released-its-vaers-safety

⁵ This is a short list of some of the conditions our community is now burdened with.

- Fibromyalgia
- Stroke
- Heart Attack
- Tinnitus
- Various autoimmune disorders

Many other patients are experiencing symptoms that have no clear diagnostic label at this stage. These include crippling neurological, gut and vascular symptoms. Appropriate testing to determine the cause of these symptoms has not yet been developed, and although there is research being done into this in other countries, Australia is lagging behind.

A unique opportunity

The NDIS has a unique opportunity to create a true test case while implementing the new NDIS structures. COVID-19 vaccine injured Australians are a cohort of newly disabled people from a wide range of ages and backgrounds. We have a number of different conditions. Most of us were not previously disabled. There is the possibility of gaining highly valuable insight and data from our experiences to enable a thorough assessment of the planning, rollout and implementation process that will be needed for such a large system change.

Recommendation 1: COVID-19 vaccine injured people are included as part of the co-design, consultation and implementation process for the NDIS Bill.

The proposed changes to the NDIS Bill, and in particular the changes to how people are able to access the NDIS and how budgets are set, raise a number of concerns for COVERSE. If these issues are not addressed during the design and implementation phase, it is our belief that those with chronic disability from the COVID-19 vaccines will continue to suffer the gaslighting, misunderstanding and lack of acknowledgement that has been their experience to date.

Access determination

As has already been described, people needing to access the NDIS due to disability from the COVID-19 vaccines have varying medical diagnoses, and in some cases their medical conditions are quite difficult to categorise. A move towards a functional capacity based assessment to determine access to the NDIS does hold some advantages in that it is not reliant upon the, at times limited, medical framework. However, the Bill does not yet clarify what tools will be used, or whether they will be appropriate for measuring the functional capacity of someone with COVID-19 vaccine disability. Given the lack of understanding of our condition within the medical and allied health community at this time, we urge Parliament to ensure that the vaccine injured community is involved in the co-design of these tools and in the education of assessors as the tools are rolled out.

Recommendation 2.1: Functional capacity assessment tools are co-designed with people with lived experience of a broad range of disability, including vaccine injuries.

Recommendation 2.2: Functional capacity assessors receive education about vaccine disability from people with lived experience.

A challenge that the NDIS will face with the roll out of this new system of determining access to the Scheme will be in building a workforce of assessors who have the experience and expertise necessary to accurately assess people with the broad range of disability that they will encounter. Given the difficulties that are likely to be encountered in providing assessors with suitable vaccine injury experience across Australia and thus enabling equity of access for all vaccine disabled Australians, and indeed any Australian with a new and emerging form of disability, we hold further concerns that limiting access determination solely to the functional capacity assessment carried out by one assessor could lead to unfair decisions, based simply on lack of experience or understanding of the impact of the disability they are assessing. We therefore are

adding an additional recommendation that for new and emerging disabilities, additional information from external professional sources should be able to be provided to help assist the assessor in making their decision. These external professional sources would include reports and letters from the applicants' medical and allied health team, guidelines from disability specific peak bodies, and published scientific research. The aim of such additional information is to help inform the assessor so that they are better equipped to make a fair and equitable assessment of the person who is presenting with a cluster of symptoms that they may otherwise unintentionally misinterpret.

Recommendation 2.3: When someone is being assessed with a new and emerging disability, special provision can be made for additional information to be provided by external sources, to assist in providing fair functional capacity assessments.

Budget-setting process

The proposed Bill does not clearly define the budget-setting process, though it describes a needs assessment which will be administered to determine funding and this funding will not be subject to an appeals process. We have a number of concerns about what this process could mean for COVID-19 vaccine disabled Australians.

As is the case with the functional capacity assessment, the use of a needs assessment to assess an outcome for people with a disability that is unfamiliar to the assessor leaves people with a vaccine disability at an unfair disadvantage. If there is going to be any chance of us addressing this disadvantage, both the tool that is developed and the assessors that administer the tool need to understand the lived experience of people with vaccine disability and how this affects their day to day needs. We believe the same process of co-design in the development of the needs assessment tools and assessor education should be implemented as we recommend for the functional capacity assessments.

Recommendation 3.1: Needs assessment tools are co-designed with people with lived experience of a broad range of disability, including vaccine injuries.

Recommendation 3.2: Needs assessors receive education about vaccine disability from people with lived experience.

Again, as with our argument with functional capacity assessments, with needs assessments we recommend that for vaccine disabled Australians, and anyone with a new and emerging disability, they be allowed to include additional information from external professional sources to aid in fair and equitable decision making processes.

Recommendation 3.3: When someone is being assessed with a new and emerging disability, special provision can be made for additional information to be provided by external sources, to assist in providing fair needs assessments.

With regards to the needs assessment not being reviewable, this is an issue of significant concern. People with vaccine injury have a fluctuating illness, which affects many areas of their abilities including energy and cognition. If a needs assessment is conducted on a day of significantly good or significantly bad function, it would make it difficult for the person to accurately participate in the assessment. Likewise, it makes it difficult for the assessor to accurately make their assessment. The fact that our cohort are new to disability and the language of the NDIS also puts us at a disadvantage, making it difficult for us to even understand the questions being asked as their meaning is different in a disability context to the world of employment that they have just been removed from. Factors such as these are ordinarily difficult, but can be overcome if a review and appeals process is in place. If this process is removed, we are at risk of being stuck with NDIS funding that is inadequate to address the real day to day needs that we have.

Recommendation 3.4: An appeals process must be included in the needs assessment process.

Conclusion

It is said that the measure of a society is how well they take care of their sick, disabled and elderly. This is particularly pertinent when it comes to how our government recognises and takes care of those who have become sick and disabled as a result of taking a vaccine in order to protect those around them who were vulnerable during a pandemic.