People with Long Covid Deserve NDIS Access

This is a statement by people with Long Covid. The World Health Organisation defines Long Covid as ongoing symptoms three months after infection or longer.

Despite the deafening silence that we hear all around us, we are still in the Covid pandemic. In the middle of a mass disabling event, you'd think that our government would expand disability services to meet the needs of all the newly disabled people with Long Covid. Instead, they plan to demolish the NDIS!

Shamefully, Mark Butler did not even mention Long Covid in his speech. No Long Covid organisation was represented at the recent senate inquiry hearings. This is orchestrated silence. If we don't talk about Covid, we don't think about it. If we don't think about it, the government gets away with forcing the cost of the pandemic onto the population.

We, the people with Long Covid, do not have the luxury of not thinking about Covid. Our symptoms remind us every moment of every day. The public should know more about our symptoms.

What is Long Covid? Long Covid is not showering, cooking or cleaning because doing any of those things could trigger full-body pain for days, weeks or months. Long Covid is peeing into a cup in your bedroom because walking to the toilet could make your health deteriorate. Long Covid is similar to being under lockdown but it's much, much worse because your body is under lockdown, not just your house. Long Covid is not being able to even make decisions because mental exertion leads to physical fatigue. Living like this, we inevitably struggle with our mental health. Long Covid is not a dignified life.

At its most extreme, Long Covid is lying in your bed in total darkness because you can't deal with light. You can't leave your bed. You can't do anything. The pain is constant. Long Covid can trigger a condition called gastroparesis, where the stomach can't function properly. People with severe gastroparesis can't eat. If you can't eat, eventually you die.

There are people with Long Covid and ME/CFS who are starving to death in this country. They applied to get onto the NDIS but they were knocked back. That is shameful.

It should be obvious that people who can't shower, eat, clean, cook or walk need the NDIS but there are many barriers for us. We are told that to get onto the NDIS we need to do Graded Exercise Therapy. Graded Exercise Therapy is a dangerous intervention that must not be forced onto us in order to qualify for NDIS access. As it stands currently, patients may argue with the support of their GP or specialist that an intervention is not appropriate or safe for their clinical presentation, or that it is

inaccessible physically, financially or geographically. Under the new bill, these contingencies will be completely removed. Anyone who has not tried all possible known “treatments” associated with their condition will not or no longer qualify for access.

Advocates are rightly raising the alarm that this will mean the forced use of chemical restraints in various psycho-social disabilities. We would like to add to this chorus our concern around Graded Exercise Therapy. This change has no regard for medical evidence, and completely undermines patient autonomy and safety.

We are told that to get onto the NDIS we need to go into a group home. This is not viable for us. Group homes do not meet our accessibility needs. The NDIS is for people with permanent disabilities. It can be hard to prove permanency when Long Covid can fluctuate. And how is a person with severe brain fog supposed to fill out a mountain of paperwork?

In short the NDIS in its current form is not cognizant of the nature of energy-limiting chronic illnesses at all. This is not accidental. Instead of consulting with us or with the scientists who understand our condition, our government pays bogus “experts” for advice about how to exclude us from the NDIS. There is no co-design. When the existing NDIS already excludes us this badly, how on Earth are we going to get support when the NDIS is cut?

These barriers are tied up with the government’s disinformation. It's true that autism makes up a huge number of primary diagnoses on the NDIS, in no small part due to patient advocacy and actual need. The loudness around neurodiversity and psycho-social conditions compared to the silence around Long Covid is telling. It is so much easier to individualize and demonise conditions like autism when Long Covid opens up questions about pandemic management, mass infection and state responsibility.

Long Covid is a union issue. It is one of the most serious Workplace Health and Safety issues of our time. Long Covid sufferers are disproportionately nurses, teachers and hospo workers; workers who caught Covid in public facing jobs where there are zero protections and the risk of workplace transmission is high.

Why should we have to live like this, lying in bed filthy, unable to shower? We are pressured to get out of bed and get back to work. Why should we be pressured? Many of us WANT to go back to work. Maybe we could get back to work IF we could get on the NDIS.

We demand a dignified life. We demand access to the NDIS. We urge all unionists and all people with a conscience to fight to expand the NDIS to include us. We thank the

Protect the NDIS Alliance for incorporating this demand. Any changes to the NDIS eligibility criteria, functional capacity assessment and funded supports should ensure it does not exclude people with invisible, energy limiting, fluctuating conditions like Long Covid and ME/CFS, especially because funding for research into effective interventions is very limited.