



NDIS SIL Inquiry - Submission September 2019



Every Australian Counts thanks the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make a submission into its inquiry into Supported Independent Living (SIL).

Every Australian Counts is the grassroots campaign that fought for the introduction of the NDIS. It is a community of people with disability, their families and carers, people who work in the sector as well as ordinary Australians who want to see a better and fairer deal for people with disability in this country. In the eight years since it was established, it has amassed thousands of supporters from all over the country.

Every Australian Counts didn't end with the introduction of the NDIS in 2013. The EAC community has stayed active and engaged as the scheme rolls out around the country. Our community continues to fight to make sure the NDIS stays true to its original vision and delivers on its promise to people with disability.

We want to begin by acknowledging once again our support for the NDIS. We have had the opportunity to both see and hear firsthand the incredible difference it has made to many lives. When it works well, it does change lives for the better – as we always hoped it would.

But our community is also all too aware that it is not working well for everyone. Too many people are falling through the gaps, and not getting the support they need. Even those who are ultimately happy with the outcome express constant frustration with NDIS processes and policies. In short – the scheme is not yet working the way we all want and need it to.

We have had the privilege of speaking to thousands of people across their country about their NDIS experience and their ideas for change. Whether face-to-face at one of our community forums, or through social media, or through phone calls and emails, or through surveys and submissions, we are constantly collating people's feedback, experiences and ideas for change. We wanted the committee to have the same opportunity to hear from everyone in our community. Not everyone can attend one of the committee's public hearings, and not everyone has the time or resources to make an individual submission.

So we opened a small page on our website asking people to contribute to this submission. In just a couple of weeks we received more than one hundred stories, statements and ideas. That is what you will find attached in the Appendix. They are as they have been submitted to us – the only editing has been for typographical errors or information that clearly, and potentially dangerously, identifies a person or their family.

The last couple of times we made a submission to you we made the decision to edit out some of the swearing. Not all, but some that we thought people may have found offensive. This time however we have left it all in. This may give the committee some idea of the level of frustration, anger and stress experienced by many participants and their families.

While we understand you will read every one of the stories in the following pages, what follows is a brief summary of the most commonly raised issues by those who have submitted.

Waiting, waiting, waiting

Like the rest of the NDIS, most common complaint from both participants and providers was the amount of time it took to apply for, and resolve issues with, SIL. To leave people with disability and their families in limbo for months is completely unacceptable. And again, like the rest of the NDIS, many people pointed out how the NDIA appeared simply unable to effectively triage those in crisis or most in need.

Too complex, too confusing

Again like the rest of the NDIS, many of the complaints about SIL were about its complexity. People consistently reported they found the process confusing and complicated – and were left alone to navigate their way through the maze with limited or no help. And again like the rest of the NDIS, the number of submissions that detailed the considerable stress and anxiety people experienced trying to navigate the maze were distressingly high.

Lack of transparency

Many people noted that the NDIA were not transparent in the way in they made decisions regarding SIL. And perhaps more disturbingly, the very way the SIL process had been constructed locked out participants and their families from participation and oversight. SIL quotes are being submitted by providers not only with no input from participants and their families, but even without their knowledge. This has left participants and families feeling that they have been “stitched up” with little opportunity to challenge or change. And given the significant shortage of suitable alternative housing or providers, the opportunity to change providers could be described as limited at best, impossible at worst.

Providers not accountable

Many people noted that despite the promise of increased choice and control, the way SIL processes were set up between providers and the NDIA left participants and their families with limited opportunities to hold providers accountable. Families spoke of incorrect invoices discovered by accident or services claimed but not provided. And again, the significant housing shortage and the lack of suitable alternatives means people cannot simply walk away and find another provider.

Complex needs

And again just like the rest of the NDIS, many of the complaints received about SIL are focused on in the inability of both the NDIA and providers to respond effectively to those with the most complex needs. Many suggested that the “let the market rip” approach of both government and the NDIA failed to ensure there were enough providers with sufficient skilled and experienced staff to meet the needs of people with more complex disabilities or circumstances. Many families noted in their submissions how difficult it was to find providers and workers with the essential experience and skills to support people in the way they needed and preferred.

Funding beyond SIL

A number of submissions noted that SIL quotes rarely covered all expenses in living and managing a home. They noted a considerable reluctance on part of the NDIA to provide additional funding to cover these expenses. This leaves people without support or out of pocket. The lack of flexibility of the SIL funding also limits the ability of those living in group housing to get out and about – the exact opposite of what was intended when the NDIS was introduced.

Crushed by red tape

Whether SIL or planning the issues with the NDIS are the same – bureaucratic rules, long wait times, lack of transparency, poor communication, lack of flexibility compromising choice and control, red tape stifling innovation and pushing people into same old same old models of care and support. So perhaps it is not surprising that the most disturbing stories provided to us as part of this submission were those which outlined fantastic innovative housing and living approaches which have been stymied by NDIS red tape and inflexible rules. It is precisely these approaches the NDIS should be encouraging and facilitating – rather than simply propping up existing models. One person summed up the situation succinctly:

“In a nutshell I think that the very great risk with the SIL funding arrangement is that those who don’t have very strong advocacy can just slip into a life that is not much different from under the old culture of block funding or institutionalisation. It seems to me that strong personal advocacy is the key – and sadly many people living in a SIL arrangement do not have that ... it’s a systemic problem not isolated to any particular service provider.”

Wrapping things up...

The most important message we would like to deliver to the committee on behalf of the EAC community is that SIL is just facilitating more of the same. It is not driving the change we wanted to see. In fact, whether intended or not, the current arrangements for SIL are simply bolstering old models rather than encouraging or facilitating new approaches. And the SIL process is not just compromising choice and control. It is far worse – it is limiting rights that are protected under the UN Convention on the Rights of Persons with Disabilities. This is not the scheme we fought for. Nor is it the scheme we will accept.

When it comes to housing and living arrangements, it's time to go back to basic principles of NDIS – individualised planning, individualised funding, the choice to live where you want and with who you want to live with. Unfortunately we have drifted so far that this now appears a radical proposition.

Again, we would like to thank the committee for the opportunity to have input into the inquiry. We want to finish by strongly urging you to carefully consider the views expressed here and the suggestions for change. In our view, it is people with disability their families and carers and people who work in the sector who have the best understanding of what needs to change, and what will and what will not work on the ground. Please listen to what they have to say – they are the ones who matter most.

Yours Sincerely

Kirsten Deane on behalf of Every Australian Counts

