# An Analysis of Supported Independent Living (SIL)

## Introduction

I am very pleased that the Australian Parliament's *Joint Standing Committee on the NDIS* has seen fit to inquire into and report on Supported Independent Living (SIL). While the Committee has suggested that submissions might address any one of three specific issues plus "any related issues", I urge the Committee to take a much broader view of the significant systemic issues with SIL. As I will explain, from NDIS participants' perspectives, the issues with SIL are many and deep-rooted. They are much more fundamental in nature than the suggested issues of approval processes, vacancy management and funding.

In making this submission, I am drawing on my considerable knowledge of disability, the NDIS and the challenges facing providers. Professionally, I work as an organisational consultant, doing much of my work in the disability sector and other human service sectors. In recent years, my consulting projects have taken me to Canada to work with numerous service providers, people, family members and Provincial governments in British Columbia, Ontario and Newfoundland and Labrador. I am a member of the NDIA's Intellectual Disability Reference Group, which forms part of the NDIA's governance structure. I describe myself as an NDIS enthusiast and am genuinely excited about the revolutionary possibilities that the NDIS might create for people with disability in Australia. I also know that if Australia gets the NDIS right, we will be setting a path that other countries and jurisdictions will be inspired to follow. So, this critique is laden with positive intent!

I am also writing from my personal perspective as the parent and plan nominee of an adult participant with intellectual disability and various other disability diagnoses. He has been and remains my greatest teacher and inspires me and many others who know him.

## SIL is fundamentally flawed

In this submission, I want to briefly identify and discuss six serious and fundamental flaws with SIL. I will seek to demonstrate that individually and collectively they are at odds with the legislated intentions of the NDIS. I will also seek to demonstrate that continuing into the future with SIL is likely to contribute to escalating costs and a significant shift of power and autonomy away from (already disadvantaged) participants to large providers of congregate accommodation services. I will discuss the first three issues together because they are inter-related.

1. SIL is arguably in breach of the NDIS Act (the Act)
2. SIL undermines the rights of all people with disability who live with a SIL service model, especially those who have high support needs
3. SIL entrenches outdated models of service delivery while undermining the Scheme's capacity to generate and support innovative approaches, choice and control, and capacity building outcomes.

Any breach of the Act is a major problem if it is true. The Objects of the Act (Part 2, Section 3 (1)) make it abundantly clear that the NDIS is a human rights reform as much or more than it is a funding model reform. I will discuss SIL in light of two Objects of the Act to demonstrate how SIL breaches the Act. Object (e) expresses the intention of the NDIS to ***enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports****.*

In contrast to this intention, SIL has been designed and implemented in a way that **almost never** *enables people with disability to exercise choice and control in the planning and delivery [of the shared elements] of their supports*. In practice, the opposite is true, with SIL having a knock-on effect to other elements of their support arrangements. SIL almost always excludes people from meaningfully being involved in discussions and decisions about how and when their shared supports are delivered.

As an example of how excluded people with intellectual disability (ID) or cognitive impairments in particular are from SIL conversations, I venture to predict that the vast majority of submissions the Committee receives on this topic will be from providers, with very few submissions from people with ID themselves. Yet these cohorts form a substantial portion of participants whose lives and supports are controlled by SIL and its processes. Their ability to meaningfully contribute submissions to the Committee is quite limited by the Committee's processes on one hand, but more importantly, by the very nature of their limited understanding of SIL and how it works on the other.

The SIL quoting tool is a complicated instrument that befuddles many disability professionals as well as a fair number of NDIA employees. It is not realistic to expect that the people with disability to whom SIL applies will be able to meaningfully *exercise choice and control in the planning and delivery of this element of their supports,* especially when the other parties involved are service providers and NDIA bureaucrats. The complexity of the instrument, the high communication support needs of many SIL participants, and the inherent power imbalance favouring service providers and the NDIA have the combined effect of excluding or minimising their already marginalised voices. They are forced into a position of dependence on a service provider to speak about their support requirements within a SIL environment on their behalf and in practice they are rarely consulted about it in any meaningful way. This speaks to point 2 above, the undermining of their fundamental rights.

The SIL participant cohort includes many participants with intellectual and cognitive disabilities and people with significant physical disabilities who require very high levels of support. Given that many of these people literally don't have a voice in the sense of using spoken words to express themselves, they are among the most disadvantaged and marginalised people in any sector of Australian society when it comes to recognising and upholding their ability to exercise *the same rights as other members of Australian society* (NDIS Act S4(1)). And while many of these participants may have an NDIS Nominee speaking with or for them, it is still unrealistic to expect that the nominee will a) have the time, motivation and capacity to understand SIL; or b) a power base that enables them to have an equal voice in discussions about the shared elements of the participant's support.

As a result, SIL not only fails to uphold this legislated clause; it actively undermines it. I expect that legislators will be concerned by any clause in the Act that is systematically undermined in practice in this way. I hope you are doubly concerned when the clause in question is an Object of the Act, expressing the very intention behind the legislation.

It is reasonable at this point to ask if SIL can be amended in ways that will reduce or eliminate this problem. My answer is a resounding NO. The reasons why I come to this conclusion will become clear as I highlight other issues.

In relation to points 1 and 3 above, my analysis leads me to conclude that SIL breaches another Object of the Act. Clause (g) states that another intention of the NDIS is to *promote the provision of high quality and* ***innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community.*** Once again, SIL not only fails to uphold this clause; it actively undermines it.

SIL is fundamental to congregate forms of accommodation support that are typified by group homes. With more than 50 years of evidence to draw upon, it is very clear that group homes as a model have NOT delivered the social and economic inclusion outcomes that the Scheme aspires to deliver. In contrast, social and economic participation and inclusion have more readily been achieved using numerous other models of supported living (which are far more successful on a proportional basis). There can be no debate about this. Group homes were a laudable and valuable innovation in the 1950s. They enabled many people with disabilities to move out of hostels and institutions and into houses that were embedded in suburban settings in an era when people knew their neighbours and interacted with them far more regularly than most do today.

The group home support model belongs to the $20^{th}$ Century not the $21^{st}$ Century. It is characteristic of a disability services paradigm that was based on “other people making decisions for people with disability in their best interests”. The NDIS is the vanguard of a new paradigm based on disability rights. It enshrines the rights of “people with disability to make their own decisions and to exercise choice and control”. Australia is leading the world by embodying our commitment to this right in national legislation. And in this new paradigm, leading contemporary approaches, best practices and innovative supports that uphold and promote this right are mostly to be found in individualised arrangements rather than congregate models of service.

For example, by its nature, SIL restricts participants’ opportunities to explore a range of options about how, where and with whom they might want to live. It’s not just a case of SIL doesn’t encourage it. As an instrument, SIL makes it difficult for participants to do this, something that is fundamentally at odds with the intention, Objects and Principles of the Act. It is difficult to conceive how a participant could realistically seek out SIL quotes from Providers A, B, and C to inform their planning goals and choices, especially when the SIL services in the group home where they live are all provided by Provider A. SIL also affects participants autonomy and choice making ability in many other ways that affect their quality of life. Most SIL participants having little control over decisions such as when they go to bed, take a shower, go to sleep or even have sex in their own bed.

Even more problematic is that SIL does not give providers any motivation to support participants who want to explore other living arrangements. This includes emerging evidence that SIL providers are “giving up” on helping participants explore SDA eligibility as its too hard, complex and/or time consuming. This means there is an increasing number of potentially SDA eligible participants living in SIL settings when they could have much better outcomes. Plotting a pathway into other living arrangements including an individualised living option is already difficult for most participants. SIL is an additional impediment to participants’ choice and control over these key aspects of their lives.

4. SIL will likely threaten the financial viability of the Scheme and derail the intention behind the Scheme

SIL is effectively a form of block funding that benefits accommodation and support providers using congregate service models. As I have shown, this is a model that systematically diminishes the choice, control and autonomy of participants. SIL quotes identify and cost up the type, nature and extent of shared supports across “a typical week” and extrapolate those costs to cover the entire year ahead in a participant’s plan. There is limited ability to include irregular hours in quotes that may cover periods when a person is unwell or even hospitalised for short periods.

However, at the point of service delivery there is no need for transparency about what shared services are actually delivered, enabling providers to invoice for quoted services whether or not these have been delivered as quoted. While there is anecdotal evidence that this is happening already, the lack of transparency means that the scale of this issue and the reasons why it is happening are not at all clear. The scale of the issue could be minor. Or it could be hiding a very significant problem that affects the Scheme’s financial sustainability.

The reasons this is happening could include one or more of the following:

- ‘A typical week’ turning out to be an atypical week;
- Automated invoicing systems being used;
- Participant absences including hospitalisations;
- Human error;
- Staff shortages;
- Needing less staff than quoted at certain periods;
- Changing a quote for a house is complex and time-consuming (which is costly to providers), meaning providers have no motivation to do this; and
- Deliberate fraud.

These situations are all predictable in the sense that we know that on the basis of human nature and human behaviour, these things will occur if the system allows them to, and has few checks in place to prevent them occurring. So, while these situations *may* represent a very small portion of all SIL situations, there is currently no way of knowing how widespread this issue is now or may become in the future. To determine that would probably require the creation of a complex compliance and regulation system that includes a ‘proof of service’ auditing process. Such a response would be suboptimal for many reasons.

The main arguments against creating such a system are that:

a) SIL is such a problematic and flawed instrument, it is not worth saving;
b) Unless every group home is audited annually, the problem still exists;
c) It does not address the fundamental rights-based issues associated with SIL in the first place; and
d) It is a massive waste of taxpayer funds that will divert significant funding away from participants’ plans into monitoring the ‘block funding’ component of the Scheme when the NDIS is supposed to be based on individualised funding and not block funding anyway.

It is entirely predictable that creating a regulatory approach to ‘improving SIL will most likely result in a future senior regulator making comments like these:

> *"The complexity of the system made it more difficult to ensure rules were followed. . . If you look at the number of laws and policies, and even the number of little departments inside bigger departments, who have some sort of role or responsibility here, it actually sets itself up for poor compliance. . . We have to improve that. This is taxpayer's money that has to be properly managed and properly looked after. . . And just like it does in every other field of government or private enterprise, [a large amount of money] does provide a chance for corruption or fraud to take place."*

While these are the actual comments made this week by Mick Keelty in relation to management of, and corruption in, the Murray-Darling Basin Plan funding, their relevance here should be self-apparent.

SIL is already showing signs that it is already testing, and will continue to test, the financial viability of the Scheme. The latest quarterly report shows the current SIL funding commitment is up to $6.12B, making SIL the largest funding category within the Scheme. The average package size is approximately $290,000 per person (national average). These are red flags showing that SIL is inefficient and likely to be a significant contributor to providers' profit margins in a way that is not aligned to the Scheme's intentions.

5. At the very least, SIL implies that participants have no recourse to procedural justice re- any perceived under-use of SIL services.

This is another argument against retaining SIL as an instrument in the NDIS, although by comparison to the foregoing issues seems relatively minor. It is, however, emblematic of the many problematic issues that are embedded in SIL by its very nature. As things currently stand, a participant (or their nominee) who perceives that they have not received "their share" of SIL services has no recourse to retrieving those funds and using them flexibly in pursuit of other plan goals. It is self-evident that this is an issue of procedural justice which the NDIA is unable to address with SIL in its current form. How long will it be until a participant uses the court system to address this issue with either the NDIA, their provider or both?

6. There are problems with how SIL interfaces with each individual participants' plan and goals.

A final issue with SIL is way it interfaces with each person's individual plan and goals. Participants who have community access and capacity building goals and are SIL residents are often not achieving these goals and are underutilising these funded services in their plans. Given that community access is frequently delivered by a third party provider, SIL providers have little motivation to engage with these third parties and assist the SIL resident to "get out of the house".

**What can be done?**

If SIL had some positive things going for it, I'd recommend it be retained and fixed. But in reality, it so at odds with what the Scheme aspires to achieve that taking that course of action runs the risk of being a very poor 'escalation of commitment' decision (see point 5 above). It is abundantly clear to those of us working with contemporary and best practice models of disability support that this part of the Scheme has not been co-designed with people who know such models well. I doubt that any of the world's leading thinkers and best-practice experts I know of would recommend keeping SIL. It is inherently flawed, and better alternatives exist.

From my own work in, and connections with policy makers, leading thinkers and service practitioners in North America and the UK, it is clear that there are alternative models which should be examined and used. Several Canadian and American jurisdictions use an approach that is not dissimilar to what was in place in WA prior to the NDIS: each individual with high/complex needs has those needs assessed to determine what a reasonable and necessary level of funding is based on their goals and functional impairment. This gives the person clarity and confidence about the funding at their disposal. They then have autonomy over which services they purchase to meet their needs, including the freedom to use it in an individualised living arrangement or a congregate arrangement as they prefer.

Determining the reasonable and necessary supports a person needs in this manner is far more consistent with the intention of the NDIS and with how funding is determined for all of a participant's other services. With that sort of funding assurance, participants will also be able to move their services more easily and without a SIL reassessment being required if they choose to do so.

I am aware (and greatly relieved) that the NDIA is currently doing some work on Individualised Living Options (ILO), including the development of an ILO model. Without being privy to what that emergent model looks like at this stage, with the right input it could well provide useful information that will enable an alternative to SIL to be developed.