



Presentation to the Joint Standing Committee on the National Disability Insurance Scheme: Supported Independent Living Inquiry.

Jane Wardlaw, 28 October 2019

I pay my deep respect to Tasmanian Aboriginal owners of this land, including others who too, have fought long and hard for self-determination and responsibility, advocating their right to self govern and reach their full potential.

Thank you to the joint standing committee on the National Disability Insurance Scheme for inviting me to present information in regards to the supported independent living (SIL) enquiry. My presentation will include a case study to illustrate some of the complexities of SIL in action and its impact on NDIS participants.

I want to dedicate my presentation today to my friends who lost their lives too soon before the NDIS was able to make a significant impact for them. These friends lived in supported independent living environments.

As an active disability rights advocate here in the State of Tasmania my perspective is by the lived experience, my professional career within the disability community, emerging researcher and disability consultant.

In my practitioner role, I've had the privilege of working alongside individuals living with disability, and their significant others to navigate NDIS, including SIL environments.

My practice experience has led me to believe that successive governments, both state/territory and Commonwealth, have long underestimated the depth and breadth of disability, as it prevails in Australia. It is also evident prior to the NDIS, successive governments' lack of transparency, accountability and poor governance arrangements about people living with disability and the services that they required, has had a significant and negative impact on quality of life for this cohort. The NDIS is expected to change this around and allow people to exercise their choices, and freedom as an equal citizen.

Despite the introduction of the NDIS, I believe that the complex administration of the NDIS here in Tasmania is still having a negative impact on the quality of life of people living with disability yet we hold hope that change is underfoot. Particularly at risk, are people living with complex and profound disability. Largely, this cohort find it difficult to navigate the NDIA, self advocate and find themselves living in mini institutional-like settings known as SIL or a group home environment.

Over the past six years, we have seen people living in supported accommodation environments transitioning into the NDIS. For example – compliance around conflict of interest concerning whole of life provision. In these environments, lack of choice, control and self-determination is evident.



SIL funding does not necessarily guarantee high levels of choice and control particularly if there is not a range of new and quality options available for housing and accommodation support to choose.

In the early days of the NDIS, it was well documented by specialist disability service providers, that other providers would enter into the market and possibly take over their businesses or at least their clients. In fact, the opposite has occurred. Particularly in the SIL environment. In Northern Tasmania for example, SIL is largely dominated by the same providers previous to the NDIS rollout. This is problematic because options are limited to traditional providers and arguably innovation in service provision is lacking without competition. Is there a risk of market failure in the lack of supply of robust, innovative SIL provision?

The operating milieu of the NDIA to roll out the scheme here in Tasmania has appeared to be an ever-changing landscape. This makes it very difficult for service providers to operate a business effectively as decisions can be made by the NDIA overnight without consultation.

There is a lack of information sharing between key stakeholders and the NDIA. Codesign is no longer evident in addressing the internal approvals process in the NDIA. People living with disability are not included in the design of the SIL operational processes of the NDIA . #OurSayMatters.

Decisions by the NDIA regarding SIL plans take too long to be made, impacting on individuals' living in supported accommodation environments to begin the process of freedom.

Waiting for SIL plan approvals is having a negative impact on the participant. Let's think about case study – "Jonathan" (not his real name), wants to relocate interstate to be closer to his family. Jonathan lives with significant intellectual disability in a supported independent living environment with three others. His supported independent living environment is far from adequate, and as a result, Jonathan has recently been medicated for depression. Hence his family are keen for an immediate move. But this won't be possible without an NDIS current plan. His plan was meant to be approved in early September. His NDIA plan review meeting occurred in August. Consider this:

- The service provider is expected to continue to pay staff for the essential supports required to Jonathan without an NDIS plan.
- Jonathan is unable to start the process of relocating.
- Jonathan's support coordinator is unable to start investigating available options interstate without first knowing what the funding mix will be particularly for SIL transition.

And time ticks by.

This is not an unusual story. And it brings to light several critical issues within the NDIA.

Firstly, let's consider the discretionary effort expected by the NDIA of SIL service providers.



The NDIA is expecting service providers to foot the bill/act like a bank whilst NDIA considers the reasonable and necessary funding allocation. Service providers are then expected to navigate the complex, bureaucratic system to recoup funds during planned gaps through a dysfunctional provider payment system. Service providers have expressed significant delays of between six - ten months until able to recoup funds from the NDIA's provider payment system. These anomalies have an impact on the participant receiving quality support because of funding uncertainty.

SIL must create certainty, be flexible, promote choice and supply options, work collaboratively with stakeholders to build the participant's capacity and overcome inequality.

Another critical issue which affects the SIL process within the NDIA is the unfinished, inferior IT system build. Personally, I feel the IT system has been an adjunct failure of the scheme. It won't allow the NDIA planner to make minor adjustments across budget streams and sometimes for SIL this could add another level of bureaucracy trying to navigate the system if there happens to be a change of circumstances for example increased need.

Most importantly, these issues of SIL plan approval, lack of certainty of adequate funding, lack of timeliness, and bureaucratic barriers within the NDIA is impacting on the NDIS participant's right to exercise their self-determination, capacity building, choice and control and enact their NDIS plan adequately.

Over the past two years, the NDIA have seen fit to minimise support coordination allocations. It is my understanding that the NDIA have brought in a process of "streaming" individuals requiring support coordination determined on participants complex interactions with other systems such as justice, child protection, and extreme situational circumstances, including SIL. Even in these situations, support coordination is minimised and capped. Often, people who require a support coordination service are underfunded and again the NDIA is dependent on the discretionary effort of service providers.

As support coordinator working with a SIL NDIS participant, requires considerable allocation of hours to ensure the participant and their significant others understand processes, become empowered and confident in order to have their daily needs met adequately by the service provider. This could be in the guise of establishing a tenancy agreement, accountability measures in regards to the spending of house monies for food and rent, ensuring more transparency of finances, assisting the individual to choose where they want to live and with whom they live with in a supported independent living environment. Support coordination is also required to ensure that the multidisciplinary team approach coordinated around the individual enhances the NDIS participants capacity. However, there has are trained by the NDIA to minimise support coordination hours in SIL NDIS participants plans.



In conclusion, it would be fitting for the Joint Standing Committee to recommend more staff in the NDIA office here across Tasmania. There needs to be increased codesign with people living with disability, their significant others in policy and processes internally with the Agency. Every SIL participant must have adequate allocation of Support Coordination funding to ensure those NDIS participants are able to have increased choice and control, understand options and assist design their support adequately to meet their needs and build their confidence as a worthy citizen and increase participation in the community. The NDIA it is to be conscious of exhausting the discretionary effort of service providers and ensure timeliness of plan reviews to be completed before the end of the current NDIS plan as opposed to having gaps between planned dates. It is unfair of the NDIA to expect service providers in a marketisation model to bankroll the NDIA during these periods. Finally, SIL needs to be more transparent, flexible, innovative and accessible so that the NDIS participant is able to creatively use their funding to meet their needs and build their capacity and capabilities. There is a concern at the lack of new, innovative SIL providers here in Tasmania and limited options for NDIS participants regarding their supported independent living. There is much work to be done – but by investing in having more staff, including key stakeholders especially people living with disability and their significant others internally and increasing engagement with us, change and be made.

Thank you for allowing me an opportunity to express my experiences.