Delivering choice & control for participants living in shared settings… An alternative to SIL

Submission to the NDIS Review

Young People In Nursing Homes National Alliance
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Introduction

The administrative system currently used by the NDIS to fund shared settings has been failing for some time.

The noticeable lack of choice and control together with the poor outcomes many participants experience from SIL services,[1] sits with an unchecked inflation in SIL costs that continues to bloat the Scheme's burgeoning funding growth.

Larger numbers of participants moving to SIL arrangements that are 351% higher than predicted and SIL payments averaging $341k compared with non-SIL payments of only $40k, are significant contributors to the NDIS' fiscal problem.[2]

Reining in the NDIS cost growth is an imperative for the scheme and the governments who fund it. Replacing the failed SIL model will not only deliver improved outcomes for people with disability living in shared settings. It will play an important role in returning the NDIS to fiscal health.

This submission outlines an alternative model for funding, contracting and delivering shared support in residential settings. It should not be seen as an endorsement of group homes but is intended to enable a shift in governance from providers to participants; build participant capacity to articulate their needs and preferences; and negotiate their services. Reforming the group home sector is a complex undertaking. This proposal is one of many steps to achieve this.

Developed and trialled by the Alliance as part of the *Taking Control of My Support* project, this model of facilitated negotiation of services in shared settings not only offers opportunity to improve participant choice and involvement in service design, funding and implementation. It will also create greater cost efficiency and transparency for the NDIA.

The flawed SIL model

With the introduction of the NDIS, SIL was developed as part of the transition from state and territory legacy disability systems and their block-funding arrangements, to the NDIS' individualised funding model.

In the absence of alternative approaches, the SIL model has continued to be used but has lacked rigour in funding and service design, in provider oversight and in participant involvement.

The problems arising from this approach have touched every area of its operation.

[1] Minister Shorten Press Club address, Canberra, 18 April 2023. See https://ministers.dss.gov.au/speeches/10911

[2] Numbers are or FY23 compared with the Jun-22 AFSR. Presentation by NDIS Scheme Actuary David Gifford, April 2023

First has been the significant and unsustainable cost escalation outlined by the Scheme Actuary. Then there is the NDIA's limited to no visibility of what SIL providers are delivering to participants; what participants, providers and funders expect; and the real and/or the inflated costs involved in service provision in these settings.

Using an individualised funding model for a shared service in SIL settings also masks systemic service delivery issues including cross subsidisation between participants, overfunding for contingencies, and fair allocation of costs for participants sharing their supports. Current SIL arrangements further mean that participants living in shared supported environments are unable to exercise choice and control as these settings lack a mechanism for joint negotiations. As a result, participants are not involved in any way in the design or delivery of their service, either during the funding process or after.

Lastly and despite the fact that the shared components in SIL settings impact all participants sharing the support, funding done on an individual basis results in little to no transparency regarding shared service delivery, funding and billing.

Cease SIL as we know it

Neither the service description for SIL nor the individualised funding approach it uses for a shared service is effective or sustainable.

Under current arrangements, the SIL provider negotiates directly with the NDIS to obtain the funding contribution the provider has calculated it needs from that participant to deliver the shared service. The provider's justification for the quantum of funding requested for a participant is based on therapy and other assessments that are used to develop a Roster of Care (RoC) that outlines the services and supports the participant will receive.

The NDIS may have an expectation that the participant will be consulted or involved in this process, but the Alliance's experience is that this expectation is rarely if ever met.

Once the provider has established a ROC and a costing, the provider submits this to the NDIA for assessment. The NDIA relies on the accuracy of the RoC and its associated funding ask to determine the level of funding that will be approved.

As the Scheme Actuary has indicated, some of these funding amounts are considerable. Yet they are, in essence, approved without the NDIA knowing or understanding the service model and its staffing arrangements; whether these are appropriate for the participants sharing the service; how much contingency has been included in the funding ask; and whether the funding represents value for money for the participant, the provider or for the Scheme itself.

Not only does the absence of any procedural requirement for the involvement of participants in the design of their support have significant implications, but it is also out of step with the objectives of the NDIS and those of the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

When their individual circumstances change and because they have no knowledge of how their supports are funded and designed, participants are vulnerable to pressure and/or coercion from support providers to request a plan review and a funding increase from the NDIS.

SIL's unsustainable commercial realities

The Alliance has seen multiple instances where providers have given ultimatums to participants that they need to secure additional funding to either keep their place in the service or retain the same level of service.

In one instance, a young woman the Alliance supported to move from residential aged care to a new shared supported service was the first person to move in and was the only person living there for several weeks while other participants were sourced. Despite not requiring or receiving 24/7 support, the SIL provider charged this participant for this higher cost and continued to do so for nearly 12 months after the other participants moved in.

It was only due to the Alliance's continuing liaison with the young woman and her support team during this time, that this overcharging was identified when the SIL provider asked the young woman to request a plan review to obtain additional funding from the NDIS because the funding in her plan was running out.

In responding to requests that the overcharged funds be reimbursed to the young woman who had not been receiving 24/7 support during this time, the SIL provider has tried to blame changes to her support roster, the fact that she was the only resident living in the service for a period of time and a lack of communication from the participant as reason for not refunding these monies. At this time, the SIL provider has still not reimbursed the funds and the participant has refused to request a plan review and additional SIL funding.

Another case involved two participants who were asked by their SIL provider to secure significant additional funding at their plan review to maintain an 'on'call' 24 hour service. The SIL provider wanted these changes to accommodate its IT system that bills hours to individual participants in the community. The provider's attempt to 'individualise SIL' in that service was not initiated to improve outcomes for participants but was driven from the need to make SIL a better fit for their billing system.

The residents of this service remain unclear about what 'individualising SIL' means for them as no other service outcomes have been discussed beyond the existing service being delivered. The first participant refused to raise the increase with the NDIS and the second is yet to have their plan review meeting. A complaint was made to the NDIS Commission by one participant about the increase in cost for no additional service, however the complaint remains unresolved.

Vulnerable to provider funding and service agreement manipulation in tandem with a complete lack of provider oversight or requirement for service change justification that these examples reveal…little wonder the SIL system is bleeding so badly.

However, delegating oversight of service design or provider use of funding to participants, families or support coordinators will not bring greater accountability.

Instead, whatever funding regime replaces SIL, it must be established as part of a strong and evident market stewardship and proactive provider management practice delivered by the NDIA itself.

Lack of transition process

For participants moving into a shared living arrangement, current SIL procedures have no transition process wherein time and support is provided to the participant and their support network to indicate their specific needs and consider their wishes and preferences regarding their new living arrangement. New members of the household are simply expected to fit in to the existing model.

So too, once participants are in a shared service, there is no formal mechanism whereby they can negotiate with each other or with the provider about the support being delivered.

In many cases seen by the Alliance, a request to negotiate a revised arrangement is rebuffed on the basis that the individual making the request is only one person in a group.

Participants and their representatives - including their support coordinators - find it difficult to initiate a discussion with other participants or their representatives because information about those respective representatives is not made available. Participants also commonly lack enough support coordinator hours to 'organise' a group position on the service.

The Alliance has found that SIL providers commonly refuse to share information or resident contact details of other participants of the service, even if that information is critical to understanding the shared service itself. The use of an individual funding model for a shared service thus enables providers to exert a control that prevents individuals from organising or collaborating as a group to influence the service's design and delivery.

The Alliance's experience is that if participants' requests are inconsistent with the provider's business model, SIL providers will not address participants' issues of concern such as staffing issues or rosters. This is particularly apparent with business models built on the profitability providers realise by employing casual staff only.

Where providers do not design SIL services around the needs and expectations of the participants using their service but around their business models and administrative systems instead, the SIL provider's corporate imperative takes priority over co-design or consultation with participants regarding staffing models, reporting, rostering or training concerns.

While some providers do take positive steps to liaise with participants in their SIL services, this is more akin to customer service and quality assurance than a commitment to proper co-design. Left to a market without regulation or administrative direction, this outcome will remain the norm.

A fully described shared support model

Cross subsidisation of support for others in a shared setting has been raised as a key concern by participants the Alliance has supported.

People do not want to subsidise other participants, particularly if they have had no say in the matter, or the cross subsidising arrangement is not part of an agreed sharing measure.

A key element missing from the flawed SIL framework is therefore a requirement for a clearly stated agreement about the sharing of supports by participants and the consequent reporting obligations of providers.

If participants do agree to share support, it is imperative that the service is funded with the following requirements:

- a fully described shared support model with clear outcomes for participants, providers and the NDIS;
- full transparency regarding the design and delivery of services;
- proactive engagement by providers with the participants they are supporting;
- evidence that the service model being funded is an outcome of a collaborative design process.

Predominance of provider interests

SIL providers have increasingly close partnerships with SDA providers and vice versa. These symbiotic relationships are evident where SIL providers advertise properties they service with their SDA provider partner, but don't mention their SDA partner and present the service as theirs alone. This removes any possibility of participants choosing their SDA provider themselves.

Where SDA providers engage a SIL provider without consideration of the needs of prospective participants moving into a new SDA service, these participants have no opportunity to consider what type of service response best suits their individual and collective needs. Nor do they have opportunity to negotiate the design and delivery of the service model that best accommodates these, or interview prospective SIL providers to determine which provider is best able to satisfy their requirements.

For SDA and SIL only properties, SIL providers are therefore the designers and implementers of the service delivered in shared settings with little if any guidance or input from tenants.

The Alliance is aware of one SDA provider implementing contract arrangements that include the SIL provider and the tenants in a single agreement. Tenants are not aware of this approach and have not had the opportunity to discuss how they want to manage their service agreements with the SIL provider. In these instances, the provider's business model again takes precedence over participant choice and control, or co-design of shared supports with the SIL provider and with other participants.

The embrace of a 'market' methodology by the NDIS has further enabled this provider-controlled approach to service design and delivery, an approach that effectively denies participants the very choice and control that is fundamental to the NDIS' conception and operation.

At present, a growing number of shared settings that use SIL as their primary funding source, are coming on line outside the SDA system. These services are generating significant income for providers who choose the location, the service model and also select the participants… often with scant regard for prospective participants' needs and/or whether the property and the service model in place are best suited to them.

To shift the power dynamic inherent in these SIL settings wherein participants are defined by the quantum of their funding, not their support needs and preferences, greater regulation of SIL only group home properties is required in the short term.

In the medium term, these services should not be funded as stand alone services as the separation of housing and support that is so important in these settings, is impossible to achieve.

Participants living in these services have extremely limited rights and choices regarding their service's design, funding and delivery. Revision of the SDA program is urgently needed to include current SIL only stock and should also involve the NDIA's direct oversight of properties that are used for shared residential support.

In the longer term, we believe the NDIA should exit the housing market altogether and grandfather existing SDA properties as it transfers regulation to community housing authorities.

Creating a value proposition for participants and the NDIS

Under present SIL arrangements, there is no discussion with participants about the value proposition for the SIL service they might utilise. The only negotiation that does exist is between providers and the NDIS through the RoC/funding and this is concerned solely with pricing.

Shared residential services are highly complex environments, with multiple factors determining how each setting works and the impact the support service has on tenants. They are also crowded spaces with multiple therapists, support coordinators, families, advocates and provider staff all contributing to the service dynamic.

In this crowded space, no one is in charge of coordinating the various interest groups and achieving agreed outcomes; there is no oversight or coordination of participants' support and service needs; and identification of changes in support need simply don't happen.

The legacy model of provider control in these shared settings has not only survived but, following transition to the NDIS SIL funding model, has thrived anew.

The inherent expectation that providers will manage all the complex issues and relationships inside these settings has remained intact and unchallenged by both participants and the NDIA, to the detriment of all involved.

Factors that adversely impact the current SIL service dynamic include

- Length of time the service has been operating
- Family involvement in the service's operations
- Complexity of resident support needs
- Compatibility of participants and families
- The level of participation/engagement of participants with the provider
- The provider's willingness to collaborate with participants on service design, funding and delivery
- The provider's willingness to be transparent about funding and service costs
- The experience of the provider and the stability of the workforce.

It is critically important that the future design and funding of shared residential services outlines a discrete value proposition for both the NDIS as funder, the provider delivering the service and the participant relying on a service that should address their wishes and preferences regarding their support needs.

In the market context of disability services, engaging a provider and the value they can derive from service provision should be a secondary consideration. To date, however, the NDIS has prioritised provider presence over other considerations, including participant sovereignty, value for money and service quality.

The intra-plan inflation being experienced in SIL is an evident consequence of the lack of definition of supports being purchased; a lack of clarity regarding outcomes the funding should be achieving for all actors; and the lack of procedural rigour and oversight by the NDIS as funder.

In the vacuum that results, providers recalculate their value proposition to seek additional funding and place pressure on participants to obtain that additional funding from the NDIS, despite the benefits of these funding increases remaining unclear to participants and to the NDIS as funder.

A participant focused support model for shared services

Each shared setting should have a clearly articulated service/support model that documents and implements participants' key priorities.

This is achieved through a co-design process where the participants and their support teams (families, therapists, advocates) undertake a facilitated process to design and document a model that details the following service elements:

- Service values and culture
- Communication and information sharing processes
- Decision making support arrangements
- Role definitions and responsibilities of the support services provider, the property (SDA) owner, the resident and the NDIA as funder
- Areas and responsibilities for participants, service providers and the NDIS regarding decision making about service delivery
- A workforce plan that includes staff profile, workforce size, worker skills and competencies, staff contingencies and replacement strategies, staff training and development, staff selection and performance review processes, recruitment strategies
- Roster planning processes and protocols for changes to rosters
- Provider's reporting arrangements to participants and the NDIS and media
- A comprehensive outline of the service's financial obligations including operating costs, reporting margins, contingencies
- Risk management strategies
- Outcomes and evaluation processes
- Vacancy management processes
- Interaction and management of on site services and individualised supports from third party providers
- Dispute resolution processes.

Once agreed and documented, these elements of the service model are built into a service structure that can be costed and performance measured. The service model then becomes the reference point for funding decisions, contracting/service agreements, evaluation and review.

The development of the model is overseen by an independent facilitator who works with participants to outline their wishes and preferences regarding the service's design and delivery. The facilitator is also the proactive link between the resident group and the service provider, facilitating their collaborative engagement as they support the participants to build their capacity to collaborate with each other and with the provider.

Unless expressly invited by participants, it's important that this process take place without existing providers taking part.

The facilitator can invite guests with industry experience to participate in the planning process so that technical issues such as OHS, business costs etc can be explained. This input must be independent and be seen as such by all involved.

For new residential services, the process of developing the service model is built in to the administrative and funding sequence required by the NDIS. For existing services, it can be introduced when service agreements are coming up for review.

A new role – Shared Support Facilitator

To develop these articulated service models in shared settings, a new role is required. Independent of the NDIS and service providers and supporting the involvement of participants, *the shared support facilitator* works with participants to co-design and negotiate their shared supports with the service provider and with each other.

The facilitators coordinate the collation of preferences and priorities of participants; provide information and organise assessments; explain OHS requirements; and are the focal point of liaison between the resident group and the NDIS in establishing the service model and then communicating this to providers.

Through these processes, the facilitator builds the capacities of participants to articulate their preferences and build their negotiating skills and decision making systems. The outcome is that participants gain greater independence as they work collaboratively with each other and the provider of their service to codesign and deliver their supports.

This role simplifies the processes involved in the organisation of shared services and will deliver transparency through its work with all parties. The product of the facilitator's involvement is documentation of a codesigned service model that includes linked service agreements with providers and is communicated to the NDIS.

The facilitator continues to maintain an active presence to ensure the resident group is resourced and active in their involvement in monitoring and evaluating the services provided by both the support provider and the SDA provider.

For the purpose of supporting participants in shared settings, these facilitators replace support coordinators for that function.

A workforce of shared support facilitators will be needed and can be developed by engaging people with support coordination experience, advocates and people with legal/paralegal training.

Support for participant involvement

Given the history of providers and funders designing services in shared residential settings, many participants in legacy services have yet to develop the capacity or obtain the resources to be active negotiators of their own supports.

It is vital that participants have access to decision making support for their involvement in discussions/negotiations and for their decision making.

Building capacity and confidence in having a say over their existing service is a key beginning for other conversations participants may wish to have about satisfaction with their current living situation or exploring alternative living options.

For people entering new shared settings (including concierge models in apartments), a process whereby participants can engage with their fellow participants and the NDIS to plan and design their service collectively, is imperative. Such an undertaking would involve an opt-out service arrangement where participants would be assumed to be included in negotiations about the development of their support. Should a participant choose not to participate in the process themselves, they must appoint a proxy.

Funding shared settings

Instead of funding shared services via individualised funding, this new approach would see the NDIS fund a codesigned service model for each setting. The co-design and negotiation involved in developing the service model ensures participant choice and control is not diminished but is collaboratively exercised before any funding decisions are made.

The very existence of a service model enables participants and their representatives to better evaluate the provider's service delivery before and after moving to the service; and to understand where gaps may emerge over time. It also provides a point of reference for participant and service funding reviews.

Remove SDA/SIL collaboration agreement

Where a group of participants contracts directly with a support provider(s) for delivery of the approved support model and forms separate agreements with the support provider and SDA provider, the requirement for a SIL/SDA collaboration agreement should be removed.

The SDA provider (or housing provider) agreement would be for tenancy while the service provision with the SIL provider would be the service agreement. Both agreements would be submitted to the NDIS for approval.

This not only enables the NDIS to have a direct line of sight of the model proposed. It also provides evidence of the funds realistically required to deliver the model and enables the NDIS and participants to assess the appropriate delivery of the services it has funded and whether value for the funds provided has resulted.

Formal entities for participants sharing support

An option to formalise the resident group's arrangements exists with incorporation into a legal entity. This remains a choice for groups however and does not need to be a requirement for participants living in shared settings to negotiate successfully with providers.

For participants of shared settings, their engagement with the NDIS can be undertaken both as a group and individually and is supported throughout by the independent facilitator.

Provider oversight

The model this submission has described will require a closer oversight of service providers at every stage of service design, service funding, service delivery and service evaluation.

The current machinery of government has the NDIS Quality and Safeguards Commission (the Commission) responsible for the regulation of providers. Retroactively responsible for managing complaints only after things have gone wrong, the Commission's role is not only inadequate to the task of managing providers engaged in service design and delivery. It also prevents the NDIS from having any role in oversighting or positively influencing the operations of providers. In short, the Commission has not managed providers effectively.

In contrast, the model we are proposing requires an active and thorough provider management function at the front end of service negotiations.

To achieve this, we recommend that the responsibility for provider management be transferred from the NDIS Commission to the NDIA. The NDIA should establish a provider management function that enables proactive communication, regular engagement and continuing education, and ensures the NDIA has a role in oversighting the negotiation process between participants and providers in shared residential settings.

Provider management should also be undertaken collaboratively with participants and have significant and visible consequence for poor service delivery. This is a function the NDIS could deliver as a proactive component of its broader market stewardship role.

In such restructured arrangements, the NDIS Commission would retain its independent complaints function but have no other role with providers.

To ensure participants can exercise choice and control in who delivers their services and supports, the existing system for provider registration requires urgent reform.

If participants are to have confidence that the workers providing their supports are appropriately skilled and reliable, the current worker registration system also requires urgent reform to deliver the worker skill development and accreditation that Australians with disability are looking for.

Conclusion

The explosion in SIL costs; the provider capture of NDIS participants living in shared settings that is emblematic of this approach; and the absence of participant choice and control over both the services that participants living in shared settings receive and their contracting of providers to deliver those services, are reason enough for the NDIA to replace the current SIL service arrangements with the model outlined in this submission.

Supporting participants to articulate their wishes and preferences regarding the design and delivery of their supports in shared settings not only reinstates the choice and control that is foundational to the operation of the NDIS. It provides a direct line of sight to the NDIS

regarding the service model that results; the reasonable and necessary nature of the model's costs; whether/how the service is being delivered to achieve resident expectations and outcomes; and the NDIA's expectations regarding the model's value for money imperative.

By collaborating with participants on service design and delivery, this model also offers providers the opportunity to deliver a bespoke service that satisfies the needs of all actors, reduces complaints and enhances their reputation as a provider of choice…an important consideration in the market economy that service provision resides in.

For participants living in shared settings, the facilitator model's benefits include the opportunity to understand the service model and how it operates before they move in. Potential participants can then decide whether it's a reasonable 'fit' for their existing support needs and expectations, or whether they should negotiate with the provider to realign the service model to accommodate their particular needs and preferences and how these might (re)align with the needs and expectations of other participants.

By engaging collaboratively and making transparency and codesign of services and their implementation the bedrock of engagement for all actors, the model this submission has argued for will deliver better fiscal outcomes for the NDIA and improved resident satisfaction, thereby supporting the sustainability of the NDIS now and in the future.

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