Summer Foundation

Improving outcomes for participants who require Supported Independent Living (SIL): Provider and Sector consultation paper

October 2020

Thanks to all Summer Foundation staff and storytellers for their input into this submission.

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RECOMMENDATIONS

Summer Foundation recommendations are:

1. Information about Supported Independent Living (SIL) and how to exercise choice and control should be available in a range of accessible formats. This information should also include alternatives to SIL, such as funding for Assistance with Daily Living and Individualised Living Options. Agency staff must be prepared to take time to explain the information directly to participants in a way that they can understand.

2. The NDIA should ensure the participant's preferred method of conducting the regular check-ins is understood and upheld. A summary overview of each check-in should be made available to the participant and support coordinator to track and to ensure the information collected is accurate and understood.

3. The NDIA should streamline the processing of SIL applications for participants moving into new housing properties, enabling SDA, SIL and assistive technology decisions to be connected thereby avoiding unnecessary delays.

4. Is expressly The NDIA should invest in a national capacity building initiative aimed at increasing awareness of housing and support options among participants with high support needs.

5. To address inequities in SIL funding:

   ● The NDIA should implement a strategy to increase transparency and openness with respect to how funding decisions are made, including a quarterly report of learnings and improvements being made as a result of Administrative Appeals Tribunal decisions.

   ● The NDIA should guarantee that participants will also be able to have the option to provide reports and assessments conducted by their preferred allied health practitioner and that these assessments will be funded by the NDIA.

   ● The NDIA should invest in building the capacity of allied health practitioners and make the training modules for independent assessors available to all allied health practitioners working with NDIS participants. This will assist with transparency and increase the consistency and reliability of allied health assessments.

   ● The NDIA should make available the report from the pilot research project into independent assessments for public consideration and to inform policy.

   ● In line with the recommendations of the Tune review, the NDIA should consult with people with disability and other disability experts on the Independent Assessments Framework.

   ● The NDIA should ensure the governance of Independent Assessments includes people with disabilities and others with disability knowledge and expertise including disabled persons organisations.

6. The NDIA should set evidence-based good practice principles and guidance for the delivery of SIL services, which signal the future market direction for SIL to be of a higher quality, more individualised and promoting independence and community participation outcomes.

7. The NDIA and state governments should work with the sector and participants to develop SIL models that integrate clinical support needs for NDIS participants with disability and complex clinical care needs. Development of these models is especially critical to reduce the number of NDIS participants in residential aged care (RAC).

8. The Home and Living Policy must include the following commitments:

   ● The participant is supported to build their capacity to understand and express their needs and preferences

   ● Funded supports reflect the individual's needs and preferences

   ● The participant is supported to make informed decisions through accessible information about the full range of housing and living options

   ● The participant is in control of where they live, who they live with and how they are supported

   ● There are clear boundaries between SIL and SDA with a commitment to full separation and the elimination of conflicts of interest

   ● Funding decisions about housing and support are made in a timely way to ensure participants are not stuck in an unsuitable housing arrangement.

9. The NDIA must address conflicts of interest by:

   ● Setting a deadline for the complete separation of SDA from SIL service provision

   ● Requiring all support coordinators to be independent of other service provision

   ● Implementing a strategy to support the achievement of full separation.

ABOUT THE SUMMER FOUNDATION

Established in 2006, the Summer Foundation works to change human service policies and practices related to young people (18-64 years old) living in, or at risk of entering residential aged care facilities.

Our Vision is that young people with disability and complex support needs live where and with whom they choose, with access to high quality housing and support options that enhance health, wellbeing and participation.

Our Mission is to create, lead, and demonstrate long-term sustainable systems change that stops young people from being forced to live in aged care because there is nowhere else for them.

The Summer Foundation has worked extensively with people with complex disability support needs to ensure they have access to all the NDIS supports essential to living the life they choose. Access to quality SIL is critical to achieve the targets of the YPIRAC Action Plan 2025.

INTRODUCTION

The Summer Foundation has extensive experience working alongside people with high and complex support needs to understand how to ensure that housing and support solutions can be developed according to their needs and preferences. We have undertaken demonstration projects and extensive research. Based on the outcomes of the research our understanding of what it takes to effectively support people with complex needs to live in the community has evolved.

Drawing on this, the Summer Foundation has outlined key problems with the current dominant SIL practice and set out a vision for a reformed SIL market. This is outlined in the table below.

DOMINANT PRACTICE	FUTURE DESIRED STATE
Outdated and non-contemporary SIL models SIL models are often implemented in congregate shared living settings with 4 or more residents. 37% of SDA enrolled dwellings are for 4 or more residents (1,634 out of a total of 4,360 dwellings).	**Housing models and support models are in line with the UNCRPD and evidence-based good practice** Key features of the market are: ● Smaller dwelling sizes ● Individualised support provision ● Tenants exercising choice over who they live with, how and by whom they are supported
Limited choice when housing and support are combined ● Housing, support and tenancy/property management are 3 separate services; yet they are often provided by the one provider. ● These models prevent participants from exercising choice over their support provider(s), requiring participants to move house if they wish to use a different support provider. This removes a critical safeguard to keep people with disability safe.	**Housing and support are provided by separate agencies** Key features of the market are: ● Participants able to remain living in their home and change support providers if and when they wish to ● Stand-alone disability housing providers grow, offering participants choice about their support provider
Participants have low understanding about housing options ● Participants are unaware of the housing choices and options available in the NDIS. ● There has been limited capacity building to support participants to understand and explore best practice housing options.	**Participants have access to information about housing and SIL options** Key features of the market are: ● Capacity building initiatives build participant, family and plan nominee understanding of good practice ● High quality information about SIL and SDA is available across all locations and tailored to the needs of particular cohorts

Housing providers and SIL providers do not share vacancies with the market • Participants cannot easily see all vacancies available that may meet their housing needs and preferences and are only aware of the housing options offered by their support provider. • Advertising for SIL support vacancies is ad hoc and at the provider level, rather than at a coordinated market level.	**Efficient market mechanisms are operating to share SIL and SDA vacancies and connect participants and providers** Key features of the market are: • Mechanisms and processes are well developed to share SIL service and SDA vacancy information with participants and those supporting them to seek housing options • Housing matching is effective through online platforms, such as the Housing Hub, that have a current and live database of all participants seeking housing and of all providers offering housing
The NDIA has implemented recent changes to streamline planning and approvals across SDA, SIL and AT. However, these improvements are yet to be realised for many participants, who are still experiencing delays across funding of these services. • Delays in SIL (and SDA and AT) approval are leading young people to enter or remain in aged care, be stuck in hospital or in inappropriate housing.	**Participants experience timely and well-coordinated decisions on SIL, SDA and AT.** Key features of the market are: • Decisions about related supports are made simultaneously by the NDIA • Participants with urgent circumstances, including those in aged care, can access fast decision-making by the NDIA

Our submission addresses only those consultation questions that relate to our work with people with complex disability support needs.

CASE STUDY

Rebekah's story*

We know that participant choice and control is paramount and must be central to all policy decisions related to SIL. This is illustrated in this younger person's real-life experience, which we present here as a case study on the importance of complete separation of SDA from SIL.

Having choice and control over my SDA and support services has been a constant fight for me. I was denied it and really, this should never happen. I used to say that if you took your car to a mechanic for a service and you weren't happy at all with the job they did, you would find a new mechanic and never return to the original one. So, what would you do if you were forced to use that shoddy mechanic repeatedly? You would lose your mind. A person with disability often faces this serious problem when it comes to being forced to use a certain company for their personal supports. Imagine living day to day with bullying and harassment from a company that has control over who gets you out of bed, who helps you in the shower, or who helps you eat dinner. It's not how anyone should have to live.

As tenants we had no say in this at all. In fact, the SIL company was chosen before any of us were. The SIL company was appointed to supply all supports to tenants. This not only included the usual shared support or concierge component, but also each tenant's personal care, one-on-one supports.

So, after I was selected by the SDA provider to move into one of their new apartments, I met with the SIL provider. The first meeting went ok. They said the right things and seemed reasonable. It was the subsequent meetings that followed which raised some red flags. I really wanted to be involved with the hiring of the support workers that would work with me. At first, I was told that was impossible. But I insisted and eventually they relented, and I was able to be involved with some interviews. That went ok and I was able to say yes or no to the support staff… although it must be said that no one I interviewed ended up ever working with me!

The staff were set, and I moved in. I always wanted a small team of support workers, at a maximum of 6. I had never had a support worker and I needed time to get used to working with them. As you can imagine, personal care is indeed, very personal. You can feel very vulnerable while having someone help you in the shower or get dressed etc. There needs to be an element of trust and having a smaller team around you helps to produce that trust. There were some support workers who were hired by the SIL company that I just was not comfortable with and I expressed my concerns about them to the company. But at times, I was forced to work with them and when they kept appearing on my roster it caused huge amounts of stress and anxiety.

Whenever my roster of supports was sent to me, usually late on a Friday afternoon, I would stress for the entire weekend before I could get any answer from the SIL company about why these support workers were again on my roster and then getting them to change it. And here's the thing about my rosters. They were never the same. There was no consistency with support workers working specific shifts. They changed all the time, so I was never able to get any form of routine going. Sometimes even my shift times needed to be changed to fit in with the times of the other tenants. The SIL provider was treating my independent living apartment as part of a group home. This is unacceptable.

I wanted out from this company, so what did I do about it? Luckily, I had the help of my support coordinator because I couldn't do this on my own. Fighting this SIL company took all the strength that I had.

I had to go through the whole complaints process, which first involved complaining directly to the SIL company themselves. This took place over a 2 and a half hour interview with the company employee who oversees the complaints process. The report from that interview came back as saying the only thing that the SIL company did wrong was not communicate enough and that I was the one being completely unreasonable with my requests. It seems this company does not see choice and control for their clients as a thing. In fact, they told me I would have no choice and control in one of my early meetings with them.

Eventually (following a complaint to the NDIS Quality and Safeguards Commission) I did manage to get my SIL provider to agree to let me take my personal care supports away from their company and just stay with them for the shared supports.

I will live my most extraordinary life and I will do so with the supports that I choose.

*Pseudonym used

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RESPONSE QUESTIONS

Initial Steps Taken to Address SIL Issues

NDIA Question 4 – What has been the impact of recent SIL changes to provider operations and participant experience?

Response

We welcome progress being made to facilitate participant control over SIL supports through the publication of the SIL Operational Guideline, the SIL Participant Information Pack and the roster of care tool. We are not currently aware of the impact that these changes have had on the participant experience.

It is important that the NDIA closely monitors the impact of these changes and goes further to maximise choice and control for participants. We are keen to provide ongoing insights on the progressive impact of the SIL changes to the NDIA, particularly how these changes are experienced by young people in or at risk of entering aged care.

The SIL Operational Guideline and all other guidelines should be developed in consultation with people with disability. The Summer Foundation is able to facilitate this through our network of young people with disabilities and our lived experience coordinators.
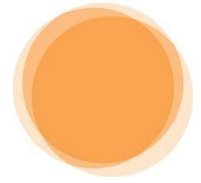
PROPOSED SHORT-TERM CHANGES

NDIA Question 5 – What advice do you have for the NDIA working more closely with participants regarding their SIL supports?

We welcome the commitment by the NDIA to strengthen participant control and understanding of their options through regular check-ins, information, tools and reference materials. It is important that this approach is tailored to the needs of each participant if it is to strengthen control over their SIL supports. Proposed check-ins must take into account and allow for all preferred and necessary forms of interaction, as calls are unsuitable for some participants.

A summary overview of each conversation should be provided to each participant following the end of the discussion or within one business day. The provision of information to participants, nominees, and families in their preferred format is crucial.

RECOMMENDATION 1

Information about SIL and how to exercise choice and control should be available in a range of accessible formats. This information should also include alternatives to SIL, such as funding for Assistance with Daily Living and Individualised Living Options. Agency staff must be prepared to take time to explain the information directly to participants in a way that they can understand.

RECOMMENDATION 2

The NDIA should ensure the participant's preferred method of conducting the regular check-ins is understood and upheld. A summary overview of each check-in should be made available to the participant and support coordinator to track and to ensure the information collected is accurate and understood.

ADMINISTRATIVE COMPLEXITY

NDIA Question 10 – What support from the NDIA would be most helpful to providers to reduce administrative challenges?

The Summer Foundation is familiar with the administrative challenges experienced by participants and providers when it comes to transitioning to new housing and support arrangements. Our focus is on young people, rather than providers and therefore will respond as such.

Young people with high and complex needs are still stuck in hospital or in RAC because of slow administrative and decision-making processes by the NDIA. This can be especially problematic when decisions are being made by multiple departments within the agency. For example, a person may have approval for SDA but are waiting for SIL or assistive technology funding to be approved.

Access to timely planning meetings and a coordination of the assessment process in a way that can lead to fast approvals of a funding plan, would be helpful to reduce administrative delays experienced by participants.

RECOMMENDATION 3

The NDIA should streamline the processing of SIL applications for participants moving into new housing properties, enabling SDA, SIL and assistive technology decisions to be connected thereby avoiding unnecessary delays.

NDIS PROPOSED PRINCIPLES FOR SHORT-TERM AND LONG-TERM APPROACHES TO IMPROVE SIL

NDIA Question 12 – Do these guiding principles appropriately shape SIL reform?

We believe that the proposed guiding principles should help to create much-needed reform to SIL.

Principle 1 - Provide participants with real support for decision-making

We welcome all the efforts to support participants to make informed decisions. This means that participants must have their housing needs and preferences respected and upheld. It means that a preference to live alone is reflected in the participant's NDIS plan.

RECOMMENDATION 4

The NDIA should invest in a national capacity building initiative aimed at increasing awareness of housing and support options among participants with high support needs.

Principal 2 – Reiterate support for participants to build their capacity

This is an important guiding principle however it needs to be expressed more clearly. For example, "Ensure there are supports and initiatives in place to build capacity, of risk and participate in social and economic activities of the person's choice".

Principle 3 – Build a transparent, simpler, and structured process that creates an equitable support model

We support NDIS strategies to increase equity and fairness in allocation and funding. We are concerned that the explanation provided in the consultation paper only refers to independent assessments as the means to achieve this principle. The Summer Foundation shares the concerns of disability advocacy organisations and Occupational Therapy Australia regarding the use of independent assessments. Our position and recommendations regarding independent assessments are available **here**.

Achieving equity in funding decisions requires an increased openness on the part of the NDIA with respect to how decisions are made. To do this well, there must be consistency in approaches used by planners to make decisions and allocate funding. For people with complex needs, it also requires a workforce of skilled, knowledgeable and experienced allied health assessors who can work closely with the person to develop a deeper understanding of their needs.

RECOMMENDATION 5

To address inequities in SIL funding:

- The NDIA should implement a strategy to increase transparency and openness with respect to how funding decisions are made, including a quarterly report of learnings and improvements being made as a result of Administrative Appeals Tribunal decisions.

- The NDIA should guarantee that participants will also be able to have the option to provide reports and assessments conducted by their preferred allied health practitioner and that these assessments will be funded by the NDIA.

- The NDIA should invest in building the capacity of allied health practitioners and make the training modules for independent assessors available to all allied health practitioners working with NDIS participants. This will assist with transparency and increase the consistency and reliability of allied health assessments.

- The NDIA should make available the report from the pilot research project into independent assessments for public consideration and to inform policy.

- In line with the recommendations of the Tune review, the NDIA should consult with people with disability and other disability experts on the Independent Assessments Framework.

- The NDIA should ensure the governance of Independent Assessments includes people with disabilities and others with disability knowledge and expertise including disabled persons organisations.

Principle 4 – Encourage market innovation

We welcome flexibility and support arrangements that encourage innovation and a move away from outdated and ineffective models of support. (37% of SDA enrolled dwellings are for 4 or more residents -1,634 out of a total of 4,360 dwellings). Currently, people with complex needs are often still limited to traditional disability accommodation, without flexibility of supports or choice of where and who to live with. Participants with SIL supports often find themselves sharing supports rather than being able to access an individualised model that allows them to live alone and have the option to choose their supports from multiple SIL providers. See Attachment 1 for further details around flexible SIL provision for different housing models.

Quality and capable SIL provision is critical to achievement of the Younger People in Residential Aged Care Strategy. SIL services that incorporate clinical supports are needed by some participants to enable them to leave RAC. They are also needed by participants with complex disability needs who are 'at risk' of admission to RAC in order to prevent hospital discharge to inappropriate housing. The NDIA must stimulate market innovation for integrative SIL models in order to meet complex needs.

RECOMMENDATION 6

The NDIA should set evidence-based good practice principles and guidance for the delivery of SIL services, which signal the future market direction for SIL to be of a higher quality, more individualised and promoting independence and community participation outcomes.

RECOMMENDATION 7

The NDIA and state governments should work with the sector and participants to develop SIL models that integrate clinical support needs for NDIS participants with disability and complex clinical care needs. Development of these models is especially critical to reduce the number of NDIS participants in RAC.

Principle 5 – Ensure continuity of support

While we understand and support the principle of continuity, we are concerned that some planners may not take active steps to support people to transition from out-dated models to newer supports. Continuity of support principle must be balanced with a principle that recognises the importance of the freedom to change support options.

Principle 6 – Improve participant safety and oversight

As the Royal Commission into Disability Violence, Abuse, Neglect and Exploitation has demonstrated, poor quality SIL provision leads to harm. Clearly defined SIL best practice guidelines and responsibilities are required to protect safety and improve oversight.
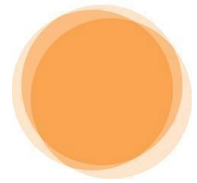
HOME AND LIVING POLICY

NDIA Question 13 – What items should a Home and Living Policy address?

We welcome the items put forward for a Home and Living Policy.

Participant-centric shifts within housing and living options are a necessary and welcome step. There must be a stronger focus on understanding and putting into action participant needs and preferences and on building participant capacity to make informed decisions.

Participants have the right to clearly consider all of the options and to be supported to express their housing needs and preferences. This is only possible if they have access to information and support to understand their options.

Information around Home and Living Options must be made plain and accessible and in a variety of formats, tailored to the needs of the individual.

Once the participant's housing needs and preferences are understood, action must be taken to translate these into the person's NDIS plan. Furthermore, they must have the necessary support in place to implement their plan, including access to specialised support coordination.

Participants should have full choice over how to utilise their core supports. Participants should not be forced to share their supports.

Clear boundaries must exist between SIL and SDA provision. The NDIA must address the necessary separation of housing and supports to avoid conflicts of interest and provide more meaningful choice and control. Participants must be in control over where they live, who they live with and how they are supported.

RECOMMENDATION 8

The Home and Living Policy must include the following commitments:

- The participant is supported to build their capacity to understand and express their needs and preference.

- Funded supports reflect the individual's needs and preferences

- The participant is supported to make informed decisions through accessible information about the full range of housing and living options

- The participant is in control of where they live, who they live with and how they are supported

- There are clear boundaries between SIL and SDA with a commitment to full separation and the elimination of conflicts of interest

- Funding decisions about housing and support are made in a timely way to ensure that participants are not stuck in an unsuitable housing arrangement

CONFLICT OF INTEREST

NDIA Question 14 – Are there any other comments or suggestions? What have we missed?

Responses:

Conflicts of Interest (CoI) remain as significant issues within SIL. Internal, unmonitored policies exist for some SIL providers, yet a larger mandate is still lacking around organisations providing multiple services. SDA providers have clearly mandated requirements in their Practice Standards, clearly distinguishing their roles and responsibilities in communication and contract. SIL operational guidelines are lacking in clarity and protections against CoI.

As such, support coordinators must be impartial and therefore separated from other service provision. There is a significant need to avoid bias in recommending their own provider organisation. If a participant requests a new coordinator from the same agency, the coordinator must not simply provide the same options – this is not providing a tailored and personalised service for the participant. Options must reflect the needs and preferences of the participant and be aligned to their values.

Non-SDA SIL providers who provide accommodation or housing outside of SDA registration remove tenancy rights for the participant and are operating under a clear CoI. This practice should be ceased. However, where this is still occurring, there must be clear messaging and transparency. Checks must be in place to ensure the participant's right to choice and control over their supports is enforced, and there must be a clear process to communicate when a person's rights are being violated.

People with disability who have not been happy with their SIL provider making decisions about house rules and how they receive support have told the Summer Foundation that they did not know who to speak to or who was responsible between the SIL provider, SDA provider, property manager and the NDIA. It was not clear to them what contracts, arrangements or shared responsibilities were in place between these parties.

RECOMMENDATION 9

The NDIA must address conflicts of interest by:

- Setting a deadline for the complete separation of SDA from SIL service provision
- Setting a deadline for all support coordinators to be independent of other service provision
- Develop and implement a strategy to achieve this and ensuring that the market can meet the needs of participants, including those with high and complex needs

ATTACHMENT 1

As people demand a broader range of housing options their demand for more flexible SIL support arrangements increases. People with complex disability support needs, including those for 24/7 support, are choosing tailor-made SIL options with more than one provider such as the following:

Examples of innovative Housing and Support Options	HOUSING	SUPPORT		
		Support Provider 1	SIL Provider 2	Supplementary Supports 3
10 +1 SDA and concierge support model	SDA Apartments	Activities of Daily Living (ADL), Core Supports, planned support, community/social/recreation support, choice of provider(s)	On-site Overnight Assistance (OOA), concierge in separate +1 apartment, shared 24-hour support, choice of provider collectively by all 10 tenants	N/A
3 SDA Villas +1 and OOA support model	SDA Villas	ADL, Core Supports, planned support, community/social/recreation support, choice of provider(s)	OOA in separate, close by +1 villa, shared 24-hour support, choice of provider by all 3 tenants	N/A
SDA 2 residents and shared SIL model	SDA any dwelling type	N/A	One shared on-site SIL provider, in the dwelling, for all supports, choice of provider by 2 tenants	N/A
SDA and ILO support model	SDA any dwelling type	ADL Core Supports, planned support, community/social/recreation support, choice of provider(s)	N/A	Informal support from host or mentor supports or on-call arrangements, structured informal supports, supported volunteers, good neighbour, drop-in support