



ADACAS

A D V O C A C Y

Response to
Supported Independent Living
(SIL) Inquiry
(by the Joint Standing
Committee on the National
Disability Insurance Scheme,
Parliament of Australia)

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1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) has been delivering advocacy for and with people with disability, people experiencing mental ill health (or psychosocial disability), older people, and carers in the ACT for 28 years. ADACAS has provides free advocacy and information to people with disability in: set areas of NSW: specifically, in set areas of Shoalhaven, the Eurobodalla Hinterland, Batemans Bay, Broulee – Tomakin, Moruya – Tuross Head

As an advocacy service, ADACAS is frequently working with people who are “falling through the cracks” in current service systems. We advocate on many topics: on housing, quality of service issues, NDIS appeals, at psychiatric treatment order tribunal hearings, on child protection matters, on restrictive practice/restraint/seclusion. ADACAS advocates also visit clients at their homes or places of the clients’ choosing. ADACAS additionally offer NDIS support coordination to a small number of NDIS participants, and have a Projects/research team, who are currently conducting action research looking at Supported Decision Making in Healthcare. We have also recently commenced delivering Redress Scheme support services to people who were victims of institutional child sexual abuse.

Throughout this submission we seek to highlight both the issues that advocates have observed, and also issues that our clients have raised with us, and will use case studies to demonstrate circumstances. We value the opportunity to provide this feedback

ADACAS acknowledges the Ngunnawal people as the traditional owners of the land on which we work, and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our community.

2. Responses to Supported Independent Living (SIL)

Inquiry topics:

Context

It has long been recognised that “separating tenancy and personal support is critical to enabling choice and control for people with disability”¹

In the ACT, however, unless a person with disability:

- owns or rents their own property (an option that is inaccessible due to financial constraints for many²)
- has a SDA provider (that is not also providing SIL) or
- lives in a household that has a Housing ACT property (whether via a headlease, or as direct tenants of Housing ACT),

they will be living in a circumstance where their SIL properties is owned by a SIL provider who then also provide the SIL services to the people within the house. A large number of houses in the ACT fit this circumstance (SIL provider is also landlord).

This situation (where the SIL provider is also the landlord) can have an inherently negative impact on the choice and control of participants, in that most of those providers require participants to accept their service as the SIL provider as a condition of allowing the participant to move into that property.

In some instances, the SIL provider/landlord encourages participants to agree that the provider will provide not only the specific SIL funding, but also other funding lines as a condition of moving into the house (such as providers which seek to claim capacity building or community participation or support coordination funding).

In our view (and through the literature), there is a clear conflict of interest when the one provider holds both the role of landlord and that of SIL provider³.

When the landlord is also the SIL provider:

- there are inherent constraints on participant choice and control (given that in many instances it is impossible for a participant to change their SIL provider unless they move out of their home: which can be a gargantuan task, given that there is high demand for SIL housing options in the ACT, that it is not uncommon for residents needing SIL to be in financially

¹ Summer Foundation (2019) SDA Market Information website, accessed via: <https://www.summerfoundation.org.au/housing/sda-market-information/> in September 2019.

² AIHW (2019), *People with disability in Australia report* (September 2019), accessed online via: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/housing> in September 2019. and

Anglicare (2019), *Rental Affordability Snapshot*, accessed online via <https://www.anglicare.asn.au/our-work/research-reports/the-rental-affordability-snapshot> in August 2019

³ Crabb, A, (2017) *Separating Housing and Support Services - A Toolkit for Providers*. Melbourne: Summer Foundation Ltd accessed via: <https://www.summerfoundation.org.au/wp-content/uploads/2018/01/separating-housing-and-support-toolkit.pdf> in September 2019.

constrained circumstances (if your primary income is a Disability Support Pension, it can be difficult to save the funds to move house) and the level of uncertainty or upheaval that moving house can entail);

- the market incentives that are meant to be built into all relationships and transactions within the NDIS, for providers to achieve and maintain high quality support (given it is hard for a participant to change SIL service provider if they are unhappy with service quality), are not present within these arrangements;
- there are reduced safeguards for participants (in that, depending on individual circumstances, they may be in contact with fewer people/organisations whom they could alert if something is going wrong if service provider support is concentrated with the one organisation);
- there are risks to housing security (for example if the relationship with the SIL provider/landlord breaks down or a dispute between tenants arises).

Whilst sometimes SIL providers manage these conflicts very mindfully, carefully, and appropriately, there are other instances where this arrangement causes great harm:

Participant experience:

Joanna, a young person with intellectual disability was living in a shared property owned by the same provider that was providing SIL supports. The level and types of support did not meet Joanna's needs. There were a number of incidents at the property (between Joanna and other residents), culminating in a complete breakdown of the relationship between the provider, other residents and Joanna. The provider then (illegally) evicted Joanna into homelessness.*

It was subsequently established that there had been significant failures in the approach taken by the SIL provider (who was also the landlord), in that therapeutic support (despite funding for a positive behaviour support plan being present in Joanna's NDIS plan) had not been arranged for her (nor supports arranged for other residents) to seek to address the issues between residents either in a pre-emptive way, or as the conflicts were emerging. In addition, Joanna's human rights (and rights under the Residential Tenancies Act) had been ignored.

Whilst the actions that the provider took were illegal (evicting on the spot, without providing the notice required under the Residential Tenancies' Act), the inherent power imbalance between the provider and Joanna was so pronounced that her health and wellbeing was jeopardised by failures of the provider to provide quality support.

As the AIHW in their latest report on *People with disability in Australia* (September 2019) advise : "A person who does not have access to affordable, secure and appropriate housing may experience several negative consequences including Homelessness, poor Health and lower rates of Employment and Education"⁴.

⁴ AIHW (2019), *People with disability in Australia report* (September 2019), accessed online via: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/housing> in September 2019.

In contrast to the models where a SIL provider is also the landlord, as mentioned above, in the ACT there are also a considerable number of houses where people receive SIL supports but where people are living in Housing ACT properties (whether as direct tenants of Housing ACT, or whether via a head lease with another service provider) and where the property is in the individual's name/s.

There are additionally a much, much smaller number of arrangements where participants who receive SIL supports own their own home or rent their property privately, but have their names on the lease. These arrangements, in addition to situations where participants have a lease with Housing ACT can allow for added safeguards, in that if the relationship with the SIL provider breaks down, it can sometimes be possible for participants (if all residents receiving SIL supports in that location agree) to change SIL provider rather than being required to move house (which allows for a much greater level of choice and control). Please refer to the further discussion in (d) other related topics.

a) The approval process for access to SIL

Whilst we are conscious that the Provider SIL pack includes newer versions of SIL forms (designed in conjunction with providers with the aim of streamlining the paperwork), it is our understanding that the approval process for access to SIL continues to still be very difficult.

If a person with disability is unable to share a property, and requires one-to-one supports, the level of documentation required is especially onerous.

Even if in principle it is agreed that SIL funding is appropriate, there are some situations where due to the level of care needs of the person with disability, it can be extremely challenging to find a SIL service provider who is willing (or able) to assist. Given that SIL providers need to complete paperwork before SIL funding can be included in an NDIS plan, this can have a profound impact:

Participant story:

Susan is a teenager living with disability who also has very complex medical needs, where ongoing monitoring is required. At the present time, she is living in the hospital, and has been doing so for over three years. Hospital is a dangerous place for her to be living in an ongoing way, due to the risk of infection. Advocacy was sought to help her find a home outside hospital.*

As part of seeking to achieve a home outside hospital, her advocate approached almost thirty SIL providers who had vacancies (sometimes in houses that had the features she needed). The greater majority declined, explaining that they were not able to assist someone with such a high level of needs. Whilst it is responsible for providers to indicate when something is beyond their skill level, it has highlighted for us the dearth of providers who are willing to work with clients where nursing-level clinical care is required. The impact on Susan (and her family) is profound. One SIL provider (who employs clinical staff) has now agreed to assist.

Susan's advocate also approached Housing ACT to seek a property – as things have worked out - due to the impacts of disability and health needs, Susan needs

a specialised property. The NDIS approved Specialist Disability Accommodation funding and a developer is now building a property to meet her needs and those of the others with whom she will share. We note that others in similar situations have died, due to hospital acquired infections, before a housing solution could be found.

b) The vacancy management process, including its management and costs

The current vacancy management processes (and vacancy management approaches of individual providers) are having some very negative impacts.

NDIS SIL funding is usually paid at a shared rate level (whether 1 staff member to 2 residents, 1 staff member to 3 residents, 1 staff member to 4 residents or another configuration), with the expectation that SIL funds from multiple participants will be combined in order to provide the staff levels that are required.

Given this providers are frequently under pressure to fill vacancies in properties (in order to be able to be in receipt of adequate funding to deliver needed services). Whilst the NDIA works with providers on this topic, there at times can be considerable financial pressure exerted on providers, who in some circumstances have ended up having to fund out of pocket portions of the aspects of the support costs (if the funding level is not adequate to cover staff when there are (for example, only 2 participants with SIL packages in the house when the funding rates have been provided as if 3 participants with SIL packages are living together).

This pressure can sometimes mean a “near enough is good enough approach” where potential tenants are at times accepted without sufficient emphasis on the choice and control of existing (and proposed new) household members, and without sufficient consideration as to whether the people involved want to live together/ have compatible life situations etc. At the present time, all too often, we have heard from participants stories of situations where matches ended up being driven by exactly this situation – i.e. by the availability of who can move in (as opposed to looking at the individual person’s wishes, or the adequacy of the matches). Please refer additionally to the comments in section d on this topic.

c) The funding of SIL

It is our experience that if a person needs a SIL package that is above the benchmarked price, that it can be sometimes be exceptionally difficult to achieve the needed level of funding. Whilst we accept that there can be perceived conflicts in that the service provider being asked to put forward the quotes is the same service provider that will receive the funding, we are also aware of situations where participants have been unfairly disadvantaged as a result of incorrect assumptions re vested interests.

Recommendation:

1. That there be continued efforts to find better ways to ensure that participants have adequate SIL funding available to meet their specific needs.

d) Any related issues

i. Concerns re service quality:

ADACAS has advocated over time in many instances where services provided by a SIL provider are not at the needed and expected levels of quality, nor of a level to correspond with the fees that participants are paying for SIL services. Participants receiving substandard services, in circumstances where their SIL provider is also their landlord (and sometimes also their support coordinator) can find themselves in exceptionally vulnerable situations.

Whilst assistance is available via advocacy services (and official visitors), and Quality and Safeguards complaints can occur, we encourage added focus in this area. We would also strongly suggest that in almost all instances, people in receipt of SIL should have a support coordinator that is from a separate organisation from their SIL provider.

Participant experience:

Earl receives a SIL supports. He lives in a Housing ACT property, and has a landlord that is separate from the SIL provider. Earl's aunt is his guardian. Earl's aunt has had two different SIL service providers working with Earl, however had ongoing concerns re service quality. Given this, she is now exploring brokerage models to find creative ways to ensure that the team of support workers that has been built to work with Earl, continues to be suitable for his needs.*

Recommendations:

2. That the NDIA work with the sector to seek to find ways to separate landlord and SIL functions, and to increase the quality of service and safeguards for people living in those circumstances.
3. That additional training and skill development (and ongoing mentoring) be made available for service providers and disability support workers, to increase the quality of support service that they can provide.
4. That the NDIA seek to work with the sector around the expectation that participants will usually have a support coordinator that is from an organisation separate to the provision of SIL services.

ii. Insufficient options

At the present time there are not enough vacancies in houses where SIL arrangements are occurring in Canberra, which means that there is frequently not enough choice when people are seeking a SIL option, or enough opportunities for emergency situations. This can also result in less-than-ideal matches where participants (or their guardians) feel compelled to take the first available option for a place in a home where SIL is occurring. (Emergency situations might arise when there is a sudden change in family circumstances such that a person who had been living happily with family is suddenly no longer able to do so, or due to transfers or evictions or changing needs).

Participant experience:

David has younger onset dementia. Due to the progression of his dementia, his housing situation became unsuitable, and he ended up in hospital. He needs 1 to 1 support 24 hours a day (2 to 1 support for personal care). Whilst a series of housing options have been explored, they have not worked out, and it has now been established that David needs to live by himself with supports (not in a shared situation with other people with disability). David's support provider and advocate are working urgently to seek to find a suitable housing option, but it is taking some time due to the limited number of vacancies available.*

Recommendations:

5. That the NDIA and State and Territory governments work together to make more independent SIL options (where the landlord is separate from the SIL provider) available.

iii. Difficulties of changing SIL provider / gap with support in this process:

As (has been discussed), NDIS participants sharing a house will generally be sharing a primary SIL service. As the provider (and the personal relationships that each tenant develops with staff) are so individual, there can also be significant variation between participant satisfaction with a service. At the present time it can be very difficult for participants to change their primary SIL provider, and generally all household members would need to reach consensus on agreeing to change, and to agree on which new provider should be appointed.

Due to the complexity of what can be involved with a change of provider (and that in some instances participants may (due to the nature of their disability) need support with decision-making), and/or wish or need to have family members and/or guardians involved), it is possible that each member of the household might need independent support, plus also there might need to be an independent facilitator taking leadership with the change process to ensure that everyone's wishes are adequately put forward and that there is no coercion. At the present time, intensive support in these situations is not easily available.

Recommendation:

6. That NDIA establish a pathway (either with State/Territory governments or via other avenues) to ensure that independent support is available to make it easier for people living in a SIL property who wish to change provider, to more easily do so.

iv. Difficulties of finding alternative SIL options

It can also be difficult for people wanting to move from a supported accommodation setting to find suitable alternatives. Whilst in the ACT, one service, Havelock Housing, has a Disability Housing Hub where there is an option to list Shared Supported Accommodation housing vacancies in private homes and whilst people can (if eligible), opt to register to seek shared social housing through Housing ACT's housing register, there are also many providers (or households) who prefer to advertise privately when a vacancy arises. It is our understanding that there continue to be insufficient options available.

3. Conclusion

NDIS participants who need SIL levels of support can sometimes be amongst the most vulnerable in our society. It is beholden upon all parties to increase the quality and safeguards around SIL arrangements to reduce risks of substandard care, or abuse.

*All participant experiences have been de-identified and consent granted to include the examples provided.