

Written Submission on the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into Supported Independent Living



Submitted To:
Joint Standing Committee on the National
Disability Insurance Scheme

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About Queenslanders with Disability Network (QDN)

[Queenslanders with Disability Network](#) (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a state-wide network of members who provide information, feedback and views from a consumer perspective to inform systemic policy feedback and advocacy to Government and peak bodies.

QDN has over 2000 members and supporters across Queensland who provide QDN with the perspectives of people with disability. This submission is informed by the lived experience of our members.

Introduction

QDN welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into Supported Independent Living (SIL). The NDIS is a critical investment in the supports and needs of people with disability to live their day to day life in their communities, based upon principles of choice and control. NDIS participants want to access quality, affordable and integrated supports across mainstream, community and specialist services. QDN is aware some members have SIL funding as a component of their NDIS funding. QDN believes it is important to critically examine the effectiveness of SIL to ensure people living in SIL arrangements have the same level of choice and control in their supports and how these are implemented in their living arrangements as other NDIS participants.

QDN's response to the NDIS SIL Inquiry is informed by:

- Our 2,000 strong membership and support base
- Our 21 [Local Support Groups](#) across the state
- QDN work and engagement with over 21,300 people with disability and their families in delivering the following projects and initiatives:

[NDIS Peer to Peer Advocacy](#)

[Getting on the NDIS Grid](#)

[Ready to go NDIS Participant Readiness project](#)

[QDN Housing Champions and their stories](#)

[QDN Housing Position Paper – Going for Gold: Accessible, Affordable Housing Now](#)

[QDN Housing Work: including Ministerial Housing Council, Engaging a disability perspective in the Partnering for Growth and Partnering for Impact Initiatives and My Housing Options Resources](#)

QDN's submission responds to the four areas of the SIL Inquiry by focusing on the lived experiences of QDN members living in SIL arrangements. It offers personal reflections from a consumer perspective with the aim of adding to the policy critique on SIL and presenting a brief summary of the issues in relation to housing and support for people with disability. QDN has asked modified questions to our members and their supporters as part of seeking member feedback on this Inquiry.

Brief summary in relation to the issues of housing and support for people with disability

People with disability are disproportionately affected by the lack of accessible, affordable, secure and safe housing in Australia. Demand far outstrips supply. Many people with disability on low incomes are forced to rent privately in a market where they face discrimination and a shortage of accessible properties. Affordable housing is often poorly located outside metropolitan areas, with limited accessible public transport, local services and employment opportunities.

QDN's Housing Position Paper [Going for Gold: Accessible, Affordable Housing Now](#) contains four key principles of Rights, Choice, Inclusion and Control along with 11 major recommendations and strategic actions that can be taken now by Government, private and community sector stakeholders to address this fundamental human need and human right – to have a place to call home.

QDN believes people with disability have the same rights to housing assistance as other people and should be supported to exercise those rights. This means housing is designed to enable family and friends with disability to visit.

QDN believes the principle of choice is achieved when people with disability choose where, how and with whom they live. This means:

- People can afford to live in housing suitable to their needs.
- People are able to make informed decisions about their housing choices.

QDN believes inclusion is achieved when housing enhances the independence and social and economic participation of people in family and community life. This means:

- Housing is non-congregate and encourages a mix of occupants with and without disability in housing developments.
- Housing is located within communities close to amenities and services.
- Housing is designed to meet the principles of universal housing design as developed in the Liveable Housing Design Guidelines and incorporates assistive technology as needed.
- Queenslanders are educated and aware of benefits of universal housing design and the need to include people with disability in local communities.

QDN believes that the principle of control is achieved when the provision and management of housing is separate from the provision and management of paid support. This means:

- Housing is primarily a person's home, not someone else's workplace; and
- A person can change their housing without affecting their support arrangements¹.

QDN believes it is essential that every person can have arrangements in place which separate their tenancy from other support services related to their personal care and community access. They also need to have clear arrangements in place that uphold their fundamental rights as tenants. At this point in time, QDN believes this is an area that needs attention and action to ensure consistency and uniformity.

QDN members have given mixed feedback in relation to SIL, many acknowledging the model gives service providers too much power. Some QDN members did say they liked the flexibility SIL provided and that SIL funding enabled them to explore moving out of the family home. QDN gives in principle support to Specialist Disability Accommodation (SDA) and SIL on the proviso that it looks beyond traditional group home models and offers a suite of options for people with disability to achieve independence. QDN believes creative, flexible housing and support options are key to the delivery of the objectives of the NDIS. SDA Housing will be key to increasing the much needed supply of affordable, accessible housing for people with disability in Australia. However, QDN does not believe that the intent of the SIL funding model should replicate previous group living arrangements that existed prior to the NDIS where people with disability had no choice about who they lived with, and a model that operated merely as a vacancy management approach. QDN believes SIL should form part of a suite of flexible supports that enable people with disability to make informed choices, achieve independence and enjoy modern, accessible housing in integrated communities. Further, QDN believes

¹ These principles have been adapted by the Queensland Department of Housing and Public Works. The objective of the Queensland Housing Strategy 2017–2027 is that 'every Queenslanders has access to a safe, secure and affordable home that meets their needs and enables participation in the social and economic life of our prosperous state'. See more information here:
<https://www.hpw.qld.gov.au/Housing/PartnershipInitiatives/Pages/HousingPrinciplesInclusiveCommunities.aspx>

investment in increasing the knowledge and understanding of people with disability who are funded in a SIL arrangement, so people with disability and their family/supporters informed choices about SIL and have the option to connect with compatible others who are seeking a housemate and alternative living arrangements across a wide range of housing options. Currently, QDN is involved in a project with Brisbane-based advocacy organisation Speaking Up For You (SUFY) on developing a user-friendly resource to inform people with disability and their supporters on their rights in relation to SIL. QDN believes more work in this area is needed.

The approval process for access to SIL

- ***What have been your experiences of accessing SIL funding as part of your NDIS plan?***

“As a resident in an existing Supported Accommodation facility the SIL arrangement was negotiated at a very similar time, almost as a group. This may have been because the facility was already ‘block funded’”, QDN Housing Champion.

Some QDN members have been funded for SIL as part of their NDIS plans, many reporting that their previous group home ‘transitioned’ to a SIL arrangement once NDIS rollout commenced in their area. A QDN member reflects on his experience: “So pre-NDIS I was already in a supported accommodation so when I transferred over to the NDIS it wasn’t much of an issue for me it was more our provider who did the running around working out the hours we needed as a house”.

A parent of a QDN member living in a SIL arrangement said: “The NDIA planner suggested it straight up. I think it saves money because they can cut down on costs”.

Another member argues that people with disability should be more involved in the process, stating: “The [SIL] quote is owned by the house and is managed between the provider and NDIA. I don’t believe people have choice and control under SIL as it gives service providers too much power”.

For some people, having the opportunity to apply for SIL as part of their NDIS plans has enabled them to explore the option of moving out of the family home similar to their siblings without disability, however, this has been met with challenges for people identified as having complex needs. A QDN member makes the following reflection on the experiences of one family: “I know a family who has worked really hard to support their son to get SIL but there seems to be a reluctance on behalf of services to take on the ‘complex’ clients in favour of the people with lower needs. How do we make it work so people with high and complex needs

are always taken care of?” This raises a potential barrier for people who already have few options available to them to explore independent living. Similar issues have been raised in the competitive market of Disability Employment Services²

Another member believes people shouldn’t be forced to live with people they do not know and have not made an informed choice to live with: “This is not choice and control under the NDIS”.

Regarding the approval process for SIL, QDN believes:

- That in the planning process, it is important for planners to work with the participant to help them understand and fully explore what people need in relation to support in their homes, with further options explored, not only SIL funding
- There needs to be transparency in costing so that participants can clearly understand what is quoted, what it means for their reasonable and necessary funding that relates to their accommodation, and that it is different to previous block funded arrangements
- There needs to be investment in building the capacity and understanding of participants about their options and rights under SIL. QDN sees that this would best sit outside NDIS and service system to avoid conflicts of interest and be independent, co-designed and peer-led by people with disability
- People with complex needs should be able to explore options for independent living both within and outside of SIL arrangements and be supported to do so

The funding of SIL

- ***How does your SIL arrangement work? Do you share with others or live in your own unit?***

“I was already in supported accommodation prior to the NDIS so when I transferred over to the NDIS nothing really changed, we are all still living in a group home arrangement”, QDN member.

Many of the members QDN spoke to about this Inquiry were already living in group homes/ supported accommodation prior to the NDIS. One QDN member describes her SIL

² See, for instance, the AFDO report: “Consumers front and centre: What consumers really think about Disability Employment Services”: https://www.deafnessforum.org.au/wp-content/uploads/documents/research_publications/what_consumers_really_think_about_the_disability_employment_services-afdo_national_report.pdf

arrangement in detail: “I have been living for more than six-and-a-half years as one of seventeen Residents in an existing Supported Accommodation facility. In this facility there are 14 self-contained apartments, made up of 12 single bedroom apartments, 2 two-bedroom apartments and two individual bedrooms with ensuite. In addition to dining/living spaces in apartments there is a shared dining room where meals are served 3-times per day from a central kitchen (weekly menu offers 2x choices at lunch and dinner). A laundry service is also offered”.

Another QDN member said that they live with two other people with disability and the SIL funding covers from 3pm–10 am weekdays with weekends being covered 24/7. The limitations of this model is that residents need to be out of the house from 10am-3pm Monday-Friday. This poses problems with choice if people want to stay home for the day or become unwell as they are required not to be there during this time period. This challenges the notion that a house is primarily someone’s home and not a facility. QDN is concerned that due to the requirement to represent value for money in the SIL quoting process, some providers are forced to cut corners, not allow for contingencies and under-represent the actual costs involved. Therefore, leaving residents without adequate supports.

One parent of a QDN member said her son now has a combination of SIL supports (which are plan managed and makes up two thirds of his funding) and core supports (which are self-managed with support from her). This arrangement allows her son greater flexibility to do things independently from his flatmate during the day. This independence was difficult to negotiate prior to the NDIS.

Conversely from the provider perspective, the community model of supported living where her son lives is having to adjust its operations as previous to the NDIS, the service engaged overseas students to live in-community with residents. This has stopped under the NDIS leading to increased costs and a more formalised structure for the service provider. The operation of service vehicles also presents a challenge under a SIL arrangement as SIL is only funded to cover supports in the home: “Transport is an essential issue for people with disability and is funded poorly under the NDIS. Previously vehicles were budgeted as a service cost and funded by [Department of] Communities”.

One QDN member reflected on the impact of emergencies in the SIL model: “At night if there is an emergency, there is only one person on shift. Which person gets assisted first? Who makes that decision?”

Hospital visits and admissions also present a challenge in SIL quotes. People cannot use SIL funding as a hospital inpatient as the NDIA considers that once a person is in hospital they are in the care of Queensland Health. Some people living in SIL arrangements do not have funding for individual core supports. Many people living in SIL arrangements have complex care needs

and cannot communicate independently and often, the who people know the most about their care needs and individual preferences are those providing their daily formal support. Not allowing people to have their support workers present at hospital could pose serious risks to their health. QDN believes this is an area of SIL requiring urgent attention.

- ***Do you get a say in who you live with?***

“No, I didn’t get a say back when they were organising housemates in 2013”, QDN member

The majority of people we spoke to said they get no choice about who they live with in their SIL arrangement. One QDN member reflected on difficulties associated with this when shortened life expectancy is a factor of the person’s disability:

“I live in a two-bedroom apartment with a shared bathroom where I am expected to share with someone that I do not know and have no choice in. Both people who have lived in the second bedroom whilst I have been living there have passed away, thankfully not in that room but in other locations. The shared bathroom is between the bedrooms, opening directly from each. There is no acoustic privacy between all three rooms. With two people sharing the apartment it is also very disruptive and noisy with staff coming and going to attend to the needs of the other resident. In fact, it is often the additional staff interaction, and the associated lack of privacy, that is the most difficult to endure and to manage. In the first instance of sharing the other person’s condition deteriorated so rapidly that I often had to alert staff if they fell out of bed or were distressed as they were not able to do so themselves. This was very disturbing, disrupting my sleep and rest. In the end their condition required the awake presence of staff overnight!”

It appears people living in SIL arrangements similar to the previous group home models continue to experience less choice in who they live with. QDN also spoke with some members considering more modern SIL arrangements with single occupancy units where there can be a combination of SIL supports and individual daily living supports. These arrangements offer more modern facilities and greater flexibility for residents as there is a focus on their individual needs and community participation. QDN looks forward to even greater flexibility in how SIL is funded so people can look beyond single occupancy models and live with family members and loved ones in SIL arrangements, replicating how all people live in the community.

In relation to the funding of SIL, QDN believes:

- Current funding of SIL leaves people in a position where they have limited choice and control over their supports during the day, causing providers to offer models similar to block funded arrangements where people had to be out of their house between

9am-4pm every day. This needs to be reviewed in its implementation to ensure people are exercising choice over what they want to do.

- Many people are in arrangements where they are paying board as a component of their tenancy, and it is important in these arrangements that people have clear tenancy agreements in place which specify what people are receiving for board versus SIL
- The model of funded supports needs to be explored to enable people to use their funded disability supports for their disability support needs whilst they are in hospital. People have specific care needs around their disability which needs to be maintained whilst they are in hospital, and people should be able to have choice to use their funding for their specific disability support in hospital, particularly people with complex needs where hospital staff may not have capacity to deliver all the formal support required for a person
- Participants could be offered a suite of innovative options and models in relation to SIL so they can make the best choice for them and use the funding to support their greater independence, as opposed to SIL replicating previously funded group home arrangements.

The vacancy management process, including its management and costs

• *How vacancies are managed in your SIL arrangement?*

“There is a waiting list. Most people moving here do so as they require a greater level of care”, QDN member.

QDN notes that many people were not aware of how vacancies were managed by providers of their SIL arrangements. This is concerning as it is consistent with the findings above that suggest people do not get a say in who they live with.

One person we spoke to had a family member living in an intentional community arrangement. An intentional community is a planned residential community designed from the start to have a high degree of social cohesion and teamwork. The members of an intentional community typically hold a common social, political, religious, or spiritual vision and often follow an alternative lifestyle³. In this arrangement much work is done when it comes to introducing a new community member. People are required to visit the community first, participate in social and community gatherings and see if they like it and fit in. Activities

³ Learn more about intentional communities here: <https://www.ic.org/directory/icadelaide/>

are Christian focused and there are opportunities for all community members (residents and care givers) to participate in social activities and retreats. For some residents this is their only experience of family. This arrangement operates differently to traditional services and vacancy management processes.

Other QDN members suggested their living arrangements were very fixed saying: “this has not happened yet, the population here is very stable” and “No one has moved out of this house in the five years I have been here”. This could be indicative of a number of things such as people not knowing how to move to another arrangement and SIL being relatively new in Queensland.

In relation to the process of vacancy management, QDN believes:

- Participants need access to information about vacancies in SIL arrangements. QDN acknowledges that previously, vacancy management occurred “behind the scenes” and was managed by state government departments, and often the options for people were based on what was available without directly working with the person about where they wanted to live and with whom. In ensuring that the NDIS delivers on choice and control for people, it is important that participants have access to information about what is out there, who they could choose to live with and ways of engaging and finding out about vacancies.
- QDN understands that within the current market, there are challenges for both participants and providers, including that providers are limited in their ability to understand the demand side of the market, ie what participants are looking for accommodation. This can result in costs to providers who hold vacancies for long periods of time, impacting upon the market in the long term. Market intervention is needed to provide seed funding to connect providers and participants. To expand the market, this service could be funded through individual plans so when it is needed, participants can purchase the service.

Any related issues

QDN members identified the following additional issues in relation to SIL arrangements:

- **No separation of housing and support:** “The property owner and the service provider are the same entity. This is never an ideal situation”.
- **Rent increases:** “My rent increased from \$412.00 per fortnight to \$595.00 per fortnight because that was “the amount on the NDIS Price Guide”. This increase of 40% happened with very little notice and no consultation”.
- **Limitations of Community Access provider:** “Use of Community Access hours in individual packages has almost been ‘commandeered’ by the service provider with

individuals strongly encouraged to use staff with whom they are familiar with through receiving personal care to accompany them on outings.

- **Workplace versus home:** “There is an attitude of this as a workplace first and the consideration that this is an individual’s home is somewhere further down the line. This would be less the case in truly independent living in a genuine community setting. Care of 17 residents under the same roof and sharing a staff ‘pool’ of more than 50 with regular agency staff added in, is not genuinely independent living”.
- **Resident compatibility:** “I think it is important for housemates to be on the same level so they can get along or you are going to have situations of misunderstandings and general dislikes of each other as the years go on”.

In relation to the additional issues raised by QDN members QDN believes:

- There needs to be clear processes put in place by the NDIA which enforces the separation of the roles and functions of housing and support. Ideally, these functions should be provided by separate providers to avoid conflict of interest. Where they are provided by the same provider, clear processes should be in place which delineate these functions. This could include setting up different arms of the service that are not co-located.
- Any increases in rent should be negotiated with the participant with a clear explanation in writing (or a format the participant understands) of the reason for these changes and what they include. Increases to rent should be reasonable, affordable and incremental if greater than 10% of original rent.
- Participants should be free to use separate providers for any funded individual core supports, including community access supports. Participants should be able to self-manage these supports, if they choose. Participants and their supporters should be given information on how to report issues where they feel that their needs or rights are not being met with regards to SIL and how they have been able to exercise using their individual core supports. This may include engagement with the NDIS Quality and Safeguards Commission.
- As part of the Code of Conduct, a training component for SIL providers could include how support is delivered individually, and assist in the cultural change in service model delivery moving from previous block-funded supports and group home models to enable people to achieve choice, control and social and economic participation.
- Requirements could be considered for SIL providers to clearly demonstrate and document processes in place to ensure co-residents have choice in who they live with, are compatible with one another, have choices to move to another arrangement if the current arrangement becomes unsuitable and that co-residents have a process in place to jointly agree upon and select a SIL provider.