



Inquiry into Supported Independent Living

**Submission to the Joint Standing Committee on
the National Disability Insurance Scheme**

September 2019

About the Office of the Public Guardian

The Office of the Public Guardian (OPG) is an independent statutory office which promotes and protects the rights and interests of children and young people in out-of-home care or staying at a visitable site, and adults with impaired decision-making capacity. The purpose of the OPG is to advocate for the human rights of our clients.

The OPG provides individual advocacy to children and young people through the following two functions:

- the child community visiting and advocacy function, which monitors and advocates for the rights of children and young people in the child protection system including out-of-home care (foster and kinship care), or at a visitable site (residential facilities, youth detention centres, authorised mental health services, and disability funded facilities), and
- the child legal advocacy function, which offers person-centred and legal advocacy for children and young people in the child protection system, and elevates the voice and participation of children and young people in decisions that affect them.

The OPG provides an entirely independent voice for children and young people to raise concerns and express their views and wishes. The OPG's child community visiting and advocacy function independently monitors and advocates for children and young people staying at visitable locations and facilitates the identification, escalation and resolution of issues by and on behalf of children and young people. The OPG's child legal advocacy function elevates the voice and participation of children and young people in the child protection system in decisions that affect them. When performing these functions, the OPG is required to seek and take into account the views and wishes of the child to the greatest practicable extent.

The OPG also promotes and protects the rights and interests of adults with impaired decision-making capacity for a matter through its guardianship, investigations and adult community visiting and advocacy functions:

- The guardianship function undertakes both supported and substituted decision-making in relation to legal, personal and health care matters, supporting adults to participate in decisions about their life and acknowledging their right to live as a valued member of society.
- The investigations function investigates complaints and allegations that an adult with impaired decision-making capacity is being neglected, exploited or abused or has inappropriate or inadequate decision-making arrangements in place.
- The adult community visiting and advocacy function independently monitors visitable sites (authorised mental health services, community care units, government forensic facilities, disability services and locations where people are receiving NDIS supports, and level 3 accredited residential services), to inquire into the appropriateness of the site and facilitate the identification, escalation and resolution of complaints by or on behalf of adults with impaired decision-making capacity staying at those sites.

When providing services and performing functions in relation to people with impaired decision-making capacity, the OPG will support the person to participate and make decisions where possible, and consult with the person and take into account their views and wishes to the greatest practicable extent.

The *Public Guardian Act 2014* and *Guardianship and Administration Act 2000* provide for the OPG's legislative functions, obligations and powers. The *Powers of Attorney Act 1998* regulates the authority for adults to appoint substitute decision makers under an advance health directive or an enduring power of attorney.

Submission to the inquiry

Position of the Public Guardian

The Office of the Public Guardian (OPG) welcomes the opportunity to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) inquiry into Supported Independent Living (the inquiry). The views contained in this submission are that of the OPG and do not purport to represent the views of the Queensland Government.

This submission addresses the inquiry's terms of reference where they relate to the experiences of the OPG and the people we serve, and raises additional issues for the Committee's consideration which the OPG considers significant to the inquiry.

The OPG would be pleased to lend any additional support as the inquiry progresses. Should clarification be required regarding any of the issues raised, the OPG would be happy to make representatives available for further discussions.

Overview and recommendations

The OPG strongly commends the inquiry and supports proposals that will bring improvements to the National Disability Insurance Scheme (NDIS). Below is a summary of the recommendations the Public Guardian sees as critical to the ongoing progression and success of the NDIS in Queensland, if it is to truly ensure 'choice and control' and that it does not, unintentionally, infringe the human rights of its participants.

The NDIS represents one of the most significant disability support reforms in recent Australian history, and provides a unique opportunity to advance the lives of people with disability. The OPG commends the Committee for inquiring into Supported Independent Living (SIL), which is of critical importance for the OPG's clients. The OPG is committed to the NDIS achieving its maximum potential in Queensland, so that our clients can access the full benefits of the scheme and exercise choice and control in their living arrangements, including living on their own with supports if they so choose.

The Public Guardian recommends:

1. The NDIS should allow for interim arrangements while gathering evidence for SIL, which enable people to transition to their SIL accommodation while undergoing the process for formal approval.
2. The NDIA should promote SIL as a positive and empowering option for people with high-level and complex disability support needs, and ensure that consistent information is provided by planners and other stakeholders.
3. The NDIA should allow SIL funding for people with disability to live alone in their own home as the norm, rather than the exception.
4. The NDIA should allow greater flexibility between the use of SIL and core supports, to enable each funding source to be used for the other purpose if required in the circumstances.

5. The planning meeting for SIL should include a discussion about the person's accommodation arrangements, and the person should be referred to appropriate services for information and advice to ensure the person understands their accommodation arrangements and has any required tenancy agreements in place prior to entering SIL.
6. The NDIA should allow funding for SIL support and advocacy, to enable the person to understand the SIL service agreement and to reduce the need for guardianship appointments to the greatest extent possible.
7. The NDIA should facilitate improved information sharing between prospective co-tenants to ensure compatibility prior to participants entering a SIL arrangement, to the greatest extent possible.
8. The NDIA should allow for increased SIL funding to ensure appropriate staffing numbers for the level of care required and number of participants residing at the SIL location.
9. The NDIA should allow for pre-SIL capacity building supports, and work collaboratively with relevant state agencies to address concerns and ensure a person's readiness for transition from state services to SIL in a timely manner.
10. The NDIA should consider establishing emergency SIL providers of last resort to ensure participants are supported through unexpected SIL placement breakdowns and relinquishments.

A. The approval process for access to SIL

In the OPG's experience, the approval process for SIL is very slow and difficult to navigate. The evidence requirements for SIL are quite onerous and prohibitive, and the person must spend significant time and resources gathering information to support an application for SIL, during which the person may be left 'in limbo' without any other suitable arrangements. The OPG has observed that some service providers will assist clients to obtain private rental property before their SIL application is approved. This results in considerable expenditure of both the person's own resources and their existing NDIS plan while awaiting SIL, as demonstrated in the case example below. The OPG has also observed an increase in guardianship appointments for previous clients, who require support to navigate the complexities of the SIL approval process. The NDIS should allow for interim arrangements while gathering evidence for SIL, which enable the person to transition to their SIL accommodation while undergoing the process for formal approval. This interim funding could be based on reports and assessments obtained within a reasonable period prior to the SIL application, and the person's funding and living arrangements under the former state or territory disability service. The SIL planning meeting should also discuss other options and contingencies for a person who is placed in a SIL, such as moving out or to another SIL.

There is inconsistency in the information provided to people about SIL and its promotion by the NDIA and other stakeholders. For example, the OPG has observed a lack of community education to stakeholders about the varying levels of support under SIL, and there is a perception that the OPG's clients should all have 24/7 support for supervision. This perception is potentially harmful as it presumes that people under guardianship require fulltime support, and does not allow for capacity building which is a key tenet of the NDIS. The OPG has also observed that in particular regions, some planners have a negative view about putting SIL into a person's plan. Planners have advised the OPG

that SIL is restrictive and too expensive, and that the client does not meet the requirements, even when there is clearly a need for that level of support. In these circumstances the planner appears to be attempting to build the client's plan around drop-in services rather than a SIL arrangement, even in places where there are a number of people living at the accommodation who may require and benefit from SIL supports. In the OPG's experience it has become more difficult to obtain SIL supports for clients in certain regions, with planners requiring more evidence for SIL even when the client has demonstrated their need for significant support requirements in their existing NDIS plan. The NDIA should promote SIL as a positive and empowering support option for people with high-level and complex needs, and ensure that consistent information is provided by planners and other stakeholders.

B. The vacancy management process, including its management and costs

The OPG has not observed any particular issues in this area.

C. The funding of SIL

It is very difficult to obtain SIL funding for a single person in their own home, even if this is the most appropriate option to reflect the rights and will of the person. It can also have a significant impact on their cultural and religious needs and personal preferences. In most cases the person is forced into shared accommodation because of cost efficiencies to the NDIA in co-locating people with disability to share supports. The OPG considers this is a grievous infringement on the person's human rights and is fundamentally contrary to article 19(a) of the United Nations *Convention on the Rights of Persons with Disabilities*, which requires State Parties to ensure that '*persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement*'. It is also contrary to the NDIS tenets of choice and control. The OPG has received information from the NDIA that to make the case that a client should live alone with one-on-one SIL support, they need to be able to show why the client *cannot* live with other people. It appears the default position is that people with disability must live together to obtain SIL funding unless they can prove otherwise. Obtaining this kind of evidence is very challenging, and almost requires the client to show that they have tried shared accommodation and the arrangement has failed. People with disability have the right to choose to live alone in their own home, equal with any other person, and should not be forced to live with others in order to obtain SIL supports. The government does not require any other person receiving supports to live with other people in order to obtain that support, therefore it should not be expected of people with disability. This practice is discriminatory and should be ceased immediately.

There is insufficient flexibility between the use of SIL and core supports that can enable funding from one source to be used for another purpose when needed. For example, the OPG was appointed guardian for an 18 year old young person who had come out of child protection, having lived in a very protective environment. The OPG advocated for a carer to be on call for the young person if they were unwell or upset about something at their day program and wanted to come home to their SIL arrangement. This arrangement required the use of additional SIL funding rather than core supports. The OPG has also observed that there may be gaps in funding between SIL and core

supports. For example, there is a half hour overlap for carers transporting clients between their day program and SIL which is not funded by either area, resulting in an eventual shortfall in funding. Conversely, the OPG has received inconsistent information that SIL providers are entitled to be paid when the client is out at their day program, on the basis that the SIL provider is providing 24/7 care for the client. However, the OPG understands that SIL is not funded while the client is out of the home and receiving other services under the core supports of their NDIS plan. The OPG recommends that greater flexibility is introduced between the use of funding provided for SIL and core support, to enable each funding source to be used for the other purpose if required in the circumstances.

D. Any related issues

SIL and tenancy agreements

The OPG has observed that participants may lack understanding about the difference between SIL and their accommodation arrangements, which places participants at risk of unstable or unfair rental arrangements. It should be standard practice that participants are protected by both SIL and tenancy agreements (where relevant) before moving into their SIL arrangement. However, many participants move into SIL on the mistaken belief that their SIL agreement with a service provider also encompasses their accommodation arrangement, when in actual fact there is no formal tenancy agreement in place. Once the participant moves into the accommodation, it is a common experience for the participant to find that the service provider has significantly increased the rent, and there is little recourse for the participant because there is no formal tenancy agreement or accommodation protections in place.

While the NDIA generally doesn't have responsibility for the accommodation arrangements of participants, the SIL planning meeting is an ideal opportunity to flag this issue with participants and refer them to appropriate services for information, advocacy and advice. The planning meeting for SIL should include a discussion about the person's accommodation arrangements, and the person should be referred to appropriate services for information and advice to ensure the person understands their accommodation arrangements and has any required tenancy agreements in place prior to entering SIL.

Complex service agreements

The service agreements for SIL are generally quite complex. The inherent complexity restricts a participant's ability to fully comprehend the implications and nuances that may apply under such agreements, and increases the risk of unfair clauses being included that benefit of agencies and service providers to the detriment of the participant. The OPG has observed unfair clauses in SIL service agreements with negative consequences for the participant. For example, participants may be charged cancellation fees if they don't give notice or attend a particular component of the arrangement such as an outing, in circumstances where they may not understand the terms of the agreement or the financial implications of failing to give notice or attend. The OPG has also observed a direct link between complex service agreements and an increase in formal guardianship appointments, where the OPG is appointed because a decision needs to be made about SIL and the complexity of the agreement has impeded the participant's ability to autonomously engage with agreement, even with decision-making support and advocacy. This has been an ongoing issue that occurred prior to the introduction of the NDIS. This increase in guardianship appointments includes

previous clients of the OPG who were in stable state service arrangements with no decisions to be made, but now require a formal substitute decision maker to transition from the state services into SIL, which contravenes the 'choice and control' objectives of the NDIS and also unfairly impact upon a person's human rights

The OPG has also observed an increase in indefinite or ongoing guardianship appointments, in circumstances where the guardianship appointment would previously have been revoked after all required decisions about disability supports and accommodation have been made. For example, prior to the NDIS, the OPG would be appointed as guardian for adults in Queensland's state-managed Accommodation Support and Respite Services (AS&RS), which was a SIL-like arrangement with block funding, and revoked after the decisions about accommodation and services were complete. However, under the NDIS the OPG is increasingly being appointed for an indefinite period of time on the basis that there are decisions that need to be made in the future, namely the review of plans. The OPG considers that an indefinite appointment is inappropriate, contrary to the participant's right to choice, control and exercise of their own autonomy, and is not the least restrictive option given it is an ongoing imposition on the person's autonomy and right to make their own decisions, potentially for the rest of their life. The NDIA should allow funding for SIL support and advocacy, to enable the person to understand, and make informed decisions about the SIL service agreement and to reduce, and where possible, entirely remove the need for guardianship appointments.

Co-tenancy and compatibility

The OPG has observed a number of issues in relation to co-tenancy and compatibility in SIL arrangements. Of 18 accommodation related issues raised by OPG's Community Visiting and Advocacy business unit in the 2018-19 financial year, 6 related to concerns about co-tenant compatibility. Factors identified through issues raised by the Community Visiting and Advocacy unit that impact on compatibility include: personality differences and general incompatibility; behaviours of an adult negatively impacting on others in the household, at times resulting in harm being reported; lack of available accommodation alternatives; and unwillingness of tenants or their decision makers to consent to accommodation changes. Given the current small market in some areas (particularly regional, rural and remote areas), the OPG is concerned about whether there are adequate vacancies to allow sufficient weight to be given to compatibility. There is also concern about whether there will be adequate sharing of information with participants and decision makers to determine if a co-tenancy arrangement is likely to be suitable. The NDIA should facilitate improved information sharing between prospective co-tenants to ensure compatibility prior to participants entering a SIL arrangement, to the greatest extent possible.

Case example

In a household where four adults with impaired capacity were residing, the behaviour of one 45 year old male adult was found to be having a profound impact on the remaining adults. The behaviours described to the Community Visitor included the man insisting on eating meals alone, insisting others stay in their rooms until he was finished so they are not visible while he was eating, and yelling loudly at the residents. The service provider reported the man to be controlling and that he often used his voice to force other residents to their rooms when he didn't want them in his area. One of the other adults directly confided to the Community Visitor that he felt unsafe due to the man's behaviour. The Community Visitor has been advocating for several months for changes to the co-tenancy arrangement. The Community Visitor spoke with the service provider, who was willing to seek a sole tenancy for the man, and informed the appointed OPG guardian of the resident who voiced feeling unsafe. The private guardian of the man refused to consent to a move out of the household into a single tenancy. The resulting situation is the Community Visitor is still advocating for change, including review of the co-tenancy arrangements and appropriate interventions to manage the impact of the behaviours.

SIL staffing

The OPG has observed a number of issues in relation to staffing in SIL arrangements. OPG's Community Visiting and Advocacy unit identified 4 issues in 2018-19 regarding staffing, including compatibility of adults and staff; and a need for increased staffing ratios due to behavioural needs. It was apparent that SIL funding levels in shared or group accommodation was a consideration when discussing choice and control in staffing. This issue is also relevant to the issues raised by the OPG in relation to shared accommodation and SIL funding at C above. The NDIA should allow for increased SIL funding to ensure appropriate staffing numbers for the level of care required and number of participants residing at the SIL location.

Case example

An issue was raised on behalf of a female adult who objected to a male support worker providing her personal care. The objections were voiced to the Community Visitor and noted on other occasions in the communication book at the site. The initial response from staff was that it had been explained to the adult that the male support worker was part of the team, no changes to the team were planned and no alternative could be offered. The lead practitioner with the service provider responded to the Community Visitor that the adult had on occasion texted her consenting to the male worker assisting with her care, but had also texted her objections with the male worker directly to the lead practitioner. The lead practitioner told the Community Visitor that the male worker had worked at the site for some years and would be continuing. The lead practitioner also reported that it was hoped that NDIS funding would allow one-on-one support for greater choice but that there were limitations on the funding that didn't allow this choice. Throughout the advocacy process the lead practitioner continued to cite funding limitations on the 2:1 model and that they were continuing negotiations to try to get more support funding through the NDIS package. After Community Visitor advocacy, shifts were adjusted so that all personal care for the adult was provided by female workers.

Transitioning from state services to SIL

The OPG has observed a number of issues in relation to continuity of supports and transitioning from state health facilities to SIL arrangements. In 2018-19 the Community Visiting and Advocacy unit raised 11 issues that relate to NDIS for people residing in Queensland Health facilities. The nature of these issues includes adequacy of supports to develop skills and progress toward discharge to community living in SIL placements; refusal of the treating team to allow discharge to a SIL due to concerns about the person's independent living skills; delays in discharge while waiting for a suitable SIL placement to become available; delays in discharge while waiting for the NDIS planning meeting; support to relocate to another part of the state; and the conduct of staff during transition from the mental health facility to the SIL. Many clients are approved for SIL but remain in an acute care unit and are unable to transition because of the lack of SIL placements. The OPG also observed a similar lack of provision and coordination of services for cases in other areas, such as an unplanned prisoner release which results in the prisoner urgently requiring SIL accommodation. While some of these issues may require primary action by Queensland Health or the relevant state agency, the NDIA should allow for pre-SIL capacity building supports, and work collaboratively with the relevant state agency to address concerns and ensure the person's readiness for transition to SIL in a timely manner.

Case example

The Community Visiting and Advocacy unit visited an adult woman in her 50s who had resided in a mental health unit over 250 days. Staff of the unit identified that the delay in discharge was due to the wait for a planning meeting and a suitable house. It was identified that the woman was one of approximately 78 patients across the Metro South Health and Hospital Service who were in hospitals awaiting NDIS plans at the time. It was identified that there were regular meetings occurring between the Department of Housing (Qld), NDIA and Queensland Health to discuss the matter of long stay patients who were awaiting NDIS plans.

Case example

A woman in her 40s spoke with the Community Visitor about her frustrations awaiting a suitable SIL placement to enable her to be discharged from the mental health unit. The woman had a completed NDIS plan with the goal of living in the community. Staff of the mental health unit reported the delay to be a result of the waiting for a suitable co-tenant to be identified.

Case example

A woman in her 50s complained to the Community Visitor that the medical officer had refused to sign a Department of Housing application which resulted in delays to discharge. The adult reported that she had NDIS funding allocated to allow her to live in the community, but the medical officer had refused to sign the housing application. The treating team reported they were not supportive of the woman living alone, that they wanted to work with the adult to acknowledge her skill limitations for independent living and to have her agree to discharge to a supported accommodation facility instead.

Relinquishment by SIL provider

The OPG has observed a significant issue whereby a participant may be relinquished by a SIL provider. In SIL locations where co-tenancy arrangements are in place, this can result in housing instability and in some instances a need for the participant to move out of their home. This issue could be alleviated by the NDIA funding more SIL arrangements for single participants living on their own, discussed at 'C. Funding of SIL' above. The NDIA should also consider establishing emergency SIL providers of last resort to ensure participants are supported through unexpected SIL placement breakdowns and relinquishments.

Case example

Two adults resided together in the site since early 2018. No co-tenancy concerns were reported by the adults when they were visited by the Community Visitor. The home was a Department of Housing property. The SIL provider made a decision to end SIL services to one of the clients due to concerns about the conduct of his private guardian. The guardian of the other client wished for him to remain with the SIL provider. As a result of the decision, the client who remained with the SIL provider had to move from the home into short term accommodation until they could source another property and a co-tenant. The client who was relinquished remained in the property supported by a new SIL provider, with intentions to advertise a vacancy. The decision taken by the SIL provider resulted in housing instability for the client they retained. OPG had to withdraw from visiting both clients as they were no longer within their legislative remit, as the property became a private dwelling and the second client went into short term accommodation.