



Purple Orange

**Submission to the Joint Standing  
Committee on the National Disability  
Insurance Scheme about Supported  
Independent Living (SIL)**

September 2019

## About the Submitter

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families. Our work is characterised by co-design and co-production, and includes hosting a number of user-led initiatives. Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community. Our work is informed by a model called *Citizenhood*.

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## Acknowledgments

JFA Purple Orange's sister organisation *inhousing* is a registered NDIS SDA provider and shared with us the stories of people's experiences with SIL that are included in this submission.

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2

JFA Purple Orange Submission on Supported Independent Living (SIL)

## Contents

1. Summary and recommendations .....	4
2. Introduction .....	7
3. Principles guiding living arrangements for people living with disability .....	8
4. The problem with legacy living arrangements .....	10
5. The problem with SIL.....	14
6. Solutions .....	19
7. Conclusion .....	23

## 1. Summary and recommendations

Supported Independent Living (SIL) is most commonly used as a mechanism for funding service providers to offer shared supports to NDIS participants in a shared living arrangement, and has enabled people living in group homes to be transitioned from government block-funded services to NDIS funded services without any change to their living arrangements.

The 2009 SHUT OUT report<sup>1</sup> and 2011 Productivity Commission inquiry report<sup>2</sup> highlighted that the pre-NDIS disability service system was both broken and underfunded. SIL has ensured that secure funding is in place to deliver supports to NDIS participants in shared living arrangements. However, providing more funding without fixing a broken system risks loading the scheme with great costs without delivering transformational benefits to NDIS participants. As the transition to the NDIS nears completion, there needs to be a renewed focus on ensuring the scheme delivers value for money in the long term. This means providing home supports in a way that is flexible to the needs and choices of participants, ensuring that money is not wasted on unnecessary or unhelpful supports but rather invested in supports aligned with building participant capacity to achieve their goals.

Congregate settings such as group homes are generally characterised by the features of an institution rather than the features of a home and do not deliver choice and inclusion for NDIS participants. The current default SIL funding allocation methodology encourages support provision to be locked into such shared arrangements. This constrains participants wanting to take up more flexible and contemporary arrangements and is therefore not compliant with article 19 of the UN Convention on the Rights of Persons with Disabilities

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<sup>1</sup> SHUT OUT: The Experience of People with Disabilities and their Families in Australia, page 19, accessed on 30 August 2019 at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

<sup>2</sup> Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra, page 111, accessed on 30 August 2019 at <https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf>

(CRPD). During the current formative period in the development of the NDIS market, merely tinkering with transitional SIL structures risks entrenching existing funding and living arrangements. It is imperative to now move to offering participants on SIL more flexible support arrangements.

We therefore recommend the following:

### **Recommendation 1**

The Joint Standing Committee on the NDIS **avoid** proposing process improvements that could enhance the attractiveness of SIL to service providers and thereby further entrench a model that is destined to continue to deliver poor outcomes for people living with disability.

### **Recommendation 2**

Facilitate the national transition of NDIS participants from SIL to more flexible support arrangements through:

- allocating individualised funding to those currently receiving SIL based on what supports are reasonable and necessary for them rather than on historic block-funded arrangements
- prioritising within the ILC program investment in individual capacity-building, in relation to building a vision of an ordinary valued life, and how group homes and comparable services cannot easily deliver this
- promotion of the Independent Living Options (ILO) support arrangements now offered in the NDIS Support Catalogue service to all providers and participants, not only those already delivering or receiving ILO supports
- further development of ILO and other flexible support funding structures and pricing which use a participant's existing funding more innovatively and do not assume co-location of participants in the same dwelling as the default
- establishing a mechanism for support providers to demonstrate support models, outside of SIL, which operate within appropriate individual participant budgets and consistent with the NDIS's values

- establishing dedicated pathways for participants to easily exit existing SIL arrangements, including an assured way of repurposing existing SIL funding to finance more flexible support arrangements.

### **Recommendation 3**

Ensure all participants currently in SIL receive adequate support coordination through their NDIS plan to enable them to freely choose their own living arrangements (including helping them to exit existing SIL arrangements if they choose) and choose the planning and delivery of their supports.

### **Recommendation 4**

Require independent supply of support coordination, personal support and housing to ensure NDIS participants retain choice and control and there is no service provider conflict of interest, e.g. where a service provider (acting as support coordinator) is responsible for ensuring consistent delivery of their own services (acting as personal support provider).

### **Recommendation 5**

Address the lack of availability of appropriate affordable housing that can lead to NDIS participants being placed in more expensive supported living arrangements:

- Escalate reforms to boost Specialist Disability Accommodation (SDA)
- Increase the availability of non-SDA housing to the 94% of NDIS participants ineligible for SDA

### **Recommendation 6**

Where participants choose to remain in group home or other congregate settings, ensure that greater control lies with the individual:

- Allow co-residents to collectively choose a different support provider if they wish
- Allow NDIS participants to use a different provider for particular aspects of their day spent away from daily living
- Guarantee residents the right to view different group home options and meet potential co-residents before they decide if they wish to proceed, just as is in the private rental market
- Promote small cluster site accommodation over standard group homes.

## 2. Introduction

The NDIS provides supports to assist participants to live independently in the community. These supports take a range of forms including: capital supports offering home modifications and Specialist Disability Accommodation (SDA); capacity building supports to increase a participant's skills or capacity for independence, and to ensure a participant obtains and retains appropriate accommodation; and core supports providing assistance or supervision with personal tasks of daily life, e.g. personal care and household tasks.<sup>3</sup>

Supported Independent Living (SIL) forms part of the core supports providing assistance with daily life, and applies to 7% of NDIS participants but constitutes approximately one third of NDIS committed support costs.<sup>4</sup> The NDIS website defines SIL as “help with and/or supervision of daily tasks to develop the skills of an individual to live as independently as possible. These are the supports provided to a participant in their home, regardless of property ownership, and can be in a shared or individual arrangement.”<sup>5</sup> However, the NDIS Price Guide 2019-20 defines SIL as “the assistance with and/or supervising tasks of daily life in a shared living environment, with a focus on developing the skills of each individual to live as autonomously as possible.” This second definition reflects SIL's most common use as a mechanism for funding service providers to offer shared supports to NDIS participants in a shared living arrangement.<sup>6</sup> In many cases, SIL appears to have been used as a way to transition people living in group homes from government block-funded services to NDIS funded services. The majority of people living in group homes live with an intellectual

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<sup>3</sup> NDIS Price Guide 2019-20, accessed on 30 August 2019 at <https://www.ndis.gov.au/providers/price-guides-and-information>

<sup>4</sup> Report to the COAG Disability Reform Council for Q4 of Y6 Full report, pages 39, 59 391, accessed on 30 August 2019 at <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

<sup>5</sup> Accessed on 30 August 2019 at <https://www.ndis.gov.au/providers/essentials-providers-working-ndia/supported-independent-living>

<sup>6</sup> See, for example, the National Disability Services Practical Guide to SIL Quoting Version 1, page 1, accessed on 30 August 2019 at <https://www.nds.org.au/images/SDP/practical-guides/NDS-Practical-Guide-SIL-Quoting.pdf>

disability,<sup>7</sup> and therefore it is reasonable to assume that most recipients of SIL funding live with an intellectual disability.

The Joint Standing Committee on the National Disability Insurance Scheme is tasked with inquiring into the implementation, performance and governance of the NDIS, and has chosen to inquire into and report on SIL, with particular reference to:

- a) the approval process for access to SIL
- b) the vacancy management process, including its management and costs
- c) the funding of SIL
- d) any related issues.

JFA Purple Orange is not a disability support provider and therefore brings an independent perspective to SIL and other support arrangements. In developing our response, we have drawn on our understanding of the principles that motivated and underpinned the creation of the NDIS and our strong links to people living with disability and their families. These equip us with valuable insights into the extent to which SIL is hindering or helping the goals of the NDIS. In addition, we have consulted with a SIL provider and a Specialist Disability Accommodation (SDA) provider that we have close relationships with in order to identify specific examples illustrating our analysis.

### **3. Principles guiding living arrangements for people living with disability**

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) lays out the rights of people living with disability to live independently. In ratifying the CRPD in 2008, Australia committed to ensuring 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

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<sup>7</sup> Bigby, C. & Bould, E. (2017) Guide to Good Group Homes, Evidence about what makes the most difference to the quality of group homes, page 2. Centre for Applied Disability Research. Available at [www.cadr.org.au](http://www.cadr.org.au)



others and are not obliged to live in a particular living arrangement” and ensuring that “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”<sup>8</sup>

The general principles guiding action under the National Disability Insurance Scheme Act 2013 echo Article 19 in stating that “Reasonable and necessary supports for people with disability should support people with disability to live independently and to be included in the community as fully participating citizens” and that “People with disability should be supported to exercise choice...in the planning and delivery of their supports”.<sup>9</sup>

In addition to the legal framework underpinning the right to live independently, it is important to recognise the basic human need to live in a residence that feels like a home, and the role of a home in supporting wellbeing and building community connections. Josey McMahon, a board member at the Community Resource Unit (CRU), eloquently describes what it means to have a home:

“Home for me is sanctuary - a place where I feel safe and secure. It is also a place where I can be myself, relax and unwind. It is a space that I can have control over and have the things that provide me comfort. It is a space that I can call my own, have my family, friends and acquaintances visit whether that be for a cuppa, a meal, a party or some entertainment. It is often the place that people get to know me the best as they can observe and witness for themselves the things that matter to me. My home tells a story about me and is much more than bricks and mortar... My home has become a launchpad into my local community where I have become connected and known by neighbours. I am a regular visitor to

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<sup>8</sup> UN Convention on the Rights of Persons with Disabilities (CRPD), pages 13-14, accessed on 30 August 2019 at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

<sup>9</sup> National Disability Insurance Scheme Act 2013, pages 6-7, accessed on 30 August 2019 at <https://www.legislation.gov.au/Details/C2013A00020>

local cafes, newsagent, chemist, post office, gifts shops etc. I am known by my name and I am not just another person being served.”<sup>10</sup>

Arguably the sanctity of home is even more important for people living with disability than for non-disabled people given: there are many situations outside of the home where people living with disability currently feel excluded or disempowered; and they may spend a large proportion of their week at home due to barriers to economic and social participation.

Policies and practices, including SIL, that influence living arrangements for people living with disability should be evaluated based on the extent to which they:

- comply with the legal framework relating to disability
- comply with the objectives of the NDIS
- support people living with disability to:
  - freely choose their own living arrangements
  - choose the planning and delivery of their supports
  - have control over and personalise the space they live in
  - be included in their local community.

## 4. The problem with legacy living arrangements

Historically, many Australians living with disability were forced to live in institutions. Nowadays, most (but not all) larger residential institutions have closed. However, many people living with disability (particularly intellectual disability) continue to live in congregate housing arrangements such as group homes, cluster housing, supported residential facilities and aged care facilities. These residences are shared by unrelated people with similar support needs and supervised by support staff. The Australian Government reports that in

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<sup>10</sup> Crucial Times August 2019 Issue 55, page 3, accessed on 30 August 2019 at <https://cru.org.au/crucial-times-55-what-it-means-to-create-a-home/>

2015-16 5.2 per cent (14,812) of disability service users were living in domestic-scale supported living facilities such as group homes and a further 2.8 per cent (8,046) were living in supported accommodation facilities.<sup>11</sup>

The 2009 SHUT OUT report on the experience of Australians living with disability and their families details why many people living with disability remain in these accommodation settings – it is often the only way people can access social and personal care supports, since such supports have typically been offered only to those residing in particular congregate settings:

“It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home...”<sup>12</sup>

While group homes do not tend to carry *all* of the problems of large residential institutions, they typically still retain several institutional characteristics:<sup>13</sup>

- Limited or no choice of whom to live with – including size of household; to what extent get on with the other people in the household; and option to live alone or with a partner, other relatives or friends who may or may not live with disability
- Limited choice of service provider and obligatory sharing of assistance with others in the household

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<sup>11</sup> Australia’s Combined Second and Third Periodic Report under the Convention on the Rights of Persons with Disabilities, 2018, page 38, accessed on 30 August 2019 at <https://www.ag.gov.au/Consultations/Documents/Convention-on-the-rights-of-persons-with-disabilities/Australias-draft-combined-second-and-third-periodic-report.pdf>

<sup>12</sup> SHUT OUT: The Experience of People with Disabilities and their Families in Australia, page 27, accessed on 30 August 2019 at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

<sup>13</sup> Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on living independently and being included in the community, pages 4-5, accessed on 30 August 2019 at <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

- Once arrangements are in place, difficult to change accommodation, housemates or service providers, even if they become unsatisfactory to a resident
- Feel more like facilities delivering services than like homes – managed and run by service providers, with residents having limited control over what happens there and limited opportunity to make the space their own or to host visitors
- Have fairly rigid routines and require residents to do activities as a group
- Expose residents to increased likelihood of being subjected to regulated restrictive practices, especially environmental restraints that limit their access to or control over shared amenities such as fridges, particular rooms of the house, mealtimes, activities, etc.<sup>14 15</sup>
- Segregate rather than acting as a gateway to community inclusion because neighbours view them as service venues rather than regular homes
- Expose residents to vulnerability from abuse or exploitation from staff and other residents through segregation.

In 2017, the UN Committee on the Rights of Persons with Disabilities adopted General Comment No. 5 (2017) on living independently and being included in the community, which aimed to assist States parties in their implementation of article 19 and fulfilling their obligations under the CRPD. General Comment No. 5 makes explicit that the following are all incompatible with article 19:

- Mandatory “package solutions” which, among other things, link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements
- The concept of personal assistance wherein the person with disabilities does not have full self-determination and self-control

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<sup>14</sup> Australian Law Reform Commission Equality, Capacity and Disability in Commonwealth Laws (DP 81), Chapter 8, accessed on 30 August 2019 at <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/8-restrictive-practices/restrictive-practices-in-australia/>

<sup>15</sup> National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018, accessed on 30 August 2019 at <https://www.legislation.gov.au/Details/F2018L00632>

- Housing only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood
- Reasoning that there are some people living with disability with more complex needs for whom it is too costly to provide services outside of an institutional setting or whom are considered unable to live outside of an institutional setting.<sup>16</sup>

In its 2013 concluding observations on the initial report of Australia, the Committee:

“encourages the State party to develop and implement a national framework for the closure of residential institutions and to allocate the resources necessary for support services that would enable persons with disabilities to live in their communities. The Committee recommends that the State party take immediate action to ensure that persons with disabilities have a free choice as to where and with whom they want to live, and that they are eligible to receive the necessary support regardless of their place of residence.”<sup>17</sup>

It is clear that congregate settings such as group homes are not compliant with article 19 of the CRPD, fail to deliver choice and inclusion as described in the National Disability Insurance Scheme Act 2013 and are generally characterised by the features of an institution (as laid out in General Comment No. 5) rather than the features of a home.

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<sup>16</sup> Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on living independently and being included in the community, pages 5-6, accessed on 30 August 2019 at <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

<sup>17</sup> UN Committee on the Rights of Persons with Disabilities (CRPD), Concluding observations on the initial report of Australia, adopted by the Committee at its 10th session, 2-13 September 2013, CRPD/C/AUS/CO/1, page 6, accessed on 30 August 2019 at <https://www.refworld.org/docid/5280b5cb4.html>

## 5. The problem with SIL

The introduction of the NDIS is a unique opportunity to transform service delivery for Australians living with disability. Previous block-funding arrangements that tied support to residence in a group home are coming to an end, and new individualised funding models are being developed under the NDIS with an ostensive aim of giving participants choice and control. It would therefore be hoped that people currently living in group homes who are transferring onto the NDIS would receive funding that allows them to receive the home supports they need from the provider of their choice in the home of their choice. Such an arrangement could deliver transformational benefits for NDIS participants living in group homes by helping them to become actively involved as a valued member of their local community.

Instead, SIL funding arrangements appear to have been developed to manage the transition of residents of congregate housing onto the NDIS with minimal disruption to existing housing and support arrangements. Thus participants continue to live together in a group home setting where they receive shared supports from a service provider. While the SIL quoting tool requires service providers to consider the needs of each individual receiving support, the tool is completed per property rather than per individual, with the service provider balancing the needs of each individual and staffing and rostering considerations when developing a quote. The SIL quoting process is primarily a discussion and agreement between a service provider and the NDIA, with limited input and oversight from the NDIS participant and their family: the NDIS participant is not necessarily given the opportunity to view the quote or the roster or to confirm it meets their needs.<sup>18</sup> This is in stark contrast to other components of the NDIS, where participants are funded through their individual plans to choose and pay for quality services directly.

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<sup>18</sup> NDIS Guide to using the Provider Supported Independent Living (SIL) Pack, September 2018, accessed on 30 August 2019 at <https://www.ndis.gov.au/providers/essentials-providers-working-ndia/supported-independent-living>

SIL is not genuine individualised funding. For example, if one participant in a home requires active overnight support in a home then it is likely that all participants in the home will have active overnight support in their plan, regardless of their individual needs. If a group home resident is unhappy with their SIL provider, they are likely to require agreement from a majority of residents in order to change providers, and under some transitional arrangements residents are tied to their current provider for a fixed period of time (e.g. residents in New South Wales transferring from state government accommodation services to SIL providers cannot change their SIL provider for the first two years<sup>19</sup>).

It may be that SIL's primary intended role was as a short-term transitional measure to enable residents of congregate housing to access the NDIS while individualised funding for supports for daily tasks is being developed for them. However, during the current formative period in the development of the NDIS market, there are major risks of entrenching the SIL funding model and group home status quo, both through service providers setting up their businesses to deliver SIL supports to group home residents and through the NDIA making cost assumptions about the NDIS based on people living in group home arrangements. SIL is attractive to service providers because there are tools and templates that make it relatively efficient and unbureaucratic to manage compared with other NDIS supports and because it accounts for a substantial proportion of NDIS spending.

While SIL allows for support to be provided to people living in individual as well as shared arrangements, in practice there are multiple drivers encouraging service provision in shared arrangements such as group homes:

- Firstly, service providers who were already providing disability supports to people in group homes are familiar with this model, and often have existing systems to deliver

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<sup>19</sup> NSW Government Information Sheet: Transfer of disability services – accommodation and service agreements, accessed on 30 August 2019 at <https://ndis.nsw.gov.au/about-ndis-nsw/transfer-of-nsw-disability-services/information-sheet-transfer-of-disability-services-accommodation-and-service-agreements/>  
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services, and therefore are likely to continue operating it in the absence of an imperative to change

- Secondly, there is a shortage of affordable housing for people living with disability (particularly in the case of people who require housing with physical accessibility features), and shared living arrangements may be appealing where they reduce the perceived volume of housing stock demanded, even if they incur greater long-term costs
- Thirdly, in some cases it is financially attractive to service providers to provide supports in shared rather than individual arrangements, since they can provide supervision to multiple participants at the same time
- Fourthly, the NDIS SIL quoting guidelines state that the purpose of a quote is to identify “supports that are shared between participants to maximise the efficient use of resources”<sup>20</sup> and in most cases the quoting tool assumes staffing ratios not based on one-to-one support, hence setting expectations for service providers.

In investing in a broken model of disability support, SIL is proving costly without delivering transformational benefits for participants. Indeed, the NDIA has identified already higher than expected SIL costs as a source of financial pressure on the NDIS.<sup>21</sup>

The NDIS SIL model seems to assume that many people living with disability who require ongoing supervision or assistance with daily tasks should receive their supports on a long term basis in a group home setting, and that if participants *can* share supports then they *should* share them (regardless of what they want or what their goals are). However, non-disabled people have a wide range of living arrangement options, including living alone, living with a partner and/or children, living with other relatives and living with friends. Most do not choose to live with a group of people they do not know well, and very few choose

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<sup>20</sup> SIL Quoting Template example, page 1, accessed on 30 August 2019 at

<https://www.ndis.gov.au/providers/essentials-providers-working-ndia/supported-independent-living>

<sup>21</sup> Report to the COAG Disability Reform Council for Q4 of Y6 Full report, page 59, accessed on 30 August 2019 at <https://www.ndis.gov.au/about-us/publications/quarterly-reports>



this option for the long-term. It is reasonable to expect that people currently based in group homes would choose a similarly wide range of different living arrangements if supported to do so. SIL therefore fails to cater to those living with disability who would prefer not to live in a group home, and the use of the word 'independent' within the SIL acronym is a misnomer.<sup>22</sup>

NDIS participants who have lived in a group home from many years are likely to be used to this living arrangement and may have become institutionalised or be unaware of alternative options. A majority of group home residents live with an intellectual disability, meaning they may have limited personal capital with which to demand change, and their families may worry that they will not receive adequate support in another setting. For these reasons, it is important that the NDIS is designed to provide participants with options and help them work out their preferred living arrangements rather than assuming the absence of any major complaint means a default arrangement can be maintained. Unfortunately, SIL has instead been set up in a way that risks trapping NDIS participants in existing group home arrangements.

Currently, there is no transparency or clarity about the process by which an NDIS participant exits SIL, and it does not appear to be a quick or easy process. Where a participant wishes to leave a group home for an alternative living arrangement, under the current SIL model the NDIS is likely to calculate the cost of this alternative arrangement based on the existing shared supports the participant is utilising. It is then probable that they will deem the proposed arrangement as not reasonable and necessary and therefore will refuse to fund it. This is unfair given equivalent arrangements are being provided to people who left group homes before they joined the NDIS, and it is at odds with the capacity-building principles of the NDIS. Moreover, participants are not necessarily asking for, and do not necessarily

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<sup>22</sup> Committee on the Rights of Persons with Disabilities General Comment No. 5 (2017) on living independently and being included in the community, page 5, accessed on 30 August 2019 at <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

require, any additional funding. Rather, they need the flexibility to use their existing funding more innovatively, for example by complementing it with informal supports and capital and capacity building supports.

Our sister organisation *inhousing* is a registered NDIS SDA provider and has shared with us stories of people living with disability whom they have sought to assist with access to appropriate housing, but where SIL is acting as a barrier to them living in the housing arrangement of their choice. Names have been changed to protect identities:

Peter is a man in his 50s with an acquired brain injury who is currently living with his ageing parents. In keeping with living an ordinary adult life, Peter and his parents have been seeking a long-term stable home for Peter to live in separately from his parents. Peter's mother had supported Peter to find a suitably accessible home in proximity to his parents' home so they could continue to provide informal supports, in line with roles typically provided by parents to their adult children. This house would give Peter an opportunity to share with a housemate, and have a room available for passive support. At the current time the NDIA has indicated that Peter is unlikely to receive adequate funding to meet his personal support needs in this house of his choice as the current tenant does not require overnight supports, and therefore the NDIA deems this housing option not to represent value for money. The NDIA did not seek to explore how more flexible and informal supports might be able to meet Peter's personal support needs.

Andrew is a man in his 50s with an acquired brain injury who is living in an SDA property. The house is adjacent to a second SDA property and SIL funding is shared between the four people living in these two houses. Andrew, with support from his family, expressed a desire to live more independently and in closer proximity to his adult children. Due to the distance and difficulties with travel, Andrew's contact with his children is very limited. If Andrew were to live near his family, he would have much greater opportunity to maintain relationships with his children and benefit from greater informal support. When an opportunity arose for Andrew to move to

an SDA property near his family, it was reported that the NDIA would not increase funding sufficiently to enable Andrew to live in the housing option of his choice. There was no exploration of flexible supports or clarity about the funding gap required for him to take up alternative support arrangements.

John is a man in his 60s with an acquired brain injury who lives in a cluster site in the city. Prior to his brain injury John lived outside the city, and he is keen to return to living near family and friends. *inhousing* have a new-build SDA property where John wants to live that would meet his accessibility needs. However, John is currently receiving SIL funding to share with six people in the cluster site. There is significant uncertainty for John and his SDA provider about whether John can release his support funding. This means he is currently unable to assess (with assistance from an independent support coordinator) if his current funding is adequate to enable him to live in his choice of home and if and how he might use flexible supports, technology or a mix of freely given support to achieve his goals.

## 6. Solutions

In reporting on its inquiry into SIL, we would caution the Joint Standing Committee on the NDIS not to recommend process improvements that could enhance the attractiveness of SIL to service providers and thereby further entrench a model that is destined to continue to deliver poor outcomes for people living with disability (**Recommendation 1**). NDIS participants deserve transformational benefits from the scheme, not simply a continuation of the well-documented unsatisfactory arrangements they had prior to joining. We propose that the committee develops a roadmap for the national transition of NDIS participants from SIL to more flexible support arrangements that deliver on the promise of individual choice and control, sometimes referred to as individual supported living arrangements.

The Individual Supported Living research project (led by Curtin University) developed a framework to describe and measure the quality of individual supported living arrangements for people living with intellectual or developmental disability and then evaluated 130 such

existing arrangements across Western Australia, New South Wales, and Victoria.<sup>23</sup> The study categorised the arrangements into four types:

- Living alone (in own home)
- Co-residency (live in own home with tenants who provide support in exchange for free or reduced rent)
- Relationships (live with friends or an intimate partner)
- Host family (live in the family home of people to whom they are not related).

In order to transfer people already living in these arrangements onto the NDIS, an Individual Living Options (ILO) template has been developed and piloted in Western Australia. As of July 2019, ILO quotes can be submitted by service providers to the NDIA based on three new line items in the NDIS Support Catalogue 2019-20 that mirror the four Individual Supported Living research categories (labelled as 'Co-residency', 'Host arrangement' and 'Rostered supports').<sup>24</sup> However, the focus to date has been on transitioning people already with ILO arrangements onto the NDIS rather than facilitating the transition of people with SIL arrangements onto ILO arrangements, which is reflected in the support item descriptions referring to "supports to maintain their existing Individual Living Option transitional arrangement". In addition, at present there is no mechanism for service providers to demonstrate other innovative support models not covered by ILO.

When considering ILO arrangements as alternatives to SIL, it is important to consider their impact on service costs and thus on the financial sustainability of the NDIS. The first thing to recognise here is that individual arrangements are often no more expensive than shared arrangements and in some circumstances can be more cost-effective:<sup>25</sup> there is evidence

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<sup>23</sup> Cocks, E. and Thoresen, S. and McVilly, K. and O'Brien, P. 2017. Quality and Outcomes of Individual Supported Living (ISL) Arrangements for Adults with Intellectual and Developmental Disabilities - Final Report, Curtin University of Technology, School of Occupational Therapy and Social Work.

<sup>24</sup> NDIS Support Catalogue 2019-20 PDF, page 8, accessed on 30 August 2019 at <https://www.ndis.gov.au/providers/price-guides-and-information>

<sup>25</sup> Felce, D., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E., & Knapp, M. (2008). Outcomes and costs of community living: Semi-independent living and fully staffed group homes. *American Journal on Mental Retardation*, 113, 87–101, accessed on 30 August 2019 at <https://www.ncbi.nlm.nih.gov/pubmed/18240878>.

that a sizeable proportion of people living in group homes live with mild intellectual disability and do not require 24-hour support so could live more independently with the right support arrangements.<sup>26</sup> Even where fewer formal support hours can be provided out of an NDIS package in an individual arrangement than in a shared arrangement, a participant may prefer to spend their support funds as they choose and then top up the hours by drawing on informal supports. Finally, the UN Committee on the Rights of Persons with Disabilities has made it clear that the cost of delivering personal services does not provide an exemption to a person's right under article 19 of the CRPD to live where and with whom they want to. Having ratified the CRPD, the Australian Government is obliged to fund supports to enable people living with disability to live independently in the community.

We make the following the recommendations to solve the problems with legacy housing arrangements and SIL:

- **Recommendation 2** – Facilitate the national transition of NDIS participants from SIL to more flexible support arrangements through:
  - allocating individualised funding to those currently receiving SIL based on what supports are reasonable and necessary for them rather than on historic block-funded arrangements
  - prioritising within the ILC program investment in individual capacity-building, in relation to building a vision of an ordinary valued life, and how group homes and comparable services cannot easily deliver this
  - promotion of the Independent Living Options (ILO) support arrangements now offered in the NDIS Support Catalogue service to all providers and participants, not only those already delivering or receiving ILO supports

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Fyffe, C., McCubbery, G.,

<sup>26</sup> Christine Bigby, Emma Bould & Julie Beadle-Brown (2018) Comparing costs and outcomes of supported living with group homes in Australia, *Journal of Intellectual & Developmental Disability*, 43:3, 295-307, page 295, accessed on 30 August 2019 at <https://www.tandfonline.com/doi/full/10.3109/13668250.2017.1299117>

- further development of ILO and other flexible support funding structures and pricing which use a participant’s existing funding more innovatively and do not assume co-location of participants in the same dwelling as the default
  - establishing a mechanism for support providers to demonstrate support models, outside of SIL, which operate within appropriate individual participant budgets and consistent with the NDIS’s values
  - establishing dedicated pathways for participants to easily exit existing SIL arrangements, including an assured way of repurposing existing SIL funding to finance more flexible support arrangements.
- **Recommendation 3** – Ensure all participants currently in SIL receive adequate support coordination through their NDIS plan to enable them to freely choose their own living arrangements (including helping them to exit existing SIL arrangements if they choose) and choose the planning and delivery of their supports.
  - **Recommendation 4** – Require independent supply of support coordination, personal support and housing to ensure NDIS participants retain choice and control and there is no service provider conflict of interest, e.g. where a service provider (acting as support coordinator) is responsible for ensuring consistent delivery of their own services (acting as personal support provider).
  - **Recommendation 5** – Address the lack of availability of appropriate affordable housing that can lead to NDIS participants being placed in more expensive supported living arrangements:
    - Escalate reforms to boost Specialist Disability Accommodation (SDA)
    - Increase the availability of non-SDA housing to the 94% of NDIS participants ineligible for SDA
  - **Recommendation 6** – Where participants choose to remain in group home or other congregate settings, ensure that greater control lies with the individual:
    - Allow co-residents to collectively choose a different support provider if they wish
    - Allow NDIS participants to use a different provider for particular aspects of their day spent away from daily living

- Guarantee residents the right to view different group home options and meet potential co-residents before they decide if they wish to proceed, just as is in the private rental market
- Promote small cluster site accommodation over standard group homes.

## 7. Conclusion

JFA Purple Orange is grateful for the opportunity to provide our views on how we believe SIL is hindering the goals of the NDIS and risks trapping people in broken group home arrangements rather than giving them choice and control over where they live and the supports they receive. Fortunately, better and often more cost-effective living arrangements are already well-established, for example in the form of ILO. However, a delay in moving to more flexible support arrangements risks entrenching the SIL funding model and group home status quo. We therefore call on the committee to push for a timely transition of NDIS participants from SIL to more flexible support arrangements, with the necessary assistance for participants and service providers to facilitate this transition.

We request the opportunity to meet with the Committee to discuss these points further.