



Inclusion Australia

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**Submission to the NDIS Home and Living  
consultation**

**September 2021**



# Inclusion Australia: Submission to the NDIS Home and Living consultation, August 2021

## Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

Inclusion Australia recognises the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

Inclusion Australia prepared this submission. To write this submission, we listened to the voices and concerns of people with intellectual disability and their families and supporters, and we thank them for sharing their lived experiences.

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## About Inclusion Australia

Inclusion Australia is the national Disability Representative Organisation for people with an intellectual disability and their families.

Inclusion Australia was founded in 1954 and was previously known as the National Council on Intellectual Disability (NCID). Our mission is to work to make sure people with intellectual disability have the same opportunities as people without disability.

Inclusion Australia works in systemic advocacy, projects, information and communication activities that advance the rights and interests of people with intellectual disability.

We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia. The members are:

- Council for Intellectual Disability (CID)
- Parent 2 Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA).



# Inclusion Australia



## Introduction

The National Disability Insurance Agency (NDIA) released a consultation paper about their new approach to Home and Living, called 'An Ordinary Life at Home' in June 2021. We call it the Home and Living Paper.

This new approach to Home and Living is closely related to the Support for Decision Making policy proposed in the NDIA's 'Supporting you to make your own decisions' Consultation paper. Supporting people with disability to make their own decisions is central to increasing choice and control around home and living supports in the NDIS.

In particular, the Home and Living Paper talks about Individualised Living Options (ILOs), moving away from Supported Independent Living (SIL) options and closing larger group homes with more than 5 residents.

Inclusion Australia thanks the NDIA for listening to the concerns of the disability community and developing policy changes to Home and Living. We have been eagerly waiting for these changes and are looking forward to the implementation.

To write this submission, Inclusion Australia listened to our member organisations around the country and their networks of people with intellectual disability, families, carers, advocates and independent support coordinators. We have also engaged with our supported decision making project, *Make Decisions Real*, peer workers with intellectual disability and other content experts involved in that project.

Our submission includes feedback on the Home and Living Paper, recommendations for the NDIS Home and Living policy and case studies to help the NDIA better understand the lived experiences of people with disability and their supporters.

We agree broadly with the principles in the Home and Living Paper. Our feedback is more focused on how these policy changes will look in practice for people with intellectual disability.

The ideas in our submission are grouped under the same 7 themes the NDIA has used in their Home and Living Paper:

1. Changing the conversation;
2. Supporting you to be an informed and empowered consumer;
3. Supporting you to make decisions;
4. Reforming the funding model;
5. Improving choice and control through flexible budgets;
6. Assisting implementation and maintenance; and
7. Engaging the market and driving innovation.

# 1. Changing the conversation

## Rights

People with disability have the right to choose where they live, who they live with and who supports them at home under Article 19 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

Article 19 also talks about the rights of people with disability to access supports to live independently in the community, rather than be isolated in segregated accommodation. This is especially important to consider for policy changes around Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA).

Australia has signed the UNCRPD and agreed to make these rights into law.

It is great to see these rights acknowledged in the NDIA's new home and living discussion themes (p. 14):

**Figure 1: Home and Living Discussion Themes**



People with disabilities have rights to make their own decisions. This is covered by Article 3, Article 4 and Article 12 of the UNCRPD. The Australian Law Reform Commission (ALRC) has suggested ways to make supported decision making rights part of Australian law. We recommend the NDIA uses the ALRC recommendations<sup>1</sup> to inform the Home and Living policy.

Inclusion Australia agrees, on the whole, that the policy changes proposed in the Home and Living Paper are aligned to the UNCRPD. We believe the NDIA understands these rights and will use a rights-based framework to inform the Home and Living policy changes.

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<sup>1</sup> Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124) available here: <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>

## 2. Supporting you to be an informed and empowered consumer

### Peer Support

The proposed Home and Living Paper relies on community and mainstream based capacity building supports, including peer support and self advocacy groups. The policy suggests peer support networks, circles of support and microboards will be used to:

- ‘help you to pursue your goals for an ordinary life’ (p. 15);
- support you to be an empowered and informed consumer (p. 15);
- support participants ‘to understand the cost of home and living supports you may wish to purchase’ (p. 17);
- ‘expand support for decision making’ (p. 26); and
- ‘assist implementation and maintenance’ (p. 27).

It’s wonderful to see the NDIA acknowledges the strengths and value that peer support brings to people’s lives. Inclusion Australia strongly agrees these settings are the best place for people with disability and their supporters to build their decision making skills and capacity, explore information and shift the balance of power.

The NDIA mentions they will ‘promote growth of peer support networks in providing support for decision making’ (p. 26). **However, there is no mention of infrastructure to support peer support networks to fulfill their integral function.**

In our experience, community based capacity building supports are poorly funded. This issue has been worsened by the redirection of state and territory disability funding towards federal grant schemes like the ILC. Peer support networks, self advocacy groups and decision making capacity building activities have recently been propped up by one-off, short-term ILC grant funding, or by not-for-profit organisations with little to spare. Now that the responsibility for ILC has moved to DSS and no plans for the scheme have been published beyond this financial year, it is not clear to these capacity building support providers *how* they will continue to run.

ILC, or Tier 2 as it is sometimes called, was specifically established for this purpose. The ILC Policy Framework (p. 6) says:

‘The NDIS will fund decision support, safeguard supports and capacity building for participants... The NDIS has an important role to play in providing decision-making supports and building individual capacity for people to advocate for themselves (self-advocacy)

...

It will also support peer support, where people with disability or their carers share lived experiences with others on similar journeys. This is an important means of capacity building that acknowledges and respects the lived experience of disability. There is an opportunity through ILC for the NDIS to support people with disability to lead peer support and promote self-advocacy amongst peers, to support individuals in their capacity to effectively exercise choice and control.’

The ILC has given rise to some wonderful decision making capacity building programs and injected new life into peer support and self advocacy groups. Unfortunately, without recurrent funding these

programs and groups are rarely able to continue beyond the life of the short-term grants. This is not a good investment of ILC funds. Some ongoing funding is required to maintain groups and programs beyond the ILC grant periods. This would ensure they remain available to people with disability and their supporters to build capacity in all the ways the Home and Living Paper suggests.

While we recognise the NDIA no longer manages the ILC program, there is still a responsibility to ensure that the capacity building supports that form part of the NDIS Home and Living Policy are adequately funded.

### **Recommendations**

We recommend the NDIA works with DSS and other government departments to ensure ongoing funding for relevant capacity building supports, including peer support and self advocacy groups, circles of support and microboards.

### **Support Coordination**

The Home and Living Paper says, 'you may even be able to access Support Coordination and specialist support with exploration and design, separate from the providers of home and living supports to reduce conflict of interest' (p. 18).

To reduce conflict of interest and undue influence, the NDIA **must** ensure that formal decision support and support coordination is provided *independent of service provision*. The NDIA acknowledges this issue (p. 12) however it does not seem adequately considered across the proposed policy changes.

It would be highly inappropriate for service providers of accommodation and home supports to support their customers to make decisions about their living situation. This issue has already been well discussed in submissions and reports on Support Coordination, including submissions to the NDIS Support Coordination Discussion Paper and the Tune Review<sup>2</sup>.

On this conflict of interest, one supporter who previously worked in a service provider that also provided SIL told us about 'provider ownership':

*"Clients are possessions. [They say] 'how dare you refer external?' even though it's part of your job description to offer choice and control."*

Our position is that independent decision-making support is best placed within independent advocacy organisations and Disability Representative Organisations (DROs) to reduce conflict of interest or undue influence, and to harness the supported decision making skills and capacity already present in these agencies. Independent advocates and DRO staff have been supporting people with disability to make their own decisions for decades.

Inclusion Australia has previously asserted in our submission to the Support Coordination Discussion Paper in September 2020:

*"There is definitely a difference between the role of a support coordinator and an independent advocate who works for a government-funded disability advocacy organisation. The key difference is that an independent advocate is always 'on the side of the person with disability*

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<sup>2</sup> See Tune Review (p. 120) for more: [https://www.dss.gov.au/sites/default/files/documents/01\\_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf](https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf)

and no-one else's'. Most support coordinators understand that their loyalties are divided between the NDIS participant (who presumes the support coordinator is on their side), their employer (who relies on billable minutes and repeat business), and the NDIA which is an essential source of participant referrals.

The relationship between support coordination and independent advocacy needs to be clearly defined and agreed to by the NDIA, the NDIS Quality and Safeguards Commission and DANA [Disability Advocacy Network Australia] as a priority. Most importantly, support coordinators - and all providers working under the NDIS Practice Standards - need to know when to call in an independent advocate.

In general, we suggest good practice for support coordinators includes contacting an independent advocate when

- There is conflict about choices or decisions that need to be made that cannot be resolved by talking it over with the person, family, friends and paid staff
- The participant is under undue or inappropriate influence by any person or organisation
- The person and their support network do not have the advocacy skills or knowledge to resolve it themselves (e.g. an abuse investigation, making an application to a Tribunal)

...

**In the same way that independent advocacy might be necessary when support coordination cannot resolve a problem, independent support for decision-making is fundamental to ensuring that support coordinators are taking direction, not making decisions.**

Some participants need independent support for decision-making to ensure that there is a clear separation between life decisions (e.g. where to live) and NDIS decisions (e.g. in-home personal care services). This can be via individualised funding to facilitate the set-up of a circle of support, or with a volunteer program like Citizen Advocacy, or through peer groups run by Disabled Peoples Organisations. Independent support for decision-making is most important for participants who will predictably need long-term, collaborative decision-making supports (e.g. circle of support)."

A participant may, then, need independent decision support *in addition to* their independent support coordination.

There are additional complications for people with complex communication support needs who require support coordination and decision support. Supporting this group of people to make decisions takes longer, but the extra hours are not sufficiently considered in participants' plans. Some people also require Specialist Support Coordination (SSC), and it is not yet clear how SSC works with exploration and design funding.

In terms of funding formal decision supporters, Inclusion Australia believes this service should be block-funded. The need for formal decision support is likely to be one-off or episodic, such as when a participant reaches a major life transition point like finishing school or moving out of the family home. It is neither efficient nor cost-effective to fund episodic support through individualised plans.

## Recommendations

We recommend the NDIS Home and Living policy aligns with formal decision support under the NDIS Support for Decision Making policy.

We recommend independent decision supporters, best placed in independent advocacy organisations and DROs, be made available to participants making decisions about home and living under the NDIS Home and Living policy.

We recommend independent decision support be block-funded.

We recommend the NDIA work closely with DROs to set up formal decision support services.

## Exploration and design funding

Exploration and design funding seems like an excellent way to give NDIS participants the opportunity to try out different living options. We know that people with intellectual disability, especially, need to be able to try out an alternative option before they can make an informed decision.

However, there are some issues with how exploration and design funding has been used in the ILO space. If the NDIA plans to expand this support, the existing issues first need to be resolved.

Independent support coordinators from the Inclusion Australia community told us about some of the difficulties they face supporting people with intellectual disability to access exploration and design funding for ILOs.

### Low rates of approval

People reported a low rate of approval for ILO exploration and design funding. It was estimated the NDIA only approves this funding about 10% of the time, which means the vast majority of NDIS participants who wanted to try a new housing option were prevented by the system that should be enabling their choice and control.

### Lack of knowledge

NDIS participants, families, planners, LACs, support coordinators and other supporters lacked knowledge on ILO options and exploration and design funding. A support coordinator in Queensland said of the one person he supports with exploration and design funding approved:

*“Now I need to find an exploration and design planner that knows what they’re talking about and that’s tricky – there doesn’t seem to be anyone in the state doing it.”*

Another participant received exploration and design funding, but then moved to a new support coordinator provider who did not understand the importance of this funding or how to use it.

### Lack of information

The lack of knowledge about both exploration and design funding and ILOs stems from a lack of information. Support coordinators told us that, in their experience with this:

*“9 times out of 10 the planners don’t know what I’m talking about. The information that NDIS planners have on different support models is really limited.”*

There is also a lack of accessible information on ILOs and exploration and design funding:

*“These is no Easy Read information on this and it’s very hard to explain to participants and their nominees.”*

Others had issues in the rare case an ILO was approved due to the lack of information on how to set this up. The NDIS had approved the participant’s plan as plan-managed, however they were then told that ILOs must be Agency managed.

### **Delays in approval**

Long wait times and delays in approving exploration and design funding for ILOs means that new living options can collapse without support.

Holly is an NDIS participant who is experiencing homelessness.

She began living with a local family in her community and they started to trial this new living option.

The situation had been tried and tested. Holly and her support team tried to set the living situation up as an ILO support at her next NDIS plan review. However, at that planning meeting the planner declined funding for either exploration and design or ILO, despite supporting evidence.

The appropriate funding was eventually approved in a later plan, but by that point the housing arrangement had already fallen away due to a lack of support and structure.

Holly is now homeless again.

### **Lack of guidance**

There is a lack of guidance around both exploration and design funding, and ILOs. In theory, both initiatives seem effective and people are willing to give them a go, but NDIS participants, families and supporters need more clear guidance on how this works.

The NDIA should develop a clear practice guide that promotes innovative ways of using funds, and give participants and their support teams the option to:

- try out arrangements for 12 months,
- gather evidence,
- present the information back to the NDIA, and
- get funded in a timely way.

The independent support coordinators spoke optimistically about the benefits of these approaches – including, safeguards and sustainability to the participant. It would be helpful if the NDIA better explained the risks and benefits so that participants can make more informed decisions about trying exploration and design funding and ILOs.

### 3. Supporting you to make decisions

Supported decision making and housing options are inextricably linked. A person with disability cannot meaningfully choose who they live, where they live or who supports them at home without appropriate decision support.

Choosing different living options is even more difficult for people with intellectual disability who frequently have historically had very limited housing options. A supporter told Inclusion Australia about this issue:

*“When they’ve lived at home with mum or dad and then moved to a SIL – they’re like, ‘what do you mean? I could live with someone else? Or do something else? I could share with my best friend up around the corner? Or move into an apartment complex with my friends?’ When you don’t have a base line it’s really hard to move through that supported decision making because there is no understanding of options... it’s really difficult.”*

#### Safeguards

Inclusion Australia was pleased to see the NDIA wants to identify appropriate safeguards, however we need more detail on how this will look in the proposed policy.

Here are some risk factors for people with intellectual disability and how they might play out in the NDIS home and living context:

Risk factor	Example
Acquiescence <sup>3</sup>	A participant agrees with their planner’s suggested option even though they do not understand it. Sometimes this could be choosing an option that goes against what the participant’s will and preference.
Echolalia <sup>4</sup>	A participant repeats back the last option given by their planner without intending that to be their decision.

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<sup>3</sup> The Speak Out resource, *Communication – it’s not a spectator sport* describes acquiescence as follows: “Many people with intellectual disability say ‘yes’ to questions or accept and agree with things, regardless of what has been asked, and often without really wanting to. This is called acquiescence. People with intellectual disability often mask their communication difficulties to avoid the stigma of being labelled as having a disability. It is very common for people to adopt a passive communication style, allowing the more powerful person to control the conversation.”

<sup>4</sup> Echolalia is the repetition of words or phrases made by another person and may or may not reflect comprehension or communicative intent. It is commonly seen in people with autism spectrum disorders, intellectual disability, acquired brain injury and psychosocial disability.

Deciding to make no change	A participant makes no changes to their current living situation. This is still a decision and should be supported as such.
Making decisions that go against one's own human rights	A participant choosing to stay in a home environment where they experience violence, abuse, neglect or exploitation.
Inadequate support for people with borderline or mild intellectual disability	A participant with borderline intellectual disability that comes across as very capable may not be provided appropriate supports to make home and living decisions in their planning conversations.

This is the story of a man who appears to decide to stay in his SIL home even though it is not an ideal living situation:

Edward is an older person with intellectual disability who lived in a large Victorian institution for many years.

The long history of violence, abuse, neglect and exploitation in this institution has been well-documented. In one such incident, Edward witnessed a fire that killed 9 of his co-residents.

When the institution was shut down, Edward was moved into a state-run group home with four other residents.

While Edward's new group home is a marked improvement on the institution, he has had multiple issues living with there.

When Edward was asked by his NDIS planner if he wanted to move out of his SIL accommodation, he emphatically responded no.

However, the planner did not appropriately support Edward to make this decision. Compared to his years spent living in an institution that many compared to a prison, his current group home seems like the far better option.

Edward was not given the information or opportunity to try out other living options. Based on his experiences of home and living, Edward is not aware that he could be living – for example – in an apartment with one other housemate of his choosing.

People with intellectual disability need opportunities to try different options before making a decision. Having an intellectual disability makes it difficult for people to understand abstract concepts. Unless people have viable options on the table, they are not being supported to make a real decision.

'Exploration and design' funding is mentioned in the NDIS Home and Living Paper but there is no clear guidance on this yet. This needs to be considered in the context of supported decision making.

Inclusion Australia recognises that it might be more expensive in the short-term for NDIS participants to try out a range of options before deciding where they want to live. This is

unavoidable for people like Edward who simply cannot make a decision based on abstract concepts about living options they have never experienced. These people need the opportunity to ‘use before they choose’.

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*People need the opportunity to ‘use before they choose’*

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Inclusion Australia believes there is an important role for independent advocates in safeguarding the supported decision making for people with intellectual disability in the NDIS. This is discussed earlier in our submission.

People with intellectual disability have put together some advice for decision supporters to ensure they are building the capacity of the decision maker and considering what the person with disability wants:

Advice for decision supporters:

- Keep a record of the different parts of the supported decision making process so there is something to look back on
- Be honest about the supported decision making process and what is or isn't working
- If the decision maker is comfortable with it, share the process with others (like a peer support group)
- Get feedback from the person with intellectual disability! Ask them if the support is right for them or if they want things to be different.
- Get feedback from other people in the person's life if they are comfortable with it
- Reflect on the process together afterwards
- Always listen to the decision maker and make sure they are at the centre of the supported decision making process

### **Recommendations**

We recommend the NDIA provides more detail on safeguards in the proposed Support for Decision Making policy.

We recommend the NDIA develops and implements adequate supported decision making training for NDIS Planners and Local Area Coordinators (LACs). This training should be co-designed and presented by people with cognitive disabilities, including intellectual disability.

We recommend ‘exploration and design’ funding is included in the Support for Decision Making policy to enable participants to make decisions based on real, viable options.

We recommend the NDIA refers participants to independent advocacy organisations when there is a need for formal, independent support for decision making.

## 4. Reforming the funding model

### Stated supports

As ILO, SIL and SDA are stated supports, there is no flexibility for NDIS participants looking to explore different options. Our community told us they were very cautious about changing their home and living line items in case the new arrangement doesn't work out and they cannot easily change back. If there were more flexible ways to try new living arrangements, participants would be more willing to explore these.

### Recommendations

We recommend the NDIA introduces more flexibility around home and living supports to safeguard participants trying out new living arrangements.

### Very high support needs

The NDIA continues to talk about the small number of participants receiving a large proportion of funding. The Home and Living Paper reads (p. 12): 'The NDIA's 2020-21 Quart 2 Report released in February 2021 identified 23,386 (5.4%) participants who access SIL, with 27% of total NDIS supports committed to participants with SIL. When SIL payments were at their highest (Quarter 4 2019-20), the average annual cost of SIL was \$325,000 per participant.'

This is a *feature* of a disability or compensation scheme; it is not something that necessarily needs to be fixed. It was, and remains, predictable that any scheme that supports Australians with the most severe and permanent disabilities will have a small percentage of participants receiving the majority of the budget. This same pattern has been observed in the previous state and territory systems, and in compensation schemes around the world. It is predictable and should be accepted as normal.

### Recommendations

We recommend the NDIA reframes the conversation around people with very complex support needs and accepts that some people will require high value home and living supports to meet their needs.

## 5. Improving choice and control through flexible budgets

Inclusion Australia strongly supports the NDIA's introduction of more flexible budgets to increase choice and control for participants.

### Personalised budgets and plan flexibility

The Minister for the NDIS, Senator the Hon Linda Reynolds CSC has explained that personal budgets and plan flexibility are tied to the controversial independent assessments and that we would need legislative change to introduce plan flexibility. Even though independent assessments are not going ahead, we believe plan flexibility can and should still be introduced.

Section 33(3) of the NDIS Act allows the NDIA to describe supports generally to allow for plan flexibility. The Administrative Appeals Tribunal has also said it is okay for Planners to use global, flexible categories, as long as they explain why the funding is sufficient to help the participant meet their goals.

We recognise the proposed personalised budgets reform would require some changes to the NDIS Act, but there is no reason under the existing law that the NDIA cannot be more flexible now. That said, it is important that plan flexibility is properly safeguarded. For example, there is a risk of service providers influencing flexible budgets.

Support coordinators talking to participants and their supports about ILOs are often asked how this is different from what they are doing now, that is, using core supports flexibly. The NDIA needs to provide more clarity around the benefits of ILOs over existing home and living options.

### Recommendations

We recommend the NDIA explains what they mean by 'business intelligence' and avoids automated systems where possible.

We recommend the NDIA still introduces some plan flexibility for participants.

We recommend the NDIA considers safeguards for plan flexibility.

### Choice and control in SIL

Increasing choice and control in SIL goes beyond flexible budgets. While the NDIS has increased choice and control for some people living in group homes, there are many SIL-specific issues that undermine participant choice and control.

For residents who previously lived in large institution, the transition to the NDIS has been life changing. One supporter described the changes she saw in the initial transition to SIL: 'increased community participation, increased choice and control, a lot of people reunifying with family members they hadn't seen in a long time because there was a reduction in the expectation around community access. There was more flexibility in the NDIS space for people to pursue their own interests as an individual'.

Unfortunately, Inclusion Australia has heard many more stories about how SIL had the opposite effect on choice and control.

Advocates and supporters of people with intellectual disability often called SIL arrangements the 'last resort'. SIL is often the only option presented to people with high support needs – it is simply not a choice. This is especially true for people who do not have a broader support network or advocate to broaden their options. It is also common for younger people with disability coming out of hospital and aged care settings to be placed in SIL.

When first placed in SIL, a person may be given some choice and control in setting up their roster of care and putting support processes in place. However, when it comes time for renewal, the SIL assessment team rarely approves changes and asks for documented evidence on even minor adjustments. As one member of our community put it:

*“A lot goes on in a year... I might not want a shower in the morning anymore, I might want a shower at night, or I might want two showers a day! It’s ridiculous that you can’t get that.”*

Funding shortfalls in SIL can be incredibly difficult for participants, families and providers. For example, a participant who has complex support needs and requires some restrictive practices is currently going through the Administrative Appeals Tribunal (AAT) to seek more funding in his SIL package. His support team have documented five years of evidence to substantiate the level of support, however the NDIA still has not approved it.

People with disability who previously had successful housing arrangements have had their choice and control torn away by SIL practices.

Matt is a 28-year-old man with an intellectual disability who has lived in a QLD Department of Housing property since the age of 18.

The home and living supports approved in Matt’s NDIS plan were for shared SIL funding.

Matt engaged a SIL provider who then decided to find a new co-tenant, move them into the Department of Housing property and add him to the lease. The Department signed off, but Matt was not advised that any of this was happening.

The new co-tenant moved into Matt’s home and caused significant damage to the property and its contents.

No longer feeling safe in his home of 10 years, Matt was relocated to live with 4 strangers in another property owned by his SIL provider.

Matt has now been displaced for over 6 months. If he wants to get his Department of Housing property back, he will need to go through the difficult and lengthy process of filing a civil claim through the Queensland Civil and Administrative Tribunal.

Matt is not the only NDIS participant who has been displaced from his public housing arrangement. This issue has been brought to the NDIA’s attention before<sup>5</sup> and – while the Agency has addressed specific case studies– the systemic issues have continued.

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<sup>5</sup> See the Victorian Office of the Public Advocate’s ‘The Illusion of ‘Choice and Control’’ for a similar example. Available here: <https://www.publicadvocate.vic.gov.au/opa-s-work/research/211-the-illusion-of-choice-and-control>

Another person who has found themselves unable to exercise choice and control in SIL is Mohamed:

Mohamed has an intellectual disability and has a legal guardian appointed to make his accommodation decisions. He was living by himself in state housing.

Without speaking to his guardian, Mohamed's SIL provider moved a new housemate into his home and added the co-tenant to his lease.

Mohamed and his supporters now want to change to a different SIL provider. However, the new housemate loves the existing provider for finding him this living arrangement and will not consent to the change.

Under SIL rules, both housemates need to have the same provider. This makes it impossible for both Mohamed and his housemate to have choice and control.

It is also very difficult for people who choose to leave SIL arrangements. Our community told us:

*"Transitioning out of SIL is incredibly complicated. Needing to give providers three months' notice..."*

*"It's easier to exit prison. Honestly, I'm not even kidding."*

Guardians, providers and NDIS staff have all argued against participants seeking to move out of SIL. Arguments we've heard include:

- 'They should be grateful to have a house'
- 'People will be really isolated if they don't have 1:2 SIL arrangements'
- 'They're already housed, why should we change it?'

Supporters tell us that the NDIA rarely approves trials for alternative housing options. For other participants, the risk of trying something new is too great. If someone does manage to move out of SIL and try out another living option, they will find it very difficult to re-enter SIL if that trial does not work out.

Sarah is a young woman who has an intellectual disability and a physical disability.

She had been living in a SIL group home for several years when she was dropped by one of her support people and suffered a major injury.

Sarah and her family did not feel like she was safe with that SIL provider anymore. So, after she was discharged from hospital, Sarah moved back home with her parents while she recovered.

Once Sarah was ready to move back into SIL, she could not get SIL funding included in her NDIS plan despite having lived in a SIL arrangement for years prior. The NDIA told Sarah and her supporters that they did not have enough information to approve SIL funding.

Sarah was eligible for SDA (at a higher cost to the NDIS) but not eligible for SIL.

The NDIA needs to develop appropriate guard rails so that people can safely try out new housing options.

Inclusion Australia recognises that some of these barriers go beyond the NDIS. There are underlying assumptions about how people with disability *should* live. However, through developing an innovative and progressive home and living policy that truly increases people's choice and control over where they live, the NDIA does hold some power to increase societal expectations for people with disability.

## Recommendations

We recommend the NDIA develops safeguards for participants who want to try new living options.

## Risk

The NDIA says, 'We will support you to take reasonable risks, to pursue your goals in the planning and delivery of your supports' (p. 17). We welcome this idea but want to ensure that the concept of risk is well-informed.

People with disability have the right to make risky and unwise decisions and should be supported to do so. Supported decision making is about the process, not the outcome.

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*"Supported decision making is not about making good decisions, it is about making the right decision for you. This might sometimes be a bad decision! But it is still our right to make bad decisions – just like everyone else."*

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Risk enablement<sup>6</sup> should be better considered in proposed policy. People with disability told us:

- We should be supported in knowing how to understand the consequences and the risks,
- We should be supported to take risks if that's what we want to do,
- People should know that it is okay to make mistakes, and this is how we all learn and become better, more independent decision makers.

It has proven difficult for service providers to strike a balance between duty of care and enabling risk. People with intellectual disability, their families and advocates tell have told Inclusion Australia that service providers often don't allow people with intellectual disability to make risky decisions and cite their 'duty of care' as the reason. Others described 'a culture of fear around perceived risks' in service providers.

There needs to be more direction for service providers on how they can support people to make their own decisions and take risks. The NDIS Quality and Safeguards Commission may be well-positioned to support this effort.

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<sup>6</sup> Relevant resources developed by Christine Bigby and Jacinta Douglas from the Living with Disability Research Centre with input from people with disability, supporters and stakeholders includes NSW CID. Available here: <https://www.enablingriskresource.com.au/>

## **Recommendations**

We recommend the NDIA provides clear guidance for NDIS staff and service providers to enable risk and support decision making.

We recommend the NDIS Quality and Safeguards Commission play a role in monitoring risk enablement in service providers.

## 6. Assisting implementation and maintenance

Inclusion Australia understands the NDIA is yet to develop an implementation plan for the home and living policy. While we agree with most of the theoretical principles, we do have some specific concerns about what this would look like in practice.

### Affordability

Inclusion Australia is concerned about the affordability of independent living options. In the Home and Living Paper, the NDIA notes that rent is an ordinary living cost and suggests that this should be covered by a person's income and income support payments, including the Disability Support Pension (DSP) (p. 10).

In most major cities around Australia, rent is unaffordable for people with an intellectual disability who rely on the DSP<sup>7</sup>.

Recent consultation Inclusion Australia has done with our community shows that the DSP is inadequate<sup>8</sup>. People with intellectual disability reported they could not afford to cover basic living costs.

Ollie has an intellectual disability and has been living independently in a public housing property for 11 years.

Ollie has had some issues with the public housing authority not fixing things properly and feels they don't know how to support her well. However, she has lived in groups homes before, and much prefers living independently despite the challenges.

Ollie is very experienced living on her own and budgets carefully.

Ollie currently relies on the DSP for all her living expenses. While she tries to supplement her DSP with paid work opportunities, Ollie has very little earning power. In her last job working for an Australian Disability Enterprise (ADE) she earned \$6 per hour which, in her words, 'didn't go very far!'

After paying for her rent, bills and groceries each fortnight, Ollie barely has \$20 leftover.

Ollie has applied for a transfer to a new public housing property closer to friends and has put aside a small pot of savings to cover moving costs when the time comes. Unfortunately, any time Ollie has an unexpected expense – like medical costs if she becomes unwell – she has no choice but to dip into her modest savings.

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<sup>7</sup> See Australian Institute of Health and Welfare report *People with disability in Australia 2020*, available here: <https://doi.org/10.25816/5ec5be4ced179>

<sup>8</sup> See Inclusion Australia's submission to the Senate Inquiry on the Purpose, Intent and Adequacy of the Disability Support Pension, available here: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/DisabilitySupportPensio/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/DisabilitySupportPensio/Submissions)

The NDIA is not responsible for the DSP, however it is inappropriate to suggest NDIS participants should be expected to pay for all independent living costs. We urge the NDIA to look at how they can innovate funding to make individual living options more affordable for participants. For example, it would be considerably cheaper for the NDIS to provide a small amount of funding to support ordinary living costs than it would be to maintain SIL arrangements.

The success stories we have heard often involve families financially supporting their loved ones to live independently.

Aaron is a young man with an intellectual disability living in Western Australia.

Aaron has previously lived in an independent living arrangement with a couple and some outside support workers. This didn't work out long-term as his co-residents felt 'burnt out' and wanted to end the arrangement.

Aaron's parents were able to invest in a disability-specific property trust. Through this service Aaron now lives independently in his own home with a lifetime tenancy.

He has 24/7 support staff funded through his NDIS plan.

Aaron and his family are very happy with his home and wonderful team of support staff.

We are concerned the suggested home and living policy could deepen the divide between people with disability from higher and lower socioeconomic backgrounds. Under the proposed policy, the NDIA is reducing SIL funding and encouraging participants to move to ILOs. While we agree that people with disability should have the option to leave SIL and try different housing options, it is problematic if they cannot afford the alternatives. It seems that people whose families are willing and able to subsidise their ordinary living costs will be okay, but many other people with disability could be either forced to stay in SIL or pushed further below the poverty line. Access to choice and control about housing should not rely on family backgrounds.

### **Recommendations**

We recommend the NDIA look to innovative funding models to ensure participant choice and control does not rely on socioeconomic status.

### **The SDA Panel**

Inclusion Australia believes the NDIA should consider changes to the operation of the current SDA panel. We hear from supporters of people with intellectual disability that the SDA panel continues to decide that applicants should live with other NDIS participants, even when that goes against the needs and preferences of the applicant.

The NDIA appears to classify people into two groups:

- 1) People who can have ordinary living options, and
- 2) People who must live with others for the sake of cost-containment.

There is no choice and control for people when the NDIA decides they must live in an SDA property with two other people who also have complex support needs. The proposed home and living policy needs to offer choice and control to people in both groups, not just the 'easier' cohort.

## Recommendations

We recommend the NDIA make changes to the SDA panel to ensure all people are given choice and control around their housing.

## Those left behind

We have significant concerns about how people with complex support needs will be included in the proposed home and living policy. The new policy needs to consider the full range of people living with disability.

The worst outcome for this policy is that some people get their ticket out of congregate living, but others get left behind. This is the long and well-worn history of people with severe intellectual disability, people with complex communication and/or complex behaviour support needs, and people with intellectual disability and multiple disabilities. These are the people who end up staying in the worst institutions, and for the longest time.

This is the story of one man who has been left behind:

Adam, 40, has been in the disability system since he was a child.

His advocate, Clare, said he was the victim of the worst restrictive practices she had seen. The biography of Adam is what Clare calls 'folklore' because disability files are archived every 12 months. As a consequence, the official story of what happened during his childhood and early adulthood is buried.

Clare said:

'What I've been told is – by staff who've known him for a really long time – is that he was sent away to a residential school as a child and they had him chained to the floor. They put bolts in the floor to chain him to. ... He landed in one of Victoria's disability institutions as a young person and what I've heard is that he was restrained with in handcuffs for up to 23 hours a day, and that those restraints have caused his shoulder cuffs to basically rust downwards, which has also made him hyper anxious — because he's been subjected to many takedowns by staff — and his response to the world now is hyper vigilance. And, if in any way made anxious, hyper violent.'

Adam now lives in an institution-like housing estate, known as 'the village', where 100 people live in group homes on the same piece of land. The village was built for people coming out of an institution whom staff believed could not be supported to live in a group home in the community.

Adam lives alone in a secure unit. His living space is separated from his co-resident by a piece of Perspex plastic. He has one service provider: 24 hours a day, 7 days a week.

'I went into his home,' Clare said. 'It is not a place you would want to live, someplace anyone would want to live. It's dilapidated, it's depressing. He's been there a long time, and it's overlooked by the institution that he previously lived in. ... He is captive.'

Since 2016, Clare has advocated for the NDIS to include a goal in Adam's plan 'to explore housing options' so that he at least has the opportunity to have some choices about where he would like to live.

Clare said:

'And because I don't have a formal role and because the NDIS doesn't recognise advocates anywhere on their system as having any legitimate role — we do not exist in their system as an entity at all — I have no possible way of contesting that a goal should have gone in the plan because what right do I have to say that he should have the chance to consider other options. And my question is: what right does anyone else have to say that he should not?

'The weight at the moment leans in the favour of keeping things how they are because anything else would be a decision, and that's how people's rights become meaningless. He has a right to look for other options, but I could not get a goal in the plan. Not in the first or second [NDIS] plan could I get that housing goal in there even though I specifically asked and everyone at the meeting agreed that it should happen. And in the third plan I said to the planner, "You will be putting a goal in there that says that he is going to be looking around."

And she said, "I think that we would need a guardian for that."

And I said, "It's not a decision to have options put in front of you."

'I also asked for independent support for decision making, I asked for the funding of an independent facilitator from a registered NDIS service provider to develop a circle of support made up of volunteers who would be willing to start exploring what his will and preferences look like within a framework — within a proper framework.

"No."

"Why not? Why not?"

"Because it's a duplication of supports."

"How is it a duplication of supports?"

"Because we funded support coordination."

I said, "The support coordinator would have a conflict of interest if they were facilitating the decision-making circle, don't you think?" A support coordinator is supposed to take the person's direction.

And she said, "Well, then he needs a guardian." And they will not fund independent support for decision-making. And I have asked for multiple [NDIS] participants who have no family, maybe one provider, maybe a day program and one provider; no one else to advocate for them and literally, absolutely zero capacity to find their way out of these systems. Zero capacity to find their way out ... and I cannot get the NDIA to fund support for decision making.'

Adam's clinical support team — made up of his house supervisor, advocate, occupational therapist and support coordinator — followed the NDIA's advice and sought the help of a guardian. The guardian advised that all he could do in this case was listen to the advice of the clinical team.

It has now been five years since Adam's advocate first asked the NDIA for support to explore housing and he is still living in the same run-down accommodation he started in.

Adam's latest NDIS plan includes the option to explore other housing options but support for decision-making was denied. He still lives in the shadow of the institution where he was restrained for up to 23 hours a day.

'It's an extreme example,' Clare said, 'but everything springs from there.'

Adam is just one of many people in village who have tried to include new home and living options in their NDIS plans. Not one of them has moved out in five years.

Adam's story highlights the need for the NDIS Support for Decision Making policy to closely interact with the proposed home and living policy. In this case, there appears to be confusion amongst NDIS planners about the difference between making options available and making a decision. There seems to be a lack of guidance for NDIS staff around who the role of planners, advocates and guardians in making decisions about home and living.

Another example of people who may be left behind is Effie:

Effie has complex support needs and multiple diagnoses including intellectual disability and autism spectrum disorder.

The safest place for Effie to live is on her own with 24/7 support.

The NDIS will not fund this living arrangement because Effie is only 11 years old.

Effie cannot live at home with her family due to harm to both herself and others in that environment. Group homes are not suitable for the same reason.

Effie's disabilities become more severe with age, and she needs extensive 1:1 care. The safest place for her is on her own.

As a workaround, Effie has been funded by a state government 'complex care pathway for children' to live in a private rental. She is much happier now she is receiving this individualised support.

Unfortunately, Effie's lease is not secure or long-term. If the landlord decided to stop renting to her provider, it would be catastrophic for her. Effie is autistic and needs consistency in her life.

There are also issues with Effie causing damage to her private rental. Her complex behaviour support needs mean that damage to property is highly likely to occur and this could be grounds for the landlord to have her removed from the home.

Custom homes are being built for people like Effie in the NDIS. However, she will not be able to access these options due to her age.

For some people with intellectual disability and complex support needs, the NDIS has not yet given them choice and control around where they live, who they live with and who supports them at home. We would like the NDIA to consider people like Adam and Effie to ensure the new NDIS home and living policy leaves nobody behind. This may involve deep consideration with how the new home and living policy's interaction with the NDIS Complex Support Needs Pathway. We ask the NDIA to refer to the advice and recommendations made in *Inclusion Australia's NDIS Complex Support Needs Pathway Review: Participant Experience Report, March 2020*.

## **Recommendations**

We recommend the NDIA deeply considers how the proposed home and living policy will interact with participants who have complex support needs.

## 7. Engaging the market and driving innovation

### Alternative housing options

Let's recall our earlier example, Edward (p. 14). If Edward gets support to make a housing decision and tells his NDIS planner that he wants to move out of SIL, what steps can he take when moving from congregated living to independent living? The waitlist for public housing is generally years-long and he is unlikely to be able to afford record-high rents in the private rental market. Edward does not have family to help him pay ordinary living costs. There is no real opportunity for him to engage in the independent housing market.

We recognise that some housing services for people with disability who want to live independently are outside of the NDIS. For example, rent assistance under the Department of Social Services or public housing provided by state and territory governments. The NDIA can and should work together with other government departments to ensure people with disability can access the right supports to live independently.

The wider government could also open up alternative living options for all Australians who need some support around home and living, such as single parents and other low-income earners. The Australian government can look to international guidance here. For example, in Canada, co-operative housing arrangements designed to keep housing affordable have been commonplace since the 1970s.

The NDIA may not have purview over other housing services, but they can fund alternative models and influence state and territory governments to improve alternative housing options for people with disability.

### Recommendations

We recommend the NDIA works together with other federal government departments and state/territory governments to improve housing options for people with disability.

### Group home construction

The NDIA is itself incentivising the construction of new congregate living options. The NDIA pays developers to build group homes and the developers are simply doing what is best for their investment portfolios.

Some NDIS participants who want to live alone need a three-bedroom home – their own bedroom, a room for informal supports to stay over and a bedroom for overnight staff. Advocates tell us that it is nearly impossible to get a three-bedroom home for an individual. Instead, the NDIA funds developers to build these properties as group homes. It is within the NDIA's control to stop incentivising the building of group homes and to promote housing options that better suit participant needs, will and preferences.

### Recommendations

We recommend the NDIA stops incentivising developers to construct new group homes.

## Thin Markets

There is no clear information in the Home and Living Paper on how the NDIA will approach thin markets. Thin markets appear in the NDIS when a participant is seeking a service but there are not any available services in their area. We see this particularly in rural and remote areas, and in new service offerings.

We have concerns that the new home and living policy will expose participants to more thin markets. The NDIA is currently doing research on thin markets and we understand the Agency will begin sharing findings in late 2021.

Our community has shared their experiences with the emerging ILO market. When a participant is approved for exploration and design funding, they need to gather evidence and present it back to the NDIA in order to get ongoing funding for their ILO arrangement to continue. This is very difficult when providers don't know how to deliver ILO services or how to undertake exploration and design planning. As it stands now, this service is not being delivered effectively or providing value for money.

We understand that providers are expected to develop business models to support ILOs when the market is mature, but until that time everyone is left in the dark. In a thin and immature market, participants are left without the support they desperately need. In the words of one supporter:

*“Participants are the guinea pigs in the middle.”*

This is not a person-centred approach. Our community is understanding that the new NDIS home and living policy is in early stages and will take time to get right, but the ambiguous detail in the Home and Living Paper does not help. The NDIA needs to engage with experts and people with lived experience to develop and co-design this policy change.

## Recommendations

We recommend the NDIA deeply consider thin and immature market issues as they relate to the proposed home and living changes.

We recommend the new home and living policy be co-developed and co-designed by experts in the disability community and people with lived experience.