

Submission: An Ordinary Life at Home

Whatever words we choose to use when we talk about housing and support for people with significant disability it should be *home* we have in mind.

Home is a rich and evocative word. It’s where you reside, but it’s more than that. Home is where you can express yourself, remove your armour, relax, feel safe, entertain friends, be accepted for who you are. In our collective imagination home is a haven from the outside world. Home is cosy and familiar; it’s where you have a sense of dominion.

A key aim of the NDIS should be to help create or maintain a sense of home. This is consistent with the objects and principles of the NDIS. For people with significant disability, this includes being well supported to live where and with whom you want.

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)1, Australia is committed to enhancing the opportunities for people with disability to “participate in all aspects of social and political life including access to employment, education, health care, information, justice, public transport and the built environment.”2 One of the six priorities of the National Disability Strategy—endorsed by COAG in 2010 and designed to help Australia meet its obligations under the UNCRDP—is ‘economic security’. Under this priority, the Strategy notes:

A secure and affordable place to live is the basis of economic and social participation in the community. For many people with disability there are additional dimensions around the capacity to visit friends and family and to choose where and with whom they wish to live. People with disability require a range of housing options, including public and social rental, and private rental and purchase.3

A priority policy action is to “improve access to housing options that are affordable and provide security of tenure”. Providing the support for some people with disability is critical to creating a home.

The NDIS is instrumental in assisting many participants with significant disability to create their home. While it is working for some NDIS participants, this experience is not universal. Comments in this submission are provided to assist with shaping the home and living policy.

# Comments

* **Take a collaborative approach to reform**

A consultation should be undertaken in such a way that it encourages stakeholders to engage and provide comment. The tone of this consultation paper does the opposite.

Group homes were a core component of the suite of disability services funded by state and territory governments over the past 40 or so years. At some stage, most governments have been significant providers of these group home supports, gradually decreasing in most jurisdictions due to the transfer of properties to the non- government sector (primarily not-for-profit organisations) to manage. The NDIS now funds some participants to live in shared arrangements.

Over the decades, a significant proportion of government funding for disability services has been directed to group homes, primarily due to the high level of support provided over the course of a week. This has continued with the NDIS, where Supported Independent Living (SIL) providers assist participants with their in-home supports needs (such as personal care, behaviour and medication management, relationship matters and meals) and some social participation; they are a complex and high-risk participant group to support. At 30 September 2020, 5.7% of NDIS participants were funded for SIL; the total value of the plans for these participants was $8.3 billion (28% of total committed funds). It is a critical support.

The home and living policy consultation paper states:

For many of you today, the options you have are limited, restrictive and don’t give you choice about who you live with. People with disability are still often living in accommodation that has been built for service delivery convenience that are invisible to the wider community. These places are often very impersonal, where privacy and your sense of home are limited. We think the move away from these types of places has been slower than what was imagined when the NDIS became available. As a result we understand that you may have low expectations of your life chances and opportunities, and possibly have low aspirations with the decisions you make because of this experience.

It paints providers of supported independent living as contributors to a diminished quality of life for the participants they support, and implies participants themselves have made a poor or inappropriate choice. This is inaccurate, unfair and wrong.

The SIL (or group home model) was created by governments and continued by the NDIS. Many of the people who live in these arrangements have done so for a considerable length of time, primarily because they need support to be constantly available whenever they are home and/or because it is the living arrangement wanted by the person’s family. It is what governments, and more recently the Agency, were prepared to fund; available funding has driven the model of support. SIL needs to remain as one housing and support option for participants and their families.

* **Acknowledge the need for a broad range of housing and support options** NDS is pleased to see the development of the Independent Living Options (ILO) resources for participants and providers. These alternative living arrangements should be assisted to develop and be available to more participants.

ILOs should not, however, be viewed as a ‘quick fix’ to rein in support costs or to resolve the community-wide problem of a serious shortage of affordable, accessible, and well-located housing. As they are generally quite time-consuming to put in place, we can expect the development of ILOs to be quite slow. In addition, they will generally suit participants who do not require intensive and/or complex support; they are not suitable for all participants seeking a housing and support option.

Community housing organisations, together with disability service providers, provide housing for people with disability. Governments must work with all relevant parties to encourage and support the development of new suitable housing for NDIS participants.

NDS stresses the need to respect the choices of participants and their families when selecting housing options; NDIA staff or intermediaries should never overly influence those making home and living decisions.

* **Give greater consideration to regional, remote and very remote areas** Some participants in most need of housing and support options live in regional, remote and very remote areas. Unfortunately, this is often where the options are most limited.

The home and living policy must give particular attention to what needs to be done to stimulate housing options in areas outside metropolitan areas. Without special attention, participants in these areas will again have limited options.

# Reach an agreement with state and territory governments to redevelop their old housing stock

State and territory governments control or own large housing portfolios, some of which is old and due for redevelopment, and much of which is well-located in respect to access to transport and other services. Negotiations between the Commonwealth and state and territory governments should focus on how the redevelopment of these assets could be undertaken in such a way as to increase the availability of affordable and accessible housing for NDIS participants.

* **Better align the SDA framework with what the NDIS will fund for support** The NDIS’s introduction of payments for Specialist Disability Accommodation was welcome and is an important incentive to develop housing suited to about 6 per cent of participants who need specialised housing and support.

A problem has emerged, however, with the over-development of apartments or units to accommodate one participant. This mismatch of supply and demand will only be resolved with better information being available to inform the decisions of developers (and available to participants to inform their choices). Another issue that needs to be addressed is the SDA payment for a 5-participant robust build property. Participants who regularly exhibit instances of challenging behaviour should live in properties with

fewer residents; no new properties of this type to accommodate five participants should be built.

NDS believes it is time for the SDA framework to be reviewed and incentives for smaller properties to be developed. Projections of an increase in SIL expenditure should not override decisions about good housing models.

# Have a strong focus on participants who are beginning to explore housing options

Group homes provide much needed accommodation and support for a relatively small proportion of participants. Over recent decades, particularly prior to the NDIS, group homes were one of the few options available for people with disability who needed significant support. Because of this, there would be some people with disability living in group homes who would have been suited to living in a more independent arrangement with less intensive support, had it been available at the time.

NDS urges the NDIS to have a strong focus on working with participants wanting to leave the family home to ensure all options are explored before choices are made.

# Draw on the knowledge of providers

Providers know the participants they support, and generally their families and friends, well. They have a deep understanding of participant support needs and their interests and aspirations.

Providers are, therefore, well-placed to identify participants who might be interested in, and suited for, a less intensive support model than SIL and to support and encourage them to explore options. This work rarely proceeds quickly. One provider who has undertaken this work estimates that it usually takes at least two years of concerted work with a participant and their family to assist a person to make the transition from SIL to a living arrangement with less intensive support. Creating a sense of home that includes a valued role in one’s local community is complex but rewarding. It cannot be rushed as it needs intense support at both the participant level and additionally with families and carers that are grieving through change.

This work requires people who have a deep knowledge of the issues and negotiation and problem-solving skills.

The mode of engagement with families and carers is crucial to success and often a huge component that providers complete without funding but is necessary.

The Agency needs to draw from the knowledge of support providers to help drive innovation. NDS is aware that a small group of providers were invited to a roundtable discussion earlier this year to discuss innovation/demonstration projects but no information has yet been released to the broader sector. We understand an expression of interest will be issued shortly to identify possible demonstration project ideas from SIL providers.

# Build capacity of coordinators to assist participants explore housing options

A number of inquiries have raised concerns about the quality of support coordination received by a participant. This variability in quality cannot be disputed; it needs to be addressed as it will be a critical support for many participants who want to explore housing options.

Related to this is the fact that there are aspects of the NDIS that require support coordinators to have strong knowledge and skills to be effective. Assisting a participant to explore and implement a home and living option is one of them.

Building the capacity of support coordinators to assist in this area needs immediate attention if good outcomes for participants are going to be achieved.

# Co-design a better way to fund shared supports

One shortcoming of SIL planning decisions is how shared supports are funded. For example, we increasingly hear of a participant living in a SIL arrangement being funded only a fraction of the cost of having a staff member on an active overnight, despite other residents only being funded for an inactive overnight. In these circumstances, there is insufficient funding to cover an active overnight. What is the provider expected to do?

Problems with insufficient funds for shared supports regularly arise when there is a vacancy; there is now insufficient funds in plans for the shared components of the remaining participants.

Shared support will be a feature of some ILO arrangements. NDS requests the NDIA work with the sector to negotiate a better mechanism of funding shared supports in all home and living arrangements.

# Co-design a better way to determine complexity

The adequacy of funding to support some participants with complex needs has been problematic since the scheme began. Inadequacy of support funding has increased since July 2020, when the Agency began to re-categorize some participants’ support needs from complex to standard without negotiation with service providers. This unilateral decision-making should not occur.

Some participants seeking an ILO arrangement will have complex support needs. As a matter of urgency, NDS requests the Agency work with the sector to develop a better way to make home and living funding decisions for participants with complex needs.

# Re-visit arrangements for ILO including for safeguarding

Many disability service providers have not decided whether they should deliver ILO supports. If the NDIA wants these support models to grow in number, more active engagement with providers is essential.

Experience from Western Australia—where ILOs are most prevalent—indicates problems emerge when ILO arrangements break down. A fast response to put in alternative supports is required, something the scheme is not yet good at delivering.

NDS is not convinced that safeguarding for people living in ILO options is adequate and suggests these should be reviewed.

# Draw more on the Western Australian experience of ILOs

Price caps on ILO put some arrangements at risk. ILO is a different approach and not always a cheaper approach. In WA, there are long term ILO arrangements that are now at risk due to the price caps.

As ILO becomes a national strategy it is timely for the NDIA to seek clarity from the ATO on the role of a Host and the reimbursement of costs versus income. Many in WA have been trying to obtain a tax ruling for many years, to no avail. This will be required as the use of ILOs expand.

In summary, successful ILOs are developed and sustained through long term partnerships between all parties (including the NDIA being ready to step in in emergencies). Greater engagement with experienced ILO providers would help refine the ILO requirements and guidelines.

A way forward is for a greater focus on the following:

* + successful ILOs are designed, developed and sustained through long term partnerships between parties
  + greater recognition of critical importance of informal support networks
  + develop and share knowledge and capability of the range of approaches— including home sharing, host family support, good neighbours, circles of support and mentoring
  + as the use of ILOs increases, constantly review and revise guidelines to assist them be sustainable
  + do not view ILOs as a cheap solution; they should be an important option but should be viewed as an option in a range of housing and support solutions
  + acknowledge the important role SIL has in supporting some participants with the highest support needs
  + collaborate with state and territory governments on how to increase housing supply

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**National Disability Services** is the peak industry body for non-government disability services. It represents service providers across Australia in their work to deliver high-quality supports and life opportunities for people with disability. Its Australia-wide membership includes more than 1200 non-government organisations which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.