

Individual Supported Living options for adults with intellectual disabilities and high support needs

Based on AHURI Final Report No. 380: Accommodating adults with intellectual disabilities and high support needs in Individual Supported Living arrangements



What this research is about

This research investigated Individual Supported Living (ISL) arrangements, which have been developed over the past decades to provide appropriate and preferred homes for individuals with intellectual disabilities, including persons with high and very high support needs.

The context of this research

In 2018 there were 4.4 million Australians with disabilities —and of these people about one-third had profound (3.2% of the whole population) or severe (2.6% of the whole population) core-activity limitations related to communication, mobility or self-care, and schooling or employment. While less than 1 per cent of persons with disabilities under the age of 65 lived in cared-accommodation, 21.2 per cent of persons with profound disabilities and 2.7 per cent of persons with severe disabilities resided in such accommodation. In total, 14,400 Australians aged 15–64 with disabilities lived in cared-accommodation in 2018.

Over the past decades, persons with intellectual disabilities and their families, together with others, have developed alternative living arrangements to those provided by traditional services. Indeed, there has been a substantial move away from those types of residential housing models, including for persons with severe or profound disabilities. In 2018, about 1 in 500 lived in cared-accommodation, whereas in 2003 about 1 in 100 lived in cared-accommodation: a five-fold decrease in 15 years.

The key findings

Individual Supported Living (ISL)

ISL is an approach to support persons with intellectual disabilities, including persons with high support needs, to live lives of their choosing in their own homes. This may take different forms. It is not focussed solely on the physical housing setting, as the nature of supports available to the individual is central to the model. ISL may include a mix of formal and informal supports, as well as opportunities for individual growth and development across a range of social and community roles tailored to the needs, preferences, strengths, vulnerabilities and ambitions of the individual.

The ISL Framework is built around three fundamental assumptions:

- all adults with disabilities can live in an ISL arrangement if they are provided with the appropriate supports
- persons with disabilities do not have to live together
- persons with disabilities in an ISL arrangement do not have to live alone or independently.

‘Disability is also associated with poverty in Australia, interrelated with low labour force participation rates, higher unemployment rates and modest social security payments.’

This research identified four different approaches to (or types of) ISL arrangements:

- **Living alone:** A person with intellectual disabilities who lives alone may have an appropriate and preferred home if there is sufficient and appropriate support. Support may be across the range of 24 hours a day, seven days a week rostered formal support to informal (unpaid) support from family, friends or mentors. It is important that this support matches the support needs, wishes and preference of the focus person.
- **Host family:** A host family arrangement—also referred to as an alternate family arrangement or adult foster care. This relates to a situation where an adult person with intellectual disabilities lives with a host family to whom they are not related.
- **Co-resident:** In co-residency arrangements, a person with intellectual disabilities lives in their own home with one or more co-residents who provide some support in exchange for free or reduced rent or board.
- **Sharing with someone in an established relationship:** Persons with intellectual disabilities may decide to share their home with someone based on established friendships or an intimate relationship. It is important to reinforce that such arrangements are based on pre-existing relationships, rather than shared arrangements based on convenience, including for cost-saving reasons, particularly when sharing with other/s with disabilities.

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Study participants highlighted the benefits of quality ISL arrangements and the challenges in developing and maintaining them. Coordination of disability and housing policies and practices will enhance the sustainability of these arrangements. This includes the need to recognise and coordinate access to affordable and suitable housing, as well as in-home support.

Economic and housing characteristics

Disability and poverty have bi-directional associations, meaning disability may lead to poverty and poverty may lead to disability. Disability is also associated with poverty in Australia, interrelated with low labour force participation rates, higher unemployment rates and modest social security payments.

Around 17 per cent of non-dependent people with disabilities who rent do so from a state or territory housing authority, while only 3 per cent of persons without disabilities live in public housing. In addition, 8.3 per cent of clients of specialist homelessness services have disabilities, of which one-third have severe or profound disabilities. Furthermore, one in 12 persons with disabilities have had to move house because of their ‘condition or age’, which is more common (32%) among persons under 65 years of age than those aged 65 years or older (11%).

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Interviews with people in ISLs

The challenges articulated were various and very individual, largely circling around staff, housemates, funding and behavioural issues of the participants with intellectual disabilities and high support needs. Such challenges resulted in pressure to find suitable and sufficient staff available to provide quality care, including behavioural intervention. When asked what worked particularly well in the ISL arrangement, the clearest and most prominent theme to emerge from interview participants was ‘having more choices and being happier’.

The analysis revealed that there were typically two different pathways to how the ISL arrangement came about:

1. moving out of the family home and starting an independent life was an expectation in keeping with the cultural background of the family
2. other accommodation models such as group homes or respite care were identified as unsuitable.

Participants who moved straight from their family homes into an ISL arrangement were generally younger, both when initially contemplating this model and at the time the person made the move.

Benefits of and concerns with ISL

There are a number of ISL characteristics that contribute to positive outcomes. Access to appropriate physical space improved quality of life for participants. In particular, having their own space improved choice, control and autonomous decision-making. Having the opportunity for independence and autonomy in people's participation in daily activities and in making their own decisions was valuable to people. Support does not necessarily do for, but provides the prompts or supports alongside a person to enhance their skills rather than doing for the person.

However, the lack of formal support services for people living in ISL arrangements can make it more difficult for them to achieve independence. In particular, the lack of formal support services make it necessary to rely on family networks and relationships to provide support. In addition, there were lower rates of access to formalised services for people living in individualised residential homes or family homes.

People with disability were still socially restricted to support workers, family and other people with disabilities. Their social networks outside the family remained primarily in disability contexts. They had limited friendships. These limited networks were difficult to rectify, as lack of formal supports also made it more difficult for people to engage in new leisure and community occupations. Even where supports were available, this could limit social inclusion and interaction. Participants' views of the assistance they received and their interactions with support workers and others suggested their support limited rather than increased opportunities for engagement in daily occupations.

WA and NSW disability housing strategies

The WA Housing Strategy 2020–2030 calls for all sectors to work together to improve housing choices and access to suitable and affordable homes—particularly for the most vulnerable. It sets clear targets to create a more agile housing system that can respond to current and future need. It commits to people with disabilities as one of the five tailored housing responses, aiming to ensure that they have a choice of homes to meet a range of needs. The strategy states that 'homes that are both financially sustainable and well-located are therefore essential for people to access services, amenities and connect to opportunities including employment'.

The NSW Housing Strategy 2041 is a 20-year plan that aims to improve choice and housing options for people. The issue of diversity is acknowledged, with a strong focus on universal design for housing, the specific needs of people with disabilities in relation to housing, across the housing spectrum and life course. The two-year action plan (2021–2022) stemming from this larger strategy

outlines five priority areas and related actions. Three actions that specifically mention disability in relation to housing include: 'Work towards the establishment of a rights framework for people in specialist disability accommodation (SDA)'; positioning NSW as a leader in universal design; and working collaboratively with the Disability Inclusion Action plan.

What this research means for policy makers

A national framework to ensure suitable housing could build on the NDIS quality standards framework, as the framework of rights are important principles that are also pertinent to housing:

- Disseminate and ensure access to accurate information about different housing options
- Disseminate and ensure access to accurate information regarding different funding options
- Disseminate and ensure access to accurate information about the different governance structures that may be drawn upon to support the continuation and development of established arrangements.

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Three interrelated areas for further policy development were identified to support the establishment and continuation of ISL arrangements:

- Develop the evidence-base of ISL and disseminate information on different approaches to ISLs.
- Establish and enhance opportunities for persons with intellectual disabilities and high support needs to plan and establish their own ISL arrangements, including planning and transitional support. These approaches have to be developed around each individual, taking into account specific needs to the built environment, in-home support needs, and community access and participation support needs.
- Establish and enhance mechanisms to safeguard and maintain ISL arrangements.

Other policy concerns

Greater coordination between state housing authorities and disability services is required to improve housing outcomes for people with intellectual disabilities and high support needs.

It is important that supports and support funding are flexible to accommodate fluctuation in support needs and changing circumstances.

Integration between housing and disability services is required to create and maintain sustainable outcomes. This may require substantial planning in both the transition phase and the continuation of the arrangements, including safeguards and layers of contingency planning. To facilitate such a planning process, the NDIS should include funding for planning and transition into one's own home, recognising that it may be a lengthy process for some. It is important that this process is sufficiently flexible to facilitate the inclusion of a range of stakeholders in the planning process.

To maintain sustainable ISL arrangements and continue to develop appropriate and preferred homes for persons with intellectual disabilities and high support needs, a range of safeguards, including governance structures, is required.

Methodology

This research presents a review of the international literature; secondary analysis of interviews carried out previously; interviews with persons with intellectual disabilities and high support needs and/or their support network; and workshops with housing and disability stakeholders.

To cite the AHURI research, please refer to:

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