EXECUTIVE SUMMARY

FINAL REPORT NO. 380

Accommodating adults with intellectual disabilities and high support needs in Individual Supported Living arrangements

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Key points

- While people with disabilities are diverse and have diverse housing needs, persons with high and very high support needs are at heightened risk of poor housing outcomes compared to people with disabilities generally. Specialist disability housing—such as group homes and other congregate models—have been the norm for persons not living with their parent/s in the family home. With an increased emphasis on 'choice and control', people with disabilities are increasingly seeking individualised living arrangements, which cater for their specific needs, circumstances, strengths and vulnerabilities.

- Individual Supported Living (ISL) arrangements 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. Previous research has shown the different approaches to support an individual to live in their own home, to live with a host family, to live with co-residents, or to share a home with someone they have an existing relationship with.

- This research project identified limited peer-reviewed research accounting for ISL arrangements for persons with intellectual disabilities and high support needs. The literature typically clusters congregate and individualised living arrangements.

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- Secondary analysis of previously collected data suggests that sufficient and appropriate support is required to facilitate good outcomes, while simply living by oneself does necessarily lead to this. Well-planned transitions over time were often more successful related to increased choice, increased safety and stability of the arrangements, and a greater sense of community belonging and inclusion.

- 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.

- The National Disability Insurance Scheme quality standards framework is also relevant to housing, and can be drawn upon to develop a national framework and guidance.

Key findings

Persons with disabilities is one of several groups at heightened risk of poor housing outcomes. Historically, persons with disabilities have resided in large residential institutions, such as asylums. More recently, there has been a shift to small group homes, collectively referred to as 'cared-accommodation' in statistics published by the Australian Institute of Health and Wellbeing (AIHW; 2020c), which may also include nursing homes and other congregate living arrangements. However, as community attitudes and expectations have changed over recent years, so have the living options for persons with disabilities, including persons with intellectual disabilities and high support needs.

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. Over multiple research projects, Cocks et al. have explored what has been coined Individual Supported Living (ISL) arrangements for persons with intellectual disabilities.[1] This research identified and described 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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1   Cocks and Boaden 2011; Cocks et al. 2011a; Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, O'Brien, McVilly et al. 2016; Cocks, Thoresen, Thomson et al. 2018; Cocks, Thoresen, Williamson et al. 2014.

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This research report presents findings drawing on four different information sources:

- a scoping review of the international peer-reviewed literature
- secondary analysis of interviews carried out in a preceding Australian Research Council (ARC) funded project on ISL (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, Thomson et al. 2018)
- interviews with persons with intellectual disabilities and high support needs and/or their support network
- workshops with housing and disability stakeholders.

The scoping literature review identified that there was limited research and information on ISL arrangements for people with intellectual disabilities and high support needs living in their own homes. There was a diversity of operational definitions and inconsistent emphasis across studies. However, identified benefits included a greater sense of autonomy and independence, and an increased sense of choice and control. Identified barriers included insufficient formal and informal supports.

The secondary analysis illustrated diverse circumstances and outcomes among persons with intellectual disabilities and high support needs living in ISL arrangements. Typically, simply living alone did not equate to a strong ISL arrangement, but receiving appropriate and sufficient support played a seminal role. Too much support or inappropriate support may hinder personal growth and development, and create an environment of overprotection. Arrangements that were deemed stronger or well-developed had adopted a holistic approach that addressed the needs of the person with intellectual disabilities and high support needs across domains:

- in the home
- in vocations or daytime activities
- in social and community connections
- in personal growth and development.

While several arrangements had been sustained for a long period of time, continuous funding emerged as a challenge for the sustainability of several arrangements as funding could be insufficient and bring about uncertainty.

The qualitative interviews identified two typical pathways into ISL arrangements, either:

- transitioning directly from the family home
- transitioning because of poor experiences in congregate living arrangements, such as group homes.

Transitions that were gradual and planned over time were considered more successful. Similarly to the findings from the secondary analysis, these interviews identified benefits related to increased choice, increased safety and stability of the arrangements, and a greater sense of community belonging and inclusion. Concerns related to continued and predictable funding were also highlighted, including strategies to maintain the arrangement when family members—parents in particular—eventually passed away.

Four fact sheets were developed to guide the workshops with key disability and housing stakeholders. These synthesised the findings from the three information sources presented earlier and were framed around these areas:

- Moving from an old to a new model of living: getting the ISL model started.
- Enablers and benefits of an ISL.
- Coping with challenges along the way.
- Managing change and planning for the future.

Feedback from workshop participants was consolidated and led to adjustment of the fact sheets (which form the appendix of this Final Report). They point to a demand within the sector for accurate and practical information related to establishing and maintaining different types of ISL arrangements for persons with disabilities and high support needs.

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Policy development options

Three interrelated areas for further policy development were identified by this research in addition to the need for national framework and guidance to support the establishment and continuation of ISL arrangements. Such arrangements may enhance and facilitate increased engagement, self-determination, and full citizenship of persons with intellectual disabilities and high support needs.

The three policy development areas for additional consideration are as follows.

1. Develop the evidence-base of ISL, and disseminate information on different approaches to supporting persons with intellectual disabilities and high support needs creating and maintaining appropriate and preferred homes for individuals.

2. 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.

3. Establish and enhance mechanisms to safeguard and maintain ISL arrangements for persons with intellectual disabilities and high support needs, taking into account housing needs, housing costs, personal care needs, and community access and participation support needs of individuals.

A national framework and guidance to ensure suitable housing for persons with disabilities and high support needs could build on the National Disability Insurance Scheme (NDIS) quality standards framework (NDIS Quality and Safeguards Commission 2020), as its principles—including that of human rights—are also pertinent to housing. Furthermore, such a framework needs to disseminate and ensure access to accurate information regarding different:

• housing options

• funding options for both housing and support to establish and maintain appropriate and preferred homes

• governance structures that may be drawn upon to support the continuation and development of established arrangements.

Such a framework has to cut across the different levels of bureaucracy among federal, state and territory governments, as well as across housing and disability services. Additionally, the framework should do the following.

1. Recognise that persons with intellectual disabilities and high support needs have the right to choose where and with whom they live, aligned with the UN Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2006), and that this extends beyond cared-accommodation or other congregate living arrangements that may be more convenient for governments and service providers.

2. Take a holistic approach to housing for persons with intellectual disabilities and high support needs, recognising that where a person lives, with whom they live, in-home support, and community access support are all integral parts of an individual's life and wellbeing.

3. Include planning and transitional support for persons with intellectual disabilities and high support needs to establish their own homes, whether they are moving out of the family home, or other living arrangements, including congregate cared-accommodation.

4. Recognise and reduce barriers for persons with intellectual disabilities and high support needs to obtain their own housing. This includes administrative and legal barriers related to obtaining identification documents, signing legal documents, accessing loans, and accessing mainstream housing support services. This may include establishing trusts or incorporations for the person with disabilities.

5. Provide sufficient and long-term sustainable funding for both housing and support, creating certainty for housing providers, service providers and families to invest in appropriate housing stock.

6. Be flexible and responsive, recognising that persons with intellectual disabilities and high support needs may have complex considerations, and that changes in their personal circumstances or that of their support network may require unforeseen adjustments.

7. Allow for adjustments and changes to living arrangements as individuals' support needs, preferences, personal circumstances, and the circumstances of their support network may change—including as people age.

8. Take into account the broader benefits to wellbeing of having one's own home, including increased opportunities for skills development and community participation.

9. Include provisions of safeguards across both housing and support, recognising that these are integral to each other for people with intellectual disabilities and high support needs. For example, insufficient support may jeopardise the living arrangement.

10. Include in-built mechanisms for active monitoring and evaluation, including rigorous complaints and oversight mechanisms.

Further policy development needs to cater for individual approaches and solutions, recognising that housing for persons with intellectual disabilities and high support needs will require individualised approaches. It is therefore crucial that the voice of the person is reflected throughout this framework.

The study

The study drew on four information sources:

- a scoping review of the international peer-reviewed literature

- secondary analysis of interviews carried out with persons with intellectual disabilities and high support needs and/or their supporters from a previous study funded by the ARC (n=19)

- interviews with persons with intellectual disabilities and high support needs and/or their supporters (n=21) in the Australian Capital Territory, New South Wales, and Western Australia

- three workshops with disability and housing stakeholders (n=2 in NSW and n=1 in WA).

A scoping review to identify recent peer-reviewed publications related to ISL for persons with intellectual disabilities and high support needs was carried out through a structured search across five databases: Scopus, Embase, Medline, CINAHL and PsycInfo. Articles published between 2000 and 2020 also had to meet specific inclusion criteria related to intellectual disability, being relevant to ISL, age of participants, and involving some form of innovation related to service provision or outcomes for participants.

Secondary analysis of interviews for a preceding ARC-funded ISL project (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, Thomson et al. 2018) utilised the 'framework method for the analysis of qualitative data' (Gale, Heath et al. 2013). This approach is aligned to the broader thematic analysis of qualitative content analysis methods. Based on self-report, level of funding, or an Assessment of Level of Support Need, 19 interviews with persons with intellectual disability and high support needs were identified that contained sufficient information for inclusion in this study.

Interviews with persons with intellectual disabilities and high support needs and/or their support network were carried out for this study. Twenty-one interviews were carried out in WA (n=11) and NSW and the ACT (n=10). Participants were recruited purposively by utilising existing contacts, including the networks of the study reference groups in WA and NSW. There were three broad inclusion criteria:

1. The person had intellectual disabilities and high support needs.

2. The person with intellectual disabilities and high support needs needed to be 18 years of age or older.

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3. The person with intellectual disabilities and high support needs was living in an appropriate and preferred home that reflected the ISL Framework. This excluded persons living in the family home (with a parent or parents) or in any congregate arrangements. A congregate arrangement refers to a home setting where a group of non-related people live. The size varies across countries—for example, a congregate residential setting is said to exist where 10 or more people reside (Health Service Executive [HSE] 2011). Group homes may also be considered congregate settings (People with Disability Australia 2020) and this may be with fewer than 10 residents, with between four and six residents common in Australia.

The interviews were carried out with the person with intellectual disabilities, support workers, co-residents, and/or with the parent or parents or other relatives of the person with intellectual disabilities and high support needs. As the COVID–19 pandemic emerged during the data collection phase, with a range of unforeseen social-distancing measures and regulations, the study had to rely on a range of strategies to adhere to these measures, as well as recognising the health conditions or vulnerabilities among some of the participants. Therefore, some interviews were conducted through audio-visual platforms.

Based on the information from the scoping review, secondary interview analysis and qualitative interviews for this project, thematic summaries or fact sheets were developed. A deductive and inductive approach to thematic analysis (Azungah 2018; Braun and Clarke 2006) was used to analyse and summarise the research findings related to four fact sheets.

Following three workshops with key stakeholders in WA and NSW—with representation from a range of stakeholder groups including housing developers and providers, disability advocates and support organisations, parents of persons with disabilities and high support needs, and academics—these fact sheets were revised and amended to incorporate the most pertinent feedback from workshop participants.

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