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



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Contents

List of tables	iv
List of figures	iv
Acronyms and abbreviations used in this report	v
Glossary	vi
Executive summary	1
1. Housing for adults with intellectual disabilities and high support needs	7
1.1 Disability and housing policy contexts	8
1.1.1 National Disability Insurance Scheme and housing	8
1.1.2 Developments in disability and housing policies in Australia	10
1.1.3 Housing for persons with disabilities in Western Australia	11
1.1.4 Housing for persons with disabilities in New South Wales	11
1.2 ISL for persons with disabilities and high support needs	11
1.3 Research methods	13
2. The benefits and challenges of Individual Supported Living	15
2.1 Themes emerging from the literature review	15
2.1.1 Definitions of ISL	15
2.1.2 Outcomes	16
2.1.3 Contributing factors to negative ISL outcomes	17
2.1.4 Contributing factors to positive ISL outcomes	18
2.2 Policy implications	18
3. Secondary analysis	20
3.1 Characteristics among included ISL arrangements	21
3.2 Matrix outcomes	23
3.2.1 Current living situation	23
3.2.2 Planning ISL	23
3.2.3 Social connections	24
3.2.4 Informal supports	25
3.2.5 Formal supports	25
3.2.6 Wellbeing	26
3.2.7 Sustainable funding	27
3.3 Policy implications	27
4. Qualitative interviews	29
4.1 Analysis	29
4.1.1 Characteristics of ISL arrangements	30
4.2 Interview findings	31
4.2.1 Before the arrangement was set up	32
4.2.2 The ISL arrangement	34
4.2.3 Future outlook	39
4.2.4 Other aspects emerging from the interviews	40
4.3 Policy recommendations from interviews	43

5. Moving to Individual Supportive Living	44
5.1 Workshop facilitation	44
5.1.1 Workshop methods	45
5.2 Thematic analysis	45
5.2.1 General comments	45
5.2.2 Reasons why people may choose to pursue ISL	45
5.2.3 Obtaining information	46
5.2.4 Managing an ISL arrangement	46
5.3 Fact Sheets	47
5.4 Next steps	50
5.5 Policy development implications	51
6. Policy development options	52
6.1 How can we continue to build an evidence-base of sustainable and suitable housing for persons with intellectual disabilities and high support needs?	53
6.1.1 Definitions and conceptualisations of good ISL arrangements	53
6.1.2 Continue building the evidence-base	54
6.2 How can we support the establishment of more individualised housing for persons with intellectual disabilities and high support needs?	54
6.2.1 What are the housing needs for persons with intellectual disabilities and high support needs?	54
6.2.2 What are the support needs required to facilitate ISL arrangements?	55
6.3 How can we support the continuation and enhanced sustainability of individualised housing for persons with intellectual disabilities and high support needs?	56
6.3.1 How can transitional and continuous planning processes be improved?	56
6.3.2 How can governance structures be implemented to safeguard appropriate and preferred homes for persons with intellectual disabilities?	57
6.4 What would a national framework and guidance to ensure suitable housing for persons with intellectual disabilities and high support needs look like?	58
6.5 Accommodating persons with intellectual disabilities and high support needs	59
References	61
Appendix A: Sources of information	65
Appendix 2: Papers included in the scoping review	71

List of tables

Table 1: Characteristics and fidelity to ISL among arrangements included in the secondary analysis	22
Table 2: Characteristics of ISL arrangements	31
Table A1: Scoping review search strategy	65
Table A2: Coding framework for secondary analysis	67
Table A3: Papers included in scoping review	71

List of figures

Figure A1: PRISMA diagram	66
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Acronyms and abbreviations used in this report

AAIDD	American Association of Intellectual and Developmental Disabilities
ACT	Australian Capital Territory
AHURI	Australian Housing and Urban Research Institute Limited
AIHW	Australian Institute of Health and Welfare
ARC	Australian Research Council
HREC	Human Research Ethics Committee
HSE	Health Service Executive (Ireland)
ICI	Index of Community Involvement
ISL	Individual Supported Living
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS QSC	National Disability Insurance Scheme Quality and Safeguards Commission
NSW	New South Wales
QOL.Q	Quality of Life Questionnaire
SDA	Specialist Disability Accommodation
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WA	Western Australia

Glossary

Carer in the context of this report refers to unpaid carers, typically parents or other family members of the person with intellectual disabilities. Carers Australia makes a clear distinction between unpaid carers and paid support workers.

Cluster-housing is where homes are situated in groupings relatively close to each other. It is often provided by a service provider or government agency, and resources, including support staff, are often shared.

Congregate living arrangement refers to a home setting where a group of non-related people live. The size of congregate settings varies across countries. For example, a congregate residential setting is said to exist where 10 or more people reside (HSE 2011). Group home and cluster-housing may also be considered congregate settings (People with Disability Australia 2020), and this may be with less than six residents.

COVID-19 is the abbreviation for coronavirus disease 2019 and refers to the global pandemic caused by the SARS-CoV-2 virus from late 2019 onwards, causing millions of deaths globally and hundreds of millions of infections.

Decision board is one of several tools often used in supported decision-making that outlines two distinct choices, often including symbols and diagrams, to support persons with intellectual disabilities and high support needs understand the different choices.

Domestic-scale supported living facilities is AIHW's terminology for group homes.

Formal support in the context of this report, and in contrast to informal support, is support provided by agencies or a paid support worker.

Group homes are, in the Australian context, family-sized accommodation where services and supports within the home and community are provided to typically four to six long-term residents.

High support needs are defined by the AAIDD at the severe or profound level. They reflect extensive support needed for daily activities or pervasive support needed for every aspect of a 'daily routine'.

Individual Supported Living (ISL) is a framework developed by Cocks et al. (2014; 2016; 2017; 2018) where adults with intellectual disabilities live in one of four arrangements: living alone, co-residency, relationships, and host family. The arrangements are guided by a set of eight themes: Leadership, My home, One person at a time, Planning, Control, Support, Thriving, and Social inclusion. Four types of ISL arrangements have been identified:

- *Living alone* in an appropriate and preferred home with sufficient and appropriate support. Support may range from 24 hours a day/seven days a week rostered formal support to informal 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 arrangement*—also referred to as alternate family arrangement or adult foster care—relates to a situation where an adult person with intellectual disabilities lives with a host family to whom they are not related.
- *Co-residency* is when 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* 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.

Individualised living options (ILO) are living arrangements that focus on the individual and can include living alone, co-residency, host family, and sharing with someone in an established relationship. Tenure arrangements are not specified for any ILO.

Informal support is unpaid support. It is typically provided by family, friends or others with an existing relationship to the person being supported.

Institutional care includes different forms of residential support services. Often a distinction is made between family-sized residences (group homes) and larger scale residences. It may be viewed as all other residential arrangements beyond private residences, including domestic-scale supported living facilities (or group homes); supported accommodation facilities; independent living unit within a retirement village; residential aged care facility; psychiatric/mental health community care facility; hospital; short-term crises, emergency or transitional accommodation facility; and public place/temporary shelter (AIHW 2020a).

ISL Framework describes the eight themes that measure the quality of individual supported living.

Microboard is a small group of people, typically family members, friends and/or advocates who are committed to the focal person with intellectual disabilities. It may be incorporated and have a formal role in managing the person's funding and supports. It is trademarked by Vela Canada (www.velacanada.org).

National Disability Insurance Agency (NDIA) is an Australian independent statutory agency responsible for the National Disability Insurance Scheme.

National Disability Insurance Scheme (NDIS) is still being phased in across Australia and is intended to provide all Australians with disabilities needs-based funding. It is a system for providing individualised funding and services for eligible persons with disabilities. This funding may be:

- *agency-managed*—where an authorised NDIS provider is responsible for managing the NDIS funding
- *self-managed*—where the person or people close to them (often parents but may also be advocates) manages the NDIS funding.
- *shared-managed*—where the person with disabilities and/or others close to them together with an authorised NDIS provider are responsible for managing the NDIS funding.

Severe or profound disability is defined in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* 5th edition as difficulty with daily activities/skills. Severe disability is described as 'requires daily assistance with self-care activities and safety supervision'. Profound disability is described as 'requires 24-hour care'.

Support workers are paid, typically by an agency but may also be employed directly by the person with intellectual disabilities and/or others who manage their NDIS funding package.

Supported decision-making is where people with disabilities are supported to make their own decisions in line with the UN Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2006), Article 12: Equal Recognition Before the Law.

Supported living refers to how people with individual personal and daily living needs can be supported to live more independently, usually in a location beyond the family home. The design of the living situation can vary from living alone, or with a small number of people not including parents.

Executive summary

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.

- **Secondary analysis of previously collected data suggests that sufficient and appropriate support is required to facilitate good outcomes, while simply living by oneself does not 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.

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.

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.

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.

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.

1. Housing for adults with intellectual disabilities and high support needs

- **People with intellectual disabilities are diverse and have diverse housing needs. There has been a move away from congregate living arrangements, including for persons with intellectual disabilities and high support needs.**
- **The National Disability Insurance Scheme (NDIS) and Specialist Disability Accommodation (SDA) programs will not provide housing for all persons with intellectual disabilities with high support needs who require support to access and maintain affordable housing.**
- **State governments have policies and strategies to support persons who may be vulnerable in the housing market to access appropriate accommodation. These policies may include special consideration of disability, along with programs to ring-fence or modify social housing stock.**
- **Persons with intellectual disabilities may experience multiple disadvantages in the housing market, including low incomes. Persons with intellectual disabilities are much more likely to rent social housing than people without disabilities. One in 12 clients of specialist homelessness services have disabilities, of which one-third have severe or profound disabilities.**
- **ISL is an approach to support persons with intellectual disabilities, including persons with high support needs, to live good lives 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. It 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.**
- **ISL may lead to more appropriate and preferred homes for persons with disabilities and high support needs, which address housing needs and the needs of the built environment, along with individual support needs.**

1.1 Disability and housing policy contexts

People with disabilities are a heterogeneous group, with diverse characteristics, interests, support needs, skill sets and vulnerabilities, including diverse ambitions for their housing and accommodation. However, as with other vulnerable groups, accommodation is often provided based on the availability of housing, rather than individual circumstances. This applies particularly for persons with intellectual disabilities with high support needs, with congregate housing—such as group homes—often presented as the only viable option outside the family (parents') home. High support needs are aligned with severe or profound levels of disabilities, which the American Association of Intellectual and Developmental Disabilities (AAIDD) defines as 'extensive support needed for daily activities or pervasive support needed for every aspect of daily routine' (Schalock, Luckasson et al. 2021).

The latest Survey of Disability, Ageing and Carers (SDAC), conducted in 2018, estimated that there were 4.4 million Australians with disabilities—or 17.7 per cent of the population (ABS 2019). 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, 195,700 Australians with disabilities lived in cared-accommodation in 2018, although only 14,400 were persons aged 15–64 (ABS 2019).

[Cared-accommodation] includes hospitals, nursing homes, aged care hostels, cared components of retirement villages, psychiatric institutions, and other 'homes' such as group homes for people with disability where a person must have been a resident, or expected to be a resident, for three months or more (ABS 2019).

These more traditional models of housing have in-built systems of support, but lack responsive and alternative support models for a diverse population with diverse needs. The traditional model with built-in core supports was funded through bulk funding. Thus, the service provider, not the individual, received funding to provide accommodation and other supports for a group of people. The family model has always relied upon (and continues to rely upon) informal and unpaid supports, with carer allowance or benefits that fall far short of the effort and cost of caring.

This section describes specific recent policy and system changes that have created a context where more individualised living options are feasible. This is seen most notably with the introduction of the National Disability Insurance Scheme (NDIS). Prior to the NDIS, there have been major developments in disability accommodation and support models, with the traditional residential centres falling to the deinstitutionalisation process, and the transition to community group homes a first step towards more integrated living in society. Much has been written about this previously (Bigby and Fyfe 2006; Wiesel and Bigby 2015).

1.1.1 National Disability Insurance Scheme and housing

The NDIS, despite continuous adjustments to the scheme, is incrementally providing funding and supports for Australians with disabilities. However, only a small fraction of the estimated 460,000 persons eligible for NDIS funding will be eligible for housing support funding through the NDIS (Buckmaster 2017). Accommodation support is the most costly disability service area, with the National Disability Agreement (NDA) contributing to 48 per cent of expenditure in 2016–2017 at 3.7 billion dollars for 39,022 users (AIHW 2018).

However, as more people transition into the NDIS, accommodation support may be funded under both the NDA and the NDIS. In the following year, 2017–2018, 28,311 persons received accommodation support under the NDA, at a cost of 2.9 billion dollars, in a year when 40,018 persons transitioned into the NDIS (AIHW 2019). This trend continued the following year, with accommodation support under the NDA falling to 1.8 billion for the 12,777 service users receiving NDA accommodation support in 2018–2019 (AIHW 2020b).

Two-thirds (65%) of the persons who transitioned from the NDA to the NDIS in 2018–2019 had an ‘intellectual or learning primary disability’ (AIHW 2020b, p.25). Proportionally, more persons with intellectual disabilities have transitioned from the NDA to the NDIS, decreasing the proportion of persons with intellectual disabilities in the NDA to 29 per cent in 2017–2018 (AIHW 2020b) from 37 per cent in 2013–2014 (AIHW 2019).

Among the 34,153 persons with intellectual disabilities who received NDA funding in 2018–2019:

- almost two-thirds (64%) lived in private residences
- about one in eight (12%) lived in domestic-scale supported living facilities
- less than one in twenty (4%) lived in supported accommodation facilities
- about one in seven (14%) lived in other arrangements.

Information was not stated or collected for the remaining persons (6%) (AIHW 2020a)².

NDIS funding for housing will be provided through Specialist Disability Accommodation (SDA). Earlier estimates by Wiesel and Habibis (2015) suggested that 83,000–122,000 NDIS participants would not have their need for affordable accommodation met in 2019. Their report discussed the challenges in providing choice and control of housing for persons with disabilities within the NDIS environment, including the strengths and weaknesses of supply and demand-driven housing policies. Wiesel and Habibis noted that ‘supply-side’ housing subsidies and housing options delivered outside the market are often associated with constraints on individual choice, and may lead to congregated housing approaches and concentration of social disadvantage in housing developments of scale (2015: 34).

Of note, it is recognised that the NDIS and SDA will not provide accommodation support for the majority of persons with disabilities. Beer, Flanagan et al. (2019) explored SDA funding as an investigative panel, and noted that ‘SDA will provide an additional 8,000 accommodation opportunities for people in need of specialist disability housing’. SDA is specifically for persons whose high support needs may ‘adversely affect their ability to live independent lives’ (2019: 7). Access to SDA funding is through NDIS plans and requires an assessment. Beer, Flanagan et al. identified that while the housing and disability support sectors are ‘poised to take up the opportunities embedded within the program’, current government structures are adding to the financial risks for the private and non-government sectors to develop new SDA housing (2019: 45).

Wiesel, Bullen et al. (2017: 4) investigated ‘shared ownership’ models that ‘would be most appropriate and beneficial for people with disability’. Shared ownership is an umbrella term for ownership models that involve a person with a disability living in the home provided by a ‘non-person’ equity partner, such as a not-for-profit organisation or government body. While recognising that this is a ‘niche’ approach and only a handful of Australians with disabilities are shared owners, it is a model that has been identified as a possible approach to expand homeownership and suitable housing for people with disabilities.

² Within these categories used by the AIHW, private residences include the home of the person with disabilities as well as those of family members. Domestic-scale supported living facilities are typically group homes, while larger congregate arrangements are included in the supported accommodation facilities. The ‘other’ category clustered a range of housing arrangements, including ‘residence within an Aboriginal/Torres Strait Islander community’; ‘boarding house/private hotel’; ‘independent living unit within a retirement village’; ‘residential aged care facility’; ‘psychiatric/mental health community care facility’; ‘hospital’; ‘short-term crises, emergency or transitional accommodation facility’; ‘public place/temporary shelter (AIHW 2020a).

SDA and shared ownership models include both individual and congregate—that is, group homes—living arrangements. Research participants in the study by Wiesel, Larmel et al. (2015b) who moved into their own homes ‘valued their privacy if they lived alone, or valued having a choice of flatmates if they shared’ (2015b: 2). It was also noted that pooling of funds such as home sharing and KeyRing housing (which involves the sharing of support) could be ‘de-stabilising when people wanted to change their housing’ (2015b: 38). The study highlighted the importance of both formal and informal support for participants to obtain and maintain their own homes. The lack of strategies to provide appropriate support was in some instances cited as the determining factor for the rejection of individualised funding for housing. This underscored the crucial, intertwined nature of support for obtaining, transitioning into, and maintaining their own homes. Thus, it is crucial that housing models for adults with intellectual disabilities and high support consider both ‘housing’ and ‘support’. This relates to both the establishment of and transition into ISL arrangements, and for ongoing living arrangements for persons with intellectual disabilities. ISL is not a fixed model, but one that emerges in response to the specific needs of the individual, incorporates physical environment and a range of supports, and will likely change over the life course as the persons needs and preferences change.

1.1.2 Developments in disability and housing policies in Australia

Housing for persons with intellectual disabilities and high support needs is complex, as it encompasses challenges around access to affordable, secure, appropriate housing stock, and the potential need for modifications to the built environment as well as direct support needs. Historically, persons with intellectual disabilities and high support needs have been accommodated in institutions, ranging from large asylums or hospitals to nursing homes, hospices and, more recently, group homes. However, there is a substantial move away from these 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 (AIHW 2020c).

Disability and poverty have bi-directional associations, meaning disability may lead to poverty and poverty may lead to disability (World Health Organization and The World Bank 2011). Disability is also associated with poverty in Australia, interrelated with low labour force participation rates, higher unemployment rates, and modest social security payments (Thoresen, Cocks et al. 2019).

According to the AIHW (2020c), 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 year or older (11%) (AIHW 2020c).

As such, while persons with intellectual disabilities and high support needs are increasingly seeking to live in their own homes rather than in congregate arrangements, they are also more vulnerable to poor housing outcomes. Stakeholders, particularly parents and not-for-profit organisations, have developed ISL approaches to create appropriate and preferred homes for persons with disabilities and high support needs as an alternative to congregate living arrangements. This study explores developments in ISL in two states in Australia: Western Australia and New South Wales/ACT. WA was one of the original pilot sites for the implementation of the NDIS and is known to be at the forefront in individualised housing options for people with disabilities and high support needs. Thus, WA provides a contrasting policy and system setting to that of NSW. In addition, the partner organisations were based in WA and NSW.

1.1.3 Housing for persons with disabilities in Western Australia

This research presents findings from a study that focussed on Western Australia (WA) and New South Wales (NSW), with some information collected from the Australian Capital Territory (ACT). In WA, there is a long history of people with disabilities—because of their economic situation—finding housing options through social housing schemes. People may have achieved access to this outcome independently or via government-facilitated processes. A significant proportion of social housing for people with disabilities and high support needs—including persons with intellectual disabilities—was allocated under a headlease scheme where an organisation would hold the housing and then sublet to people with disabilities, usually based on prioritisation of need. Multiple approaches by government have been made over the past 40 years towards the provision of appropriate social housing stock for people with disabilities (Menck 2014).

The WA Housing Strategy (Government of Western Australia 2020) set the objectives to build liveable, inclusive and connected communities, improve the availability of liveable designed housing that improves social and economic participation, creating jobs and contributing to the state's economy, and to improve outcomes through a more integrated approach to housing and service assistance. The WA Housing Strategy 2020–2030 is a call to action for all sectors to work together to improve housing choices and access to suitable and affordable homes—particularly for the most vulnerable. The strategy was kickstarted by the \$444 million Housing Stimulus Package announced in June 2020. This included the \$319 million Social Housing Economic Recovery package that will refurbish 1,500 homes, build and purchase about 250 new dwellings and deliver a regional maintenance program to 3,800 homes. This comes on top of the \$150 million Housing Investment Package announced in December 2019 and the \$394 million Social and Affordable Housing and Jobs Package announced in 2018.

The WA Housing Strategy 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' (Government of Western Australia 2020, p.20).

1.1.4 Housing for persons with disabilities in New South Wales

The NSW Housing Strategy 2041 (NSW Government 2021b) 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) (NSW Government 2021a) 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)' (action 2.3.6); positioning NSW as a leader in universal design; and working collaboratively with the Disability Inclusion Action plan (action 2.7.3).

Additionally, the Disability Modifications Policy 2018 (NSW Government 2018) provides directives on adaptations, while Housing NSW is the main provider of social housing. A national initiative, the Housing Hub, is a database of available accessible properties that can be searched state by state, and outlines specific preferences in terms of accessibility and the nature of supports that the individual requires.

1.2 ISL for persons with disabilities and high support needs

ISL is an approach to support persons with intellectual disabilities living lives of their choosing in their own homes proposed by Cocks³ and colleagues in 2009, and has been refined over three subsequent research stages. The first stage, 2009–2011, developed the concept through six longitudinal case studies and a Delphi study with persons considered international research and practice leaders.

³ The significant contributions by Emeritus Professor Errol Cocks to ISL need to be acknowledged, as well as his significant contributions towards this research project. He was initially the chief investigator of the project from which this research report presents findings but had to withdraw due to personal circumstances.

The second research phase by Cocks, Thoresen, Williamson et al. (2014) operationalised the initial conceptual framework into the ISL Manual (Cocks et al. 2011a) and Scoring Booklet (Cocks et al. 2011b). The ISL Manual and framework offers an alternative to the prevailing approach in the literature, which emphasises a service-oriented approach to community living, particularly deinstitutionalisation leading to the development of group homes. ISL offers a value-based and process-based approach to create and maintain individual homes for persons with intellectual disabilities, aligned with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): living independently and being included in the community.

Furthermore, the ISL Framework is built around three fundamental assumptions, congruent with the UNCRPD (Cocks and Thoresen 2017: 2):

- 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.

A third phase funded by the Australian Research Council (ARC) validated the properties of the instrument and cumulated in a revised version of the ISL Manual (Cocks and Thoresen 2017) through evaluating 130 ISL arrangements across Australia. It concluded that the instrument had good internal and concurrent reliability and validity (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, Thomson et al. 2018). The study also identified and described four different approaches to, or types of, ISL arrangements (Cocks and Thoresen 2017; Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, O'Brien, McVilly et al. 2016; Cocks, Thoresen, Thomson et al. 2018):

- **Living alone:** Any person with intellectual disabilities who lives alone in their own home may have a strong ISL arrangement if there is sufficient and appropriate support. Support may be across the range, from 24 hours a day, seven days a week rostered formal support to informal support from family, friends or mentors. It is important that this support matches the support needs, wishes and preferences of the person with disabilities.
- **Host family:** A host family arrangement—also referred to as alternate family arrangement or adult foster care. This involves an adult person with intellectual disabilities living with a host family. This is often a relatively formal arrangement, which may involve management, governance and agency support, including provisions for payment of costs of board, lodging and direct supports—for example personal care.
- **Co-resident:** Co-residency arrangements refer to when 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. Often this support focuses on social networks and skills development, while there may be additional formal supports provided by external carers—for example, personal care support needs. Thus co-residents are housemates, not live-in carers.
- **Sharing with someone in an established relationship:** Persons with intellectual disabilities may decide to share their home with someone based on existing friendships or more intimate relationships. It is important to emphasise that such arrangements are based on established relationships, rather than shared arrangements based on convenience, particularly when sharing with other/s with disabilities.

The ISL Framework and Manual, and the four approaches outlined above, guide the present study in terms of inclusion criteria for what is ISL, and what exists outside of ISL. However, the authors acknowledge that ISL is not a fixed model, and these approaches provide guidance about alternative models of living that incorporate a person-centred approach, which seeks to adapt environmental factors to ensure the person with disability has access to an appropriate physical home setting, with appropriate and adequate supports to live in that setting and surrounding community, and is directed by the individual's needs and preferences. Within the ISL Framework, ownership is an important indicator of control, choice and autonomy, but other models can demonstrate that the individual has choice without having outright ownership of the home.

The strength of the ISL Manual work is that it presents a quality framework that can be used to plan new arrangements or evaluate existing arrangements, and that it highlights important features. Despite the work carried out by Cocks et al. (Cocks and Boaden 2011; Cocks, Thoresen, Williamson et al. 2014; Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, O'Brien, McVilly et al. 2016; Cocks, Thoresen, Thomson et al. 2018; Cocks et al. 2011a) in defining, operationalising and creating an evidence-base for ISL, limited research has been carried out to inform policy options for establishing and maintaining personalised and individualised housing options for persons with intellectual disabilities and high support needs. Although there are assumptions underpinning the values of the ISL Framework, there is limited empirical research illustrating approaches to accommodate persons with intellectual disabilities and high support needs in ways that are personalised and individualised.

In addition, it should be noted that the framework does not provide guidance on obtaining and maintaining funding to establish and continue ISL arrangements. Drawing on the body of work carried out by Cocks et al. over the preceding three phases of the ISL research stream, the current study aimed to address three specific research questions:

1. How are ISL arrangements established?
2. How does the quality of housing and support arrangements in ISL arrangements contribute to positive outcomes and benefits?
3. How are high quality ISL arrangements sustained over time?

1.3 Research methods

There were four distinct elements or research components to this project (see Appendix 1). It consisted of:

- a scoping literature review
- secondary analysis of interviews carried out in the previously ARC-funded ISL study
- interviews carried out as part of this AHURI-funded study
- thematic fact sheets that drew on the findings from the preceding three information sources and were refined as part of the workshops with key disability and housing stakeholders in NSW and WA.

The findings from these four research components are presented separately in Sections 2–5, while the policy development options in Section 6 synthesise the findings from these individual components into recommendations to enhance housing options and practices for persons with disabilities and high support needs.

Previous work carried out by Cocks et al.⁴ focussed on persons with intellectual disabilities, while the current study focuses on persons with intellectual disabilities with high support needs.

An additional qualitative interviews for 21 different ISL arrangements of people with intellectual disabilities and high support needs were carried out for this project. This included 11 interviews in WA and another 10 interviews in NSW and the ACT. The interviews were conducted between November 2020 and April 2021. Interview participants were recruited through purposive sampling and snowball approaches by utilising existing contacts, including the networks of the reference groups in WA and NSW, NGOs and advocacy organisations known to the researchers, or persons that were involved with the preceding ARC-funded study. It was estimated that about one-third of the participants interviewed as part of the present AHURI-funded study had contributed to previous ISL research.

⁴ Cocks et al. 2011a; Cocks and Boaden 2011; 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).

There are different ways to operationalise support needs or high support needs. For the purposes of this research project, it was decided to continue the emphasis on intellectual and developmental disabilities, recognising comorbidities, multiple diagnoses and high support needs. High support needs are defined by AAIDD as ‘extensive support needed for daily activities or pervasive support needed for every aspect of daily routine’. As such, research participants in this study were persons with intellectual and developmental disabilities and high support needs, as identified through self-reporting, funding levels, or assessments as specified in the respective sections.

There are several limitations that should be noted. The scoping review was exploratory and intentionally used contemporary language as search terms. Therefore, it may not have captured all studies relevant to the project. It should also be noted that many of the focal persons with intellectual disabilities had limited verbal communication skills and their voices were not directly captured in the interviews. In most cases, family members or support staff acted as proxy informants. It is possible the level of support led to some focal persons opting not to be present at the interviews, or their supports chose not to include them.

It is not possible to ascertain how—or if—this approach skewed the data. For future projects, it will be an advantage to look at alternative and more flexible ways to include people with intellectual disability with high support needs. However, within the resource limitations of this project that was not viewed as feasible, and it is acknowledged that the voices of the persons with intellectual disabilities and high support needs are not reflected to the desired extent.

The COVID-19 pandemic has had profound impact on people’s lives across the globe. People with intellectual disabilities and high support needs are often viewed as particularly vulnerable, due to their poor verbal communication and comprehension, and possibly underlying health conditions. Many people with intellectual disabilities were often unable to experience community connection across the lockdown period, which reflected on how they were experiencing the ISL model. Shortages of support staff were another issue throughout the pandemic.

Changes arising from the pandemic lead to the need for electronic interviewing, which slowed the start of the project, as did reaching out to organisations to identify people with high support needs who were living within an ISL model. Recruitment needed to take second place as organisational priority was adapting to the pandemic. As a result, close on half of the interviews were done through videoconferencing, which worked against people with intellectual disabilities participating more flexibly. Pandemic restrictions were also experienced by some family members and supporters, who were unable to join the person with intellectual disability in their own home for the interview.

2. The benefits and challenges of Individual Supported Living

- **There is limited information on ISL for people with intellectual and developmental disability and high support needs in the academic peer-reviewed literature. Operational definitions or areas of emphasis are inconsistent.**
- **Identified benefits of ISL arrangements include a greater sense of autonomy and independence, and an increased sense of choice and control.**
- **A lack of formal and informal support services for people in ISL arrangements can hinder individualised approaches, and may increase the reliance on family networks—particularly parents—and relationships.**

2.1 Themes emerging from the literature review

As noted in Section 1, a scoping review of the formal peer-reviewed literature concerning ISL was carried out in June 2020, with searchers covering five databases. A total of 10 articles were deemed to meet the inclusion criteria across all four domains among the 435 identified papers.

Specifically, the papers needed to include an ISL model and a sample of participants with intellectual disabilities and high support needs. There is a broad literature on independent living for people with variable degrees of disabilities, though less specifically on the group with intellectual and high support needs as this scoping demonstrated. An overview of these studies is provided in Appendix 2, which outlines the aims of the papers and operational definition of ISL. There were three studies focussing on the Republic of Ireland and Northern Ireland, two studies each from Australia, the UK and the USA, and one Canadian study.

2.1.1 Definitions of ISL

The definitions of ISL across these studies were not consistent. While many definitions were thematically similar in most cases, it was clear that there were differences across the papers as to the specific configuration of supported living arrangements. The scope of use of the term 'supported living' in some cases was quite broad and non-specific, and was referred to in opposition to institutionalised living. In some cases supported living referred to people living in settings after deinstitutionalisation, but otherwise remaining in relatively congregated settings, such as community-based group homes (James, Harvey et al. 2018). Other papers described different models of community-based living. Ashley, Fossey et al. (2019) described ISL in the context of their study as 'a supported living situation, either alone or with up to three other people, where provision of accommodation and support were separated'. Kim and Dymond (2020) described community-based living similarly, and offered group homes and supported apartments as examples of community-based residential options.

Isaacson, Cocks et al. (2014) described the experiences of two men living independently in their own apartments with the support of service providers and family. Marlow and Walker (2015) provided the most comprehensive description of the participants' independent supported living setting, which clearly illustrated the transition from their previous congregated living settings. This description outlined the physical settings as well as the support arrangements.

The tenants in this study were moved from two shared houses to purpose-built individual flats which are all in the same block. The flats are situated in a busy urban environment surrounded by ordinary housing stock and next door to a similar block of flats which have been purchased by members of the local community through a shared ownership scheme. The tenants are supported in their new flats by the same staff team who were supporting them in the two houses prior to the move. The support by the staff team was provided on a 24-hour basis and this continued at the same level after the move. The agency employing the staff also remained the same. The tenants moved into their own flats in February 2013. (2015: 314)

McConkey et al. referred to supported living, but not necessarily independent supported living (McConkey 2007; McConkey and Collins 2010; McConkey, Keogh et al. 2016). In particular, these studies dealt with clustered supported living, dispersed supported living, small group homes, campus living and residential homes. These studies explicitly delineated between personalised arrangements, community group homes and congregated settings. The element of support was also highlighted in addition to the nature of the home and the living arrangement—that is, who the person lives with. The variable definitions made it difficult to know if comparisons are appropriate.

2.1.2 Outcomes

The specific outcomes associated with ISL were varied across the papers. Some of the indicators used in the papers included social inclusion, relationships, use of community amenities, visitors to the home and increased choice and control.

However, there was a consistent theme of overall improvement in at least one area for people who had transitioned to some form of individualised living arrangement. In particular, some of the papers noted that people felt a greater sense of autonomy and independence (Ashley, Fossey et al. 2019; Isaacson, Cocks et al. 2014; Marlow and Walker 2015; McConkey, Keogh et al. 2016). Their sense of choice and control was also increased. This was particularly notable for arrangements where the person lived in individualised accommodation with supports, rather than in a congregated setting (Ashley, Fossey et al. 2019; Isaacson, Cocks et al. 2014; Marlow and Walker 2015). McConkey (2007) also confirmed that the outcomes of a person living in a supported arrangement were affected by the type of accommodation they were living in. Particularly, people in ISL schemes tended to have greater levels of social inclusion than those in small group homes or residential homes. People living in campus-style settings had the lowest levels of social inclusion of all groups (McConkey 2007; McConkey and Collins 2010; McConkey, Keogh et al. 2016). These findings were consistent across all three included studies by McConkey et al. (McConkey 2007; McConkey and Collins 2010; McConkey, Keogh et al. 2016).

One notable outcome described by Marlow and Walker (2015) was a decrease in challenging behaviour among men who had moved from a congregate setting to individualised arrangements, which was sustained six months after the transition. They also noted a significant improvement in the overall mood of the men, which was also sustained six months after transition.

2.1.3 Contributing factors to negative ISL outcomes

The review of the literature identified a number of experiences that contributed to negative outcomes in ISL arrangements. These experiences contributed to diminished outcomes for people living in a setting and context where choice and autonomy were not facilitated.

James, Harvey et al. (2018) found that people with intellectual disabilities living in larger supported accommodation models—which were less aligned with a truly independent model, although still included in that paper—were experiencing regimented routines that were focussed on mealtimes and bedtimes, for the convenience of staff. This substantially limited their autonomy, choice and control. James, Harvey et al. suggested this regimentation was more pronounced in settings that did not adopt an independent service model or ethos, despite being described as independent or community settings, as they noted a difference between service settings. Walker (2012) also suggested that ethos affected delivery. Marlow and Walker (2015) reported similar findings around bedtime, and specifically find the amount of time that the tenants spend in bed needs to be lessened by offering more activities for the tenants in the evenings, which might encourage them to stay up later and potentially change learned routines around bedtime.

Isaacson, Cocks et al. (2014) noted that the lack of formal support services for people living in ISL arrangements made it more difficult for them to achieve independence. In particular, they noted the lack of informal support services made it necessary to rely on family networks and relationships to provide support. Similarly, Stainton, Brown et al. (2011) found that there were lower rates of access to formalised services for people living in individualised residential homes or family homes.

Despite moving out of their family homes, the case studies described by Isaacson, Cocks et al. (2014) 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 (Isaacson, Cocks et al. 2014; Marlow and Walker 2015). 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 (Marlow and Walker 2015).

Kim and Dymond (2020) reported a number of behaviours that contributed to people living in ISL arrangements losing the supported living placement. These behaviours are:

- dangerous behaviour to self or others
- medical issues
- financial issues
- guardian or family decision
- noncompliance with house rules
- voluntary decision to move out
- need for more intensive care
- move to more independent living setting
- illegal acts/drug use/sexual offending.

Other negative outcomes including quality of life were related to inadequate physical space, or space that was poorly organised or restricted.

2.1.4 Contributing factors to positive ISL outcomes

There were a number of identified characteristics of ISL arrangements that contributed 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 across a number of the studies (Isaacson, Cocks et al. 2014; Marlow and Walker 2015). For example, participants managed their own daily activities; some described structured daily routines while others lacked routines, characterised by getting up at a time of their own choosing, and having naps during the day.

Having autonomous space also improved social relationships to a smaller extent. Isaacson, Cocks et al. (2014) reported that one of the participants was now able to invite friends to socialise in his flat when he liked, rather than having it facilitated by support workers or family members. The studies by McConkey et al. (McConkey 2007; McConkey and Collins 2010; McConkey, Keogh et al. 2016) also found that there was a greater opportunity for people to invite friends or relatives to their home for a meal or to stay overnight when they lived in personalised arrangements, whereas people in more congregated settings had fewer opportunities to socialise independently. McConkey and Collins (2010) also found that more personalised settings fostered greater levels of overall social inclusion, beyond relationships.

Isaacson, Cocks et al. (2014) found particularly that having their own place to live and being self-reliant were important to participants in this study. More specifically, while some participants identified some negative aspects of their home's physical environment (such as space and sensory qualities), they highly valued having their own home as it enabled self-reliance, safety and security (Isaacson, Cocks et al. 2014).

2.2 Policy implications

This scoping review identified a relatively modest body of research concerning itself with ISL for persons with intellectual disabilities and high support needs. While there are a number of documented challenges and benefits of ISL identified in these studies, it is difficult to expand on the policy development implications from this relative limited evidence-base.

Expanding the evidence-base of ISL outcomes

- The limited research reporting on ISL outcomes, despite a growing interest for this approach to provide housing and support for persons with intellectual disabilities and high support needs, suggests that there is a substantial need to enhance the evidence-base of ISL outcomes. This includes the need to differentiate between the range of different approaches to providing ISL, different levels of support needs, different housing models, and other pertinent constellations of interrelated factors that impact both on the input required to support persons obtaining and maintaining their own homes, as well as the confounding factors affecting outcomes.
- Objective and comparable data is also required to evaluate the outcomes of ISL. Within the Australian context—and the context of this report—it would be advantageous for different administrative datasets to firstly record, as well as link, pertinent housing outcomes for persons with intellectual disabilities and high support needs. This may require alignment of NDIS funding codes with the Disability Services National Minimum Dataset combined with identifiers related to ISL. That is, a recording of whether it is an individualised arrangement with individualised support, in addition to the number of persons living together.
- It would also be beneficial to ascertain the cost-benefits of ISL. Previous research carried out by Cocks et al. indicates that ISL arrangements leverage substantial informal supports, which are often integral to these arrangements, both increasing the quality of outcomes—for example, sustainability, social networks, and social inclusion—as well as reducing the need for paid supports (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, O'Brien, McVilly et al. 2016; Cocks, Thoresen, Williamson et al. 2014). Such a cost-benefit analysis will have to account for the confounding impact of level of support need as well as the quality of outcomes.

Exploring the demand for and operationalisation of ISL

- It is difficult to ascertain demand for ISL, particularly given the diverging operational definitions of individualised arrangements in the academic peer-reviewed literature. It will be pertinent to critically review how these definitions have been operationalised and what the implications are for different contexts—including the demand for ISL.
- Given the general trend in Australia away from congregate living arrangements for people with intellectual disabilities, it will be important to carry out further analysis of the future demand for ISL arrangements. It is important that such an analysis accounts for the NDIS context, different housing arrangement options, level of support need, as well as potential changes in needs over time. ISL approaches include long-term planning, including foreseen future transitions—for example, as a person ages.
- Finally, although not specifically identified within the scoping review, it is important to review how housing for persons with intellectual disabilities and high support needs can be facilitated and supported by the mainstream housing support systems. While persons with intellectual disabilities and high support needs may have specific vulnerabilities, that does *not* mean that their housing options should be limited to those provided under specialist disability housing schemes.

3. Secondary analysis

- **Persons with intellectual disabilities and high support needs living in ISL arrangements were diverse: there was a range of circumstances and outcomes.**
- **Simply living alone, or another arrangement aligned to the characteristics of ISL, does not in itself create an appropriate and preferred home or generate good outcomes. Rather, it is important persons receive *appropriate* support.**
- **Support may be paid or unpaid. It is important that both the type and level of support matches the needs of the person with intellectual disabilities, providing assistance as well as opportunities for growth and development. Too much support or inappropriate support may hinder personal growth and development, and create an environment of overprotection.**
- **Strong ISL arrangements viewed the person holistically, including in the home, vocations or daytime activities, social and community connections, and personal growth and development. Having an appropriate and preferred home is essential for wellbeing.**
- **The sustainability of arrangements is vulnerable to continued and sustainable funding. Despite challenges, a number of strong arrangements had been maintained for a long time.**

3.1 Characteristics among included ISL arrangements

The identified 19 ISL arrangements from the earlier ARC-funded study were analysed using the framework method (Gale, Heath et al. 2013), as indicated in Section 1. In addition to a qualitative interview, these evaluations included a range of demographic information as well as the characteristics of the ISL arrangement: living alone, living with a co-resident, or sharing with someone with whom they had an established relationship (there were no participants living in a host family arrangement in that sample), as well as the hours of paid and unpaid support.

The study carried out ISL evaluations using the ISL Manual (Cocks and Thoresen 2017), which is a process-based fidelity measure to gather evidence from an ISL arrangement to ascertain whether indicators for each attribute within the ISL Framework are reflected in the arrangement. In addition, quality of life was explored using the Quality of Life Questionnaire (QOL.Q; Schalock and Keith 1993 and 2004), and social and community inclusion was explored using the Index of Community Involvement (ICI; Raynes 1988). An Assessment of Level of Support based on the International Classification of Functioning, Disability and Health (ICF) (Noonan et al. 2009) was also administered, but the values from this are not included in this report due to some missing data.

The possible range for the ISL evaluations is 21–105 (with 105 being optimal) and for the QOL.Q 40–120 (with 120 being optimal). The ICI accounts for the number of times each of 16 different community activities occurred during the last 30 days among participants. Recognising that there are limitations to any instrument, including those chosen for this study, the selection of these was based on their previous use in research with persons with intellectual and developmental disabilities and opportunity to utilise proxy-respondents.

Table 1 presents the individual socio-demographic characteristics, ISL total score, QOL.Q score, domains of the ICI, and matrix scores among these 19 participants. The rationale for presenting these for each individual is to illustrate the range and diverse characteristics and outcomes. Furthermore, given the relatively small heterogeneous sample, descriptive and qualitative analysis are more appropriate than statistical and quantitative analysis.

There were substantially more male (n=13) than female (n=6) participants and the majority were younger persons in their 20s (n=5) or 30s (n=9) (three participants in the 40s, one in the 50s, and one in the 60s). The majority of the participants lived alone (n=9) or with co-residents (n=7), with only a small proportion sharing with someone with whom they had a relationship (n=3).

Despite the relative younger age within the group, the length of time in the home was across the range, from less than one year to 20 years. Four participants had been in their home for 10 years or longer, while another six participants had been in their home for five years or longer. While a number of persons were in paid employment (n=3), self-employed (n=3), or carried out volunteer work (n=1), the majority were participating in non-vocational daytime activities such as alternatives to employment (n=9) or 'other' activity (n=2) (missing information for one participant).

While the remainder of this section accounts for the outcomes among participants within the framework method, including support and outcomes, the substantial range in hours of support among participants illustrated in Table 1 is noteworthy. There is no clear association trend between the hours of support (either paid, unpaid or combined) and outcomes such as ISL, QOL.Q, ICI or matrix scores (presented as percentages out of the theoretical maximum based on number of themes rated). It is important to note that the study only gathered hours of support received, but did not measure unmet support need—although some insight into this was provided in the interviews.

3. Secondary analysis

Table 1: Characteristics and fidelity to ISL among arrangements included in the secondary analysis

	Gender	Age	Type of ISL	Time in home	Daytime activity	Weekly hours of support			ISL score	QOL.Q score	ICI areas	Matrix score (%)
						Paid	Unpaid	Total				
1	Male	39	Alone	10 years	-	-*	-*	-*	67	107	10	64
2	Male	21	Alone	5 years	Alternatives to employment	124	44	168	82	105	12	78
3	Female	35	Alone	< 1 year**	Self-employed	13	45	58	68	95	14	58
4	Male	34	Co-resident	13 years	Paid and volunteer work	25	60	85	88	99	12	81
5	Male	30	Co-resident	3 years	Self-employed	209	4	213	79	100	9	91
6	Male	55	Alone	2 years	Alternatives to employment	40	0	40	57	87	8	31
7	Female	30	Co-resident	6 years	Other	23	28	51	73	82	11	64
8	Female	49	Alone	5 years	Alternatives to employment	5	4	9	74	90	8	62
9	Male	42	Alone	12 years	Alternatives to employment	131	11	142	65	74	1	69
10	Female	35	Alone	7 years	Alternatives to employment	96	72	168	86	86	11	48
11	Male	27	Alone	3 years	Other	306	50	356	74	53	0	57
12	Female	27	Co-resident	4 years	Alternatives to employment	54	20	74	65	82	11	43
13	Male	62	Relationship	20 years	Alternatives to employment	9	0	9	72	89	6	31
14	Male	34	Co-resident	< 1 year**	Alternatives to employment	33	54	87	78	73	9	92
15	Female	32	Relationship	3 years	Volunteer work	4	3	7	67	88	5	43
16	Male	47	Co-resident	1 year	Self-employed	173	0	173	73	102	8	71
17	Male	22	Alone	< 1 year**	Alternatives to employment	117	51	168	72	-*	9	55
18	Male	33	Co-resident	8 years	Paid work	27	8	35	70	80	7	78
19	Male	25	Relationship	7 years	Self-employed	28	88	116	80	-*	-*	86
Mean	-*	35.7	-*	5.9**	-*	78.8	30.1	108.8	73.1	87.7	8.3	63.2
SD	-*	5.6	-*	5.0**	-*	83.5	28.3	90.6	7.7	30.5	4.0	18.6

* A dash (-) indicates missing data or not applicable. ** < 1 year was interpreted as 1 year for calculating mean and standard deviation. SD = standard deviation.

Source: Authors.

3.2 Matrix outcomes

Of the 19 ISL arrangements evaluated using the framework method, about half (n=9) were strong arrangements (rated as 5 or 6), with a similar number (n=8) viewed as mid-range (rated as 3 or 4). Two arrangements were poor (rated as 1 or 2).

An account of the characteristics of strong, mid-range, and poor arrangements across the matrix outcomes for each of the six themes within the matrix follows.

3.2.1 Current living situation

The current living situation was viewed as strong for eight of the arrangements. These eight arrangements shared characteristics, such as being developed over time with a specific emphasis on the person with intellectual disabilities, often including governance systems such as 'circles of support', a Microboard™ or other mechanisms to involve a range of stakeholders such as family, friends, advocates, co-residents and service providers. Circles of support may take many different shapes and forms but are often an informal group of friends who have made some form of commitment to provide support or otherwise advocate or be part of the person's life. Microboards may be an extension of these, usually consisting of a small group of people such as family and friends who form a non-profit organisation to support and even manage the formal and financial components of an ISL arrangement (Cocks and Thoresen 2017).

An additional characteristic of strong arrangements for the current living situation was evidence of development through hard-fought battles with bureaucracies for funding, housing and support, and the involvement of a range of stakeholders including family, friends, advocates and service providers, who provided safeguards. There was also evidence of meticulous work towards developing the arrangement for the person with intellectual disabilities, including substantial effort in recruiting appropriate support persons, including co-residents, who suited the person.

Arrangements that were mid-range reflected many of the same characteristics of those that were strong, but often had fewer safeguards. For example, they were driven by a parent without support from other stakeholder groups, such as service providers or friends. In other instances, there were vulnerabilities around the driving force behind the current living situation which meant that it may be unable to continue for the long run—for example, when parents were ageing. Common characteristics for other current living arrangements that were developing, included working out challenges—for example, support and funding or other adjustments to the current living situation that had not yet been resolved, but were typically being addressed.

The two arrangements that were viewed as poor current living situations both reflected 'service-oriented' characteristics, with the needs of the service providers treated as being of greater importance than the individual needs, goals, strengths and vulnerabilities of the person with intellectual disabilities and high support needs. In one instance, it was also indicated that the person was transitioning into a group home.

3.2.2 Planning ISL

About half (n=9) of the arrangements were viewed as strong with regards to planning the ISL arrangement. They shared characteristics such as:

- purposeful planning around the specific needs of the person, with multiple layers of safeguards
- substantial researching and planning of different housing models
- involvement of multiple stakeholders, such as family and friends, independent advocates, service providers, and even government or disability services representatives.

These were common characteristics shared by other arrangements viewed as strong. Although in several of these instances there had typically been ongoing struggles with obtaining and maintaining funding or otherwise sourcing the resources to support the establishment and maintenance of the arrangement, but these were eventually overcome.

For about one-third (n=6), the planning arrangements were viewed as mid-range. In these instances, there were similar challenges as those encountered among the strong arrangements, but they were typically still ongoing. Other characteristics included reservations among key stakeholders—including parents—regarding how individualised the living arrangement would or could be. In these instances, there had typically been previous adverse events, including funding cuts, which had negative impacts on the establishment or maintenance of the arrangement. This also triggered the consideration of congregate options, such as group homes. This suggests that both establishing and maintaining ISL arrangements requires substantial ongoing commitment, which may be pivotal for the continuous pursuit of individualised living arrangements.

Recognising that there may have been limited information provided for the establishment of some of these arrangements, those that were deemed as not developing did not include any explicit person-centred planning, but appeared to be more crisis-driven. As such, there was limited long-term or developmental planning.

Among the four arrangements viewed as not developing, one arrangement was given the lowest possible rating. There was no evidence of any meaningful planning, currently or previously, congruent with the ISL Framework, as arrangements appeared crisis-driven and were supported by mental health and specialist homelessness services. While there were identified goals—for example, around relocating closer to social supports including family and work—no planning to facilitate this was identified for that arrangement.

3.2.3 Social connections

Social connections was one area with the greatest potential for further development. Only four arrangements were viewed as strong in social connections. While this may reflect a generic recognition of there always being room or opportunities for more meaningful social and community connections, there were a range of natural developing relationships and increased social and community roles that had been facilitated through the arrangement. This included friendships with co-residents that had expanded to their friends and families, employment opportunities that were expanding, and a range of meaningful community activities. Close and lasting friendships were also reflected among the other strong arrangements, as well as additional social connections with family and acquaintances, along with community participation.

About two-thirds (n=12) of the arrangements were viewed as mid-range for social connections. Typically, the person with intellectual disabilities and high support needs was developing social networks through a community presence—for example, by utilising community services—but there may have been identified opportunities or desires for further social connection, including with family members, developing friendships, and in the community more broadly. Examples included a desire to develop stronger relationships with siblings, developing more meaningful friendships, or participating in specific community activities or having more meaningful roles in such activities—for example, moving from being an observer to an active participant in specific activities.

Recognising that developing friendships may be complex and challenging, the development of social connections generally is ongoing for many. However, three arrangements were viewed as not developed with regards to this theme. In these instances, there were multiple references to the person being lonely or the information indicated a clear lack of social connections, including with family. In these instances, social connections were typically limited to those provided through segregated, disability-specific activities under the auspice of service providers. However, as noted by several of the informants, mere presence does not equal social connections. Congregate arenas such as group homes or alternatives to employment programs for persons with intellectual disabilities and high support needs do not necessarily enhance social connections.

3.2.4 Informal supports

Informal or unpaid support inevitably draws on social connections, and was one of the least developed themes. However, about one-quarter (n=5) of the arrangements were strong, and leveraged informal supports that were integrated with the social connections discussed earlier. In these instances, the range of informal supports were facilitated by stakeholders, including co-residents, family, friends of the family, as well as their networks more broadly. There were also examples of how the boundaries between formal and informal supports blurred, reflecting both the development of genuine relationships with carers and co-residents who would provide informal support in some instances, but also act as formal supports in other instances.

The informal supports were viewed as mid-range for another four arrangements. In these instances, this support was often family-driven, and additional efforts to leverage other informal supports had been unsuccessful or unsustainable. This included attempts to connect with volunteers but without a suitable match, or the utilisation of an advocacy organisation that provided support and advocacy on a strategic level, but not in terms of connecting directly with the person at an individual or relationship level.

Thus, the majority of arrangements were not developed with regards to informal support. In two instances there was insufficient information to rate this theme, but it may also have indicated that there was no informal support to speak of. In the remaining eight arrangements that were viewed as poor, informal support was often provided by the family—frequently the mother. However, this was typically the only form of informal support available, and in many instances it was unsustainable. This partly reflected insufficient funding for formal support, with the mother or other family members having to step in to provide additional support to sustain the arrangement. In one instance, it was conveyed that this was so untenable that the mother had reached the decision of placing the person in a group home, as she did not have the stamina to continue. However, this should not be interpreted as insufficient informal support being detrimental to the continuation of this arrangement. Rather, it is an indication of insufficient formal supports, with informal supports having to step in and take on that role, instead of being a conduit to enhanced social connections and community inclusion.

3.2.5 Formal supports

While there may be various challenges or hurdles related to formal supports when it came to obtaining funding, and the rules and regulations for staffing, including occupational health and safety, eight of the arrangements were viewed as strong regarding formal supports.

In these instances, there were typically a range of formal supports, which were flexible and included contingency plans for when a support worker became unable to work at short notice. They included in-built routines or protocols for dealing with challenges and adverse health events, as well as drawing on a range of appropriate specialist services to foster development—for example, involving a speech pathologist to improve communication and comprehension. The speech pathologist also developed strategies for the support teams and support workers in the ISL arrangement to further expand the communication and comprehension skill of the focal person. As mentioned earlier, there were also instances where the roles became blurred, with formal supports becoming part of the person's informal network in an individual capacity—for example, as an advocate, and developed close relationships and friendships. In these instances, the roles of formal and informal support often became blurred.

Formal supports were mid-range in about half the arrangements (n=9). In other words, the formal supports were found to be adequate, both in terms of amount of support and in terms of types of services, but there were still opportunities for additional development. It may be that there were wishes for expansion of funding to facilitate more community-based activities, pursue specific skills development or enhance the flexibility of when support was provided. It may also reflect that the amount of support was restricted due to limited funding, in some cases due to a conscious decision to emphasise quality over quantity. Opportunities could be identified for additional personal development or strengthening of the arrangement if additional formal support were available.

In two instances there were clearly insufficient formal supports, and this placed the living arrangement in jeopardy. To a certain degree, family members and others had provided substantial informal supports to mitigate this.

It is also important to note that the formal support needs to be suited to the person with intellectual disabilities and high support needs. For example, if the person is not comfortable with a specific support worker, it can be detrimental to the arrangement. Furthermore, formal supports may also play a crucial role in skills development and personal growth, and it is important that these match the interests, needs and ambitions of the person. For example, if there is a desire for the person to become more independent with house chores, a support worker who 'does for' instead of 'with' the person will not foster the needed personal or skills development.

3.2.6 Wellbeing

Wellbeing was rated as strong for the persons with intellectual disabilities and high support needs in seven arrangements. In these instances, it was clearly tangible that the wellbeing of the person was paramount to the arrangement, and was the primary focus of everyone involved. This led to expansion of social roles, independence, skills, and articulations of thriving in one's own home—which may or may not have been verbalised, based on the level of support needs among the focus persons. Typically, these were meaningful (from the standpoint of the focus person) and normalised activities, which avoided congregate settings typical in mainstream disability services. There were layers of safeguards to protect progress made, and no obvious gaps were identified regarding additional activities that could or should be pursued. It was obvious that the person was thriving in their home, and that the ISL arrangement facilitated a range of additional positive outcomes related to normative social roles, social and community activities, and reduction in challenging behaviours, as well as improved health—including mental health. The fruits of the work put into developing these ISL arrangements were evident, both to those involved with the living arrangements and to the researchers.

For the majority of participants, wellbeing was mid-range. In these instances, it was obvious that the wellbeing of the person with intellectual disabilities and high support needs had improved, and that people involved were overall satisfied. However, there may have been vulnerabilities regarding what safeguarded the progress—for example, it may have been contingent on a specific person without any backup. In other instances, it may have been clear that substantial progress had been made, but that there was still additional work to be done to achieve desired outcomes, often related to expanding social networks or relationships. In many instances, stakeholders were aware of these issues, even articulating ideal scenarios and dreams they were working towards, acknowledging that there were still substantial work and challenges ahead.

The wellbeing theme also reflected how key stakeholders in these arrangements were attuned to the needs, preferences, strengths and vulnerabilities of the persons with intellectual disabilities and high support needs. However, two arrangements were viewed as not developed in this area. In one instance, it was clear that the lack of support was having a detrimental effect on the person's wellbeing. His support needs included assistance with toileting, but he did not receive this during the weekends and had to rely on diapers, which was clearly unsatisfactory. The other arrangement appeared to be very service-oriented, with emphasis on staffing and complying with agency requirements, without much attention to the needs and wishes of the person who was lonely, and with no evidence to suggest that his wellbeing was improving.

These last examples highlight some of the risks of congregate housing and care models to the wellbeing of persons with intellectual disabilities and high support needs. While congregate models have not been the focus of this research, these approaches have inherent challenges when the interest of the service providers and the persons with intellectual disabilities and high support needs diverge, or if there is too much emphasis on service providers' rules and regulations. These challenges, including the issue around toileting, were accounted for in the Interim Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Commonwealth of Australia 2020), which highlighted the challenges with service provision for persons with disabilities in Australia.

3.2.7 Sustainable funding

Recognising the contemporary transition of disability services funding into the NDIS, the strategies to obtain and maintain sustainable funding are still applicable despite this information being gathered from the preceding ARC-funded study. The small proportion (n=4) viewed as having strong strategies to obtain and maintain funding had secure housing through social housing schemes (n=3) capped to their level of income—in this instance their Disability Support Pension—and one person with intellectual disabilities and high support needs lived in a home purchased for them by their family.

The funding arrangements for about half the participants were viewed as mid-range (n=9). While there was limited information concerning the specifics of these funding arrangements—including three arrangements that could not be rated because of lack of this information—it was clear that there were challenges to obtaining sufficient funding across the different areas required to make the ISL arrangement sustainable.

However, the majority of these arrangements had made provisions to overcome these challenges. One example related to the lack of formal supports, which was compensated by co-residents doing direct care work. While this approach enabled the maintenance of the living arrangement in public housing, it is unclear how sustainable it was as the required lifts, without supporting equipment, most likely did not conform to occupational health and safety standards and may have detracted from the other roles of the co-residents. Other examples included arrangements that had secured substantial funding, but still not sufficient to cover the required support needs, and therefore the informal network often had to provide additional support to maintain the living arrangement.

In three instances, the arrangements were viewed as poor regarding sustainable funding. In these cases, it was obvious that the lack of funding was either having a detrimental impact on the wellbeing of the focus person, or on the resources of the parents. In cases where parents were subsidising funding, they had spent their funds and would no longer be able to subsidise the arrangement. Thus the parents were contemplating congregate options, such as group homes or renting out a room to another person with disabilities to enable 'sharing of supports'.

These examples show how it is not just funding for or access to affordable and appropriate housing that is a challenge to create and maintain sustainable homes for persons with intellectual disabilities and high support needs, but also access to in-home support.

Most of the arrangements viewed as developing regarding sustainable funding were managing the limited funding and leveraging informal networks and support to manage. While leveraging both formal and informal supports is an advantage of the ISL approach, there is also a danger that if there is insufficient support, the limited support available (both formal and informal) gets redirected towards direct care support rather than developing skills, relationships and valued social roles. It reflects a disability service culture of managing with the resources available, rather than seeing opportunities for further development. While the NDIS aims to sufficiently fund disability services based on individual needs, emphasising an actuary model that may favour early intervention and investment of resources that may reduce lifetime costs, these ambitions may be limited by annual budgets and planning cycles.

3.3 Policy implications

Reviewing the secondary information gathered from the preceding ARC-funded study by individual themes according to the framework method has enabled the identification of strengths and weaknesses at a more granular level than an overall analysis of individual arrangements.

Creating appropriate and preferred homes

- It is clear that the ISL Framework is an approach that can create appropriate and preferred homes. However, for this to be successful, it is crucial that there is sufficient, ongoing short-term and long-term planning. This requires access to affordable, secure long-term housing combined with sufficient direct care and informal support. While previous state-based disability and housing schemes were aimed at facilitating this, it is unclear how this will be incorporated into the NDIS, while recognising the needs and diversity of persons with intellectual disabilities and high support needs.

Appropriate mix of sufficient formal and informal supports

- Most people with intellectual disabilities and high support needs require both formal and informal supports. This may facilitate appropriate and preferred; enhance social connections with family, friends and in the community; and improve overall wellbeing. Both housing and disability policies need to facilitate sufficient formal and informal supports. This may include specific concessions concerning sharing arrangements in social and public housing—for example, for co-residents.

Sustainable funding

- Sustainable funding for both housing and support was identified as a substantial and often ongoing challenge. For persons with intellectual disabilities and high support needs, predictable and stable funding is crucial to both create and maintain appropriate and preferred homes. Current NDIS-planning processes may not sufficiently enable the long-term planning required to create appropriate and preferred homes, nor a sense of security of access to funding or supports given the planning and funding cycles.
- Current disability funding and disability housing models have retained many of the features from congregate care models, emphasising the grouping of people with disabilities in, for example, group homes or alternatives to employment daytime activities. There may be perceived cost-saving in this approach through the sharing of resources. However, this does not take into account the substantial costs associated with poor outcomes for persons with intellectual disabilities and high support needs identified in the Interim Report of the Royal Commission, nor the substantial costs to and lost productivity of family members, particularly parents. Therefore, both housing and disability policies and practices need to adopt a more holistic and long-term approach to funding models that support persons with intellectual disabilities and high support needs living good lives in their own homes.

4. Qualitative interviews

- **Persons with intellectual disabilities usually had two different pathways into ISL arrangements: they either moved directly from their family home, or they decided on the arrangement after congregate arrangements proved unsuitable.**
- **Transition into ISL arrangements was considered more successful when it happened gradually.**
- **Benefits of ISL arrangements included having more choices, increased safety and stability of the arrangement, and a sense of belonging in the community.**
- **A major fear identified related to continuous and predictable levels of funding for the arrangement, and how the arrangement would be sustained after the parents of persons with disabilities passed away.**

4.1 Analysis

As described in Section 1, 21 qualitative interviews with persons with intellectual disabilities or others central to the specific ISL arrangements were carried out in late 2020 and early 2021. These interviews covered:

- the development of the ISL arrangement—the pre-decision time and the decision time
- the arrangement—how things worked, challenges, funding, supports, and plans for the future
- the level of support and community involvement.

The voices of the participants with intellectual disabilities and high support needs were only captured in a few instances in these interviews, which is a limitation. Future studies will be strengthened if the study design captures more than verbal communication, such as observations within the living situation. This was not possible in the current study because of social-distancing requirements and other COVID-19 pandemic restrictions, as noted earlier.

The analysis consisted of a combination of deductive and inductive coding, drawing on content analysis methods (Azungah 2018; Boyatzis 1998; Mayring 2014). Interview transcripts and notes were analysed using the qualitative data analysis software MAXQDA (Release 11.2.5 by VERBI Berlin), with text deductively assigned to thematic areas of the interview questions and then inductively coded according to content. An initial coding structure and a preliminary coding system were developed by three researchers from the project team, who individually reviewed four interview transcripts (two from WA and two from NSW/ACT). The results of this initial analysis were then cross-checked between the researchers, and the final coding approach for the interviews was agreed upon between the researchers before the rest of the interview material was analysed.

These subcategories were later included in the framing of thematic categories, as appropriate, and represented as themes that emerged from the dataset. The qualitative data in the MAXQDA software was complimented by the inclusion of socio-demographic variables, such as:

- the gender of the person with intellectual disabilities—female/male
- the type of living arrangement—alone, with co-resident, host family
- the tenancy model of the arrangement—private rental, owned, public housing.

This enabled comparisons between cases and situations by identifying contextual differences and commonalities between cases.

4.1.1 Characteristics of ISL arrangements

An overview of the characteristics of 21 ISL arrangements is presented in Table 2. The majority of persons with intellectual disabilities were males (n=16) who typically lived alone (n=16), while four individuals lived with co-residents and one with a host family.

The tenancy arrangements included:

- ownership (n=10)
- private rental (n=8)
- public or social housing (n=3).

The arrangements were managed, using the NDIA management categories (see glossary) by an agency (n=11), self-managed (n=7) typically by the family, shared management (n=2) between an agency and the family, and by a Microboard (n=1). The respective attendees in the interviews are also shown.

Table 2: Characteristics of ISL arrangements

Case	Sex/gender	Arrangement type	Tenancy model	Management type
WA-1*	Female	Living alone	Ownership	Self-managed
WA-2	Male	Living alone	Private rental	Agency
WA-3	Male	Living alone	Ownership trust	Shared management
WA-4*	Male	Living alone	Private rental	Agency
WA-5	Male	Living alone	Ownership	Self-managed
WA-6	Male	Living alone	Ownership/ trust	Self-managed
WA-7	Male	Living alone	Ownership	Agency
WA-8*	Male	Living alone	Ownership	Agency
WA-9*	Male	Co-resident	Private rental	Microboard
WA-10*	Male	Living alone	Public/social housing	Agency
WA-11*	Female	Living alone	Private rental	Agency
NSW/ACT-1	Male	Living alone	Private rental	Agency
NSW/ACT-2*	Female	Living alone	Public/social housing	Agency
NSW/ACT-3*	Female	Living alone	Private rental	Self-managed
NSW/ACT-4	Male	Living alone	Ownership	Shared management
NSW/ACT-5	Male	Living alone	Private rental	Self-managed
NSW/ACT-6	Male	Co-resident	Ownership	Agency
NSW/ACT-7	Female	Host family	Ownership ⁵	Self-managed
NSW/ACT-8*	Male	Living alone	Ownership	Self-managed
NSW/ACT-9*	Male	Co-resident	Private rental	Agency
NSW/ACT-10	Male	Co-resident	Public/social housing	Agency

* Indicates that the focus person with intellectual disabilities was present during the interview.

Ownership for persons with intellectual disabilities and high support needs can be complex. The 'ownership' tenancy model in this table refers to the focal person with intellectual disabilities and high support needs and/or their family having ownership of the home.

Source: Authors.

4.2 Interview findings

The findings from these interviews are presented chronologically across three different phases:

- before the arrangement was set up
- the current situation with the arrangement up and running
- future outlook.

⁵ The person with disabilities was part-time living in a host family but also lived part-time at home with her parents, who had built a granny flat in her backyard that is owned and planned to provide her with a home in the future.

4.2.1 Before the arrangement was set up

Participants reported that the current arrangements had existed between six months and 20 years. Prior to their current ISL arrangement, they lived at home with their families, in public or social housing (without ISL-specific supports), in respite care, or in a group home, including a combination of these settings.

However, 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 with intellectual disabilities made the move. However, a young male who moved into an ISL arrangement at the age of 19 had already had a three-year history outside the family home, including living in respite care and a shared arrangement, before the ISL arrangement was pursued after a violent episode.

An illustration of the influence of the cultural background on pursuing an ISL arrangement came from the mother of a person with Down Syndrome, who explained how she viewed it as a cultural expectation to leave the family home and move into one's own home:

I come from the UK, we tend to leave home, you know, to go to university et cetera, rather than here where people don't tend to do that. Uh, so my feeling was there, this would be important for [person with intellectual disabilities] to leave home as well. (NSW/ACT-6).

For others, an ISL arrangement was only pursued after a turning point or a break in another living arrangement. Interestingly, cultural expectations to move out and start one's own life were more often raised for male persons with intellectual disabilities, whereas critical turning points were more often reported for females. Two female persons with intellectual disabilities had specifically abusive experiences, with one being raped in a group home and another had to be removed when it appeared she was in a relationship with an abusive spouse. In this regard, her mother stated:

She was married for three [years] or so, and through no fault of her own there was a situation developed and [she] needed to leave that partnership, um, and without any warning at all she was, she had to come home with me that day. Um, and her baby (WA-1).

In another instance, the realisation that the person with intellectual disabilities was capable of living in their own home developed after the father was away on a holiday and the individual being supported in the family home by respite support workers. When the father returned, the person with intellectual disabilities had become accustomed to that arrangement. According to the father:

So when I returned, [person with intellectual disabilities] basically said, 'Well, who are you? What are you doing here? I'm just doing fine by myself' [...] and so [I thought] the time has probably come that maybe we should look a bit more seriously about where [he] might live (NSW/ACT-8).

Poor experiences with congregate living arrangements, which were not able to accommodate the individual, instigated others to pursue more individualised living arrangements. Another aspect concerning how the arrangement came about was a lack of person-centredness, which could typically be found in group home settings. A mother from WA reported that her son's previous living arrangement was clearly not taking his needs and wishes into account when she mentioned:

[Person with intellectual disabilities] just used to get left to sit in the corner because he was easy to look after, so I wasn't extremely happy with it. I thought he was getting ignored a bit (Mother, WA-3).

Another relative of a person with intellectual disabilities reported that:

[Person with intellectual disabilities]'s sister took her out of the group home because they were rough with [her]. Sometimes she would have to have dinner at 4 pm and go to bed at 6 pm (WA-11).

The concept of ISL arrangements is not necessarily commonly known, and for some this possibility was considered after it was recommended by others who were familiar with the model and who considered it feasible for the person with intellectual disabilities. For example, a mother reported:

[Person with intellectual disabilities]'s current housemate had lived in an arrangement in England where he lived in a flat with somebody with a disability in return for free rent. That was a model like he had—he knew about and had experience. [...] So he was a support worker whom we got to know quite well. Anyway, over time, we discussed it and we decided we'd like to try it (NSW/ACT-6).

The majority of these ISL arrangements were established as a joint effort between the family and a disability support organisation. Participants reported that these organisations were particularly useful because of their sector knowledge and familiarity with legislation and related processes.

Some participants mentioned that they chose the support of an organisation as it had managers and support worker teams in place, or that the organisation had the capacity to put in the necessary applications to obtain funding for the arrangement. In a joint interview with a support manager and the parents of the person with intellectual disabilities, the support manager highlighted that the organisation could only work successfully on the set-up because the parents provided constant feedback. This highlights the importance of cooperation between all stakeholders involved for success.

Interviewees were also asked about the biggest influences while setting up the arrangement. Most of the interviewees answered that a strong personality in the disability scene either inspired them to embark on the adventure of setting up an ISL arrangement, or that the respective arrangement was recommended to them by a former team leader or local area coordinator. Other interviewees reported that they had a good existing network of peer supports that helped them to decide on an ISL arrangement. In one case, the father of a person with intellectual disabilities stated that he used NDIS information sessions to build and expand his knowledge about the ISL model before deciding to pursue this approach together with his son:

Yes, I talked to other carers but also lots of information on the NDIS was happening. There was lot of information sessions happening. So I used to attend them—what is the expression—attend them on a regular basis. And I knew it was gonna be huge. And I have been following NDIS coming in even when it was happening in UK slightly different—and when Australia admitted, yes, that is human rights abuse of disabled people in Australia, I knew the change was coming. And of course, they brought it in because people with cerebral palsy et cetera were put with aged care people and that's a huge human rights issue for both people of aged care plus disabled people (NSW/ACT-1).

The typical response to how the move into the ISL arrangement occurred was that it happened gradually over time:

It was a gradual process so that she felt comfortable, um, so we furnished it and made sure so that then she might come in the morning or she might come for a little while, she might come back for a week and then she started spending a little bit more time, not necessarily on her own and or with me or whatever. And then when she decided it was the time, she did her first night sleepover and then it grew from there (Mother, WA-1).

Choosing the right support staff emerged as an important element in setting up the arrangement. Some interviewees shared their careful search prior to selecting support workers. They indicated that they had to ensure that the support workers they employed would not cause harm to the person with intellectual disabilities, recognising specific vulnerabilities. Other considerations for some were the need for using familiar language and communication techniques, so as not to overwhelm the person with intellectual disabilities. In other instances, some respondents viewed themselves as fortunate that they were able to transfer support workers from the previous arrangements—which meant that the persons with intellectual disabilities did not have to get accustomed to new support staff. This was viewed positively by some for turning the new arrangement into a success.

Among the challenges involve in setting up the arrangement were funding and working with funding agencies. In another instance, a participant commented on how cultural expectations and community pressure had initially hindered the pursuit of an individualised living arrangement. Being from a South-Asian background, his parents feared that his son, their grandchild, could be abused in an individualised arrangement. Their community also raised concerns over placing his child in overnight respite. However, after overcoming these cultural barriers, the father deemed the ISL arrangement, supported by the NDIS, as phenomenal (NSW/ACT-1).

4.2.2 The ISL arrangement

What does a normal day in an ISL arrangement look like?

The informants reflected on the support needs of the persons with intellectual disabilities, or the various activities they were engaged in when asked what a typical day looked like. These were broadly related to community participation and physical exercise, along with activities related to individuals' preferences or interest areas. The most common activities for community participation included staff taking the persons with intellectual disabilities to their choice of outings, such as meeting friends, going out to walk the dog of the host family, attending music gigs, and visiting hospitality venues such as coffee shops, pubs or restaurants. In terms of typical physical activities, the most common activity was going swimming, followed by going for a walk and going to the gym. Regarding individuals' preferences and interests, the affinity for wellness treatments and spas was reported in one instance: '*... he loves being pampered, having [a] head massage*' (WA-6).

In contrast to what is commonly the case in congregate settings, informants emphasised support needs with household and related chores, such as doing the weekly shopping. These are tasks usually covered by support or domestic staff in group homes. For one person with intellectual disabilities, their personal progress or skills development in this arena was attributed to the new ISL arrangement. The individual, who lived part-time in a host-family arrangement, had made substantial improvements:

Some things are not as much hand-over-hand and it's more prompting, you know, prompting her, you know, now what to do next, what to do next, you know (NSW/ACT-7).

This example illustrates an important attitude pertinent to ISL arrangements. 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 (although in the short term that may be a faster way to complete the task).

Enablers and benefits of the current arrangement

Interview participants were asked what worked particularly well in the ISL arrangement, or what enabled the arrangement in the first place. The clearest and most prominent theme to emerge in the analysis was 'having more choices and being happier'. An example of these choices in everyday life that led to being happier was given by a mother of a participant with autism and high support needs:

So if they take [person with intellectual disabilities] shopping they ask him, 'What does he want to eat?' Pizza or pasta or something that [he] chooses. But you know, if parents, also I am a mum, mum always chooses what you [your child will eat]. So this is why if you're still with parents, maybe also with autism, they feel stressed I think, so now I think [he] is happier than before (NSW/ACT-1).

Emphasising the person-centredness of the ISL arrangement, another parent replied:

So, um, he gets to choose what he wants to do on a daily basis. So if he feels up to it he'll, you know, choose to go out; if he's not feeling great, um, he can stay at home and that's okay. Um, if he wants to watch a movie on, on TV or if he wants to listen to music or watch his YouTube, his favourite activities, he, he can do that (NSW/ACT-5).

Having choices and choosing meaningful activities were viewed as an important part of good ISL arrangements. To enable this, catering for the mobility needs of individuals was noted as crucial. Participants reported that they had been able to acquire a car or a van, sometimes including specially adapted features such as harnesses that allowed them or their family member to participate in community life, attend leisure activities, or visit friends and families. The necessity of a car, and the granting of a mobility allowance, could be justified through the voluntary work of the person with intellectual disabilities. It was highlighted that cars and vans are not typically funded through the NDIS, and funds typically had to be sought from elsewhere. However, once the funds for a car were granted it could be used for a variety of purposes that were greatly valued. Once purchased, the running costs were typically incorporated into the individual support package:

Mother: 'That's—he funds the fuel, um, and it's handy to have the car because if you took him to a football match and he, he played up—misbehaved, you could at least go out and get away and with him.'

Father: 'That's invaluable, yeah' (WA-2).

Another major theme regarding the positive outcomes of the arrangements was safety and stability. Regarding the person with intellectual disabilities who had been sexually abused in a group home (referred to earlier), safety was the major outcome of the ISL arrangement, as her sister elaborated:

Well, I think the positive outcomes for [her] is that a, she's got her own place, she doesn't have to worry about being here. Because those sort of things do come back to her and she'll just break out and cry. Um, she's got safety. So she's, you know, she's got the one-on-one attention that she needs because she needs a lot of support because she's deteriorating (NSW/ACT-3).

The risk of loneliness is a criticism of persons with intellectual disabilities and high support needs living in more individualised arrangements, or non-congregate settings. However, the participants in this study challenged that position, reporting that the persons with intellectual disabilities enjoyed a life in the community in which they felt valued and included. Community members became engaged in people's lives and considered their needs and interests after getting to know them as individuals. This was illustrated by a father who explained how his son had inherited a musical instrument from a shop owner who passed away.

This is, he has, he has a, he has an organ that belongs to his, um, um. It belonged to the man, she, the wife of the man who owns the local music shop and he knew that [person with intellectual disabilities], um uh, liked music and he gave it to [him] (NSW/ACT-8).

This quote clearly shows that the individual was not just known as an identity in the community, but that his personal interests and hobbies such as music were known as well. Another interviewee gave an example of community inclusion through being a regular participant at what was known as 'street drinks', a weekly or fortnightly occasion to meet with neighbours and have a chat to catch up. As narrated by her mother, this also had additional benefits regarding her safety in the community:

Now, she now goes to drinks every Friday night up here and she rides her bicycle up here to all of these people, so she's got a whole lot of safe houses very much dotted within walking distance of here where she knows a lot of people (WA-1).

Three additional and interrelated themes emphasising the benefits of the ISL related to 'increased independence', 'the person's life is less restricted than before', and 'the person has more freedom'. These themes sat in contrast to previous living arrangements.

When ISL arrangements are developed around an individual, their specific needs and vulnerabilities can be addressed within that arrangement. One of the persons with intellectual disabilities had struggled with his diabetes when he lived alone in a public housing setting, and had entered respite care as it had been life-threatening. After setting up an ISL arrangement as a co-residency model, he now successfully manages his diabetes with the support of his housemate. Others also reported health improvements due to a better diet, with some stating that they better manage their obesity or that they ate healthier meals compared to their previous living situations. For one individual who struggled with anxiety, living in an ISL arrangement had led to having significantly fewer seizures than in the previous group home setting, creating significant improvements in his quality of life.

There were also several individually reported benefits, including a person with intellectual disabilities who no longer self-harmed since moving into an ISL arrangement; another person with intellectual disabilities who was much more relaxed; and interviewees who praised the ISL arrangement as being flexible. These arrangements did not only prove beneficial for the persons with intellectual disabilities, but also for their families or co-residents. One family reported having peace of mind as they no longer worried about whether their family member with intellectual disabilities was cared for sufficiently. As narrated by his mother:

For me, so for the family, for me and my other sons, what that does is, it gives us the peace of mind. Well, it gives us the confidence that he's well looked after. So, because he's got, I kind of see it as circles of safeguards. He's got [his co-resident]. [His co-resident is] his main safeguard and I'd say [the co-resident] knows [the person with intellectual disabilities] better than I know him now. And then he's got the small group of key support workers who really don't change much and then he's got the community and then he's got [his disability support organisation] and then he's got his family and these are all the sort of safeguarding (NSW/ACT-10).

Another interviewee stated that being and acting as a co-resident had helped him to find a purpose in his life, while another co-resident reported planning to get qualified as a support worker so that he can either work in other settings or help his co-resident with intellectual disabilities in a more support-oriented way.

Barriers and challenges for the current arrangement

One of the more common challenges related to the skill set and attitudes of support workers and different approaches within the support team. Experienced support workers who had built their relationship and knowledge of the person with intellectual disabilities over a long time had developed specific routines that suited the respective individual. It was reported that these routines were sometimes challenged by other support workers who did not know the person that well, or who wanted to try a new approach for other reasons. While these suggestions may have been with the best intentions, unless new approaches were trialled in a consistent and coordinated way, there could be risks to progress that had already been made, and potentially detrimental impacts for the person with intellectual disabilities. Participants reported that it is crucial that staff are on the same page, and that sometimes support workers had to be replaced if they were unable to follow established routines:

Support worker: 'Yeah, one person can stuff it up for six other people, they wanna do it their way, not the right way that suits [person with intellectual disabilities] or nitpick ...'

Mother: 'We say all the time: don't try anything new with him unless you [are] gonna pass it by the rest of the team, and we used to have regular team meetings to discuss all these things and there would still be one to do it their own way' (WA-3).

To keep staff 'on the same page', one interviewee reported that they had put up a whiteboard in the home of the person with intellectual disabilities with all necessary information about day-to-day care and where recent changes were noted, so that the rostered staff received all information to successfully complete their shifts.

In line with keeping routines for better outcomes, another common issue was reported for persons with intellectual disabilities who disliked changes and would get anxious when unexpected things happened. For one person with intellectual disabilities, their mother reported that instead of drawing on casual agency staff, she would fill in vacant shifts herself to avoid this risk:

And there isn't the highest staff turnover that he used to have, he doesn't cope with new faces and that's why I prefer to do a night with him instead of emergency staff called in (WA-2).

Another commonly voiced challenge was about housemates, their retention, and strategies to remove an incompatible person from the arrangement when necessary. How such challenges emerged, potentially unforeseen and without anyone at fault, was illustrated in the interview notes for a participant who declined to be audio-recorded:

The first housemate was generously remunerated to live with [person with intellectual disabilities] and contribute to his life. However, after the death of someone close to him, this went downhill rapidly and it was difficult to have the housemate removed from the living arrangement (WA-9).

The impact of such challenges was succinctly voiced by another person with intellectual disabilities, indicating that the high turnover of housemates in his arrangement 'hasn't helped' and this was 'annoying'.

The family in another case raised their dissatisfaction with their support coordinator, who had to be chased up to do his duties. Although this family praised the cooperation with the organisation generally, the support coordinator created tensions that risked the success of the arrangement. Thus the family aimed to get him replaced by the organisation. Another example of the impact one individual could have on the sustainability of an arrangement related to another case when a housemate, who had been living with the person with intellectual disabilities for a year, decided to suddenly leave the arrangement. This all occurred when the mother of the person with intellectual disabilities—who self-managed the arrangement—was abroad and had to come up with an interim solution while overseas. Eventually, the situation was resolved with the help of an external support coordinator.

These examples illustrate the potential vulnerabilities of arrangements that are reliant on individuals who spearhead the development and continuation of the arrangements. Layers of safeguards, flexibility and varied supports are important components of the ISL Framework, and can mitigate the reliance on a single individual for the continuation of the arrangement.

Funding and financial hurdles spanned a range of issues. The insecurity of relying on private rentals was voiced by a father who feared that the landlord could cancel the tenancy at any time, which would place the whole arrangement at risk. Potential discrimination against persons with intellectual disabilities in the housing market was also raised as another challenge or barrier for establishing ISL arrangements.

An illustration of the complexities and challenges regarding funding arrangements and housing market dynamics was provided by the mother of a man with high support needs in WA. They reported that they felt pressured to accept a house-sharing arrangement in order to receive the required NDIS funds to support their son's living arrangement in the house they had purpose-built for him. When they tried to separate the arrangement out from the housemate, the housemate took the family to court and claimed tenancy rights. This was an unpleasant experience, and the family will now only consider a sharing arrangement if the family funds are insufficient to pay for the necessary care.

Concerning funding, a mother reported that their arrangement was substantially challenged after the NDIS cut their funding by over two-thirds the following year:

We had, uh, we, the first year of NDIS funding was really good and it worked really well, but the second year they really pulled the rug from under us. They cut the funding by 70 per cent (NSW/ACT-5).

Another family also reflected on their dependence on the funding, indicating that as long as they retained their NDIS funds things would progress well, but that uncertainty was a source of concern:

Father: 'But, um, yeah, it's all really comes down to the normal thing, funding, you know, everyone's thing you know, as long as the NDIS ...'

Mother: '—as long as that doesn't stop.'

Father: 'Yeah.'

Mother: 'We have to pay the carers.'

Father: 'Of course, the NDIA⁶ try to cut back wherever they can. But, um. Yeah. And trying. Yeah. They give us a hard time every time they review, but, but like everyone. Yeah' (NSW/ACT-4).

An interrelated funding issue was attracting suitable staff. The limited funds provided for a WA arrangement made it challenging to find suitable staff. While the arrangement had the main staffing in place, it required additional casual staff to fill occasional bottlenecks. However, as summarised by a current staff member, there are industry-based challenges:

But I think, it just seems as if the industry doesn't have aged care but they need casual workers. But to be a casual worker, you have to be able to afford to be a casual worker, so to have that kind of lifestyle (WA-3).

This quote reflects the understanding that casual work may create financial uncertainty for the worker, as shifts may be intermittent. However, given the limited funding available, the additional costs of weekend and night rates was inhibiting for that specific arrangement.

Another staff-related challenge was reported by a family member who articulated a different opinion about the quality of personal care between her and her staff members. She expected her sister with intellectual disabilities to appear neat and well-groomed, but sometimes found that the staff were not meticulous with the personal care of her sister. She mentioned that because of this difference in views, her sister's staff consider that she was too strict. She elaborated on the issue:

I just like, like certain things, like [person with intellectual disabilities] has whiskers. And I'm very anal about that because I believe that she can't get rid of them. So it's up to the staff to do it. Um, I like her to dress nice. I like her hair to be done. Look, I don't feel like [...] I'm asking for too much. But some staff might, might think I am. (NSW/ACT-3)

To conclude, the challenges articulated in the interviews of this study 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.

⁶ NDIA is the National Disability Insurance Agency, the government agency in charge of the NDIS. NDIS funding is typically provided for a year at a time and attached to an individual plan, which is reviewed at these annual meetings.

4.2.3 Future outlook

For some persons with intellectual disabilities, it was reported that the outcome of the ISL arrangement was much better than expected, so that ideas about the arrangement developed into even more positive attitudes over time. One family stated that the living situation of their son had improved by a lot compared to his previous group home arrangement. For another participant, it was reported that the person with intellectual disabilities had become more social because there were more staff and support workers in the ISL arrangement:

Having the rotation of staff actually is a lot better because he is getting more people into his life, instead of just one or two. So that side of things is improved like, I reckon, 90 per cent (WA-3).

Another mother, who was asked if her ideas about the arrangement had changed over time, replied that the basic ideas were still the same, but that if she were to establish the arrangement now, she would do things differently. However, this insight was because of her increased knowledge and experience from creating the arrangement.

Reflecting on the outlook for the future, in an ideal scenario and provided that the current funding levels stay the same, interviewees would prefer if the persons with intellectual disabilities could simply keep their current supports and stay with the organisations that provide such supports. For example, a sister reported:

I'd sort of like, um, the future is that she'll always stay with [support organisation]. Because it's working for us. [...] And she's happy. So that would be something that I just stay with, um, there's no need for me to change anything like that. Because this is obviously how it works. So, yeah, she'll be with [support organisation] until she passes, I would say (NSW/ACT-3).

Other interviewees had concerns about specific issues or processes. The mother of a person with autism and high support needs raised funding concerns specifically related to the annual NDIS review, as it always entailed the risk of funding being cut. Her hopes for the future included handing over the responsibilities to a trust that would then be responsible for these annual reviews. However, her husband raised his concerns with the trust being responsible for the arrangement. While that couple mentioned they had another son without disability, there was no indication of him taking on the responsibilities for the arrangement or taking a guardianship role.

The issues related to siblings' roles can be challenging. As indicated earlier in this chapter, siblings may play central roles in ISL arrangements. However, people may have other family commitments, and parents may be reluctant to place expectations on their other children on taking on their carer roles:

We have a son who sometimes does fly-in ... with two young children so he's, he's busy, and a daughter, who would be very good, lives [in] country Victoria so with a small child and she has her own health problems so, the children, we don't want them to have to do what we're doing (WA-2).

In this interview, the family stated that they were aware of possible support available through the Department of Communities, but that they were not considering doing so yet.

Examples of alternative arrangements were provided by other participants, particularly for families without siblings who could take over guardianship roles. A mother was planning to hand over guardianship to a young relative, but also hoped that she could hand over care-related decision-making to the current main carer of her son. However, she indicated that this main carer had just 10 more years before she would retire herself. This illustrates that decisions that are based on trust and carers of choice might not be sustainable for the entire future lifespan of the person with intellectual disabilities. Instead, other participants frequently named specific organisations that offered to take over and organise guardianship and caring duties.

In stark contrast, other mothers reported being quite relaxed about the future because they knew the siblings of the persons with intellectual disabilities would take over caring and decision-making responsibilities when they were no longer able to do so:

Funding is in place, but we also have that cohesive family, so everybody in the family, like [person with intellectual disabilities]'s siblings, um, they are all of the opinions that this is vital. It's vital for [her] and they will all support it. [...] I can actually depart in peace knowing that I have three people who will take responsibility to make sure that the safeguards are in place for [her] (WA-1).

Another mother gave a similar account:

So, I think there's always, you know, dangers, that risks, that things could change but—and if I'm around I'll be able to deal with them but I've got three sons, none of whom live here, which is a shame, but they all know, they know the philosophy, they know the arrangement, they know, they know what I would want and what [person with intellectual disabilities] would want so, so I would have some confidence that they would step in and push for and continue in the best possible way (NSW/ACT-10).

However, despite the best-laid plans, unforeseen challenges may emerge. One participant indicated that her views about the organisation that was envisaged to take over the caring and guardianship roles for her child had moved away from the ISL philosophy, which made her realise that she had to make changes to her will to ensure the continued wellbeing of the person with intellectual disabilities after her passing. However, in general terms, families that had arranged future collaborations with organisations appeared satisfied and did not appear to have these types of future concerns, as long as the nominated organisation would stay intact.

As already indicated, some interviewees were concerned about the continuity of their NDIS funding and named various reasons future NDIS funding could be influenced. One interviewee feared that in the future the NDIS would change their decision-making basis to financially based rather than quality-of-life-based. Another interviewee feared that another global crisis could influence the funding generosity and capabilities of the NDIS. One interviewee's son lived in a co-residency arrangement in a small community in a public housing complex, where two other persons with disabilities lived in a similar arrangement. They worried that should the NDIS aim for an even higher ratio of disabled persons in this particular community, it would challenge the inclusive character of the community.

Beside the future of funding and caring arrangements, a more individual outlook to the future was given to some persons with intellectual disabilities with certain identified goals. For example, one individual dreamed of living in a bigger house with more housemates around, and had undertaken a recent trip to a holiday home to try out how a bigger arrangement would feel. For another person with intellectual disabilities, the wish to go on holidays in the future was a major goal; yet another person articulated that he would like to have and live with a family and children of his own in the future. Similarly, one individual refused to unpack her moving boxes as she wanted to move in with her boyfriend soon. However, as her sister relayed, they had just recently set up the current ISL arrangement with integrated support services and thus opposed her sister's plans. Such tensions raise the issue that ISL arrangements need to have safeguards in-built to ensure that the choice of the person is the priority.

4.2.4 Other aspects emerging from the interviews

Support system

A key aspect that emerged from the interviews related to the support system—including the funding and recruitment of support staff. Comments relating to what the families would do if more funding were available included employing a house manager, which would ease their responsibilities:

We'd like a house manager because I can't be on the phone chasing people in appointments from sometimes eight-thirty in the morning until six o'clock at night, um, but that's, that really happens (WA-2).

Others would use the additional funding to have more occupational therapy for the person with intellectual disabilities, or to increase the support ratio to 2-to-1 for the person with intellectual disabilities.

Recruiting support staff was another important element of the support system. When asked how support staff for the persons with intellectual disabilities were identified, some interviewees indicated that they had found people through word-of-mouth, who they privately employed. Strategies to find good matching staff included letting the persons with intellectual disabilities interview prospective support staff themselves. Others mentioned that a crucial selection criterion for the person with disabilities was to get on well with the support workers, and that the persons with intellectual disabilities had to feel safe with the support worker. Emphasis was also placed on a committed view towards disability inclusion and independent living. Regarding supporting the staff, and enhancing staff retention, one mother reported that she regularly met up with support workers, and that she always tried to act as an emotional and mental support for the staff:

But, and I think just showing appreciation and being there as a backup, you know, an emotional and mental backup if not necessarily a physical one, although I can, I can do that too. [...] It's just really important (NSW/ACT-10).

Housing

When the participants spoke about the accommodation of the persons with intellectual disabilities and high support needs, they mostly focussed on the type of tenancy and whether the accommodation was rented, owned or provided through public or social housing. Most of the places were leased, either as private market rentals or through public housing schemes.

However, a reasonable proportion of interviewees also reported that they had purchased the premises for their family member with intellectual disabilities and high support needs (see Table 2). Among those who had purchased a house, some had then handed the property over to the Future Living Trust, which ensured lifelong tenancy rights for the focal person.

Such transfers do raise the issue of how family members or third-party advocates can safeguard the involvement of the person with intellectual disabilities and high support needs in decisions that impact where and how the persons live. This may include the use of supported decision-making strategies. Use of circles of support, role-play, decision-boards⁷, and observation can all be used to safeguard against families exercising paternalistic control. One example of how the family arranged the home in accordance with the interests of the person with intellectual disabilities and high support needs included the remodelling of a purchased house. The garage housed a truck, which at one stage had been used to deliver newspapers that their son enjoyed collecting, while in the home there was a stage for drama rehearsals and a music space with a display of guitars:

And then you've got a, there's a, there's a few posters on the wall and stuff like that, um, that's probably the things of, of particular interests I guess in his house, yeah, um, so it's like it's [name of person with intellectual disabilities]'s house, it's growing a bit over our way [...] to make the house that deals with [his] particular interests ... (NSW/ACT-8).

A Zoom viewing of the house was provided at the end of an audiovisual interview where the person's joy was observed as he moved around the spaces in his house. His father summed up how the spaces reflected his son's choices:

[He]'s also, also a keen musician so he needs in his, the man in his, in his, um, lounge room, he has a stage. What you're looking at there is the curtain of the stage and then, then on his stage, he's got a num- and a couple of, well a number of guitars I think and a, um, a piano keyboard and a microphone which he from time to time, he entertains us with a concert. He's actually got a very good, a good musical ear, you really ought to play in a band really, um, because you can pick things up (NSW/ACT-8).

⁷ See glossary.

Disability-specific adaptations to make the house suitable for people with high support needs emerged as a specific subtheme. This related to both those houses that had been purpose-built or later undergone specific adaptations to accommodate the needs of the persons with high support needs. Some participants specifically mentioned SDA-funded adaptations allocated through the NDIS.

The housing for persons with high support needs, especially those that received 24-hour support seven days a week, typically included a bedroom for staff on shifts. Other interviewees noted that a room in the house had been turned into a disability-specific therapy room. For example, a person with autism had a sensory room in his home that provided a calm space:

Just, just a room that is fairly dark and not too much, um, yeah, basically a fairly bare room. So, so that it's not visually overstimulating. Yeah, so, and somewhere quiet. Yeah (NSW/ACT-5).

Ten families confirmed that they contributed financially to the arrangement either by covering some of the living costs or by providing the house or home for the persons with intellectual disabilities. For privacy reasons, families were not asked to disclose the specific details of the financial arrangements. Two interviewees happily reported that they did not have to contribute financially at all because of the very generous funding from the NDIS.

It was reported that the families of some persons with intellectual disabilities contributed by administering the ISL arrangement, which sometimes took a considerable amount of (unpaid) time. One family stated that they had to administer the arrangement because their support coordinator barely did so.

Social relationships

Social relationships were another theme that emerged in the interviews, with some participants emphasising that the person with intellectual disabilities had a strong desire for social interaction, even though that was sometimes hindered for various reasons. Co-residents were often specified as a facilitator of social relationships and interactions. The qualitative data analysis indicated that there were differences between the social interactions between the persons with intellectual disabilities with co-residents to that of support staff. While paid support staff usually did not choose the type of activity they wanted to do with the persons with intellectual disabilities, co-residents usually only agreed to activities for which both the person with intellectual disabilities and the co-resident had a shared interest in, such as going out for drinks or going to the movies. The relationships between co-residents and persons with intellectual disabilities appeared more as reciprocal friendships in which mutual interests were respected. In contrast, paid support staff did all kinds of activities with the persons with intellectual disabilities and followed a person-centred approach with a focus on independent living and self-determination.

Regarding the different roles of co-residents, one interviewee, a co-resident, elaborated on the companionship this entailed:

But also just like having someone around to, you know, like to chat to or just have company and I think you really appreciate that, [person with intellectual disabilities]? You don't necessarily need like, um, you know, like someone else to go out the door to think here, you have your friends and things like that but just having someone around, it's just a nice thing (WA-9).

Another co-resident reported that he had actively chosen his new role after burnout in his former role as a support coordinator, where he had to administer NDIS supports. His new role allowed him to focus more on building relationships—in contrast to the previous paperwork-focussed role—and he had started to enjoy his work in the disability sector again. As such, the benefits of ISL may extend beyond contributing towards a more inclusive life for people with high support needs but also provide different opportunities for workers in the disability sector.

4.3 Policy recommendations from interviews

The interviews provide a holistic insight into current ISL arrangements, mostly funded under NDIS schemes in WA, NSW and the ACT. The findings illustrated substantial improvement in participants' living arrangements compared to previous arrangements, particularly group homes or respite care settings.

To enable more people to benefit from ISL models that create appropriate and preferred homes for persons with intellectual disabilities and high support needs, enhancing policy and practice in the following areas is recommended.

Establishing ISL arrangements

- The interviews illustrated the benefits of collaborations with organisations that specialise in establishing and supporting ISL arrangements. Support to develop collaborations with these organisations early in the planning process will be beneficial. This may require additional funding of such organisations for advocacy and training purposes beyond what is currently available in the NDIS funding system, as many of these services are not currently funded to support the development of ISL plans. An important component of the support these organisations may provide includes the actual applications for NDIS funding to establish ISL arrangements.
- Recognising that it may be time-consuming to transition into a new ISL arrangement, and drawing on the research findings that suggest that a gradual transition can be beneficial—and that funding arrangements need to accommodate this.
- Choice and control are important elements to both the NDIS and ISL arrangements. Policies and practices to enhance this in the establishment of ISL arrangements will improve outcomes, including around where the accommodation is, recruitment of support staff, selection of co-residents (if any), and management arrangements including agency, family and shared-management options.
- Given the specific needs many people with intellectual disabilities and high support needs have, security of tenure is crucial. This is particularly true for those who require housing to be purpose-built or undergo substantial alterations to the built environment to suit the needs of the persons. The interviews illustrated how some families had managed to purpose-build and finance the home. Further policies to enable families to purpose-build and purchase housing will substantially enhance the sustainability of housing outcomes for this group. Additional policies to enhance such outcomes may include additional targeted support through public and social housing schemes for this group of particularly vulnerable persons. This could reduce the heavy burden that is placed upon families who work to set up an ISL arrangement for their family member who is dependent on their support for decision-making.

Maintaining ISL arrangements

- The interviews outlined a number of benefits of the ISL arrangements. These spanned different domains, including increased health and wellbeing, enhanced community engagement and social relationships, increased skill levels, different social roles including work and volunteer work. To sustain ISL arrangements, it is important that these domains—which are facilitated by the living arrangements—are viewed holistically. Therefore, funding and support need to be flexible across different domains to allow for maintenance of the arrangements.
- Policies and practices need to allow for the arrangements to remain flexible. This includes the recruitment, maintenance, and change of support workers, housemates and co-residents, as appropriate.
- Recognising the driving force of parents, who now may be ageing, in establishing and maintaining ISL arrangements; policies and practices need to support the maintenance of these arrangements after parents pass away. This may include transitional support arrangements to establish trusts or other self-managed arrangements, or to transition the administration of these arrangements to specialist service providers.

5. Moving to Individual Supportive Living

- **Four fact sheets were developed to guide workshops:**
 - 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.
- **Three workshops across WA and NSW facilitated feedback from key stakeholders, including people with intellectual disabilities and high support needs, their families, researchers, disability service professionals, inclusive housing providers, and others from the sector.**
- **Development of the fact sheets and the stakeholder workshops elicited important information for knowledge translation of the project findings and future directions in ISL research.**

5.1 Workshop facilitation

Four fact sheets were developed to synthesise the findings from all three preceding data sources in this research project. These fact sheets provided a succinct summary of the key findings, which were presented to a number of disability and housing stakeholders across three workshops: two in NSW and one in WA. Twenty-one people attended the first workshop in NSW, and 10 attended the second, while 21 stakeholders attended the workshop in WA. Workshop participants included disability service professionals, inclusive housing providers, families of people with high support needs, researchers, and other experts in the field. The workshops served two main purposes:

- to present and verify preliminary project findings
- to obtain feedback on the developed fact sheets, including their dissemination and implementation into practice.

5.1.1 Workshop methods

The first NSW workshop and the WA event were derived from World Café methodology (Fouché and Light 2011). After a welcome and introduction, the research project was briefly introduced to participants before the group was split up into several smaller groups consisting of approximately three to five participants. Each group initially discussed one feedback sheet. Discussion was facilitated by a member of the research team who also took notes. After approximately 20 minutes of discussion, when no new themes emerged, the facilitator presented the next fact sheet, and the exchange began again. Questions that guided fact sheet discussion were 'Is the information presented in line with your experience?' and 'What more do you think could be added here?' After the small groups had discussed the fact sheets, they came back together and the most important points from their conversations were shared with the rest of the large group and noted down.

The second NSW workshop was smaller, and provided feedback and verification of the findings from the initial NSW workshop. Participants were members of the reference group of the project. After a short presentation of project progress, the feedback from the first workshop was presented and discussed with reference group members. Together, ideas for feedback implementation and research translation were developed.

Feedback was summarised for each workshop in WA and NSW. The three sets of feedback were then combined into one document and each piece of feedback categorised by type, comments, potential changes to the fact sheets, and future directions.

5.2 Thematic analysis

5.2.1 General comments

General discussion of ISL included the acknowledgement that it comes with responsibilities for the person with intellectual disabilities and high support needs, and challenges sometimes brought about adaptation, such as when COVID-19 necessitated social groups to continue on Zoom. It was noted that there may be more than four types of ISL, including when two families team up to create an arrangement for two people with intellectual disabilities who want to live together. A comment about the overall purpose of the fact sheets indicated they should be used to raise awareness of ISL arrangements, their feasibility, desirability and potential for increasing choice and control for people with intellectual disabilities. It should be noted that the ISL Framework specifically rejects congregate models where people with intellectual disabilities are required to live together for specific reasons beyond it being their own individual choice, including financial or cost-saving reasons (Cocks and Thoresen 2017).

5.2.2 Reasons why people may choose to pursue ISL

Participants noted various reasons why people with intellectual disabilities and high support needs may choose an ISL arrangement. These included:

- it is a typical part of growing up to live independently
- it may improve the parent-child relationship as parents move away from the carer role
- the person and their family need a break from each other.

Considering that ISL has sometimes been reported following major life incidents, such as the death of a carer or ill-health in an earlier living arrangement, it may offer preventative pathways from such incidents. However, it was mentioned that medical concerns and emergencies can also jeopardise ISL arrangements if additional support is not easily implemented or funded.

5.2.3 Obtaining information

Participants highlighted that getting information about ISL was critical, but services such as NDIS providers could sometimes act as gatekeepers for this information. It was emphasised that people with intellectual disabilities and their families need access to independent advice from places that are not selling them a service. Advocates were important for helping people with intellectual disabilities and their families navigate systems. The ISL Manual is a potential resource for information, although it needs to be more accessible for persons with intellectual disabilities. It was suggested that setting a date to prepare people for the transition to ISL may be helpful, as well as a database linking people with similar interests who are socially isolated, with the aim of increasing social inclusion before moving to an ISL arrangement.

5.2.4 Managing an ISL arrangement

Management for ISL was discussed in terms of the strong support networks needed to maintain an arrangement and the ongoing planning process that needs to be shared. Interestingly, informal networks may need some funding to be sustainable. The support worker role should have clear guidelines, and preferably carers would work with a small number of people to ensure more personalised and quality care for the people they support. One participant suggested that greater carer involvement would result in greater responsibility taken by carers. It was also noted that decision-making about ISL needs to incorporate consideration of cultural background and values.

In line with the feedback from the workshops, some changes were made to the preliminary fact sheets. The final fact sheets are numbered and should be presented as a set. Person-centred, family-centred and supporter-centred language was applied throughout the fact sheets. This was done to acknowledge different cultural backgrounds, and to be inclusive of people with intellectual disabilities who are not supported by family members. The importance of the goals, needs and wellbeing of the person with intellectual disabilities and high support needs is emphasised in the fact sheets, especially regarding setting up the arrangement and managing change. Finally, Fact sheet 3—which addresses common challenges for ISL arrangements—highlights that it can be helpful to put clearly defined processes or frameworks in place, but that ISL is ultimately an individualised approach that should not become restrictive.

5.3 Fact Sheets

Fact Sheet 1: Moving from an old to a new model of living: getting the ISL model started

When setting up an ISL arrangement, the goals, needs and wellbeing of the person with intellectual disabilities should be at the centre of all decision-making (called person-centred planning). Consider what is important to the person and ensure that it is reflected in the arrangement. Examples for this can be:

- the hobbies, favourite activities or interests of the person
- the people that are important to them
- their culture and religion.

There are plenty of reasons for people with intellectual disabilities and high support needs to live in a more individualised arrangement:

- They wish for higher degrees of freedom and independence—this wish can also be sparked by an important life event.
- A previous arrangement proves no longer suitable.
- Their family or people who support them cannot continue their caring duties but want to stay involved about who cares for the person with intellectual disabilities and high support needs.

Setting up an ISL takes some substantial and continuous planning that can take several years. Having a strong advocate for the person in receipt of ISL can be useful to ensure that their needs and goals are respected.

Several actors can function as advocates:

- The person with intellectual disabilities can be a strong self-advocate who steps in for their own needs and goals.
- People who support the person with intellectual disabilities, including family members or friends.
- Case workers from several organisations.

Involvement of family and people who support has an influence on the success of the new arrangement. Having a strong vision of what the new arrangement should look like can help in making it reality. Several actors can provide support for families and people who support:

- Organisations can be a pool of knowledge and experience and provide support along the way and in various regards.
- Knowledgeable family members or friends can also be beneficial actors while setting up an ISL arrangement.
- The ISL Manual and the NDIS Individualised Living Options (ILO) guidelines can be a helpful tool to plan and review ISL arrangements.

There is no prototype of a successful ISL arrangement. Rather, it is related to the support needs and wishes of the person with intellectual disabilities. Common types include the following:

- Co-resident models—a person with intellectual disabilities lives permanently with a non-disabled housemate.
- Host-family arrangements—a person with intellectual disabilities moves into and lives with another family, sometimes also just as a part-time solution.
- Independent supported living solutions—a person with intellectual disabilities lives alone but receives the necessary support.

Moving into an ISL arrangement doesn't necessarily mean a complete change from one day to the other, sometimes, such a move can be even more successful when the transition into the new arrangement happens gradually and over time.

Fact Sheet 2: Benefits and enablers of an ISL

There are some clear benefits of ISL arrangements. A common theme of benefits is around the increased autonomy residents of an ISL can experience:

- Many people who live in ISL, or their carers, report an increase in choices, which gives them more control and allows them to shape their day-to-day lives around their preferences and needs.
- ISL arrangements can also cater for the mobility needs of the person with intellectual disabilities, with some of them having their own cars or vans available, which are adapted to their support needs.

One of the commonly reported benefits of an ISL arrangement are impacts on health and wellbeing of the person with intellectual disabilities:

- The more focussed approach of individualised living solutions might contribute to health improvements for some people, such as fewer seizures than in previous settings, or better-managed diabetes because of a better diet.
- Many people report that the increase in choices has made them happier, and that the person-centred approach of their new living arrangement has improved their wellbeing. This links in with existing evidence that ISL can improve the person's quality of life in some areas.

ISL arrangements can also facilitate increased engagement of people with intellectual disabilities:

- Because of the individualised and person-centred support, people living in an ISL might develop some new skills and become more confident and independent.
- ISL arrangements enable their residents to engage with the community they live in and become known and valued community members.

Some factors can support setting up an ISL arrangement, and therefore work as enablers:

- The use of personalised assistive technology allows people to live independently, and improves their choice and control, including improved cost-benefit.
- A successful ISL arrangement needs a strong support network and close cooperation between the individual providers of formal and informal support. This can create strong relationships and valuable new friendships.

Fact Sheet 3: Coping with challenges along the way

There can be some challenges when maintaining an ISL arrangement. These challenges are often very individual. However, some of the challenges are more common than others. Many study participants reported challenges around support and funding:

- There can be a lot of responsibility on the shoulders of a single family member or other person who supports. This can threaten the arrangement if there is no safety net for when this key figure will be unable to provide support. A strategy to overcome this can be building up a strong support network—for example, Microboards, circles of support.
- Medical concerns and challenging behaviour are reported most frequently as reasons for losing placement. When needs change or health deteriorates, supports might not be sufficient anymore.
- Some people who provide support experience a continuous struggle to obtain funding, or fear losing their funding. Even when funding is not currently threatened, it can be a cause for anxiety. Often ISL arrangements have to be subsidised by the parent/s—which is not always sustainable.

Settling into and maintaining the new home:

- Settling into the new arrangement can take some time, both for the person with intellectual disabilities and for the people who support them.
- Unsuitable co-residents or a high turnover of co-residents can be challenging, so housemates must be carefully chosen. If the co-resident arrangement doesn't work, they'll have to move out in time before the arrangement is challenged.

People who live in an independent arrangement might also experience some barriers to community engagement. If there are not enough meaningful community connections and providers of informal supports, this can cause loneliness.

Setting up and maintaining an ISL requires close cooperation with many organisations and services, which can sometimes be challenging:

- Service-driven approaches that focus on independent living but do not incorporate person-centred planning and personalisation of the living arrangement can undermine the person's needs.
- People in independent settings might also experience poorer access to services or limited satisfaction with the services provided. In small towns, there can also be a lack of resources and adequate supports.

To prevent and overcome challenges, it is helpful to put clear processes and frameworks in place and to define the roles and responsibilities of the people involved. However, keep in mind that an ISL is a highly individualised arrangement that should not become restrictive.

Fact Sheet 4: Managing change and planning for the future

There was limited evidence around how to successfully manage change and best plan for the future. Below are the common themes that we could find in the data.

Talking about the future, many people mentioned dreams and goals they have:

- Some might want to find a partner and live with them, move in with a friend, move to a different location or a bigger house, or simply go on a holiday.

Many families and people who support persons with intellectual disabilities have engaged in long-term and person-centred planning for the future and created safeguards to maintain the chosen living arrangement:

- Putting precautions into place can ease concerns about the future. Many people who support persons with intellectual disabilities prepare future arrangements, such as setting up plans with organisations that will take over care duties, amending their wills or setting up a power of attorney. However, some people might not be at that stage yet.

ISL is not a 'set and forget' model, but requires ongoing planning. There are a few things that can be helpful when thinking about change and planning for the future:

- Ensure that even when things change or become more challenging, the goals, needs and wellbeing of the person with intellectual disabilities and high support needs remain at the heart of planning and decision-making.
- There is no one model of change—what works for one person might not work for another. Furthermore, change is an ongoing process and things will often take some time.
- Coming together with people who share similar concerns and interests—for example, as a community of practice—can assist with change and the different processes involved.

5.4 Next steps

Potential next steps for the research were identified, including applying the findings of the research to help with the NDIS application process for ISL funding. This may mean an additional fact sheet detailing the NDIS guidelines relating to ISL arrangements and clear information being available for the purposes of NDIS applications about the relationship between support and engagement with ISL. This may include key questions that could assist people in setting up an ISL arrangement, and information on how to maintain ISL when the key planner is not there anymore. Following are some key questions that arose from the workshops that indicate potential directions for future ISL research:

- In terms of co-residents, how do you pick the right person?
- What happens when a person in ISL wants to move on and have a family of their own?
- When people are not connected to family or networks, how does ISL happen?
- Are there alternative models of ISL beyond the four that have been identified?

5.5 Policy development implications

Drawing on the body of work that was the foundation of these fact sheets, the workshop processes also provide pertinent policy development implications.

Timely and accurate access to information

- People with intellectual disabilities and high support needs together with their families need access to timely and accurate housing information. In addition to congregate models such as group homes, information related to ISL models also needs to be readily available in accessible formats.
- While there are a few organisations who have specialised in advocating for, establishing or maintaining ISL models, most disability services still rely on congregate care models, including housing models. Independent organisations that do not have vested interests in specific housing models should be funded to provide information on the range of housing options.
- Information that targets and is accessible for a range of stakeholders needs to be made available. This includes individuals with intellectual disabilities and high support needs; families, carers, and support workers; service coordinators, NDIA, disability and advocacy organisations; inclusive housing services; and state government housing agencies.

Need for a national framework

- A national framework is needed to inform stakeholders of housing options for persons with intellectual disabilities and high support needs.
- Although not specifically raised in the workshops, a national framework that ensures stakeholders have timely and accurate access to information would resolve many of the concerns raised. For example, it could obligate NDIA-funded or NDIS-funded organisations to provide information on how to establish and maintain ISL arrangements through NDIS-funded packages.
- It would also be important to ensure that a national framework includes funding to support connections between individuals and organisations, including networks, advocacy and information databases that can monitor and evaluate the implementation of such a framework.
- Funding for advocacy services at a national level, drawing on state-based experiences and learnings, would ensure a national reach, and enhance equity in access to information.

6. Policy development options

- **Policy development options should emphasise three interrelated but distinct areas:**
 - 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.
 - Establish and enhance opportunities for persons with intellectual disabilities and high support needs to plan and establish their own ISL arrangements.
 - Establish and enhance mechanisms to safeguard and maintain ISL arrangements for persons with intellectual disabilities and high support needs.
- **Develop a national framework and guidance to enhance access to timely and accurate information.**

This research report has reviewed ISL arrangements for people with intellectual disabilities and high support needs, drawing on multiple sources of information including a scoping review of the peer-reviewed research literature, secondary analysis of previous research data, interviews with persons with intellectual disabilities and high support needs living in ISL arrangements and/or their supporters, and stakeholder workshops.

Among research participants there was a substantial demand for more individualised approaches to provide what they described as appropriate and preferred homes, rather than grouped residences for people with disabilities and high support needs. There are substantial challenges in establishing and maintaining ISL arrangements. As such, policy development options should emphasise three interrelated but distinct areas.

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 the housing needs, housing costs, personal care needs, and community access and participation needs of individuals.

Additionally, to enhance the transparency and equity of such an approach, in line with multiple national and international commitments made by Australian governments, including to the Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2006), a national framework and guidance will enhance access to timely and accurate information. This may also create an important foundation for enhancing engagement, self-determination, and full citizenship of persons with intellectual disabilities and high support needs.

6.1 How can we continue to build an evidence-base of sustainable and suitable housing for persons with intellectual disabilities and high support needs?

As identified in previous research (Cocks and Boaden 2011; Cocks, Thoresen, O'Brien, McVilly et al. 2016; Cocks, Thoresen, Williamson et al. 2014), although ISL arrangements have been developed and maintained for persons with intellectual disabilities and high support needs for the past several decades, the evidence-base is poor, both in Australia and internationally. Best-practice policy implementation develops policy responses on sound data and for research, monitoring and evaluation to continue to feed into the policy implementation, allowing for adjustments as required to improve outcomes. While there is an emerging evidence-base, there is substantial room to enhance this.

6.1.1 Definitions and conceptualisations of good ISL arrangements

While the contexts of housing for persons with intellectual disabilities and high support needs vary across jurisdictions, the trajectories are similar regarding how and where people want to live. There is a move away from traditional congregate housing models towards more individualised approaches. However, as identified in the scoping review, what constitutes an individualised approach is varied, and in many cases may include 'cared-accommodation' such as group homes. This research report adopted the concept of ISL, developed by Cocks et al. (Cocks and Boaden 2011; 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), accounted for specifically within the ISL Manual (Cocks and Thoresen 2017). This is a framework consisting of eight themes and 21 attributes, which have been identified as influential for creating and maintaining good ISL arrangements for the target group. However, it is recognised that there may be many other approaches to achieving this.

People desire an appropriate and preferred home, which includes both housing attributes and wellbeing components, and these are seldom accounted for specifically, either in the peer-reviewed international literature or in Australian administrative datasets. To enable the continued development of desired housing approaches for persons with intellectual disabilities and high support needs, greater transparency and consistent definitions across datasets are required. This will enable persons with intellectual disabilities and their families to make informed choices; this may be through the use of supported decision-making with the involvement of families and advocates. This will further allow funders and policy-makers to make informed comparisons and evaluate the impact of different approaches.

6.1.2 Continue building the evidence-base

There is a need for further research, monitoring and evaluation to continue building the evidence-base of what constitutes suitable homes beyond congregate models for persons with intellectual disabilities and high support needs. This includes a range of different studies, incorporating interventions and longitudinal studies that include both quantitative and qualitative information.

Furthermore, it is important that these efforts include an emphasis on the intersection of housing and disability services, noting that both are prerequisites to facilitate the creation of appropriate and preferred homes for people with intellectual disabilities and high support needs. These efforts need to be aligned to consistent and transparent definitions, as noted earlier, to enable comparisons across time and jurisdictions, as well as across different models of supported living. For example, the current interviews indicated evidence of companionship within co-residency, which contrasts to earlier research where supported living had been aligned with:

- loneliness (Bigby, Bould et al. 2016)
- the need for support in making interpersonal relationships (Bigby, Bould et al. 2018)
- the enablement of social inclusion (Ashley, Fossey et al. 2019).

These findings resonate with those of the earlier studies of ISL (Cocks, Thoresen, O'Brien and McVilly 2017) where scores of the theme of social inclusion were the lowest when networks were largely restricted to paid staff and other persons with disabilities.

Data collected in Australia does not readily identify persons with intellectual disabilities living in ISL arrangements or other non-congregate individualised or personalised homes. While the AIHW publish annual data concerning people with disabilities, including related to housing, this does not go beyond the 'bricks and mortar' of the living arrangements. The latest available data suggest that 83 per cent of persons with disabilities who received funded disability services lived in a 'private residence', with 9 per cent residing in 'other types of residential settings including boarding houses or private hostels', with an additional 3 per cent living in 'domestic-scale supported-living facilities' (which includes group homes), and 1 per cent in other 'supported accommodation facilities' (AIHW 2020b: 21).

While it is probable that many persons living in a 'private residence' may be living in their desired home, which may be aligned with ISL, there is no indication of how the tenure arrangements are in these instances and if, for example, this reflects persons living in the family home with parent/s rather than in their own home. As such, it is not possible to disaggregate persons living in ISL arrangements from this dataset, nor does it provide an indication of the unmet need or demand for ISL arrangements. Thus, future research should also be undertaken to fill this gap, which will enable governments to develop and implement evidence-based policies founded on actual demand.

6.2 How can we support the establishment of more individualised housing for persons with intellectual disabilities and high support needs?

Recognising that there is a demand for more individualised housing for persons with disabilities and high support needs, and that this is likely to continue in the foreseeable future, the question becomes: how can this process best be facilitated? Drawing on the findings in this study, there are clear challenges related to both the housing and the support required to establish ISL arrangements, often requiring substantial planning.

6.2.1 What are the housing needs for persons with intellectual disabilities and high support needs?

People with intellectual disabilities and high support needs are diverse, and their housing needs are diverse. However, as with other vulnerable groups in the housing market, there are housing affordability issues that may be further compounded by support needs (see subsection 6.2.2). Support needs may be related to direct care,

community access and participation needs, as well as to needs of the built environment. Additionally, adjustments to the built environment that address the specific support needs of the person with intellectual disabilities and high support needs may, over time, reduce other support needs. This was illustrated in the interviews with the example of creating a sensory room within the ISL arrangement. Specific physical adjustments to the home, taking into account the specific needs of the focus person, may facilitate skills development and, over time, reduced support needs.

For persons with intellectual disabilities and high support needs, the housing needs may be different to other persons who are vulnerable in the housing market. As the examples in this research illustrated, multiple participants lived with co-residents who received reduced or free rent and/or board in return for providing informal support—for example, being there for the focus person over night or at dinner times. Other participants, who were characterised as living alone, received around-the-clock support, with rostered staff throughout. Smaller units, particularly one-bedroom apartments, would therefore not be suitable for these individuals, and this must be taken into consideration.

Furthermore, persons with intellectual disabilities and high support needs often have complex disabilities, spanning the physical environment, sensory stimuli and cognitive functioning. It is possible to mitigate the impact of some disabilities through adjustments to the built environment. While obvious regarding physical disabilities and the need for ramps and rails, as well as wider doorways and hallways to make a home wheelchair-accessible, there are other adjustments to the built environment that can greatly improve the liveability for persons with intellectual disabilities and high support needs. These may include:

- sound insulation and shading to reduce sensory stimuli
- locating the home in a community in which the person is familiar and comfortable
- locating the home in a community where the person has a support network.

These are considerations that may require substantial investments, sometimes best achieved through purpose-building a home, and in other instances require retrofitting of existing housing stock. Such undertakings are costly investments, particularly for individuals, although some of the participants in this study had achieved this through substantial family support. Individuals or families that cannot afford to purchase a home for the person with intellectual disabilities often rely on public or social housing to ensure security of tenure, as in most cases it is unfeasible to make these types of adjustments to private rental properties.

Greater coordination between state housing authorities and disability services is required to improve housing outcomes for people with intellectual disabilities and high support needs. While individuals may be able to obtain funding for reasonable and necessary adjustments to their homes to mitigate the impact of their disabilities, this may require additional coordination between housing and disability services in the planning stages to create suitable housing stock. Otherwise, the danger is that cared-accommodation, such as group homes, will continue to be a prevailing housing option for persons with high and very high support needs. It may be that some individuals, or families, pool their funds to purpose-build new 'group homes' under the NDIS funding scheme. These arrangements may still encompass many of the vulnerabilities of current congregate living models—particularly if these are a result of needing to pool funding, rather than existing relationships or friendships between the persons with intellectual disabilities.

6.2.2 What are the support needs required to facilitate ISL arrangements?

Recognising that persons with intellectual disabilities are diverse, it follows that their support needs are also diverse. The NDIS has created new opportunities for persons with disabilities by moving towards a support funding package for individualised living options (ILO) qualified by a reasonable and necessary criteria that may not include that of high support needs (National Disability Insurance Agency 2021). Also within the package there does not appear to be the same emphasis on the integration between housing and support, which is core to the ISL. At the same time, there are also challenges with the overall NDIS individualised funding model with potential impact for establishing and maintaining ISL arrangements. Specifically, this relates to the individual planning and funding cycles, which are typically annual, whereas it often takes several years to establish and create a sustainable ISL arrangement.

Furthermore—and arguably a strength of ISL arrangements—these approaches typically draw on a mix of formal (paid) and informal (unpaid) support from support workers, co-residents, family, friends, advocates, service providers and community members. Often there is overlap between formal and informal roles, which means that support workers may provide a set of paid hours of support, but also provide unpaid informal support through development of a genuine relationship with the focus person—for example, inviting them to a social event outside of ‘work’. In other instances, the social network of the person with intellectual disabilities may step up—for example, covering support shifts when paid support workers are unavailable (as illustrated in the interviews).

Therefore it is important that supports and support funding are flexible, to accommodate fluctuation in support needs and changing circumstances. Furthermore, the integral role of formal and informal supports to establish and maintain an ISL arrangement cannot be understated. Both suitable housing and suitable support are prerequisites to create and maintain appropriate and preferred homes for persons with intellectual disabilities and high support needs, and sustainable funding across both domains is required to create predictable, secure, and appropriate and preferred homes.

6.3 How can we support the continuation and enhanced sustainability of individualised housing for persons with intellectual disabilities and high support needs?

For both the establishment of and continuation of ISL arrangements for persons with intellectual disabilities and high support needs, 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. This recognises both the vulnerability of the focus persons, as well as the seminal role individuals may play in both the establishment and continuation of these arrangements, particularly parents.

6.3.1 How can transitional and continuous planning processes be improved?

It is crucial that both the voice and individual preferences of the person with intellectual disabilities are heard and understood. This requires that those involved in planning know the person well, and for the person with intellectual disabilities to be involved as much as possible in the planning process. This is commonly referred to in the disability field as person-centred planning, and is an integral part of the framework set out in the ISL Manual (Cocks and Thoresen 2017). The ISL Manual presents a quality framework that can be used to plan new arrangements or evaluate existing arrangements. As such, it provides the outline of the important features for quality arrangements, which may create appropriate and preferred homes for persons with intellectual disabilities and high support needs—but it does not provide guidance on obtaining and maintaining funding to establish and maintain ISL arrangements.

As argued earlier, to improve appropriate and preferred housing outcomes for persons with intellectual disabilities and high support needs, the integration between housing and disability services needs to be enhanced. This should be from the onset of the early planning processes, through any transitional phases, and throughout the maintenance phase after the arrangement is established. This approach recognises that there are different approaches for persons with intellectual disabilities and high support needs to have their own homes, as outlined in this research report, and that these different approaches may require different types of housing as well as different types of support. Furthermore, it recognises that people’s needs may change over time, which may also impact on what type of housing is appropriate.

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—who may be different for different stages of the planning process—and which may activate the social networks of the person with intellectual disabilities when they actively contribute to this process. It is equally important that a range of

housing stakeholders is involved (as appropriate) throughout this process, which may include public or social housing agencies, real estate agencies or even housing developers. Inclusion of these housing stakeholders in the planning phase may mitigate fears and enhance understanding of the specific circumstances of the focus person. Fears and prejudice are common factors in discrimination, including discrimination against persons with intellectual disabilities in the housing market.

Recognising that the circumstances of persons with intellectual disabilities and high support needs are often complex, it is important that the planning is flexible and includes various contingency plans. This may relate to both the individual circumstances of the focus person, as well as significant others who may take leading roles in the advocacy, planning and implementation of creating and maintaining an appropriate and preferred home for the person with intellectual disabilities. As illustrated in some of the interviews, this may include various layers of governance and safeguards to maintain the arrangements, including when significant others are no longer able to do so—for example, as parents age or pass away.

6.3.2 How can governance structures be implemented to safeguard appropriate and preferred homes for persons with intellectual disabilities?

This research report identified a number of formal and informal structures that were implemented to safeguard the ISL arrangements of research participants—for example, the involvement of family and friends together with service providers in different management arrangements, including shared management, which is one of the different management models of the NDIS. However, this approach mainly relates to the day-to-day running of the arrangement and, as illustrated in some of the arrangements, circumstances can change, which means that the nature of these collaborations may have to evolve over time.

Among the more established and sustainable ISL arrangements reviewed as part of this research, stakeholders had developed different governance structures to secure the home of the focus person. This included approaches such as the creation of less formal 'circles of friends', where people close to the focus person met regularly to review the arrangement and consider future opportunities, to more formal arrangements such as creating an incorporation to manage the arrangement, including within the framework of a Microboard. Typically, these arrangements included some form of guiding principles, vision or purpose related to the focus person's best interest and maintaining the living arrangement. Persons involved included current or former support workers and co-residents, family members, friends and family friends, and advocates. While parents often maintain a very active role within these governance structures, these were established in part in recognition that others also knew the focus person well and had their 'best interests at heart', as well as an acknowledgement that parent/s would not be able to continue to spearhead the arrangement indefinitely. The findings of the study fall short of family members reporting how they have aligned governance with the rights of their family member. If ISL is to be aligned with Article 12, Equal Recognition before the Law, of the UN Convention on the Rights of Persons with Disabilities (United Nations General Assembly 2006), supported decision-making needs to be built into its principles and practices.

There may be a range of other governance structures that may suit other persons with intellectual disabilities and high support needs, and individuals' circumstances may also influence which models are feasible. However, 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.

6.4 What would a national framework and guidance to ensure suitable housing for persons with intellectual disabilities and high support needs look like?

Disability services have come a long way. But they are still characterised by long waiting lists, and people have to accept what is on offer or choose between limited options. While the NDIS is supposed to change the premises of disability services—putting individuals in control of their funding and enabling them to purchase the services they need—limited financial and human resources have created bottlenecks in the expansion of services and individual choice for persons with disabilities in Australia.

While the NDIS specifies the quality standards for NDIS-registered service providers, together with a Code of Conduct that has multiple modules and quality indicators (NDIS Quality and Safeguards Commission [NDIS QSC] 2020), it does not cover housing in the broader sense as conceptualised within this research report. Rather, the Code of Conduct is developed for service providers and covers four core and seven supplementary modules. The core modules are framed around ‘rights and responsibility for participants, governance and operational management, provision of supports, and the support provision environment’ (NDIS QSC 2020: 4). The supplementary modules relate to ‘high intensity daily personal activities, specialist behaviour support, implementing behaviour support plans, early childhood supports, specialised support coordination, and specialist disability accommodation’ (NDIS QSC 2020: 4).

The quality standards include a framework of rights building on person-centred supports, individual values and beliefs, privacy and dignity, independence and informed choice, as well as the absence of violence, abuse, neglect, exploitation and discrimination (NDIS QSC 2020: 5–7). However, with the exception of the supplementary module related to specialist disability accommodation—more commonly referred to as group homes, and classified as cared-accommodation by the AIHW—housing does not feature within this framework. Despite this, support is a prominent feature and, as argued in this research, housing and support are integral to create and maintain appropriate and preferred homes for persons with intellectual disabilities and high support needs.

A national framework and national guidance to ensure suitable housing for persons with intellectual disabilities and high support needs could build on the NDIS quality standards framework, as the framework of rights are important principles that are also pertinent to housing. Furthermore, such a framework needs to do the following:

- Disseminate and ensure access to accurate information about different housing options. This has to extend beyond the traditional cared-accommodation models and include approaches to support persons with intellectual disabilities and high support needs to live alone, live with a host family, live with co-resident/s, and share with someone they have an existing relationship with such as friend/s or an intimate partner.
- Disseminate and ensure access to accurate information regarding different funding options for both housing and support to establish and maintain appropriate and preferred homes. This should include both mainstream funding options—including shared equity schemes and other strategies to support persons on low incomes to purchase their own homes—as well as collaborations between public and social housing providers and disability services.
- 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. This would allow for greater sustainability for parent/s and other drivers when they are no longer in a position to continue maintaining the arrangement, or want to step back from that responsibility.

Such approaches and practices have to cut across the different levels of bureaucracy between federal, state and territory governments, as well as across housing and disability services. As the findings in this report have indicated, it is important that the following steps are carried out.

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 focus person.
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 those of their support network may require unforeseen adjustments.

Furthermore, as additional developmental and safeguarding mechanisms, such approaches and practices may also do the following:

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 individual wellbeing and broader benefits from having your own home, including opportunities for skills development and community participation.
9. Include provisions for safeguards across both housing and support, recognising that these are integral for people with intellectual disabilities and high support needs, and that insufficient support, for example, 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 with intellectual disabilities and high support needs is reflected throughout this framework.

6.5 Accommodating persons with intellectual disabilities and high support needs

Where and how we live has immense influence across most of the domains of everyday life. For persons with disabilities and high support needs, this has typically been in cared-accommodation, including various forms of congregated living arrangements such as asylums, hospitals and, more recently, group homes. While these arrangements are not commonly referred to as cared-accommodation in the disability sector, it may be an apt description, as these models typically provide wraparound 'care' within a formal structure that does not accommodate the person with intellectual disabilities, but rather the rosters, schedules, activities and options of the service providers.

In recent decades, persons with intellectual disabilities, their families, advocates and some service providers have developed alternatives to these traditional cared-accommodation models—including those aligned with ISL models described in this research report.

Well-developed ISL arrangements are developed around the unique identity of the individual, taking into account their preferences, strengths and vulnerabilities, and they have multiple layers of safeguards to create appropriate and preferred homes that facilitate growth, development and enhanced wellbeing.

Appropriate and preferred homes for persons with intellectual disabilities and high support needs accommodate their individual situations. While a fundamental right in itself, appropriate and preferred homes go beyond shelter and may be a platform for being seen and developing as an individual. Persons with intellectual disabilities and high support needs are vulnerable because of their support needs, often relying on others as well as the formal support systems. When appropriately supported, such living arrangements have created a platform from where individuals develop, may benefit from and contribute to their communities, and enjoy the full rights and obligations as individual citizens. Accommodating people with intellectual disabilities and high support needs is to create appropriate and preferred homes for individuals, not simply shelter in cared-accommodation.

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Appendix A: Sources of information

Scoping literature review

A scoping review of the literature on ISL was conducted in 2020, following the previous literature review by Cocks, Thoresen et al. (2014). A structured search was carried out in five databases: Scopus, Embase, Medline, CINAHL and PsycInfo.

In addition to the specific inclusion and exclusion criteria related to disability, fidelity with ISL, age and innovation, included studies had to be English language peer-reviewed journals published between 2000 and 2020. The inclusion and exclusion criteria and related search terms are provided in Table A1.

Because of time constraints, it was not feasible to undertake a complete systematic review. As such inclusion criteria are specific and restrictive, in that additional search terms such as 'mental retardation' (used in the USA until recently) and specific alternative definitions and names corresponding to ISL were not included. However, the search did incorporate the nature of tenancy with the nature of supports. The findings represent a scoping of new literature in this area but do not claim to be comprehensive of all new literature. Also, the population of interest was people with intellectual disability and high support needs, and if the literature did not incorporate this high support group, the paper was excluded. 'High support' was not a term within the search strategy but was a criteria for reviewing inclusion in the abstract and full-text review process.

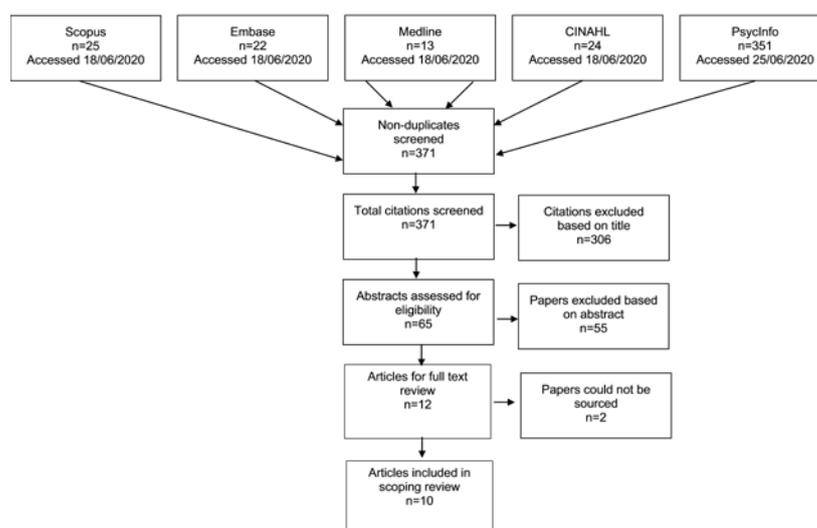
Table A1: Scoping review search strategy

Domain	Inclusion	Exclusion	Search term
1. Disability	Intellectual disabilities, ('learning disabilities' in UK), developmental disabilities	No intellectual disability, cognitive impairment associated with ageing (dementia, early onset dementia)	(intellectual disability*) OR (developmental disability*) OR (learning disability*) OR (autism) OR (ID) OR (IDD) OR (ASD) AND
2. Individual supported living	Living alone, supported and shared living arrangements as defined in ISL Manual	Congregate living arrangements (group homes, institutions, shared arrangements that are not by choice); living in the family home (with parent/s)	(Individualised Supported Living) OR (supported living) OR (own home) OR (living alone) AND
3. Adults	18 years or older	Children, under 17 years or younger	Adult* AND
4. Innovation in individualised housing/housing support	Personalised approaches, individualised funding, flexible supports, mix of formal and informal supports, transition	Congregate housing models, congregate support models	(innovation) OR (improve*) OR (wellbeing) OR (quality of life) OR (inclusion)

Source: Authors.

The initial search resulted in 435 papers being identified. These were reviewed by title and then by abstract by two researchers. The review process is outlined in the PRISMA diagram (Moher, Liberati et al. 2009) in Figure 1. The final number of included papers based on the relevant criteria were 10: six qualitative studies and four quantitative studies. Given that this was a scoping review, the emphasis was on identifying new learning in this space and less so on the quality and methodological rigour of the papers. The papers were reviewed using a thematic analysis framework to identify commonalities in theme around positive and negative characteristics of ISL arrangements, as well as outcomes.

Figure A1: PRISMA diagram



Source: Authors.

Secondary analysis

Information collected during the preceding ARC-funded ISL project (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, Thomson et al. 2018) was reanalysed for this project. Among the 130 participants in that study, 23 were identified based on self-report, level of funding, or an Assessment of Level of Support Need as having high or very high support needs, had intellectual disabilities, and had completed the housing pathway interview that provided information on the establishment and maintenance of their ISL arrangement. Four of the 23 interviews did not provide sufficient detail, so this section of the research report presents findings from 19 ISL arrangements.

The secondary analysis of these interviews 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, consisting of six stages: i) transcription, ii) familiarisation with the interviews, iii) coding, iv) developing a working analytic framework, v) applying the analytical framework, and vi) charting the data into the framework matrix (Gale, Heath et al. 2013). Two authors who worked on the preceding ARC-funded study (Cocks, Thoresen, O'Brien and McVilly 2017; Cocks, Thoresen, Thomson et al. 2018) completed the first three stages using a subset of the interviews. Based on agreement and consultation with the broader research group, the analytical framework was then developed, drawing on an approach developed for another study⁸. It consisted of seven themes that were rated from 'not developed' to 'well-developed' using a six-point scale guided by descriptors for each theme and rating. The descriptors used for this matrix are presented in Table A2.

⁸ The framework used to code and extract information from the earlier interviews drew on a qualitative framework developed for an ARC-funded linkage project, LP170100044, *Navigating through life*. We would like to acknowledge the contributions from the research team who developed that framework, in particular Donna Chung, Reinie Cordier, David Hodgson, Lynelle Watts and Brontë Walter.

Each theme was rated as poor, mid-range or strong. Where there was insufficient information in the interview to rate the theme, it was not given a score. The theoretical matrix score range is from a low of 7 and a high of 21. However, as there were instances where an individual theme was not scored due to a lack of information, the matrix score is presented as a percentage out of the theoretical maximum based on the number of themes rated for each interview. Findings from the secondary analysis are presented in Section 3, organised according to these themes.

Table A2: Coding framework for secondary analysis

Theme	No information	Poor	Mid-range	Strong
Current Living Situation	There is no information provided in the interview related to the current living situation; it is not possible to rate this theme.	There is little evidence to support that the current living arrangement reflects the attributes and indicators of ISL.	There is some evidence to support that the current living arrangement reflects ISL; most of the attributes and indicators suggest that it is developing.	Most or all evidence suggests that the current living arrangement reflects the attributes and indicators of ISL.
Planning ISL	There is no information provided in the interview related to ISL; it is not possible to rate this theme.	There is little evidence to support that there has been long-term, person-centred and meaningful planning.	There is some evidence to support that there has been long-term, person-centred and meaningful planning, and/or that there is long-term, person-centred and meaningful planning for the future.	Most or all evidence suggests that there has been and is future long-term, person-centred and meaningful planning.
Social connections (family, friends and community)	There is no information provided in the interview related to the social connections; it is not possible to rate this theme.	There is little evidence to support that the person has meaningful social connections with family, friends, and in the community more broadly.	There is some evidence to support that the person has social connections and takes part in the community, and most of the evidence suggest that this is developing.	Most or all the evidence supports that the person has close and long-lasting relationships, a rich social network, and takes part in the community.
Informal supports	There is no information provided in the interview related to the informal supports; it is not possible to rate this theme.	There is little evidence to support that there are informal supports.	There is some evidence to support that the person has informal supports and most of the evidence suggests that flexible supports that suit the person are developing.	Most or all the evidence supports that the person has flexible supports that suit the person.
Formal supports and/or services	There is no information provided in the interview related to formal supports or services; it is not possible to rate this theme.	There is little evidence to support that the person has formal supports or receives required services to live in the home and develop or partake in the community.	There is some evidence to support that the person has formal supports or receives required services. Most of the evidence suggests that formal supports and access to services are developing.	Most or all the evidence suggests that the person has formal supports and access to services that suit the person's needs across a range of areas.
Wellbeing	There is no information provided in the interview related to wellbeing; it is not possible to rate this theme.	There is little evidence to support that the person's lifestyle and wellbeing is improving.	There is some evidence to support that the person's lifestyle and wellbeing is improving and most of the evidence suggests that this is developing.	Most or all the evidence suggests that the person's lifestyle and wellbeing is improving, the person has valued social roles and there are many opportunities for growth and development.
Sustainable funding	There is no information provided in the interview related to sustainable funding; it is not possible to rate this theme.	There is little evidence to support that the funding arrangements are sustainable, and the arrangement is characterised by uncertainty due to funding arrangements.	There is some evidence to support that the funding arrangements are sustainable and innovative, and most of the evidence suggests that this is developing.	Most or all the evidence suggests that the funding arrangements are sustainable and there are innovative, agile, and/or flexible approaches to ensure financial sustainability.

Source: Authors.

Interviews

Additional qualitative interviews for 21 different ISL arrangements of people with intellectual disabilities and high support needs were carried out for this project. This included 11 interviews in WA and another 10 interviews in NSW and the ACT. The interviews were conducted between November 2020 and April 2021. Interview participants were recruited through purposive sampling and snowball approaches by utilising existing contacts, including the networks of the reference groups in WA and NSW, NGOs and advocacy organisations known to the researchers, or persons that were involved with the preceding ARC-funded study. It was estimated that about one-third of the participants interviewed as part of the present AHURI-funded study had contributed to previous ISL research.⁹ There were three broad inclusion criteria for the purposive sampling:

1. The focus person had to be 18 years of age or older.
2. The person had intellectual disabilities and high support needs. The person may or may not have had other disabilities. There are many different approaches to operationalise 'high support needs', such as level of funding, eligibility for certain services, or needing assistance for a range of self-care or other activities of daily living. For the purposes of recruitment, persons who required a lot of support in at least one of the following areas were considered as having high support needs, independent of how this was derived—for example, self-assessments or formal assessments—aligned with the AAIDD definition of high support needs (Schalock, Luckasson et al. 2021):
 - physical or emotional health
 - community and social inclusion
 - education, training and employment
 - finances
 - self-care
 - other domains of daily living.
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 parent/s) or in any congregate arrangements.

Of the 21 interviews, 15 were recorded, while six interviews relied on the notes of the interviewer. The six interviews that were not recorded related to technical issues as well as participants' preferences. These interview notes were analysed in the same way as the transcripts and did not impact the quality of the data, although it did reduce (but not eliminate) quotes for the report—for example, WA-11 and WA-9. Ten of these interviews were either carried out with the persons with disabilities in the presence of support workers or agency staff (n=7), co-residents (n=1), or with the parent/s or other relatives of the focus persons (n=6) that were involved in supporting or developing the ISL arrangement.¹⁰ If there were sections of the interview the participants were unable to answer—for example, if the person with disabilities and/or support workers/co-residents did not have sufficient information on the establishment of the arrangement—additional information was sought from parents or other key informants.

⁹ Reviewing consent forms, it may be that two participants from the secondary analysis participated in the new interviews.

¹⁰ In some of the interviews conducted with or in the presence of the focal person with intellectual disabilities, there were multiple people present, which could include a mix of parents, support workers, agency staff, and/or co-residents.

The focal person with intellectual disabilities was invited to participate in all interviews. In WA, six of the 11 persons with intellectual disabilities were present during the interview. In NSW, only two of the 10 participants were present and contributed to the interview. Six family members indicated from past experiences that the person would not be able to contribute to the conversation and could become distressed if they were confined to a particular space. Two other participants were present, but engaged in other activities during the interview, such as craft work.¹¹

As the COVID-19 pandemic emerged during the data collection phase of this study, 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, not all interviews were face-to-face and eight interviews were conducted through audiovisual platforms. Prior to the COVID-related restrictions and modified research protocol, the focal persons with intellectual disabilities were invited to lead the interviewers on a tour of their home. Curtin University Human Research Ethics Committee (HREC) approved the study protocol, including amendments to facilitate audiovisual interviews (Curtin HREC approval number HRE2020-0330), with The University of Sydney HREC granting reciprocal approval.

Workshops

Based on the information from the scoping review, secondary interview analysis and qualitative interviews for this project, thematic summaries—or fact sheets—were developed. These served two purposes:

- As a vehicle to share preliminary project findings and generate discussion with a group of project stakeholders, including disability service professionals, inclusive housing providers, families of people with high support needs, researchers and other experts in the field.
- As a project output to educate and raise awareness about the concept of ISL.

A deductive and inductive approach to thematic analysis (Azungah 2018; Braun and Clarke 2006) was used to analyse and summarise the research findings in the four areas that were then presented in these fact sheets:

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

Subordinate codes were developed based on the concepts and topics represented in the data. Similar and related sub-codes were summarised as sub-themes that formed the content of the 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, academics, and parents of persons with disabilities and high support needs—these fact sheets were revised and amended to incorporate the most pertinent feedback from workshop participants. The findings from these workshops are presented in Section 4.

¹¹ While further work and research to increase the involvement of persons with intellectual disabilities and high support needs in research may be warranted, current techniques to ensure their voices are captured requires specialist skill sets that were beyond the research team, despite their extensive research experience with persons with intellectual disabilities and high support needs. This should be noted as a limitation of the study.

Limitations

There are several limitations that should be noted. The scoping review was exploratory and intentionally used contemporary language as search terms. Therefore, it may not have captured all studies relevant to the project. It should also be noted that many of the focal persons with intellectual disabilities had limited verbal communication skills and their voices were not directly captured in the interviews. In most cases, family members or support staff acted as proxy informants. It is possible the level of support led to some focal persons opting not to be present at the interviews, or their supports chose not to include them.

It is not possible to ascertain how—or if—this approach skewed the data. For future projects, it will be an advantage to look at alternative and more flexible ways to include people with intellectual disability with high support needs. However, within the resource limitations of this project that was not viewed as feasible, and it is acknowledged that the voices of the persons with intellectual disabilities and high support needs are not reflected to the desired extent.

The COVID-19 pandemic has had profound impact on people's lives across the globe. People with intellectual disabilities and high support needs are often viewed as particularly vulnerable, due to their poor verbal communication and comprehension, and possibly underlying health conditions. Many people with intellectual disabilities were often unable to experience community connection across the lockdown period, which reflected on how they were experiencing the ISL model. Shortages of support staff were another issue throughout the pandemic.

Changes arising from the pandemic lead to the need for electronic interviewing, which slowed the start of the project, as did reaching out to organisations to identify people with high support needs who were living within an ISL model. Recruitment needed to take second place as organisational priority was adapting to the pandemic. As a result, close on half of the interviews were done through videoconferencing, which worked against people with intellectual disabilities participating more flexibly. Pandemic restrictions were also experienced by some family members and supporters, who were unable to join the person with intellectual disability in their own home for the interview.

Appendix 2: Papers included in the scoping review

Table A3: Papers included in scoping review

Author and year	Aim	Country	ISL definition
Ashley, Fossey & Bigby, 2019	To describe the characteristics or qualities of the home environments of six people with intellectual disabilities in supported living and occupational engagement.	Australia	A supported living situation, either alone or with up to three other people, where provision of accommodation and support were separate.
Isaacson, Cocks & Netto, 2014	To explore the experiences of two young people with intellectual disability moving into ISL and the impact of WA funding approach.	Australia	ISL, in which people with disability live in their own home and are provided with the level and type of assistance that they require.
James, Harvey & Mitchell, 2018	To answer the question 'do people living in the community experience independence or do institutional routines define their lives', emphasising evening routines.	UK	Community home setting.
Kim & Dymond, 2020	To investigate critical independent living skills for adults with intellectual and developmental disabilities who live in the community, and common reasons for why individuals lose their residential placement.	USA	Community home setting, including group homes and supported apartments.
Marlow & Walker, 2015	To explore whether a move to supported living from residential arrangements improved quality of life.	UK	Purpose-built individual flats in the same busy urban block surrounded by similar blocks of flats. 24-hour staff support by same staff team from previous shared houses.
McConkey, 2007	To compare the level of social inclusion among people with disabilities living in supported living (clustered and non-clustered) arrangements with that of people with disability living in traditional residential care.	Northern Ireland, Republic of Ireland	Clustered supported living: purpose-built groupings of houses or apartments with shared staffing across the houses. Fifteen tenants may live in the same cluster with tenancy agreements, in single-person or shared housing. Dispersed supported living: the person holds a tenancy agreement for an ordinary house or apartment on either an individual or shared basis; usually with no more than two other persons. Support staff are provided according to assessed needs, and they visit on a regular basis. The houses are dispersed among other properties.

Author and year	Aim	Country	ISL definition
McConkey & Collins, 2010	To answer the question: can person-centred goal setting increase the choice and social inclusion of people with intellectual disabilities living in four different types of accommodation setting?	Northern Ireland	The supported living services consisted of people living in a cluster of dwellings and those who lived in dispersed housing within the community. Individual support was provided to both sets of tenants.
McConkey, Keogh, Bunting, Iriarte & Watson, 2016	To compare outcomes for people in ISL, group home and institutionalised settings.	Northern Ireland, Republic of Ireland	Rented accommodation in 'ordinary' homes. Property chosen by tenant. Usually, tenants received drop-in support as required, with a few individuals receiving 24/7 support.
Stainton, Brown, Crawford, Hole & Charles, 2011	To compare outcomes across four settings: group home, family model home, independent home or apartment, and family home.	Canada	Those in independent settings would receive support of some form and hence would fall into the general 'supported living' category. 'Family model home' referred to adults living in the homes of non-relatives who were paid to provide support.
Walker, 2012	To identify strategies used by organisations as they make transition from group home to individualised supports.	USA	Supported living expressed a fundamentally different relationship to people with developmental disabilities than most other approaches to service: instead of controlling people with disabilities in order to 'fix them', supported living workers sought to cooperate with people with disabilities in order to develop the assistance they needed to get on with their own lives.

Source: Authors.



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