

Wednesday 20 July | 10:00am – 11:30am (AEST) | #AHURIwebinar

# Independent Supported Living Arrangements for adults with intellectual disabilities and high support needs

## Speaker

Professor Angus Buchanan, Curtin University

Associate Professor Mary-Ann O'Donovan, University of Sydney

## Respondent

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# Welcome

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# Presentation

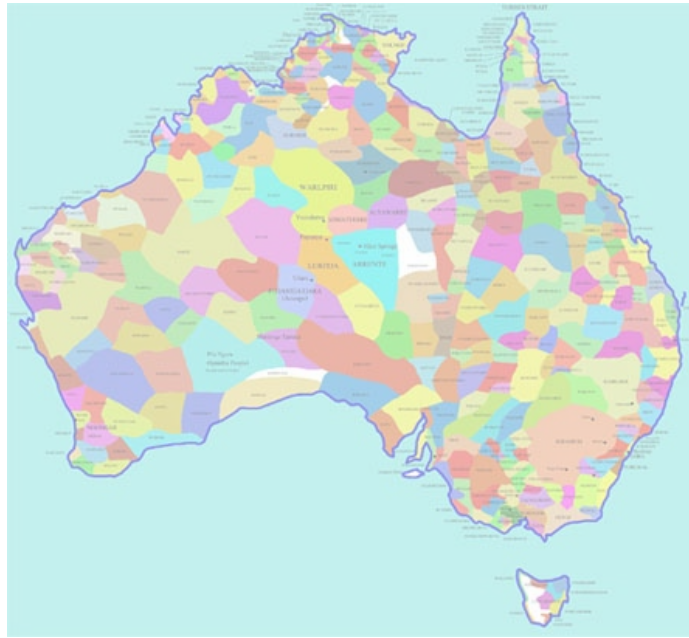
## Individual Supported Living arrangements

Professor Angus Buchanan - Curtin University

Associate Professor Mary-Ann O'Donovan – University of Sydney



# Acknowledgement of Country



# Research Team

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# Background

- 4.4 million Australians with disabilities (17.7%)(ABS 2019).
- One-third has profound (3.2%) or severe (2.6%) core-activity limitations related to communication, mobility or self-care, and schooling or employment.
- 195,700 Australians with disabilities lived in cared-accommodation in 2018, although only 14,400 were persons aged 15–64 (ABS 2019).
- 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 have been the norm for persons not living with their parent/s in the family home.
- People with disabilities are increasingly seeking individualised living, arrangements, which cater for their specific needs, circumstances, strengths and vulnerabilities.
- 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.

# What is Individual Supported Living (ISL)

Individual Supported Living (ISL) (Cocks et al. 2014; 2016; 2017; 2018)

Guided by eight themes: Leadership, My home, One person at a time, Planning, Control, Support, Thriving, and Social inclusion.

Four types of ISL arrangements :

1. **Living alone** in an appropriate and preferred home with sufficient and appropriate support.
2. **Host family** arrangement—also referred to as alternate family arrangement or adult foster Care
3. **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.
4. **Sharing with someone** in an established relationship based on established friendships or an intimate relationship.

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.

# Current context

- 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
- 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
- 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.
- 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

# Research approach

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 (n=19) carried out in the previously ARC-funded ISL study
- Interviews (n = 21) 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 (n = 21)

# Themes from the Literature

- Limited literature identified
- Operational definitions were inconsistent
  - Comprehensive – physical setting and supports
- Improvement in at least one area of life post transition
  - Choice, control, social inclusion, autonomy, independence
- Challenges - lack of formal support resulting in increased reliance on family networks
- Enablers – appropriate physical space



# Learnings from current arrangements

- Range of circumstances and outcomes
  - Majority living alone or with co-resident
- Simply living alone does not in itself create an appropriate and preferred home or generate good outcomes
  - Key= appropriate support
- Wide range in support hours accessed
  - Paid and unpaid

Type of ISL	Time in home	Weekly hours of support		
		Paid	Unpaid	Total
		—*	—*	—*
Alone	10 years			
Alone	5 years	124	44	168
Alone	< 1 year**	13	45	58
Co-resident	13 years	25	60	85
Co-resident	3 years	209	4	213
Alone	2 years	40	0	40
Co-resident	6 years	23	28	51
Alone	5 years	5	4	9
Alone	12 years	131	11	142
Alone	7 years	96	72	168
Alone	3 years	306	50	356
Co-resident	4 years	54	20	74
Relationship	20 years	9	0	9
Co-resident	< 1 year**	33	54	87
Relationship	3 years	4	3	7
Co-resident	1 year	173	0	173
Alone	< 1 year**	117	51	168
Co-resident	8 years	27	8	35
Relationship	7 years	28	88	116

- **Common characteristics** of strong ISL arrangements
  - Developed over time
  - Person centred and holistic
  - Hard fought battles
  - Governance and meticulous detail in development
  - Substantial research and planning
  - Involvement of multiple stakeholders
- **Sustainability** of arrangements dependent on on-going funding
- **Informal supports**
  - One of the least developed area
  - Over-reliance on family (typically mother)
- **Formal supports**
  - Range; flexible; contingency planning

# Learnings from people with disabilities (interviews)

- Two different pathways into ISL arrangements:
  - moved directly from their family home, or
  - decided on the arrangement after congregate arrangements proved unsuitable

*[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)*

*[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).*

# Learnings from people with disabilities (interviews)

- Transition into ISL arrangements was considered more successful when it happened gradually

*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).*



# Learnings from people with disabilities (interviews)

- Benefits of ISL arrangements included having more choices, increased safety and stability of the arrangement, and a sense of belonging in the community

*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).*

*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).*

# Learnings from people with disabilities (interviews)

- Fear related to future planning - predictable levels of funding for the arrangement and sustainability after the parents of persons with disabilities passed away.

*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).*

*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).*

# Fact Sheets

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

- No prototype
- Person with intellectual disability central
- Substantial and continuous planning
- Multiple people can act as advocates
- ISL and NDIS ILO manuals
- Gradual process

## 2. Enablers and benefits of an ISL

- Increased autonomy
- Improved health and wellbeing
- Increased choice
- More confident and independent

# Fact Sheets

## 3. Coping with challenges along the way

- Settling in takes time
- Unsuitable co-residents and staff turnover challenging
- Access to services may be hampered

## 4. Managing change and planning for the future

- Talking about the future
- Planning and putting contingencies in place
- Community of practice and other supports
- Person with intellectual disability remains at heart of all planning

# Policy development

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.



# Summary

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

Download the report: [ahuri.edu.au/research/final-reports/380](http://ahuri.edu.au/research/final-reports/380)

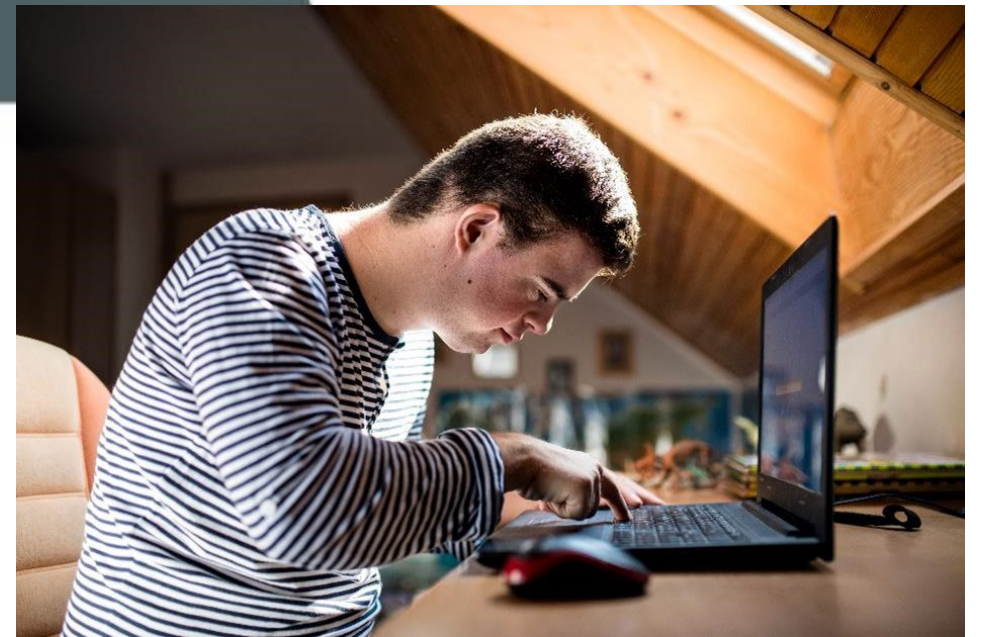
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