

School of Occupational Therapy and Social Work

QUALITY AND OUTCOMES OF INDIVIDUAL SUPPORTED LIVING (ISL) ARRANGEMENTS FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Final Report July 2017

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A number of partner organisations supported the project throughout:

- My Place Foundation (WA)
- National Disability Services (AUS)
- Integrated Living Australia (NSW)
- Avivo Live Life (previously Perth Home Care Services) (WA)
- Achieve Australia (NSW)
- Inclusion Melbourne (VIC)

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- Dr Allyson Thomson
- Dr Meredith Prain
- · Jenny Crosbie
- Friederike Gadow

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Executive Summary

Background

In 2007, in the School of Occupational Therapy and Social Work at Curtin University in Western Australia, we began a project to examine the characteristics and outcomes achieved when adults with intellectual and developmental disabilities were provided with necessary support to enable them to live in their own homes. We were influenced by the appropriateness of the strong movement away from congregate options for adults with disabilities, particularly from institutions and group homes.

The aim of the project was to learn more about the characteristics of Individual Supported Living (ISL) in order to inform, educate, and influence greater "take-up" of these options by families and support services to enhance the lives of adults with intellectual and developmental disabilities and their families.

An increasing number of families were seeking individual options for their sons and daughters and small, specialist NGOs were emerging to provide support to families and adults with disabilities to enable this to occur. We were also influenced by the development of Local Area Coordination which was "tailor made" to provide the kinds of support that were needed, and the introduction of individualised funding, both of which were first developed in WA around 1980. Finally, the UN Convention on the Rights of Persons with Disabilities was very clear about the rights of adults with disabilities to choose where and with whom they lived.

The 3-stage research project was initially named the "Personalised Residential Supports Project" which was renamed in the second stage as the "Individual Supported Living (ISL) Project". Early on we made a clear distinction between the terms "independent" and "individual", with no intention that independence was a requirement before people could live in a home of their own. The first two stages were supported by two small grants from the WA Lotteries Commission, and the third stage by an Australian Research Council Linkage Grant. All three stages were well supported by many NGOs, families, and persons with disabilities. The third stage introduced research colleagues from Deakin (latterly, Melbourne) University, and Sydney University.

This is the Final Report of the third stage of the research. It provides background detail and the outcomes of evaluating 130 examples of ISL "arrangements" in WA, Victoria, and NSW.

Methods

There were three principal methods that were used throughout the Project.

First, we needed to deepen our understanding of Individual Supported Living. This was achieved by following a small number of adults with intellectual and developmental disabilities over an extended period of time and endeavouring to document all that seemed relevant to their journeys; from both family homes and institutional care to individual arrangements that took a number of forms.

Second, we then needed to "operationalise" that knowledge into a way of evaluating living arrangements in order to agree that an arrangement was indeed an ISL arrangement, and also to measure the quality of that arrangement. To do this, we worked with a group of people who were experienced in developing and supporting individual arrangements in order to create a "fidelity measure" - a way of evaluating the extent to which key outcomes are achieved. We called this, the *ISL Manual*. This measure became the primary method to evaluate and review arrangements in the Project.

Third, working with colleagues from Sydney and Deakin/Melbourne Universities, we trained small teams led by trained team leaders to carry out 130 evaluations of ISL arrangements across the three States. We also developed the early training materials and provided many presentations at conferences and public events.

Themes

The ISL Manual is described in more detail in this Report. It consists of 8 Themes that are made up from 21 Attributes. The tool has good construct and face validity because of the way it was developed. Similarly, it achieves good test-retest reliability that we obtained from a sample of arrangements. The Project carried out a minor revision of the ISL Manual at the conclusion of the 130 evaluations and now is published in a second edition.

Conclusion

This has been an exciting and rewarding Project for those who have been engaged in it. The experience has confirmed the value of enabling adults with intellectual and developmental disabilities to live in their own homes. It has also identified the relative strengths and weaknesses of ISL arrangements. The National Disability Insurance Scheme (NDIS) emphasises individual supports. Our findings provide much needed evidence of what constitutes good practice in ISL, and the resources needed to establish and monitor the quality of these arrangements.

Introduction

Origins of the project

Adults with intellectual and developmental disabilities are particularly vulnerable to being marginalised and socially excluded as they experience barriers to the rights and opportunities available to other citizens. Traditional forms of providing disability accommodation may share common characteristics that include:

- use of paid staff
- established routines
- ownership of the place of residence usually vested in a government or NGO service with no guarantee of continuity
- congregation of adults with disabilities in group homes and institutions, that offer no choice in choosing the people with whom they share their home

In contrast, Individual Supported Living (ISL) means that adults with disabilities live in their own home with a range of enabling supports that may include both paid and unpaid support persons, and engages family and friends². ISL should not be confused with 'supported living', which has been defined as living with no more than two persons (not parents or siblings) and with separate organisations responsible for the housing and the support services³.

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – *Living independently and being included in the community* – recognises the '…equal right of all persons with disabilities to live in the community, with choices equal to others…' by ensuring choice in both place of residence and living companion, and by enabling access to supports for living in the community. As a signatory to the UNCRPD, Australia has an obligation to support these rights. National and local policies and practices have facilitated the development of ISL across Australia during the past decades. Chief among these policies has been individualised funding which empowers individuals and their families to choose the supports they want and from whom they receive them. This policy context has been given crucial support with the launch of the National Disability Insurance Scheme (NDIS) that aims to enable persons with disabilities to achieve greater choice and control in their lives.

¹World Health Organization. (2011). World Report on Disability. Malta: WHO Press.

²Cocks, E., & Boaden, R. (2011). A quality framework for personalised residential supports for adults with developmental disabilities. *Journal of Intellectual Disability Research*, 55(8), 720-731. doi:10.1111/j.1365-2788.2010.01296.x

³Bigby, C., Bould, E., & Beadle-Brown, J. (2016). Conundrums of supported living: The experiences of people with intellectual disability. *Journal of Intellectual & Developmental Disabilities*, 1-11. doi:10.3109/13668250.2016.1253051

⁴United Nations General Assembly. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

This research project has been in progress since 2007 and has incorporated three stages. The first two stages produced the ISL Manual, a tool to describe and measure the quality of individual supported living arrangements. In stage one, (the Personalised Residential Supports Project) an initial ISL framework was developed to describe the key themes and attributes of ISL. Over two years, six persons with disabilities living in ISL arrangements were followed, and a range of activities brought experienced persons together to further develop the framework.

The second phase began in 2010 and refined the ISL framework through a series of World Café style workshops with service providers, family members, academics, and advocates, all of whom had experience of ISL, in some cases spanning decades. The framework was "operationalised", that is, the themes and attributes incorporated measurement to reflect the levels of quality achieved by an ISL arrangement. Further refinement of the framework involved ten pilot evaluations of ISL arrangements. The second stage resulted in the publication of the ISL Manual consisting of 21 Attributes within eight Themes. These are listed in Table 1 below.

⁵National Disability Insurance Scheme Act 2013, (October 17, 2013).

⁶Cocks, E., Williamson, M., & Thoresen, S. (2011). Individual Supported Living Manual. Bentley: Curtin University.

⁷Cocks, E., Thoresen, S., Williamson, M., & Boaden, R. (2014). The Individual Supported Living (ISL) Manual: A planning and review instrument for individual supported living arrangements for adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 58(7), 614-624. doi:10.1111/jir.12059

Table 1: Themes and Attributes of the ISL Framework

1. Leadership

- 1.1 The arrangement is based on a clear vision and strong ideas.
- 1.2 Key people provide the leadership to set up and continue the arrangement.

2. My Home

- 2.1 The person has secure tenure in the home.
- 2.2 The person does normal things that people do in their homes.
- 2.3 The person's home reflects who the person is and what he or she likes.

3. One Person at a Time

- 3.1 The arrangement is developed around the person.
- 3.2 The living arrangement does not group persons with disabilities.

4. Planning

- 4.1 Planning focuses on the person.
- 4.2 People close to the person are involved in planning.
- 4.3 The person's future is central to planning.

5. Control

- 5.1 The person and those close to him or her (if appropriate) have control over the person's life.
- 5.2 Self-determination for the person is central to the arrangement.
- 5.3 The person and those close to him or her (if appropriate) have control of the arrangement.

6. Support

- 6.1 Supports are flexible and adapt to changes in the person's needs.
- 6.2 A variety of supports are in place that suit the person.

7. Thriving

- 7.1 The person's lifestyle and wellbeing are improving.
- 7.2 The person has valued roles.
- 7.3 There are many opportunities for growth and development.

8. Social Inclusion

- 8.1 The person has close and long-lasting relationships.
- 8.2 The person has a rich social network.
- 8.3 The person takes part in the community.

Using the ISL Framework and Manual to review an arrangement

The ISL Framework can be used to review an existing arrangement in three ways:

- 1. Internally by persons who are involved and familiar with the arrangement
- 2. Externally by persons who are not directly involved with the arrangement
- 3. Involving both internal and external reviewers

An ISL review looks at how the living arrangement has developed and how it can continue to develop. Reviews benefit substantially from facilitation provided by a person who has received training on the use of the ISL Manual. Other persons participating in a review also benefit from preparation. Facilitation helps to explain and clarify Themes and Attributes, to assist the identification of what is working well within the arrangement, and to identify where improvements can be made.

Objectives of the project

The aim of this third stage of the research was to measure the impact of ISL quality on outcomes for adults with intellectual and developmental disabilities, determined by evaluations conducted using the ISL Framework and Manual.

People and organisations involved

The support of the disability sector for this project was reflected in the organisations that supported the project, either as partner organisations or as contributors to the reference groups. They represented a wide cross section of stakeholders across three states.

Partner Organisations included:

- My Place Foundation (WA)
- National Disability Services (AUS)
- Integrated Living Australia (NSW)
- Avivo Live Life (previously Perth Home Care Services) (WA)
- Achieve Australia (NSW)
- Inclusion Melbourne (VIC)

Additional agencies provided links to participants:

- Ability Options (VIC)
- ACSO (VIC)
- Belonging Matters (VIC)
- Break Thru (NSW)
- Cam Can (WA)
- Community Living Association Albany (WA)
- Developmental Disabilities WA
- Enable South West (WA)
- Life Assist (VIC)
- Life Without Barriers (NSW)
- Northern Support Services (VIC)
- Senses (WA)
- Sunshine (NSW)
- Uniting (NSW)
- WA Individualised Services

Invaluable contributions were made by research participants, their families and support persons.

Methods

Ethics approval

The protocol for this project was reviewed and subsequently approved by the Human Research Ethics committees of the participating universities.

Data collection

The assessments of quality and outcomes were carried out through reviews of 130 individual living arrangements across Western Australia, New South Wales, and Victoria. Each review comprised an evaluation using the ISL Manual and Review Scoring Booklet, and a set of outcome measures and protocols.

The *evaluations* followed a set of procedures based on methods commonly employed in human service process evaluations⁸. The ISL reviews consisted of three steps outlined below:

- Evaluation teams comprised three or four members: a trained Facilitator from a pool identified by each State Reference Group, and two or three Team Members drawn from family members and support workers who were trained in the ISL arrangement and the review processes by the Facilitator.
- 2. Each review took several days to complete. Teams gathered data through observation, consultations with key stakeholders, and review of relevant documentation in accordance with the ISL tool.
- 3. Finally, each team member independently rated the 21 attributes. The lowest score of 1 for an attribute indicated that this area is 'not addressed', while the highest score of 5 indicated that this attribute is 'optimal'. The team then met to complete conciliated ratings through group discussion and consensus. ISL arrangements were then given a total score. Theoretical scores range from a low of 21 (which suggests that the arrangement may not be an ISL arrangement as no attribute is addressed) to a high of 105 (indicating that all attributes are optimal and no improvements can be identified).

In addition to the ISL reviews, the Facilitator or research staff completed the following *outcome measures and protocols* by interviewing appropriate persons including the adult with disabilities, family member/s, and/or support worker/s.

- The QOL.Q for quality of life⁹. This instrument contains four sub-scales: Satisfaction, Competence/Productivity, Empowerment/Independence, and Social Belonging/ Community Integration.
- The Index of Community Involvement¹⁰. This is a measure of the number of times each of 16 different community activities have occurred in the last 30 days.
- The Assessment of Level of Support measures the level of difficulty or level of support need for each of 12 items¹¹.
- The sources of funding for daily activities and for accommodation, hours of paid and unpaid support, and the providers of formal and informal support.
- The decision pathways made by key stakeholders in the development of each ISL arrangement, the processes of moving into the arrangement, and a description of the type of accommodation, location, type and length of tenure, governance structure, and co-residents as applicable.

⁹Schalock, R. and Keith, K. (1993 & 2004). *Quality of Life Questionnaire Manual.* IDS Publishing Company, Worthington, Ohio.

¹⁰Raynes, N. V. (1988). *Annotated Directory of Measures of Environmental Quality for use in Residential Services for People with a Mental Handicap.* Manchester: University of Manchester.

¹¹Noonan, V. K., Kopec, J. A., Noreau, L., Singer, J., Chan, A., Mâsse, L. C., & Dvorak, M. F. (2009). Comparing the content of participation instruments using the International Classification of Functioning, Disability and Health. *Health and Quality of Life Outcomes*, 7(1), 93. doi:10.1186/1477-7525-7-93

Findings

The ISL Manual and Scoring Booklet

- One purpose of this project was to determine the inter-rater reliability of the ISL Manual and review process. Each of 13 arrangements was evaluated by two teams (3 or 4 members in each team) simultaneously. Conciliated ratings for each of the 21 attributes were compared between teams. An exact match meant the responses were the same, and a close match represented no more than one unit difference between the ratings. For exact agreement, the error rate was 50.2% (95% CI: 43.2 57.2) and for close agreement, 3.3% (95% CI: 1.2% 5.4%). Therefore fewer than 5 percent of the ratings differed between teams by more than one unit.
- Confirmatory factor analysis identified that all Themes were located on a single factor that
 explained 65% of the variance in Themes. Similarly, all Attributes initially were located on
 a single factor that explained 49% of the variance in Attributes. All Themes and Attributes
 contributed significantly to the whole measure and therefore were important components
 of the Manual and Scoring Review.
- Concurrent validity is tested by examining the agreement between two different sources
 of information. Total ISL score was significantly associated with total quality of life and
 with both measures of community involvement. This shows that the ISL Themes, as
 anticipated, reflect both quality of life and community involvement for participants.

Types of ISL arrangements

The study placed most living arrangements for adults with intellectual and developmental disabilities into one of four types: Living alone, Co-residency, Relationships, and Host family. These are briefly described below and more fully in a journal article¹². The arrangements clearly illustrated that ISL arrangements take many forms (even within the four types described here) and reflected the needs and interests of the persons with disabilities and the family members, friends, and services that supported them.

Living Alone

Many adults with disabilities lived alone in their own home. They used the full range of formal (that is, paid), and informal supports that included 24 hours a day/seven days a week rostered formal support; occasional drop-in formal support; and informal support from family, friends, and advocates. Support reflected the person's needs, preferences, and interests.

¹²Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J. and Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities* 20, 100-108. doi:10.1177/1744629516629854.

Co-Residency

Co-residency refers to an arrangement where an adult with disabilities lived in their own home with one or more co-residents who provided support in exchange for free or reduced rent. Other living costs may also be shared. Paid or unpaid support may also be involved, particularly when the co-resident is otherwise engaged, for example, at work. We observed that often the relationship with co-residents grows into friendship and also found that co-residents' friendship networks may extend the social network of the person with disabilities.

Relationships

It is consistent with ISL principles when adults with disabilities decided to share their home with someone based on an existing friendship or more intimate relationship. Grouping of adults with disabilities within ISL arrangements should clearly reflect each person's choice and preferences. Supports may be individually provided for each resident. In the study, we found a small number of adults with disabilities who lived in close partnerships, including marriage.

Host Family

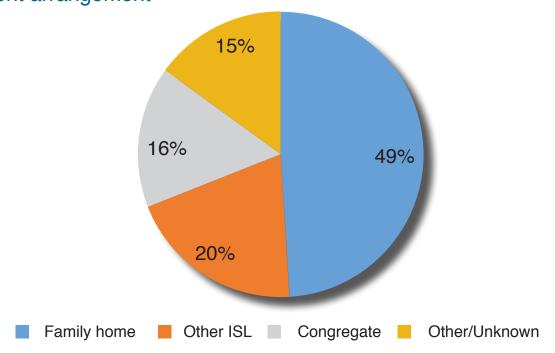
A host or alternate family arrangement involved adults with disabilities living in the family home of persons to whom they were not related. The host family members provided varying degrees of care, with or without paid staff involvement. We encountered a number of these arrangements in Western Australia, some of which had been ongoing for over 20 years. The resilience and outcomes of these arrangements were quite impressive.

An important conclusion from these examples of ISL was how important and valuable was the involvement of both informal and formal support, particularly when family members and NGOs that were supportive and experienced in ISL arrangements worked together to establish and develop such arrangements.

Characteristics of participants

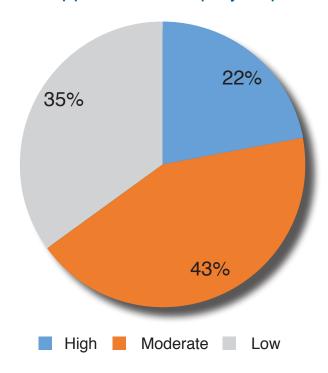
- Of the 130 persons whose living arrangements were reviewed, the genders were evenly divided and a large majority had never married. Participants were between 21 and 66 years old, with an average age of 40 years.
- There was a great variety of scores on the Assessment of Level of Support (average 27; range 12-55; theoretical range 12-60). This indicated that some persons had no difficulty doing some tasks while others either needed a lot of support or could not carry out some activities at all.





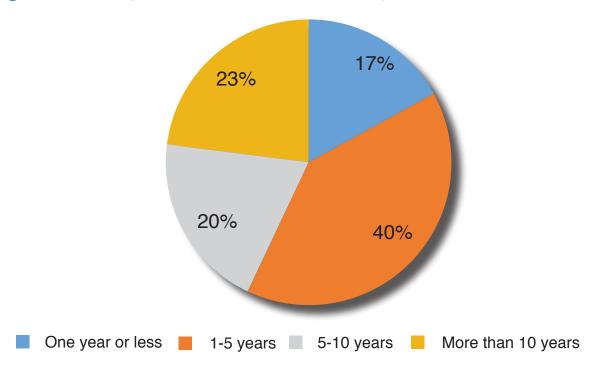
 Almost half (49%) of the participants had lived in the family home before moving to their ISL arrangement, 20% had lived in some other ISL arrangement, and 16% had come from group homes or other congregate care.

Figure 2. Reported support need for project participants



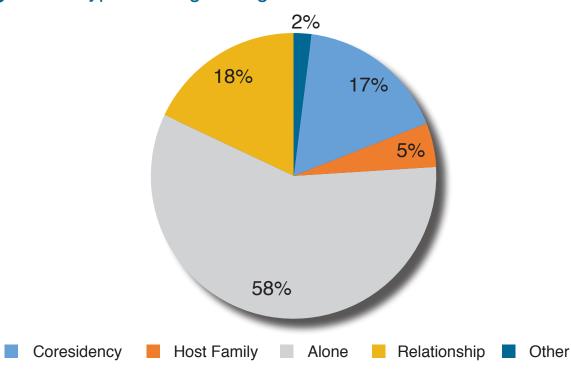
 Support need for the participants was described as High (22%), Moderate (43%), and Low (35%).

Figure 3. Length of time in current arrangement



• Participants had lived in their current arrangement between one month and more than 30 years (average 7 years), and 40% had lived in their home for between one and five years.

Figure 4. Type of living arrangement



• More participants lived alone in their home (58%) than lived in a relationship (18%), with a co-resident (17%), or with a host family (5%).

Support provided to participants

- The hours of both formal (paid) and informal (unpaid) support accessed by participants varied widely: total support hours ranged from 0.5 hours per week to 356 hours per week.
 The average total hours per week was 49, while the average for paid support was 37 hours, and for unpaid support it was 12 hours per week.
- More participants (45%) received an average of less than 10 hours per week of support than received between 10-60 hours (27%), or more than 60 hours (28%).
- Participants with more hours of informal support generally had higher hours of formal support.
- Many families (31%) contributed financially to the living arrangement of their relative, however, 56% of the participants received government funding for their accommodation, and 65% received funds to support participation in a range of activities.
- Most participants (75%) had an agency or disability support organisation that provided management and/or support.
- Many participants in ISL arrangements (76%) faced on-going accommodation costs, such as rent, and generally paid these from their Disability Support Pension.

In summary, there was a wide range of effective formal and informal support provided to participants in the ISL arrangements. Financial support came from a number of sources including families and government agencies that supported participant community activities and housing provision.

Participant activities

- Participants reported a wide range of involvement in the community. Some individuals
 visited up to 14 named community places, on average 26 times (range 0-47 times), over
 the previous month. Some participants (3%) rarely, if ever, went to any named places
 in the community, 4% went to the community places 6 or fewer times over the previous
 month.
- The community activities in which participants most often engaged at least once in the last month were shopping (94%), going to a café or restaurant (85%), and using public transport (69%).
- Using public transport (52%), going to a café or restaurant (48%) and shopping (46%) were the activities most often engaged at least four times per month.
- Few participants had people to stay overnight in their home (25%) or attended a sporting event (27%). Even fewer participants had been to a concert or play (11%) or to church (11%) in the previous month.

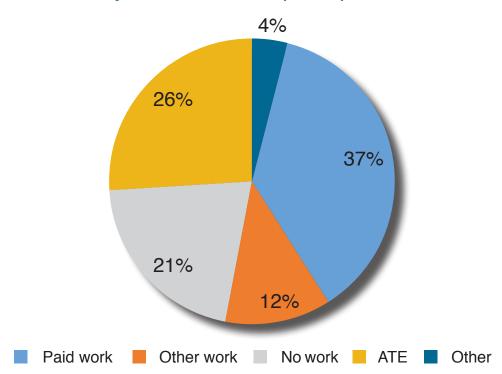


Figure 5. Main daytime activities of participants

Participants engaged in various daytime occupations:

- Paid work (37%) in open employment, social enterprises, self-employed or Australian Disability Enterprises (formerly known as sheltered workshops)
- Other work, such as volunteer work (12%)
- Looking for work or unable to work (21%)
- Engaged in 'Alternatives to Employment' (ATE), community activities or day centre activities (26%).

In summary, there was a wide range of community participation. However, the ISL Manual Theme of Social Inclusion scores (mean 3.13; Table 2) indicated that social and community engagement remained a challenging area in ISL arrangements for many participants as it also does in congregate forms of supported living.

Quality of arrangements as determined from the ISL Manual evaluations

- Total ISL review score: mean 73 (range 42-98) from the total possible range of 21-105.
- Participants with low support needs who were living with a friend or intimate partner had higher total ISL review scores.
- The total ISL review score was lower for persons who had previously lived in congregate settings or other ISL arrangements before moving to their current home.
- The quality of ISL arrangements, as assessed by total ISL review scores, was not correlated with participant age, time spent in the current ISL arrangement, the type of arrangement, the hours of formal or informal support received, or major daytime occupation.

Table 2: Comparison of ISL review scores by theme

Theme	Mean score per Attribute *
Leadership	3.58
My Home	3.72
One Person at a Time	4.07
Planning	3.22
Control	3.62
Support	3.29
Thriving	3.31
Social Inclusion	3.13

^{*}Scale 1-5

- The highest scoring Theme was 'One Person at a Time'. This was not surprising as
 two requirements for inclusion in this project were that the living arrangement be set up
 around an individual, and that adults with disabilities were not grouped unless they chose
 to live together.
- The Theme 'My Home' also scored highly in the reviews performed for this project. Participants did the things that other people do in their homes, and their homes reflected the personalities of the participants. Persons living alone or in relationships, and those with low support needs were most likely to score highly on this Theme.
- The lowest scoring Theme was 'Social Inclusion'. Many participants had social networks
 that were largely restricted to paid staff and other persons with disabilities. The review
 scores for this Theme were lowest with persons receiving minimal informal supports and
 with persons who attended 'Alternative to Employment' or day centres, or with persons
 who did not work at all.

- 'Planning' was another Theme with room for improvement. This Theme included the lowest scoring Attribute: 'The person's future is central to planning'. Generally, the planning for persons participating in this project encompassed either yearly 'plans' or day-to-day decision-making. Longer term planning was rare, as were reviews of living arrangements, particularly reviews by outside parties.
- The type of previous home influenced scores for the Themes 'Leadership' and 'Thriving'.
 Persons who had lived in the family home before moving into their ISL arrangement
 generally had higher scores on one or both these Themes compared with persons
 moving from congregate care or other ISL arrangements. This could be a reflection of
 the continued involvement of family members after transition to an ISL arrangement.
- Highest scoring attributes:
 - 3.2 The living arrangement does not group people with disability
 - 5.1 The person and those close to him or her have control of the person's life
 - 3.1 The arrangement is developed around the person
- Lowest scoring attributes:
 - 4.3 The person's future is central to the arrangement
 - 7.3 There are many opportunities for growth and development
 - 8.2 The person has a rich social network

Outcome measures

- (QOL.Q) Quality of Life: Mean 89, range 52-112 (theoretical range 40-120). Those with higher quality of life scores generally scored highly on the ISL review. Quality of life was higher for persons who received fewer hours of support, but scores reduced with increasing age.
- Participants who reported going to more places in the community and more often generally scored highly on the ISL review. Participants who visited fewer community places and less often, were likely to be older, to have previously lived in other ISL arrangements, or to have previously lived in a congregate setting and had more hours of support per week.

Outputs

- Revised Manual. As a result of feedback from persons involved in the review process there were changes made to the Individual Supported Living Manual and the Individual Supported Living Review Scoring Booklet. The revised editions have since been published and are available from the Research team.
- Training and Education Material. A number of training modules are being designed that
 will assist with educating persons in the principles and practices of ISL and ISL reviews.
 The training modules will be available in a variety of modes, including webinar, online
 learning, and face-to-face group workshop.

Module 1: Introduction to ISL Principles and the ISL Manual

Module 2: ISL Research Findings: Outcomes and Benefits

Module 3: Planning for ISL: Advocacy, Funding and Housing Issues

Module 4: ISL Team Member Training

Module 5: ISL Facilitator Training

- The first research paper from this study was published in a special edition of the *Journal* of *Intellectual Disabilities* in 2016.
- An overview of the project was published in a special (National Disability Insurance Scheme) edition of *Parity*, the journal of the Council to Homeless Persons, in 2017
- Several manuscripts are in preparation.
- The results of this project have been presented at conferences in Melbourne, Perth, Sydney, Hobart, Thailand, Korea, Ireland, Scotland, and Austria.
- This project was a recipient of the 2015 Zero Project Award for innovation. The Awards are part of an international programme which recognises innovations and solutions to the problems people with disabilities face in being included in their communities, consistent with requirements of the United Nations Convention on the Rights of Persons with Disabilities.

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