Examples of individual supported living (ISL) for adults with intellectual disability

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ABSTRACT:

Background: This article provides a qualitative account of four models of support for adults with intellectual disability in individual supported living (ISL) arrangements.
Materials and Methods: Completion of the first 50 evaluations of 150 arrangements for the third phase of the ISL project provided the examples.
Results: Four approaches are described: living alone, co-residency, relationship, and host family. Within each type, wide variations occur particularly based on security of tenure, formal and informal support, and management variations.
Conclusion: Fifty evaluations so far illustrated a wide range of approaches to ISL, providing evidence of the critical importance of the formal and informal support environment and reinforcing the contention that ISL is appropriate for people with high support needs.

Keywords: Adults with intellectual disability, Australia, home, individual supported living (ISL), support need.

Conflict of interest:

None.

Introduction

Personalisation of support services for people with intellectual disability is a crucial strategy to address the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations General Assembly, 2006). We view this as a necessary but not sufficient approach to meet the CRPD obligations, particularly as expressed in Article 19 – "Living independently and being included in the community" (United Nations General Assembly, 2006). Article 19 addressed choice and support as follows.

a) …people with disabilities have the right to choose how and with whom they live.

b) …people with disabilities have the right to the full range of in-home and community supports to realise and sustain their living arrangement of choice and more broadly for social and community inclusion and participation.

We also assert that the priority should not be on *independence*, which is a status rarely achieved and better expressed as *interdependence* (Northway, 2015), but rather acknowledge the crucial role of formal and informal support, particularly for people with high support needs. Individual supported living (ISL) may include forms of "independent living", but does not require that a person with disability must live alone or be independent.

The research project upon which this paper is drawn defines ISL as based on three assumptions that are fully consistent with Article 19 of the UNCRPD.

i) All adults with disability can live in an ISL arrangement if they are provided with the appropriate supports.

ii)   People with disability do not have to live together.

iii)   People in an ISL arrangement do not have to live alone or independently.

There are many different ways adults with intellectual disability can live in an ISL arrangement. Because congregation of people with disability continues to dominate service provision, with group homes the option of choice in Australian jurisdictions, the principles underpinning ISL mean that an adult with intellectual disability may make an explicit and informed decision to live with another person/people with disability based on normative reasons such as friendship or close relationship, and not because funding or agency rules, guidelines, or convenience require congregation (Cocks and Boaden, 2011; Cocks et al., 2014). We acknowledge how challenging this principle is.

The essential differences between ISL and other living arrangements are that ISL arrangements are highly personalised; provide individualised support that addresses the needs, ambitions, and capacities of the person; and are planned to continue to be for that person, captured in the term "one person at a time".

ISL incorporates the universally understood concept of "my home". One's home is much more than the physical aspects of a place where one lives. It also incorporates the emotional and spiritual aspects of life, including one's sense of identity, wellbeing, and growth and development (Annison, 2000). "Home" is highly contextualized by cultural influences. ISL arrangements may be influenced by factors such as conditions and security of tenure, funding, planning, support, and management arrangements.

This paper describes four types of ISL arrangements as vignettes that illustrate different approaches to providing the homes of adults with intellectual disability. Two reviews of empirical literature carried out in the earlier stages of this research suggested that the evidence base of ISL is very underdeveloped with the emphasis of ongoing research strongly focused on examining congregate and formal options, although the "soft" literature abounds with material focused on ISL principles that go back decades (Cocks and Boaden, 2011; Cocks et al., 2014).

Background

This research project has been in progress since 2007 and incorporates three stages. The first two stages produced a measurement tool, the ISL Manual (Cocks et al., 2011), consistent with the development of methodologies that measure the fidelity of services to an explicit statement of underpinning principles. Examples of this approach germane to disability services include disability employment services (Bond et al., 1997; Cocks and Boaden, 2009a), Normalization and Social Role Valorisation (Wolfensberger and Thomas, 1983), and acquired brain injury (Parvaneh and Cocks, 2012).

In stage one, (the "Personalised Residential Supports" Project) an initial ISL framework was developed that included the key themes and attributes of ISL (Cocks and Boaden, 2009b; Cocks and Boaden, 2011). Over two years, six people living in ISL arrangements were followed, and a range of activities brought people together to inform the framework. The second phase began in 2010 and refined and operationalized the ISL framework through a series of World Café style workshops (Brown and Isaacs, 2005; Tan and Brown, 2005) with service providers, family

members, academics, and advocates all of whom had experience of ISL, in some cases spanning decades. Further refinement of the framework involved ten pilot evaluations of ISL arrangements. This stage resulted in the publication of the evaluation ISL Manual consisting of 21 attributes across eight themes (Cocks et al., 2014; Cocks et al., 2011). These are outlined in Table 1.

Insert Table 1 about here

This third phase of the ISL project, funded by the Australian Research Council and supported by many non-government organisations, commenced in 2015. It aims to establish the psychometric properties of the Manual and scoring process and to develop an evidence base of ISL arrangements by carrying out 150 evaluations across Western Australia, New South Wales, and Victoria. Evaluations explore the quality of an ISL arrangement using the ISL Manual and measurement of additional outcomes including quality of life, community participation, and accounts of the pathways taken that led to the adoption of ISL arrangements. This paper describes four types of ISL arrangement drawn from the initial 50 evaluations in 2015 and discusses the common threads supporting ISL arrangements.

Methods

The study was approved by the Human Research Ethics Committees of Curtin University (HR210/2014), The University of Sydney (2015/088), and Deakin University (2014-252). Participants in the evaluations were recruited through partner organisations and personal networks. All participants provided informed consent.

The evaluation processes were based on methods used in the fidelity studies referenced above. Small teams comprising a facilitator from the university research team and two or three trained team members carried out the evaluations. These consisted of a semi-structured overview interview that typically included the person with a disability, and often included others such as people living in the setting as co-residents, key support person/s, and family member/s. If necessary, additional information was sought on another occasion, personally or by telephone, from people who were instrumental in establishing the arrangement. One or two team members looked around the home if appropriate, everyone being mindful and respectful in treating the location as the person's home.

Following the overview interview, each team member rated the 21 attributes independently. Then, a conciliation meeting headed by the team leader served to reach consensus on each rating following discussion on "evidence" brought forward by team members. If consensus could not be reached, the team leader decided the rating after providing reasons.

It is notable that the project incorporates training regimes and workshops that explain ISL and prepare people to participate on teams. To date, over 150 people have participated in related training events. An important and acknowledged outcome of the evaluation processes is a deeper understanding of the nature of ISL.

Findings

The findings reported here are vignettes of examples of four well-developed and successful ISL arrangements, the types of which may be familiar to many readers of

this paper. Examples were selected, based on relatively high rating scores, by members of the research team. The person with intellectual disability and/or others close to them provided input and approved use of the vignettes. Pseudonyms are used. We acknowledge that these vignettes do not capture fully the breadth of ISL arrangements, however all arrangements within the 50 completed evaluations have been allocated to one of these types.

Living Alone

Any adult with intellectual disability who lives alone in their own home may have a strong ISL arrangement if the right supports are in place. Supports can include the full spectrum of formal and informal supports, including 24 hours a day/seven days a week rostered formal support; participation in specialist and/or mainstream services or activities in the home and/or community; and informal support from family, friends, or mentors. These are matched to the person's needs, preferences, and interests.

Colin

Colin was in his late thirties and had intellectual disability, mild cerebral palsy, and a mental illness. He lived in a small country area where there were few job opportunities and travel to another town was difficult. He began to feel isolated and to develop depression. Twelve years ago, with strong parental support, Colin moved to a rental property in a nearby town where he has continued to live. He had six different "housemates" over an eleven-year period. He developed skills, confidence, and friendships and he made the explicit decision to live alone. He had three hours of drop-in paid support each week and this, combined with support from housemates, enabled Colin to be quite self- sufficient around the house.

Colin's social networks were strong. Some housemates became friends and maintained contact and he was well connected in his neighbourhood. He volunteered at the local farmer's market and at a foodbank. He was a fanatical football club supporter and most weekends he could be found watching his team with friends or family, or at the local pub. His parents had phone contact most days and he visited family members twice a week. Three days a week Colin worked in a small business, mainly in the front reception area answering the phone, greeting people, filing, and doing the mail. He walked into town each day for work and coffee. After contact with Colin, it is not difficult to see his life unfolding further and the possibility of the development of an ongoing close personal relationship.

Melanie

Melanie was in her mid-thirties and had Prader-Willi syndrome and complex communication needs. She lived alone in a small town in a house purchased in her name, assisted by a government grant that supports people to purchase their first home, and with additional contributions from her parents. Her home clearly reflected her likes and interests. Melanie had a mixture of paid and unpaid support around the clock, including three days per week from her parents. A previous support worker was now a friend and sometimes stayed overnight with Melanie. Melanie had the final say when employing support workers. They did not have keys to the property.

She prepared her own meals and enjoyed the company of her cat. She grew herbs, vegetables and fruit which were entered in the Royal Agricultural Show and sold at garage sales. Melanie exercised daily, including walks, often with a friend. She knew her neighbours and attended the annual street Christmas party. She enjoyed going to the local club, especially on country music nights, doing craft activities, and playing

games on her iPad. A former neighbour now lived in the aged care home where she volunteered and she saw him weekly. Melanie also worked in a supported employment laundry three days a week.

Co-residency

Co-residency refers to arrangements where a person with intellectual disability lives in their own home with one or more co-residents who provide some support in exchange for free or reduced rent. The project has encountered a number of examples where co-residency has served as a means for the person with a disability establishing themselves for the first time away from the family home. The example below illustrates how this may lead to the person living alone. There are other examples where the arrangement is ongoing. What is particularly noteworthy about these arrangements is how the person with a disability is drawn into the social networks of co-residents. In the first stage of the project, one of the young participants who was followed for nearly two years lived with residents who were of his age group. As co-residents moved on, much the same as occurs commonly within student living environments, rather than having to advertise for a new co-resident, the existing co-resident social networks provided new co-residents who were known to the young man with a disability.

Bert

Bert, in his mid-twenties, had epilepsy, cerebral palsy, and complex communication needs. He had lived in his own home, rented from a social housing provider, with Frank, a co-resident, for five years. Bert's parents established a circle of friends that worked toward establishing and maintaining the arrangement. They wanted Bert to

have a life 'as normal as possible', and considered that the current arrangement supported that goal. Frank was the key support and companion for Bert with staff from a service provider also important to the arrangement.

A small business enterprise was developed around Bert. This generated an income and provided Bert with valued social roles: business owner, worker, and employer (of his support worker/s). There was substantial overlap in the support he received across his small business enterprise and the ISL arrangement, however Bert needed to be responsible within both settings. He would shortly add the role of 'traveller' when he flew off on a holiday. Extensive planning over the past year was facilitating this trip, including negotiations with the airline and airport for Bert to become familiar with these environments. This was a reflection of the thoroughness in every aspect of Bert's ISL arrangement. The people who support Bert included his family, circle of friends, agency coordinator, support workers, neighbours, and Frank.

Since moving into his own home, Bert was more relaxed. He had developed skills at home and now stayed alone at home for short periods of time. His communication skills continued to improve. His family and friends acknowledged the ISL arrangement and 'setting the bar high' had enhanced social and economic participation and inclusion beyond his home.

Relationships

People often choose to live together based on friendships or intimate relationships and this is consistent with ISL principles, although congregate arrangements can primarily come about because of bureaucratic, organizational, or financial constraints. It is

consistent with ISL principles when adults with intellectual disability decide to share their home based on an existing friendship or more intimate relationship. Grouping of people with disability within ISL arrangements should clearly reflect each person's choice and preferences. The following vignette outlines an arrangement that reflects a strong relationship, between two friends sharing a flat and their landlady.

Tara and Helen

Tara, in her early twenties, and Helen, in her early thirties, were friends who met in a hostel for women with intellectual disability. Neither Tara nor Helen had any close family contact. They decided to live together and now shared the top floor flat of Virginia's home. Virginia, the landlady, was a single woman in her thirties who lived in the ground floor and shared the front door and hallway with Tara and Helen.

Tara and Helen both worked in supported employment. Virginia worked full-time and had a busy lifestyle. All three women sometimes enjoyed catching up after their work day, and they occasionally shared meals in either flat. They had developed a friendship and introduced each other to their respective groups of friends. They all saw becoming integrated in each other's social networks as an enriching experience.

According to Tara and Helen, the most enjoyable aspect of living in their own flat was the ability to invite friends over for social gatherings. One of their fondest memories was the celebration of Tara's 21st birthday in the house. Whilst the women did not receive any formal support, Virginia provided informal support by "[keeping] a watchful eye on them" and giving the women occasional lifts to appointments. Virginia admired the women's resilience and resourcefulness, and their ability "to live

on the smell of an oily rag", whilst Tara and Helen saw Virginia as a great friend who had facilitated many opportunities for them to have a rich, fulfilling, and self-determined life.

Host family

A host or alternate family arrangement involves an adult with intellectual disability living with a host family. This is commonly a relatively formal arrangement that may have some implications for the governance and management of the arrangement through requirements of funding agencies. Management arrangements may include payment of costs of board and lodging to the host family. Throughout the different phases of this project, the researchers have been impressed by the resilience of such arrangements. This type of arrangement is likely to score lower on the 'My Home' domain than other types. In the first stage of the project, two host family arrangements were followed for nearly two years. Both involved people with high support needs and have continued, one for over 20 years and the other for nearly 10 years.

Sofia

Susan and her husband had provided a host-family arrangement for Sofia, who was in her mid-thirties and had high support needs, for the past four years. Sofia and Susan knew each other well before this arrangement was set up as Susan provided respite care for a number of years while Sofia still lived with her family. Susan's home was adapted to accommodate some of Sofia's preferences, such as providing a deep bath, and specially covered lounge chairs were placed in several locations throughout the home for Sofia to choose from. Sofia enjoyed using the lounge room and listening to music. She would often initiate interactions: she would go to the side of the bath if she

wanted a bath, and would stand by the door at her parents' home when it was time to go home. Sofia clearly signified unhappiness with things she didn't like and would refuse to cooperate. Since moving to Susan's home, Sofia was reported to be more relaxed, less agitated, and less likely to self-injure. The health of her parents had improved since they were no longer responsible for all of Sofia's care. Sofia spent one weekend a month in her family home with her parents and siblings.

The arrangement was supported by an agency. Sofia participated in a day program facilitated by the agency during the working week. She also visited Susan's friends, dined at restaurants, and went for walks and drives. Most of Sofia's personal care was handled by Susan, but her husband and mother helped as needed. Susan's daytime work was flexible enough for her to care for Sofia in the event of illness or another problem.

Discussion

The principles of ISL that are set out in the ISL Manual provide a challenge to reliance on congregation and formality as the dominant form of support provision for adults with intellectual disability. The four ISL examples described here are not fully representative of the ways in which ISL can be achieved. They are particularly chosen as arrangements that have been successful and reflect some key ingredients for success. It is clearly the case that arrangements have grown from leadership, often by family members, some of whom promoted and supported arrangements in the face of uncertainty and often resistance. Equally, the mix of formal, paid support, and informal support through relationships and friendships is a strong component of ISL arrangements and reflects the UNCPD emphasis on the provision of appropriate

support. We have encountered many examples of people with intellectual disability in ISL arrangements becoming part of the social networks of both formal and informal support people.

Support arrangements range from no formal or paid supports to around the clock paid supports. However, no project participant to date has been completely without support, with informal support coming from home-owners, friends, neighbours, and family members. This reflects the importance of interdependency and questions the meaning of "independence" in this context. Supports provide practical assistance, skills development, decision-making support, employment or day activity support, and assistance with forming and sustaining relationships (Fisher et al., 2014; Tichá et al., 2012). Supports have been described as "a bridge between 'What Is' and 'What Can Be'" (Thompson et al., 2009: p137) and mitigate the impact of impairments on the life of a person. Supports and funding can be self-managed, family-managed or agency managed, and management may be shared (Therapy Focus, 2014).

Conclusion

This paper has presented early findings from the third phase of the ISL project. The vignettes provide only a glimpse of the different types of ISL arrangements and do not capture the complexities in setting up and continuing these arrangements. We anticipate future publications will focus on the relationship between the attributes of ISL as reflected in the ISL Manual and a range of outcomes. With 150 evaluations to be completed, the project will explore in more detail the range of ISL approaches and contribute to the evidence base for ISL arrangements.

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