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Individual Supported Living (ISL) Manual 1 — A tool to inform the planning and evaluation of individual living arrangements.

The National Disability Insurance Scheme (NDIS) is not responsible for providing accommodation for people in need of housing assistance. 2 What the NDIS is responsible for are the supports to assist a person with disability to live in the community, including building their capacity to maintain a tenancy. This policy imperative is consistent with Australia’s obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 3 which includes the obligation to support people to achieve their rights to live in and be included in the community (Article 19).

In the context of an NDIS funding environment, questions therefore arise as to what constitutes quality (and indeed value for money) in individualised community living; and how might people and their families plan for and demonstrate quality outcomes that are sustainable over time? The Individual Supported Living (ISL) framework provides a research backed approach with practical guidance to address these questions.

Individual Supported Living Framework

The ISL framework is based on three assumptions:

1. With appropriate support, any person with disability can live in an ISL arrangement.
2. People do not have to live with other people with disability, or people with whom they have not specifically chosen to share a home.
3. People with disability who live in an ISL arrangement do not have to live on their own.

Framework Development

The ISL framework and manual has been developed in three research-supported stages.

Stage 1

Consultation with people living in established ISL arrangements facilitated the initial development of the ISL manual.

Stage 2

The ISL manual was evaluated and further refined in consultation with people with the lived experience of disability and their families.

Stage 3

A large-scale evaluation of ISL arrangements using the ISL Manual was then undertaken across Western Australia, New South Wales and Victoria. This component of the project was conducted with support of a Linkage Grant from the Australian Research Council (ARC), which enabled a partnership between Curtin University, The University of Sydney, the University of Melbourne, and a number of leading service provider agencies.

"It is the robust consultation process that gives credence to the methodology in the development of ISL" — Errol Cocks*, 2017.

Insights

In addition to the strong evidence-base supporting the ISL Framework as a means of establishing and sustaining quality individualised living arrangements, many important insights have been revealed that can inform the future planning of others who desire to establish such arrangements.

Results to date have revealed a wide variety of ISL arrangements. 4 There is no one way to do ISL.

Sarahs’* Story

I used to go to a ‘special school’. I left home at 18 years of age, and moved into public housing. When things started getting a bit much, the only avenue of action that was available was to go through what they call a tenancy tribunal. I left as well, because, you know him (the neighbour) and his mates knew where I lived so I was out of there.

For a while, I was just couch surfing, slept in a car a few times, slept on the street. Going home again just wasn’t an option.

I think back to what I did next and it probably wasn’t a good idea. I found a hospital so I stayed there, the things I saw. Well you know.

I’ve seen quite a few interesting things over the years.

I lived in a hostel for a few years. Well a few but there was a main one that I stayed at. They opened a second one and I became the night caretaker. I got free rent basically, and a small amount on the side. I basically had a breakdown after a series of things that happened in the hostel. No one would have known, no one was there to see it. Until 2008 they [services] let me fall through the gap. The depression got diagnosed in 2008 soon after I asked a supported facility if they had any space. That is where I ended up. The services provided a roof over my head. They did everything for us. Two friends still live there and I always hear about stuff going missing. They didn’t even trust us with the laundry. There were 60 people living there in the end. As a result, lots of things used to happen. Eventually, towards the end of 2011, I had sort of had enough so I moved out.

A friend at church helped me out as far as getting a unit for me. Every church I have been to has been able to fix it and help out.

In 2013, I came to [the town in which I now live]. I decided I liked it so much I thought I’d live here. I was living by myself but I couldn’t handle it. I didn’t do cooking or anything. Sometime after I moved here, we [husband] reconnected on Facebook.

Early 2015 he moved here. We now pay rent to his parents. He keeps in contact with them still, that’s for sure. Dad came over for the wedding.

In five years’ time, we’ll probably still be married. I don’t think we will move anywhere. We kinda like it here.

Most important for us two being able to maintain this arrangement? Oh, I guess making sure that there is adequate and appropriate support. Which there is, from all respective parties. If we didn’t get funding, that would be a threat.

ISL arrangement evaluation process

The framework is structured around eight themes. These themes describe what needs to be in place to achieve a quality and sustainable ISL arrangement. Each theme has multiple attributes, which are the good practices that when combined establish ‘the theme’. These are summarised below.

Figure 1. Theme 2: My Home, its related attributes, indicators and evidence.

Theme 2: My Home

The person has secure tenure in the home.

Attributes

2.1

The person has secure tenure in their home.

Indicators

1. The person has secure tenure in their home.
2. There are formal and/or informal measures within the arrangement that recognise and protect the person’s security of tenure in this home or her home.

Evidence

a) Is the person living in the type of home and in a location that they prefer?

b) What measures provide security of tenure for the person? For example:
1. The person has formal ownership or tenancy of the home.
2. The person is included in a formal agreement regarding their living in the home of another person.
3. The person’s name is on bills for utilities, etc.
4. The person has keys to the home.

3c) Are decisions about moving from the home and/or having another person living in the home made by or in consultation with the person?
interests and preferences. The person chooses where they live and with whom they live.

Theme four — Planning
The person and those close to them (where appropriate) actively work together to plan to achieve the person’s goals. They look to the future in a systematic way, and not just focus on the current situation.

Theme five — Control
The individual and people close to them (where appropriate) exercise choice and control over the arrangement. The person’s self-determination is maximised in all planning and decision-making processes, and support is provided for the person to develop their self-determination.

Theme six — Support
The person has just the right amount of support they need at any given time. The supports vary based on the person’s needs. They are flexible and responsive to changing circumstances. Support may come from formal (paid) sources and/or informal sources such as friends and family.

Theme seven — Thriving
The person is supported to assume valued social roles in their community (for example, being a student, being an employee, being a volunteer) and has opportunities for personal growth and development. They clearly have a ‘good life’.

Theme eight — Social Inclusion
The person is connected with others, knows many different people on different levels, and takes part in the community.

The themes and their attributes provide the framework that people and their support networks can use to ‘start a conversation’ about developing an individualised living arrangement, and establish an action plan. These same themes and attributes can also be used to monitor and evaluate how the ISL arrangement is progressing. Importantly, the themes and attributes can be used to highlight where things are working for the person, and where attention to detail is required to ensure the arrangement is sustainable, and supporting the person’s quality of life. See figure 1 for an example of theme two: My Home, its related attributes, indicators and evidence.

Summary
While the NDIS is not primarily responsible for providing accommodation for people in need of housing assistance, it is responsible for ensuring that a person receives appropriate support to ‘live in, and be included in the community.’ The ISL framework is a tool that can be utilised to plan for and review people’s community living arrangements. It has the potential to identify the issues that are facilitating and/or inhibiting the strength of a person’s arrangement, and consequently inform the supports they require to improve, strengthen and secure the arrangement well into the future.

* Professor Errol Cocks is a Research Professor in the Centre for Research into Disability and Society, School of Occupational Therapy and Social Work at Curtin University, and a Chief Investigator of the ISL research.

** The identity of the participant and minor details have been modified to protect confidentiality.

Endnotes

Figure 2. Source: Cocks E, Williamson, M, Thoresen S 2011 Individual Supported Living Manual, Curtin University, Bentley, viewed 7 June 2017