



Curtin University

School of Occupational Therapy
and Social Work

INDIVIDUAL SUPPORTED LIVING MANUAL

2nd Edition

Professor Errol Cocks
Dr Stian H Thoresen



Australian Government
Australian Research Council



THE UNIVERSITY OF
MELBOURNE



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SYDNEY

**INDIVIDUAL
SUPPORTED LIVING
MANUAL**

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Professor Errol Cocks
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INTRODUCTION

What is Individual Supported Living?

Individual Supported Living (ISL) goes beyond accommodation for persons with disabilities to the creation of homes that are based on universally valued principles of what makes a home for each person. Homes are where we live, develop, pursue our interests, and foster relationships. A person's home is the foundation for ISL. The Themes of ISL describe what is needed to create and maintain a home for a person with disabilities. These Themes have been developed and explored in three consecutive research projects since 2007. They are the foundation of the ISL Framework and this Manual. As a comprehensive Framework, ISL is particularly relevant for persons with significant daily living limitations or who may require substantial support in daily life.

Persons with disabilities in ISL arrangements are supported to develop characteristics that lead to a 'good life'. People living a good life have a place to call home; live with whomever they wish; are assisted to plan for their future; have choice and control over their lives; receive the support they want and need; have opportunities for growth and development; and are included in the wider community. People living a good life participate in personally and culturally appropriate activities, relationships, and events.

Personalisation of support services for persons with disabilities is a crucial strategy to address the UN Convention on the Rights of Persons with Disabilities (UNCRPD)¹. Personalisation of support services is viewed as a necessary but not sufficient approach to meet the UNCRPD obligations, particularly as expressed in Article 19 – "Living independently and being included in the community". Article 19 addresses choice and support as follows:

- a) Persons with disabilities have the right to choose how and with whom they live.
- b) Persons 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.

The priority should not be on independence, which is a status rarely achieved and better expressed as interdependence², but rather to acknowledge the crucial role of formal and informal supports, particularly for people with high support needs. ISL may include forms of "independent living", but does not require that a person with disabilities must live alone or be fully independent.

1 United 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>

2 Northway, R. (2015). What does independence mean? *Journal of Intellectual Disabilities*, 19(3), 203-204. doi:10.1177/1744629515593659

This Framework defines ISL as based on three assumptions that are fully consistent with Article 19 of the UNCRPD.

- i) All adults with disabilities can live in an ISL arrangement if they are provided with the appropriate supports.
- ii) Persons with disabilities do not have to live together.
- iii) Persons with disabilities in an ISL arrangement do not have to live alone or independently.

ISL arrangements for persons with disabilities have developed in many places over the last three decades and there are many different ways ISL arrangements have been organised. Some have been set up by families, some by service providers, and some by persons with disabilities. Many have been established with support from government and non-government organisations.

How was this ISL Framework and Manual developed?

The Manual builds on a Framework that was developed over two research projects carried out between 2007 and 2011. This revised version was produced after the completion of a third research project carried out over 2015-2017.

The first research project explored person-centred approaches to supported living for persons with disabilities. This was done by carrying out an extensive literature review, focus group discussions and surveys of people experienced in ISL. In addition, six ISL arrangements were followed for 18 months. This work identified the Themes which make up the Framework of ISL³. It also identified a number of Attributes of each Theme.

The second research project further developed and refined the ISL Framework and this Manual. A small group of people with extensive knowledge and experience in ISL participated in two workshops in which the Indicators for each Attribute were identified. Indicators describe what you might look for in a supported living arrangement that fits the Attribute and are consistent with the Theme and the ISL Framework. The workshops also identified the Evidence that supports each Indicator.

In 2010 and 2011, two sets of five reviews of a range of ISL arrangements were carried out in the Western Australian metropolitan and rural areas. The reviews were facilitated by the researchers. Some arrangements had been set up and were run by families, others by service providers, and some were in the initial planning stages. The arrangements were organised in a number of ways. They included persons with disabilities living alone, with co-residents, with a host family, and with live-in, 24-hour support. Some arrangements were in houses and

others in semi-detached houses or apartments. Some were in the metropolitan area and others in rural areas. The age range of participants varied from late teens to fifties. Most had family involvement.

Feedback on what was working well and what could be improved was provided to each arrangement reviewed. Feedback on the ISL Framework and Manual was provided by participants in the reviews. The valuable feedback from those reviews was influential in the development of the first version of the Manual⁴ and the accompanying Review Scoring Booklet⁵.

The auspice for the first research project was the Developmental Disability Council of WA and the second project, National Disability Services WA. The first two projects were funded by Lotterywest. The research was carried out by researchers from the Centre for Research into Disability and Society in the School of Occupational Therapy and Social Work at Curtin University.

Why was the Manual revised?

The third project started in 2015 and involved the evaluation of 130 ISL arrangements across Western Australia, Victoria, New South Wales, and the Australian Capital Territory. The research was conducted by researchers from the School of Occupational Therapy and Social Work at Curtin University, the Centre for Disability Studies at the University of Sydney, Deakin University, and the University of Melbourne.

Support was provided by disability organisations from each state. The research was funded by an Australian Research Council (ARC) Linkage Project Grant LP140100522.

This first large-scale use of the ISL Manual led to further revision of the Manual. All people who received training and subsequently were members of evaluation teams had the opportunity to provide feedback on the Manual and its use. This feedback, combined with the experience of the research team, supported the revision of the Manual to improve its readability, usability, and relevance to the disability sector in today's Australia.

What did the research find?

The research project clearly showed that adults with all levels of support need can be supported to live in an ISL arrangement. One quarter of participants reported high support need, half had moderate support need, and the final quarter had low support need. The support participants received ranged from minimal drop-in assistance of less than one hour up to 233 hours of paid and unpaid supports per week. The amount of support required for activities of daily living was not associated with the total ISL score, indicating that the quality of the arrangement was not related to the amount of support required by an individual.

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

5 Cocks, E., Williamson, M., & Thoresen, S. (2011). *Individual Supported Living Review Scoring Booklet*. Bentley: Curtin University.

Just over half of the participants had lived in the family home immediately before moving into the ISL arrangement and a further quarter had previously lived in another ISL arrangement. Most of the remainder had previously lived in group homes, community residential units, or other congregate options. The time people had spent living in the ISL arrangement varied from less than one month to more than 30 years. The length of time in the arrangement did not affect the quality of the arrangement as indicated by the total ISL score.

Participants went to an average of 9 places in the community, such as shops and concerts, over the last month. The number of times participants went to the listed community places ranged between 6 and more than 47 occasions. Around a third of participants were engaged in work, either in open or regular employment, Australian Disability Enterprises (sheltered workshops), or as volunteers. Similar numbers attended Alternatives To Employment, day centres, Community Access Programs, or other non-vocational activities. People who had work tended to attain a higher overall ISL score than people who did not work.

Each stage of the three research projects was overseen by a steering group, which included representatives from families, disability organisations, and the WA Disability Services Commission. Most of the people and organisations in Western Australia involved in the first project were also involved in the subsequent projects.

What is the purpose of this Manual?

The main purpose of this Manual is to provide a tool to review and develop ISL arrangements. Its aim is to assist people involved with ISL arrangements to identify what is working well and what can be improved. The ISL Framework can also be used to assist people to plan or establish an ISL arrangement.

The accompanying ISL Review Scoring Booklet is particularly useful for reviewing established living arrangements. The Review Scoring Booklet should be used in combination with this Manual.

The Manual has considerable potential for education purposes that aim to inform stakeholders about ISL arrangements. For example, training to perform evaluations using the ISL instrument will deepen understanding of ISL and inform the development of high quality ISL arrangements. Workshop formats can be developed based on the framework. These education and training packages are in the early stages of development.

The following section provides a short summary of the ISL arrangements observed during the first project, and one extra arrangement from the third project. These are included in this Manual because they were important to the development of the ISL Framework and they provide examples of the different forms an ISL arrangement can take. This section is followed by instructions on how to use the ISL Framework, the Review Framework itself, and a brief Resources section.

Limitations of this Manual

This Framework and Manual were developed within the Australian context. The third phase took place across the early stages of the roll out of the National Disability Insurance Scheme and this may have some bearing on the material included in the Manual.

All three phases of the ISL project have involved people with intellectual disabilities. The studies have achieved high face and content validity for the Manual, however it may be necessary to adapt the material and re-validate for different cultural contexts, languages, and disability groups.

Acknowledgments

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Substantial contributions were made to the third project by research participants, their families and support people, and additional organisations that provided links to participants as well as evaluation team members: Cam Can, Developmental Disabilities WA, WA Individualised Services, Enable South West, Community Living Association Albany, Senses WA, Belonging Matters, Northern Support Services, Life Assist, ACSO, Ability Options, Sunshine, Uniting, Life Without Barriers, and BreakThru.

The authors also acknowledge the funding provided by Lotterywest for the first two research projects. The authors acknowledge and thank everyone involved in those research projects, in particular Ross Boaden, the people who allowed the researchers to follow the living arrangements, members of the Reference Groups, and the auspice organisations: the Development Disability Council of WA and National Disability Services WA. The authors also acknowledge and thank the people who allowed the researchers to review their living arrangement through the six initial arrangements studied and the ten pilot reviews.

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Michelle Stanton and Monique Williamson contributed to the original Manual development, with Bob Jackson and Allyson Thomson contributing to the revised edition.

EXAMPLES OF INDIVIDUAL SUPPORTED LIVING ARRANGEMENTS

A key part of developing the ISL Framework was following six ISL arrangements for 18 months from 2008-2010. Through the third phase of the research four main types of support arrangement were recognised⁶. These are described below, each one followed by a summary of example arrangements. The examples provide insight into what is needed to set up and maintain effective ISL arrangements.

Living Alone

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

Lisa

Lisa was a woman in her mid-20s who lived by herself in a villa she owned. This was arranged by her family when her mother passed away. Lisa had a strong family network.

Lisa had an active lifestyle and took care of most of her day-to-day life. She had a few hours of drop-in support each week which was provided by a non-government organisation. They helped with diet, budgeting, mail, and other things with which Lisa needed a hand. Lisa's lifestyle was quite busy. She travelled independently to and from work, the shops, and to visit family. Her long term goal was to get a job in open employment or a regular job. This would add new challenges and opportunities to the lifestyle that Lisa enjoyed.

Lisa's arrangement is sometimes called a 'shared management model'. The non-government organisation, together with Lisa and her family, worked to support Lisa in her home. The non-government organisation coordinated the staffing and funding. The arrangement was set up to suit Lisa's needs and her family's wishes. They shared the work and responsibility of making Lisa's arrangement work.

6 Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J. & Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities*, 20(2), 100-108. doi:10.1177/1744629516629854

Co-residency

Co-residency refers to arrangements where 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. The project has encountered a number of examples where co-residency has served as a means for a person with disabilities establishing themselves for the first time away from the family home. What is particularly noteworthy about these arrangements is the potential for the person with disabilities to be included into the social networks of their co-residents. In the first stage of the project, one of the young participants who was followed for nearly two years lived with co-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 disability.

Rob

Rob was a man in his late 30s. He rented an inner-city townhouse together with two co-residents who did not have disabilities. Rob's ISL arrangement began 14 years before we contacted him in 2008. His mother and a non-government organisation organised this together. It had been a stable home life for Rob. Rob's co-residents had not changed often and he was still friends with some of his former co-residents. Rob was involved with recruiting the first co-residents through advertisements, but there had been no need to advertise for new ones as they had come through Rob's social network, which had grown over time.

Rob had moderate support needs at the time we met. His needs were much greater when the arrangement was initially set up. The ISL arrangement had been rich and supportive with Rob's skills and wellbeing developing greatly over time. In the beginning, expansion of his social network was planned whereas when we saw Rob it was growing in a more informal way. Rob's social network included some close friends and many acquaintances. Rob had travelled around Australia and overseas. He was welcomed at many businesses in the inner-city and he had a range of work roles.

Rob's co-residents received a discount on rent in exchange for supporting Rob in the evening and overnight, and providing some day-to-day assistance. To make the arrangement more secure, the organisation supporting Rob held the lease on the home. They arranged for support staff for a few hours on weekdays, supporting Rob in a range of activities. While the organisation and support staff oversaw the arrangement, this was done from a distance. Rob was also close to his mother and they spent a lot of time together.

Andre

Andre was a woman in her 40s whose parents had bought her a house of her own. Andre was supported by a non-government organisation to live in her home. Her parents were very close to Andre and they had fought hard to get services and funding to meet her needs. They worked closely with the organisation supporting Andre and had done so for more than ten years. After trying different group home arrangements that were not right for Andre, they set up her own home. When we contacted Andre, she had been living in her home for about ten years. Andre needed a lot of support which included many areas of her day-to-day life. Communication and understanding what happened around her could be difficult so there had to be people who knew her well to understand what Andre needed.

Different support models had been used and some did not suit Andre. At the time of the last visit, the organisation provided a staff member who lived in Andre's home with three weekends per month of respite. Andre also went to respite for five weeks per year so her support worker could take holidays. When no support was available, Andre's parents helped out. Her ISL arrangement was now stable, and her lifestyle and general wellbeing were also settled. Andre's parents and the organisation supporting her were moving towards exploring her connections in the community. This included the possibility of changing from sheltered employment to open employment.

Paul

Paul was a young man in his late teens when we met him and he was living with his parents in his family home. Paul needed considerable support. His communication was limited so it was important to have people around who knew him well and understood what he wanted and needed.

Paul's parents worked hard for many years to set up a good ISL arrangement. There was a lot to learn from this arrangement on how to plan. It also showed the important role his parents had in being leaders in setting up an ISL arrangement.

When we first met them, Paul's parents were working on setting up a good ISL arrangement and had been in contact with people who knew a lot about ISL. Some of these people were international experts. Paul's parents were also working to create a social support network and had also received funding for Paul.

In 2010, when Paul was 23, he moved into his own home (social housing) with a co-resident and daily support. The arrangement has worked really well – even allowing for the ups and downs that can be expected.

With help from a few other people, Paul's parents set up a 'Microboard' to help support Paul. A microboard is a small group of people, usually family and friends, who form a non-profit organization to support one individual. Paul's Microboard was incorporated in October 2013. Besides his parents, all of its members are Paul's friends. They know him well and pay close attention to what he says he needs, wants and likes. They support Paul to make his own decisions and help make sure that the paid support arrangements are working well.

Paul now has a growing network of friends. He has two volunteer roles in community organisations and he has two overseas holidays, including one to Vancouver.

Host family

A host or alternate family arrangement, sometimes called adult foster care, involves an adult with intellectual disabilities 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 and sustainability of such arrangements.

Geoff

Geoff was in his 50s. He shared a home with a married couple in a large town in rural Australia. This ISL arrangement had been in place for about 13 years. Geoff had high support needs. When he was young, he went to special classes and a day centre in the state capital. His parents had disagreements with the disability services so they decided to stop sending Geoff to these services. After that, Geoff lived with his parents for more than 20 years. When his father died and his mother became ill, another living arrangement for Geoff had to be organised. Geoff's brother and sister-in-law decided they wanted him to live close to them. They lived in rural Australia. Geoff's brother was also his legal guardian. A local non-government organisation was approached and helped Geoff and his family to set up the host family arrangement. Geoff's mother also moved to rural Australia. She received good care in a nursing home. She died a couple of years before we were introduced to Geoff and his living arrangement.

Geoff had his own room, bathroom, lounge, and television. He needed help with some self-care activities. He also had a few health problems. The local non-government organisation provided 36 hours of support per week and organised day activities for Geoff. He was fully included in the social lives of the couple he lived with. They thought carefully about living with Geoff – making sure they had common interests and lifestyles.

Jude

Jude was in her early 60s. Her parents were farmers in rural Australia. When Jude was nine months old, she began having seizures. These were difficult to control and were associated with a severe developmental disability. Jude's parents received support from their family to care for Jude, especially from her grandmother. Jude spent about a year at a specialist centre in the state capital. When she returned home, Jude and her family received support from a non-government organisation. She also had short stays in respite.

In the late 1980s, a government initiative in their area began to support people with disability and their families. Peter, a government officer in the disability sector introduced himself to the family. He suggested that Jude share a house in a nearby town. At first, Peter's suggestion

challenged the family's thinking and Jude's mother "threw him out of our house once". However, Peter continued working closely with Jude and her family. Initially, Jude moved into a home with another woman with disabilities, however the arrangement didn't work out. An arrangement through a non-government organisation was then set up. Jude moved in with Kathy and her family in a nearby town. This host family arrangement lasted for more than 15 years. When Kathy's family situation changed Jude moved in with Kathy's sister. She had been involved in Jude's life and had been providing occasional support for about 13 years. Jude's circle of family and friends had been stable within these support arrangements for almost 20 years.

A local non-government organisation provided 108 hours of support per week and her host family provided all other care for Jude.

Relationships

Consistent with ISL principles, adults with intellectual disabilities may decide to share their home based on an existing friendship or more intimate relationship with another person with or without disabilities. Grouping of people within ISL arrangements should clearly reflect each person's choice and preferences. There will be no financial payment or incentive for one person to move in with another.

Tara and Helen⁷

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 enjoyed participating in each other's social networks saw it 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 rich, fulfilling, and self-determined lives.

7 Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J. & Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities, 20*(2), 100-108. doi:10.1177/1744629516629854

THE ISL FRAMEWORK

Overview of the Framework

The ISL Framework is underpinned by three key assumptions:

1. All people with the right supports can live in an ISL arrangement.
2. Persons with disabilities do not need to live together.
3. People in an ISL arrangement do not have to live alone or independently.

For an arrangement to reflect ISL, evidence gathered through interviews, conversations, documentation, and observations should be consistent with these assumptions. The emphasis is on:

- The arrangement reflecting the person's support needs and preferences.
- The arrangement not grouping persons with disabilities together, unless it is because of the person's own preferences and choice.
- The arrangement not requiring persons with disabilities to live alone or independently unless it is because of the person's own choice and preferences.

Structure of the Framework

The ISL Framework can be used to review or improve an existing arrangement, or to plan for a future arrangement. The ISL Framework identifies and describes eight Themes, each of which represents an important area of ISL. There are two to three Attributes in each Theme, 21 Attributes in total. The Attributes explain the important components of each Theme. The ISL Framework includes a description for each Theme and Attribute.

Each Attribute has one or more Indicator/s. The Indicator is what to look for when doing an ISL review or what to include when planning an ISL arrangement.

The ISL Framework also includes Evidence associated with each Attribute. Evidence can be sought from different sources. It can come from asking or interviewing people, looking at documents, or through observing the arrangement. Sometimes there can be contradictions between the different sources of evidence, for example what people say and what documents say. In these cases, it is important to make a judgement about what source of evidence is most important or likely to be accurate. Usually it is the evidence of what we see and hear that is a more accurate account of how the arrangement is working. It is also important to understand why there may be differences between the sources of evidence and why some evidence is considered more important than other evidence.

Understanding why people disagree is also important. Involving a number of people in a review is valuable because discussion and exchange of views enables better understanding of the issues associated with the Themes.

The following diagram illustrates the relationships between the Themes, Attributes, Indicators and Evidence. Inevitably there is some overlap between different Themes and Attributes. For example, some aspects of the Theme Thriving interconnect with aspects of Social Inclusion, particularly with regard to community involvement and relationships.

Theme Two: My Home

Attribute 2.1

The person has secure tenure in the home.

Indicators:

1. The person has secure tenure in his or her home.
2. There are formal and/or informal measures within the arrangement that recognise and protect the person's security of tenure in his 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:
 - The person has formal ownership or tenancy of the home.
 - The person is included in a formal agreement regarding their living in the home of another person.
 - The person's name is on bills for utilities etc.
 - The person has keys to their home.
- c. Are decisions about moving from the home and/or having another person living in the home are made by, or in consultation with the person?

USING THE ISL FRAMEWORK

The ISL Framework can be used for several specific purposes:

- Education and awareness-raising
- Setting up a new arrangement
- Reviewing an existing arrangement
- Improving an existing arrangement

Using the ISL Framework to Plan and Establish an Arrangement

To plan for the establishment of an ISL arrangement, it is crucial that the person and/or people who know and understand the person well are involved. This will make it more likely that important opportunities for continued development are identified and supported.

It may also be useful to include people who are external to the arrangement. External people can often provide fresh ideas and new opportunities. These people may be from disability organisations or advocacy groups; be trained in planning processes; or have some other role in the person's life, such as teacher or employer.

When planning to set up or improve an arrangement, it is important to consider:

- Continuous personal development, including cultural and community participation, and development of relationships
- Including significant people in the person's life, particularly family and friends, in the planning or evaluation process
- Building on the individual's strengths and interests
- The vulnerabilities of the person and the need for appropriate safeguards

Using the ISL Framework to Review an Arrangement

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

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

An ISL review will ideally look at how the arrangement has developed and how it can continue

to develop optimally. A review team should be led by a trained facilitator (see below) who will have a deep knowledge and understanding of ISL, and who is skilled in facilitating the review process. People participating in a review should read the Manual and the Framework, and need to have the opportunity to discuss and seek clarification before beginning a review. It is important that everyone understands that the review is about the **arrangement** and not the person whose home is being reviewed.

A small team of three to five people is recommended for both internal and external reviews. Information and evidence to review an ISL arrangement can be gathered by talking to different people involved in the arrangement, observing how the arrangement is set up, and by examining documents. Talking to different people in different settings can provide useful information. It may be appropriate to visit as a group or as an individual, depending on the person's wishes.

It is important to have the person whose arrangement is being evaluated present at the home visit. Even in the absence of verbal communication, information supporting a number of Attributes can be gathered by observing the person's interactions with family members, support staff, and the home environment. A family member or long-term supporter may be useful to provide information on the process of establishing the arrangement. Involvement of people with first-hand experience of ISL can make a major contribution to reviews. This includes persons with disabilities, family members, and friends/advocates.

The process should be respectful, especially if a visit to someone's home is involved. Personal information should be treated confidentially.

Deepening Understanding of ISL by Facilitation

Lessons learnt from the three ISL projects to date suggest that reviews benefit substantially from facilitation provided by a facilitator who has received training on the use of the ISL Manual. 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. With guidance from the facilitator, participation in a review can be a significant learning experience for review team members. Facilitated reviews require about 2-4 hours of group discussion after the conclusion of the information-gathering phase of the evaluation.

Reviews take considerable time as information needs to be gathered from a range of sources. Each team member should visit the home, if possible. Each living arrangement is a person's home. People feel differently about others visiting their home. It is important to be respectful and to understand what is OK (e.g. time to visit, who else should be present, how many should visit at the same time, how long to stay, and how to look around the home). The pilot studies indicated that it was beneficial to visit, observe, and talk to different people in a range of

different settings. This included talking to the person whose arrangement was reviewed both in private and, when appropriate, with other stakeholders present. Confidentiality should be highly respected in reviews. For the pilot studies, reviews were spread over at least one week.

For practical reasons, the reviews conducted for the third project were condensed into a single visit to the person's home with an interview led by a trained facilitator. Almost all team members received training in the use of the ISL Manual. Occasionally additional details were gathered by phone contact with another person, such as a parent or support worker who was unable to attend the interview. The process, including the conciliation meeting, could be completed in a single day, or over two days.

Individual review team members scored each Attribute individually, based on evidence gathered prior to a conciliation meeting. Additional information, for example from the person/s visiting the arrangement, was then provided at the meeting and a conciliated score agreed upon.

Reviews can contribute to improving the arrangement by identifying what is and is not working well. The Review Scoring Booklet will assist reviews. It is useful for each review team member to score each Attribute individually and include notes to support their opinions. At the team meeting the Indicators and supporting Evidence for each Attribute are discussed. Discussions will focus on evidence and observations from the site visit rather than the score given by each team member. The whole review team can then come to an agreed (conciliated) score for each Attribute. This process requires a trained facilitator.

The conciliated scores for each Attribute can guide the development of a short participant/family/support worker feedback paper or face-to-face session. It is recommended that the two or three highest rated Attributes and the one or two lowest rated be included in the report. Suggestions on how to improve the lower ratings should also be provided.

Using the ISL Framework to Improve an Arrangement

Information from a formal review or from an informal meeting and discussion can guide the improvement of an arrangement. Areas within the ISL Framework that are identified as being poorly developed can act as focal points for future planning to address the Attributes that would benefit from development. Sometimes identifying Attributes that are not well developed is a sufficient stimulus for improvement. Awareness of poorly developed Attributes can act as a springboard to greater emphasis on developing them further.

In some instances it may be necessary for people involved in the planning and maintenance of the arrangement to locate training or other opportunities to improve their capacity to assist the development of the Attribute. For example, it is likely that staff will need training in supported decision-making and/or person-centred approaches if the goal is to improve self-determination for the individual they support.

In using the manual, on some occasions a balance is required between the need for protection of the person and respecting the person’s choices and desires. Common sense will be required when scoring on some Attributes as a result, but Team members should keep in mind that people with high support needs have traditionally been overprotected so a bias towards the persons’ desires and choices may be appropriate. It is crucial to protect what is working well and to develop what can be improved.

Attribute Scoring

Each Attribute is scored on the following scale:

1.	Not Addressed:	There is no evidence that the Attribute is being addressed.
2.	Not Developing:	There is little evidence to support the Indicators and little Evidence to suggest that the Attribute is developing.
3.	Developing:	There is some evidence to support the Indicators and some of the Evidence suggests that the Attribute is developing.
4.	Well-developed:	Most evidence shows that the Indicators are being addressed and most of the Evidence suggests that the Attribute is well-developed or developing.
5.	Optimal:	All the Evidence indicates that the Attribute is fully developed and cannot be improved.

Theme 1: Leadership

'Leadership' has two Attributes:



Theme Description

ISL arrangements are shaped by what the person and those close to him or her believe represents a good life. Thought and effort goes into creating a clear vision and strong ideas. In some cases, it may take years for the vision and ideas to become clearly articulated. ISL arrangements support and facilitate lifestyles consistent with the vision of what is a good life for each person. There needs to be continued leadership to support the vision, and strong ideas so that the living arrangements continue to develop.

For ISL arrangements to be established and successful, strong leadership is needed. Trying new and different things, sometimes learned from other supported living arrangements, can be part of leadership. One or more persons will lead each arrangement. People will have a clear vision and be transparent about what a good life looks like. Leaders may need to influence others and fight for this vision, particularly if there are insufficient supports available. This will be particularly evident in the early establishment periods of ISL arrangements.

Leadership is also important for the continued development of ISL arrangements. Anyone can be a leader. Leadership often comes from:

- The person with disabilities
- A family member
- Another person such as a friend or advocate
- A professional who may be in a formal leadership position

Leadership may also come from a combination of these people. A lack of leadership is a risk to the establishment and continued development of ISL arrangements.

1.1 The arrangement is based on a clear vision and strong ideas.

Attribute Description

An ISL arrangement is driven by a set of positive beliefs. It builds on strengths and by looking at the big picture. It is designed around the identity of the person: his or her strengths, interests, beliefs, values, and culture. The arrangement will have a clear and articulated vision of what makes a good life for the person. Sometimes, the leaders will have had to fight for or defend this vision and ideas for the person to live a good life. The leaders will have a set of positive assumptions that reflect ISL, as listed at the beginning of the ISL Framework:

- All people with the right supports can live in an ISL arrangement.
- Persons with disabilities do not need to live together.
- People in an ISL arrangement do not have to live alone or independently.

Indicators

- A clear and articulated vision for what is a good life for the person drives the living arrangement.
- The vision clearly reflects the identity of the person.
- There are clear and positive assumptions, beliefs, and expectations about the person to have a good life.
- There are clear and positive assumptions, beliefs and, expectations for the person to continue to develop.
- The vision and ideas have been clearly expressed.

Evidence

- ✓ How did the arrangement begin?
- ✓ How did the vision and ideas develop?
- ✓ What does a good life look like for the person?
- ✓ How are the vision and ideas expressed in support of a good life for the person?
- ✓ How do the vision and ideas reflect the person's needs, likes, and dislikes?

1.2 Key people provide the leadership to set up and continue the arrangement

Attribute description

Key people can be identified as the leader or leaders in the establishment and/or continued development of the living arrangement. One or more of these leaders is the driving force behind the arrangement. Without them, the arrangement may be at risk.

The key leader or leaders will encourage other people important to the arrangement to develop their understanding of how the arrangement supports a good life for the person.

Indicators

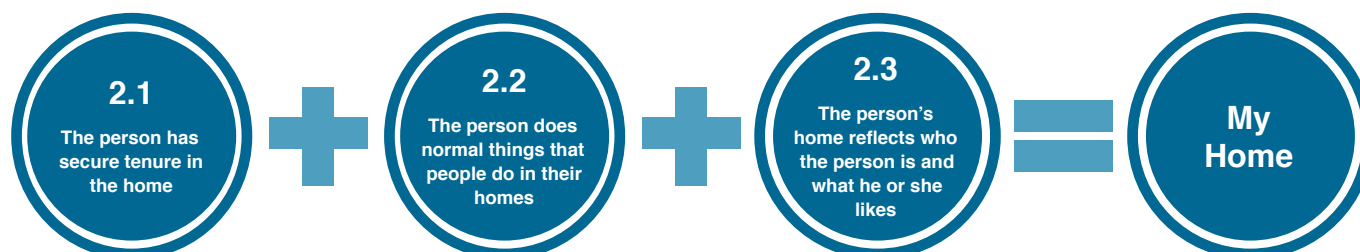
- One or more persons stand out as important for the creation of the arrangement.
- One or more persons stand out as important for the continued development of the arrangement.
- People can describe the actions of the leader or leaders.
- All stakeholders can describe the leader's or leaders' role in developing, carrying out, and communicating the vision and ideas for the arrangement to support a good life for the person.

Evidence

- ✓ Who were the key people involved in the early stages of the arrangement?
- ✓ Who are the key people keeping the arrangement going and developing?
- ✓ How is their leadership described?
- ✓ How did the leader or leaders convince people of the vision for the arrangement?
- ✓ Were there times when the arrangement needed strong support and/or defending? What role did the leader or leaders play in this?
- ✓ How do people describe the leader's or leaders' role in developing, carrying out, and communicating the vision and ideas for the arrangement to support a good life for the person?

Theme 2: My Home

'My Home' has three Attributes:



Theme Description

'My Home' means that ISL arrangements create each person's own home, not just somewhere to stay. Many people dream about living in and owning their own home. By living in his or her own home and not just 'accommodation' the person makes choices about the home. The person does the normal, everyday things that make a home, such as household duties, having routines, relaxing, and enjoying privacy.

The Theme 'My Home' has two major parts. First, the word 'My' means that it really is the home of the person. Having one's own home is widely seen as central to a satisfying and secure lifestyle. Ownership can take many forms. For example, it can include outright ownership or secure rental tenancy. Whatever shape the person's stake in his/her home takes, it is real both on paper and in the person's daily experience. Having one's own home allows a much greater freedom of choice, movement, and expression than that available in any public place. It also brings responsibilities, such as paying bills, housework, gardening, and relations with neighbours.

Second, the word 'Home' is used here in its fullest sense as understood by most people. As a building, home takes many forms such as a house, villa, unit, or apartment. Most people agree and understand that a home is much more than 'bricks and mortar' or a building. For most people, home is a place where they can fully and freely express who they are. Home is a place – perhaps the only place – where they can just be themselves. The furniture, fittings, decoration, location, and style of the home reflect the preferences and personality of a person. The different aspects of home reflect what the person likes best or the best choices available at that time. Home also provides security, comfort, and privacy. It is a place in which a person can choose who to have around and who not to have around.

These deeper meanings of home are different from the ways in which accommodation is often provided in formal human services.

2.1 The person has secure tenure in the home.

Attribute description

The person's living arrangement is secure in their home. The person cannot be moved from the home by someone else without their approval. Security varies with different forms of tenure such as home ownership, renting or leasing a property, and shared equity schemes. Owning a home in the person's name is usually the most secure tenure. If a home is rented or leased, security can be reflected by a long-term tenure or contract. There are also other safeguards for secure tenure, such as renting through an organisation or forms of social housing.

Indicators

- The person has secure tenure in his or her home.
- There are formal and/or informal measures within the arrangement that recognise and protect the person's security of tenure in his or her home.

Evidence

- ✓ Is the person living in the type of home and in a location that they prefer?
- ✓ What measures provide security of tenure for the person? For example:
 - The person has formal ownership or tenancy of the home.
 - The person is included in a formal agreement regarding their living in the home of another person.
 - The person's name is on bills for utilities etc.
 - The person has keys to their home.
- ✓ Decisions about moving from the home and/or having another person living in the home are made by or in consultation with the person.

2.2 The person does normal things that people do in their homes.

Attribute description

Having a home involves a range of normal, everyday activities, relationships, freedoms, and responsibilities. In ISL arrangements, the person's experience of home is damaged if the person's place in the home is not respected. For example this can happen if:

- Other people have more freedoms or entitlements in the home than the person.
- An agency's identity is more obvious than the person's.
- There are too many rules or routines.

Indicators

- ➔ There is respect for the person's natural authority and control in his or her own home.
- ➔ The person is involved in the full range of normal, everyday homemaking practices, including household activities, routines, relationships, and freedoms.
- ➔ The person has typical roles and responsibilities associated with their home.

Evidence

- ✓ Is the person involved in decision-making in his or her home? For example:
 - When to go to bed/get up in the morning
 - What and when to eat
 - Inviting others to visit
 - Routines for household tasks, such as cleaning and laundry
- ✓ Is the person involved in everyday activities? For example:
 - Cleaning and tidying the home
 - Preparing meals
 - Doing laundry
 - Entertaining friends or family
 - Gardening
 - Collecting mail
 - Interacting with neighbours
 - Putting out the rubbish
 - Dealing with house-mates (if applicable)
 - Making a welcoming environment

- ✓ Does the person have access to suitable equipment and technology to assist with creating their home and participating in household activities?
- ✓ Does the person have the freedom to leave the home and go out into the community (if appropriate)?
- ✓ How do others encourage and support participation in household activities?
- ✓ Do others have more freedom in the home than the person?

2.3 The person's home reflects who the person is and what he or she likes.

Attribute description

Each person's home reflects his or her personality and preferences. Personal effects such as photographs, ornaments, and objects are usually displayed. These may give insight into the person's culture, likes, and history.

Each person's interests and preferences are reflected in the way their home is decorated, what is displayed, the music that is played, and entertainment such as television shows. In shared homes this may be more obvious in the person's private space.

The routines of the home, such as when and where meals occur, and how people are entertained, reflect the person's preferences. Visitors learn a lot about the person when they spend time with the person in his or her home.

Indicators

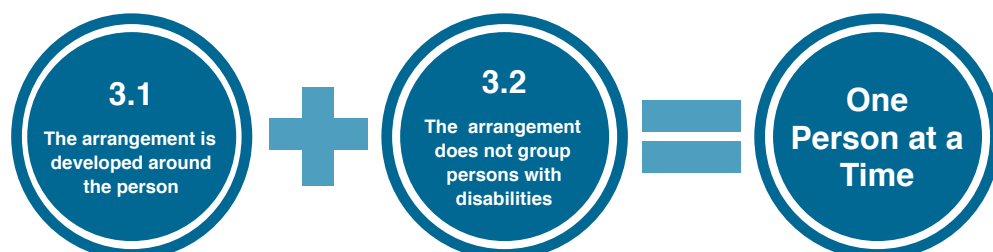
- ➔ The person's home reflects who the person is and what he or she likes.
- ➔ The person's activities in the home reflect his or her personal preferences.

Evidence

- ✓ Do decorations and fittings reflect the person's identity and personal preferences?
- ✓ Does the person arrange the furniture and decorations to suit themselves?
- ✓ Does the person play music/watch TV/play games as he or she wishes?
- ✓ What things does the person like about his or her home and how does he or she describe them or interact with them?
- ✓ Are there aspects of their life and home that the person is not happy about? Are these being addressed?

Theme 3: One Person at a Time

'One Person at a Time' has two Attributes:



Theme Description

ISL arrangements avoid grouping persons with disabilities. Each living arrangement is unique and focuses on one individual. His or her voice is central. ISL arrangements are driven by and focused on a single person, based on personal knowledge of that person, and guided by people who genuinely care for him or her and want to do what is best for that person. Particular care is taken to preserve the individualised approach when a person with disabilities shares the living arrangement with another person with disabilities.

This Theme most clearly differentiates ISL arrangements from other grouped or congregated supported living models. This is because arrangements are planned, developed, and implemented around an individual person. The leaders and others involved will be wary of traditional models of grouped living, especially those that require persons with disabilities to live in groups in order to have access to services. The vision held by those supporting ISL arrangements is the person having a full, good life that reflects the lives of other people of similar age. Grouped living is likely to mean the person's needs may be overlooked or difficult fully to address.

ISL arrangements are shaped by the person's own choices, with the support of others acting on the person's behalf if necessary. The person might live alone, with a family, within a marriage or other intimate relationship, with friends, or with other people.

A person living alone is not necessarily in an ISL arrangement. Living alone may present unacceptable risks if sufficient supports are not provided. Living alone may not be what the person chooses. He or she may be isolated, lonely, or at risk of exploitation.

Situations that are not ISL arrangements include those that group people together because they have disabilities. It is important to note that this does not mean that a person with disabilities cannot choose to live with someone else with disabilities. This may be an intimate partner or a friend. For these to be ISL arrangements, the choices made and the resulting arrangement must clearly reflect the preferences and needs of the person with disabilities. Grouping of persons with disabilities made by other people for reasons that include avoiding loneliness or pooling of resources do not reflect this Theme.

3.1 The arrangement is developed around the person.

Attribute Description

Key people in the development of ISL arrangements know each person well. They can communicate with the person and are responsive to the person's choices, needs, and concerns. One person with disabilities will be at the centre of each vision and the ongoing efforts of each arrangement. All decisions that impact on ISL arrangements will take account of the person's choices and needs. Special attention will be paid to ensuring the choices and needs of other persons with disabilities do not interfere with addressing the interests of the focal person in ISL arrangements.

Indicators

- ➔ The arrangement is designed around the unique identity of one person.
- ➔ Key people know the person well.
- ➔ The person's voice is heard, even if communication is difficult.
- ➔ All decisions, especially major ones, are based on ongoing efforts to tune into the person's point of view. These include decisions about the nature of the arrangement, or about any aspect of the person's lifestyle or wellbeing.

Evidence

- ✓ How well do key people know the person?
- ✓ How does the person communicate his or her choices? If there is a communication difficulty, how is this managed?
- ✓ What examples are there of how the person's voice is central to this arrangement?
- ✓ Do the person and other key people feel that the person's voice is heard?
- ✓ How does the arrangement reflect the choices and needs of the person, for example, in type of housing, location, support, and activities?
- ✓ On what occasions have the person's choices not been heard or acted upon? How was this responded to?
- ✓ How does the living arrangement influence the person's lifestyle?

3.2 The living arrangement does not group persons with disabilities.

Attribute description

The thinking, decisions, and actions of the people involved in developing ISL arrangements are based on a determination that the arrangement is, and will continue to be, for one person. Any form of grouping or congregation for reasons other than the person's own choice is avoided. Key people are very aware of the potential impacts of moving away from individual arrangements to any form of group or congregate living. If the person lives with another person with disabilities, this is from their own free choice, not for administrative reasons or agency requirements.

If arrangements do group more than one person with disabilities, they are unlikely to achieve the highest rating unless it is clear that the individuals freely chose this option. Discussion is required to carefully consider how other aspects of the Theme and Attribute also impact on the Attribute scoring.

Indicators

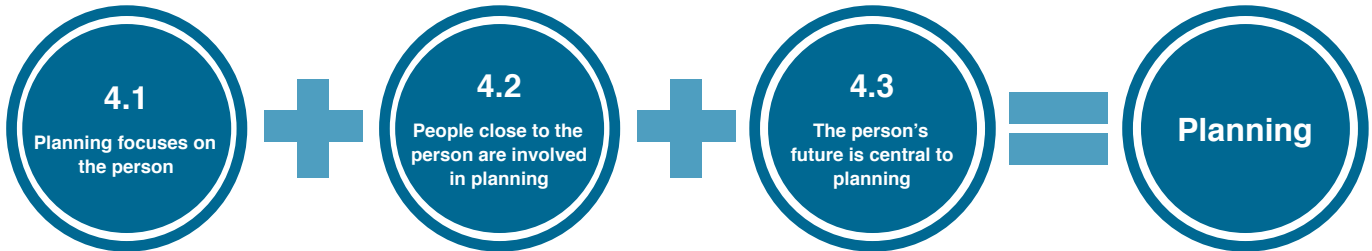
- ➔ The arrangement avoids grouping persons with disabilities together unless it is the person's own choice.
- ➔ The thinking and actions of all people involved show a determination that the arrangement is, and will continue to be, for the one person.
- ➔ If the arrangement groups persons with disabilities together, it is clear that this fits with the person's needs and preferences.

Evidence

- ✓ Who lives together in the arrangement, and how and why did this occur?
- ✓ If some form of group living was considered as the ISL evolved, how was a final decision resolved?
- ✓ What were the reasons that reflected the concept of 'One Person at a Time' in the ISL evolution?
- ✓ Where more than one person with disabilities are living in the arrangement:
 - Did they freely choose to live together?
 - Was it because of a relationship such as friendship or common interests?

Theme 4: Planning

‘Planning’ has three Attributes:



Theme description

ISL arrangements require careful planning, short-term and long-term. Planning may take a lot of time and effort, and is focused on the person. It is done by people close to the person who know him or her well. Planning includes safeguards and reviews of the living arrangement.

Planning is defined broadly. It refers to a range of processes that lead to decisions being made about the person's future, both immediate and long-term. Some decisions may be about ordinary, day-to-day issues. Other decisions may lead to significant lifestyle changes. Short-term planning occurs regularly and is likely to be informal, with adjustments made on the basis of changing circumstances and desires of the person.

Within ISL arrangements, planning is both formal and informal. Formal planning involves meetings, documentation, and monitoring of defined outcomes. Informal planning takes place as a natural part of normal everyday events – a decision may be made around the dinner table. Both types of processes may be used, reflecting the nature of the decisions that are required.

Planning is based on high expectations for the person with disabilities and the planned arrangement. It also recognises the preferences, strengths, and capacities of the person, and does not focus on deficits.

Planning will cover the following points:

Long term perspective

Planning, especially for significant lifestyle changes, begins as early as possible so that a situation does not become critical. Significant lifestyle changes include where the person lives, who the person lives with, and how the person is supported. Over time, the person's needs will change, perhaps associated with increasing age. Good planning processes anticipate these changes and include them in a longer-term outlook.

Safeguards for persons with disabilities and their ISL arrangements

ISL arrangements are based on an awareness of vulnerabilities that people may have, for example, risks associated with health challenges. Planning addresses these vulnerabilities and provides safeguards that are built into ISL arrangements. At times ISL arrangements may themselves be vulnerable. For example, an important support person may be moving on. Within ISL arrangements, there is awareness of the possible consequences of the loss of important relationships, and safeguards are in place to identify and address risks.

Planning includes reviews of the arrangement

Reviews look closely at how ISL arrangements are working. Reviews can be formal or informal. A review may take the shape of an external, independent group that formally evaluates the arrangement, or it may simply involve interested people such as friends who are willing to provide useful feedback.

Planning takes a lot of time and effort

Planning is considered to be an essential part of ISL arrangements. If need be, resources such as time and financial support are used to facilitate ongoing planning.

4.1 Planning focuses on the person.

Attribute Description

Planning in ISL arrangements focuses on one person. Decisions involve the person as much as possible. The person's interests are more important than other interests, particularly those of the formal system. The emphasis is on how ISL arrangements can meet the person's needs and wishes, not how they can fit into the system.

The person's presence and voice should be obvious and influence the planning process. Communication difficulties, limitations of capacity, and cultural issues will be addressed so that each person's voice is heard. The natural authority of the person to represent his or her own interests will be respected. Planning processes acknowledge the preferences and strengths of the person, and reflect high expectations for their future.

Indicators

- Planning is focused on the person.
- The person's presence and voice are obvious, and influence the planning process.
- Planning focuses on the person's uniqueness, strengths, capacities, and needs. For this to happen, others involved in planning must know the person well.

- The person's interests are more important than other interests, particularly those of the formal system.
- Planning processes include both formal and informal approaches as appropriate.

Evidence

- ✓ How is planning done?
- ✓ How is the person involved in planning?
- ✓ How are the person's wishes understood?
- ✓ What is done to ensure that planning stays focused on the person?

4.2 People close to the person are involved in planning.

Attribute description

It may be appropriate for the person's interests to be represented within planning processes by people who know them well. Family members, friends, advocates, and people who provide support may be able to represent the person's interests. Consideration is given to the natural authority of family members, which is normal in most cultures. Planning processes are flexible and support the involvement of other key people, particularly when important decisions are being made.

Indicators

- People close to the person are involved in planning.
- Planning involves people closely associated with the arrangement.

Evidence

- ✓ Who are the significant people in the person's life?
- ✓ How are significant people involved in planning?
- ✓ Is that involvement appropriate?
- ✓ How are the person's wishes about who should be involved in the planning respected?
- ✓ How have past decisions been made?

4.3 The person's future is central to planning

Attribute description

In ISL arrangements, planning for the person's future and long-term wellbeing is very important. Planning needs to include both short-term and long-term perspectives. Long-term planning may involve a formalised environment where long-term goals are both set and reviewed, safeguards are considered and reviewed, and some recording of the process is made. Planning in ISL arrangements is ongoing. The aim of such planning is to maintain the vision for the person into the future. The planning itself may take different forms - such as conversations, planning meetings, and evaluations. There is continuing renewal within ISL arrangements as required.

Indicators

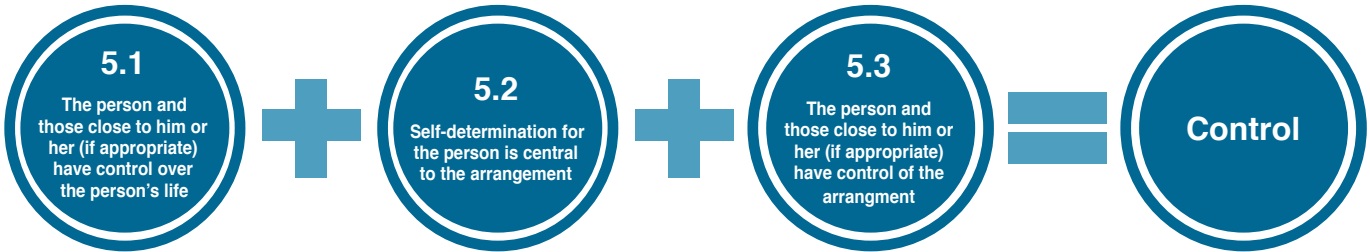
- Planning includes a long-term outlook and addresses major life changes.
- Safeguards based on the vulnerabilities of the person are planned to ensure ongoing quality of the arrangement.
- There is an ongoing process for reviewing the arrangement.
- People closely involved with the arrangement are involved in the review of how well the arrangement is operating and how it might be improved.
- Considerable ongoing time and effort is spent in planning.

Evidence

- ✓ What formal and informal planning occurs?
- ✓ How is it known if the person's needs change and/or the arrangement has to change?
- ✓ What are the major changes in the person's life and what plans are there for addressing these transitions?
- ✓ What are the person's future plans, dreams and visions, and how are these reflected in planning?
- ✓ Where is the person seen to be in **two years'** time? **Five years'** time?
- ✓ What vulnerabilities and risks are there for the person and how are these safeguarded?
- ✓ How are arrangements reviewed and who is involved in this?
- ✓ How are external people involved in the review?
- ✓ What responses have there been to reviews of the arrangement?
- ✓ What resources go into understanding the current situation and how this could be improved? Are these resources adequate? Why/why not?

Theme 5: Control

‘Control’ has three Attributes:



Theme Description

In ISL arrangements, the person and those close to him or her, have a big influence over the planning and maintenance of the living arrangement. In most cultures, it is common practice to get advice from family members when making decisions. Family members are usually key people when a person has limited decision-making capacity. There are also other forms of supported and substitute decision-making, including formal means such as public advocacy.

The person, and/or a legitimate decision-maker when necessary and appropriate, may control everything about the arrangement or give some responsibilities to others as they choose. The person and/or family members may choose to have little control, but still may have clear views on how an arrangement should be developed. Other people may have some influence on the arrangement. For example, an agency may be responsible for matters such as funding and staffing. An advocate may provide important representation of some of the person's interests. In ISL arrangements, distinctions can often be made between “family business”, “service business”, and “shared business”.

Where there is shared responsibility, partnerships will be based on trust. For example, a person who wishes an agency to handle funding and related matters will have an open and trusting relationship with agency personnel. They, in turn, will communicate openly, and work with the person or their representative to supply services as the person wishes.

A person may be severely impaired in his or her ability to contribute directly to aspects of the arrangement. The person may have no family or other close relationships. In this case, other people, such as agency management and support staff, will make a lot of effort to know and understand the person. They will provide support in a way that reflects the person's needs and preferences. They may work to introduce other people into the person's life who might in time speak and act on his or her behalf. The arrangement will acknowledge the possible conflicts of interest that occur when service providers also have substantial control in the lives of people who may be vulnerable.

5.1 The person and those close to him or her (if appropriate) have control over the person's life.

Attribute description

This Attribute addresses a broad range of issues in the person's life. In daily life, the person and others close to him or her, when appropriate, make decisions about and influence his or her lifestyle and personal affairs. For example, this includes control over:

- Household matters
- Relationships
- Pursuing new ideas for a job, education, or a hobby
- Leisure activities and holidays

Indicators

- ➔ The person and those close to him or her have appropriate control over his or her life.
- ➔ The person is not held back by rigid agency rules, regulations, or practices.
- ➔ What the person wants is actually happening with help and support from people close to him or her.

Evidence

- ✓ How is the running of the household decided?
- ✓ To what extent does the person and those close to him or her make decisions about and influence his or her life?
- ✓ What are some examples of how the person and those close to him or her influence his or her life?
- ✓ Is the balance of control appropriate in different matters?

5.2 Self-determination for the person is central to the arrangement.

Attribute description

The arrangement emphasises and respects the person's capacity to determine his or her own affairs, and to make his or her own choices and decisions. People involved in the arrangement will know the person well, assist the person to express his or her wishes, and encourage others to respect the person's wishes. The person's own outlook and prospects for the future are enriched rather than constrained by people who provide support. The arrangement encourages and supports the person to develop further capacity for responsible decision-making.

Indicators

- The person's self-determination is central to the arrangement and is emphasised as important by the person and/or others.
- Opportunities are provided for the person to determine matters in his or her life and to develop more capacity to do this responsibly.
- The person's natural authority to determine his or her life is respected.

Evidence

- ✓ What opportunities are provided for the person to determine matters in his or her life?
- ✓ What decisions are important to the person?
- ✓ What examples are there of the person successfully expressing his or her preferences?
- ✓ How do key stakeholders foster the person's capacity for self-determination?
- ✓ How is overprotection avoided?

5.3 The person and those close to him or her (if appropriate) have control over the arrangement.

Attribute description

This Attribute addresses aspects of control in the development and day-to-day running of the arrangement. Important decisions about managing the arrangement will be made directly by the person. If appropriate, these decisions will also involve people in close relationships with the person. These may be a family member, friend, advocate, and/or service provider.

Aspects of the arrangement may include the set-up of ownership or tenancy, funding processes, and hiring of support workers. Responsibilities will be divided to the satisfaction of people concerned and according to the principle of self-determination. If agency personnel are the only people able to speak directly for the person, they will work towards involving other people who act in the best interest of the person with disabilities, such as family, friends, and advocates.

Indicator

→ Important aspects of the ISL arrangement are determined and managed directly by the person, with the appropriate involvement of people in close relationships, or in partnership with another stakeholder such as an agency.

Evidence

- ✓ What are the management arrangements for:
 - Ownership or tenancy?
 - Funding?
 - Staffing?
 - Overall management?
- ✓ How were these arrangements determined?
- ✓ How does the person exert control over the arrangement and any changes, with appropriate support from others?
- ✓ How have any disagreements about aspects of the arrangement been resolved?

Theme 6: Support

'Support' has two Attributes:



Theme Description

Supports in ISL arrangements come from many people including family, friends, neighbours, advocates, and paid workers. These supports are both formal and informal. ISL arrangements aim to balance formal and informal supports.

The amount and types of supports are flexible, and will change as the person's needs and wishes change. This requires that there are sufficient supports within each arrangement. A range of different types of supports, including informal or unpaid support, will be available.

A range of stakeholders and people may provide support. People may occupy different roles, and may provide both formal and informal support at different times. Formal supports are those provided by people in a paid capacity or 'fee for service'. Informal support, sometimes also referred to as natural support, is unpaid and typically stems from a reciprocal relationship. Supports may be provided by:

- Service providers (government, non-government, private, and not-for-profit)
- Support workers
- Family members
- Friends
- Advocates
- Neighbours and other community members
- Co-residents, host family, housemates, or others who may live within the support arrangement

6.1 Supports are flexible and adapt to changes in the person's needs.

Attribute description

ISL arrangements use different types of support that are adapted as required. The amount and types of supports provided are as flexible as possible to suit the person's needs and preferences. Flexible supports allow arrangements to act upon the full range of educational, vocational and leisure opportunities as they arise, and to address health and wellbeing needs. Contingency and back-up plans are in place, and are acted upon as required.

ISL arrangements adapt as the person's needs and wishes change, or if the external environment changes. ISL arrangements monitor the need to adjust supports. The external environment includes:

- The location and types of physical environment
- People who may live within arrangements
- People and agencies who provide supports and/or services
- Any other aspects of the ISL arrangements

ISL arrangements generally operate under formal agreements, such as regulations or funding requirements. These will be adhered to creatively, acknowledging how they may undermine some ISL principles. As far as possible, rules and regulations will be minimised in ISL arrangements.

Indicators

- Supports are flexible and innovative.
- Supports adapt to changes in the person's needs.

Evidence

- ✓ How are supports arranged?
- ✓ What back-up plans are in place, for example if a support person is unavailable or something unexpected occurs?
- ✓ How are changes in the person's needs identified? How has the arrangement responded to these changes?
- ✓ What examples are there of how the supports have been flexible and creative?
- ✓ Are there sufficient supports to allow the arrangement to be flexible?
- ✓ How are contractual and regulatory obligations met without risking the integrity of the ISL arrangement?

6.2 A variety of supports are in place that suit the person.

Attribute description

There is a variety of supports in place that suits the needs and wishes of the person. ISL arrangements acknowledge both paid and unpaid supports as important. They are outward-looking and actively seek informal supports while understanding this may be undermined by paid supports.

Indicators

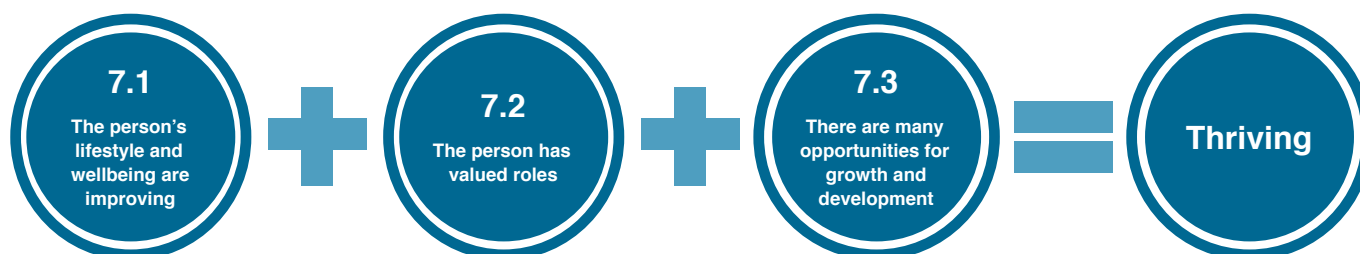
- A variety of supports are in place that suit the person.
- Informal, unpaid supports are part of the arrangement.

Evidence

- ✓ Who provides supports to the person inside and outside the home?
- ✓ What kinds of supports are provided?
- ✓ What informal supports are there?
- ✓ What paid supports are there?
- ✓ Do formal and informal supports complement each other appropriately?
- ✓ How does this suit the needs and wishes of the person?
- ✓ What opportunities are provided to enhance and encourage informal supports?
- ✓ How are other people kept involved?

Theme 7: Thriving

'Thriving' has three Attributes:



Theme Description

ISL arrangements improve the person's lifestyle and wellbeing. They help the person to grow and develop in the areas of independence, self-determination, skills, and valued roles in the home and community. While there is often much initial enthusiasm for growth and development, this can fade over time unless there is a high level of awareness within the arrangement.

This Theme looks at some of the important personal outcomes of ISL arrangements. ISL arrangements enable each person to grow in the areas of:

- Personal wellbeing and happiness
- Acquiring valued social roles at home and in the community
- Personal growth and development

If ISL arrangements are focused on the needs and preferences of the person, they are more likely to support that person's continued or improved wellbeing and this will be reflected in a healthier, happier, and more engaged person.

Valued social roles will come from engagement in the full range of roles and responsibilities associated with home, culture, and community. When considering valued roles for persons in ISL arrangements it is helpful to consider the type and number of valued roles commonly held by persons of a similar age.

ISL arrangements will provide opportunities for experiences that will enable the person to develop relevant skills. There will be development towards greater independence and self-determination.

When ISL arrangements are established and operate in line with the expectations of people involved, the person with disabilities is often described as thriving and generally doing well as a result. Key people who have been involved for a long time can often describe important and positive changes in the person, and can identify what it is about ISL arrangements that contribute to those changes.

7.1 The person's lifestyle and wellbeing are improving.

Attribute description

Lifestyle refers to the way a person spends his or her time day-to-day, week-by-week. It includes:

- Work
- Recreation and leisure activities
- Relationships
- Cultural and community engagement

Wellbeing is a broad term that includes a person's health, their energy and enthusiasm, how they feel about themselves, and how involved and happy they are.

ISL arrangements include the development of a number of benefits to the person's lifestyle and wellbeing. Key people will know the threats to the person's wellbeing and will deal with these in ways that help the person to thrive. This is an ongoing process that continues to be apparent even after arrangements are well established. There will be an awareness that progress can plateau over time.

Indicators

- ➔ The person's lifestyle and general wellbeing are improving as a result of the arrangement. This is apparent in areas such as:
 - Activities in the home and in the community
 - Cultural and community engagement
 - Relationships
- ➔ The person's well-being is improving as a result of the arrangement, in areas such as:
 - General happiness and enthusiasm
 - Health
 - Self-confidence

Evidence

- ✓ How has this arrangement influenced the person's lifestyle?
- ✓ How has this arrangement influenced the person's wellbeing?
- ✓ How are the person's lifestyle and wellbeing continuing to develop?
- ✓ How are improvements to the person's lifestyle and wellbeing being sustained?

7.2 The person has valued roles.

Attribute description

Valued social roles bring many benefits including respect and access to the good things of life. They protect people against roles that are not valued and which lead to poor life experiences. Because of the support and opportunities provided in ISL arrangements, people will develop new and existing valued social roles at home and in the community.

Valued roles vary in impact. Some roles, such as family member, are present but may not be fully utilised. Other roles, such as worker or team member, can have considerable impact in promoting community relationships. In considering this Attribute, the relative power of valued roles should be considered and contrasted with persons of a similar age.

Valued roles in the home include:	Valued roles in the community include:
• Home owner or renter	• Friend
• Family member	• Employee
• Partner/boyfriend/girlfriend	• Work-mate
• Neighbour	• Team mate (sporting)
• House-mate	• Person of faith
• Host	• Student
• Cook	• Companion
• Decorator	• Consumer/shopper
• Gardener	• Volunteer
• Friend	• Traveller
	• Club member/supporter
	• Cultural identity

Indicators

- The arrangement has helped the person to gain and keep valued roles:
 - At home
 - In the community
- Key people in the arrangement know that valued roles are important and are determined to protect progress made.
- Key people in the arrangement are aware of the damage resulting from negative roles.
- Key people acknowledge the need to aspire to a similar range and depth of valued roles to persons of a similar age.

Evidence

- ✓ What are the strengths and capacities of the person?
- ✓ What sorts of valued roles does the person have:
 - Around the home?
 - Outside the home?
- ✓ Which of these roles are more important in the person's life?
- ✓ How does the arrangement help the person to:
 - Develop these roles?
 - Keep these roles going?
- ✓ Are the roles currently held likely to lead to other valued roles such as friend or colleague?
- ✓ Is there evidence of the person recently gaining one or more valued roles?
- ✓ How do people in the arrangement avoid negative roles?

7.3 There are many opportunities for growth and development.

Attribute description

Having one's own home brings many opportunities for personal growth and development. ISL arrangements will make the most of this. They will fully involve the person in all aspects of planning and actions to do with household roles and responsibilities. ISL arrangements involve the person in typical neighbourhood, cultural, and community roles.

Within ISL arrangements there will be awareness that some persons with disabilities have been exposed to a lifetime of limited supports or low expectations, whereas high expectations and good supports are necessary for continued growth and development.

Support needs will be met in ways that encourage each person to accept as much responsibility as possible and there will be access to appropriate assistive technology to achieve this. ISL arrangements ensure the approaches are developmental and not over-protective of the person.

Indicators

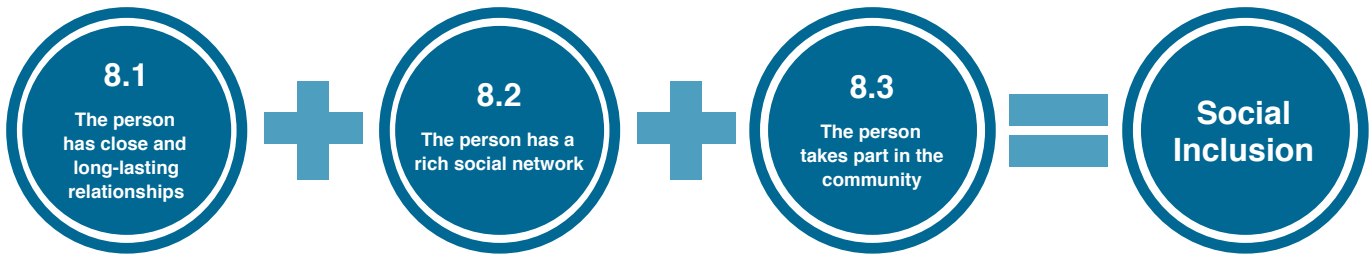
- ➔ The arrangement provides many opportunities for the person's growth and development.
- ➔ There are high and positive expectations surrounding the person.
- ➔ Appropriate supports are available for continued growth and development for the person.

Evidence

- ✓ What opportunities are there for the person to learn, grow, and develop inside the home and outside the home?
- ✓ Are there examples of the person's involvement in challenging community environments that demonstrate high expectations for the person's growth?
- ✓ What are the expectations on the person to fulfil typical household tasks?
- ✓ Are there examples of specific support and teaching of additional skills in the home?
- ✓ What growth and development has been achieved to date through the influence of the arrangement?
- ✓ What expectations are there for the person's development in the future?
- ✓ What assistive technology is provided, if necessary, to support the person to participate more fully at home and in the community?

Theme 8: Social Inclusion

‘Social Inclusion’ has three Attributes:



Theme Description

ISL arrangements build wider community inclusion in two ways:

- By encouraging personal relationships with community members and not grouping persons with disabilities.
- By encouraging community participation and not separating the person with disabilities from the community.

For persons in ISL arrangements, this means being involved in the community and not being socially isolated. One key way this occurs is through having a range of relationships with people. Relationships provide the necessary opportunities to participate and to make connections with the community.

This Theme looks at how ISL arrangements help people to be included in the community. It is about the valued roles the person has by being a respected member of different communities. Social inclusion means:

- Being involved in cultural and community life, particularly through relationships with people
- Spending time physically in community settings
- Participating in culturally-appropriate activities
- Participating in community settings through reciprocal relationships and activities
- Participating in inclusive community activities rather than disability-specific activities

8.1 The person has close and long-lasting relationships.

Attribute Description

ISL arrangements encourage and support persons in their relationships with others that are close and develop over time. Key leaders know these relationships are important. People supporting ISL arrangements know about these important relationships and work to sustain them, and also to develop new relationships.

Indicators

- ➔ The person has close and long-lasting relationships that are encouraged and supported by the arrangement.
- ➔ Leaders and key people know these relationships are important and actively safeguard them.

Evidence

- ✓ With whom does the person have relationships?
- ✓ Which of these relationships are close and long-lasting?
- ✓ Why are these relationships important?
- ✓ What benefits does the person get from the relationships?
- ✓ How does the arrangement safeguard, encourage, and support existing relationships, and encourage the development of new ones?

8.2 The person has a rich social network.

Attribute description

Social networks are made up of the person's relationships with people who may or may not have disabilities. Relationships vary in terms of closeness, from close friends and family relationships through to casual acquaintances. Relationships occur in the person's home, the family home, when at social, cultural and community activities, at school, and at work. Relationships can be between people with varying characteristics such as age, gender, and cultural background. These opportunities create the link between relationships and social inclusion.

People in ISL arrangements will have developing social networks, both within the home and outside the home. Relationships will be reciprocal, that is, the person will contribute to those relationships and his or her contribution will be appreciated. An ISL arrangement will support and welcome the involvement of a range of people from the community in the person's life.

Indicators

- ➔ The person has a rich and varied social network that includes many people without disability.
- ➔ Relationships in various places are helped and supported by people involved in the arrangement.

Evidence

- ✓ Who are the people in the person's social network, for example family, close friends, and acquaintances?
- ✓ Where are these relationships located? To what extent do these occur in inclusive surroundings?
- ✓ How does the person benefit from these relationships and how does the person contribute to them?
- ✓ How does the arrangement support the person to maintain and develop relationships?

8.3 The person takes part in the community.

Attribute Description

ISL arrangements enable persons with disabilities to take part in a wide variety of cultural and community activities, including many that are not disability-specific. Participation in the community provides opportunities for each person to develop valued social roles and to forge new relationships.

Persons with disabilities take part in a range of cultural and community settings within their local neighbourhood, workplace, recreational facilities, and education centres. Participation reflects each person's interests, likes, and capacities.

Indicators

- The arrangement creates opportunities for the person to take part in a range of inclusive and culturally appropriate community settings.
- The person takes part in many activities with persons without disability.

Evidence

- ✓ In which community settings does the person take part?
- ✓ Which of these settings are inclusive?
- ✓ How do these community settings reflect the person's interests and likes?
- ✓ How does the person actually take part and what are his or her roles in each of these settings?
- ✓ How has participation contributed to the development of relationships?
- ✓ Which relationships are with persons without disability?
- ✓ How have relationships contributed to the development of community inclusion?
- ✓ How does the arrangement support these involvements?

RESOURCES

The School of Occupational Therapy and Social Work at Curtin University has progressed the ISL Framework and Manual since 2007. The following publications may be of interest:

- Cocks, 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. Available from:

<http://hdl.handle.net/20.500.11937/21720>

- Cocks, 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. Available from:

<http://hdl.handle.net/20.500.11937/3769>

- Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J & Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities*, 20(2), 100-108. Available from:

<http://hdl.handle.net/20.500.11937/9918>

Additional publications and information:

- Cocks, E. & Boaden, R. 2009. *A guide to developing personalised residential supports (PRS) for adults with developmental disabilities and their families*. Bentley: School of Occupational Therapy and Social Work, Curtin University. Available from:

<http://hdl.handle.net/20.500.11937/23358>

For people interested in Person-Centred and Individual Needs Planning, the following resource might be useful:

- Parsons, L., Cocks, E. & Williamson, M. 2009. *A Review of Best Practice in Individual Needs Planning*. Bentley: Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, School of Occupation Therapy and Social Work, Curtin University. Available from:

<http://hdl.handle.net/20.500.11937/46262>

We are continuing to develop the ISL Framework and Manual and welcome feedback from people who have utilised these resources.

If you have any comments or suggestions, please email Stian H Thoresen at s.thoresen@curtin.edu.au



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