



Centre for Research into Disability and Society
Curtin Health Innovation Research Institute

INDIVIDUAL SUPPORTED LIVING MANUAL

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INTRODUCTION

Individual Supported Living (ISL) refers to living arrangements for persons who require support due to a disability. ISL goes beyond accommodation 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 disability. These themes have been developed and explored in two 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.

ISL arrangements for persons with disability have developed in many places over the last 20 years or more. 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 disability. 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 the two research projects carried out between 2007 and 2011.

The first research project explored person-centred approaches to supported living for adults with developmental disability. 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 ISL. 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 for each indicator.

In 2010 and 2011, two sets of five reviews of a range of ISL arrangements were carried out in the WA 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 disability living alone, with co-residents, with a family, and with live-in, 24-hour support. Some arrangements were in houses and others in semi-detached houses or units. 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 this version of the Manual and the accompanying Review Scoring Booklet.

The two research projects were overseen by a steering group which included representatives from families, key service providers, and the WA Disability Services Commission. Most of the people and organisations involved in the first project were also involved in the second project.

The auspice for the first research project was the WA Developmental Disability Council and the second project, WA National Disability Services. Both 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.

This Manual

The main purpose of this Manual is to provide a tool to review and develop ISL arrangements and planned 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. From the first research project, a Guide to develop ISL arrangements was published (Cocks and Boaden 2009) and details on how to access it are provided in the Resources section at the end of this Manual.

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 also has considerable potential for training purposes that aim to inform stakeholders about ISL arrangements. For example, training 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. This potential has not yet been explored.

The following section provides a short summary of the six ISL arrangements observed during the first project. These are included 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 is followed by some instructions on how to use the ISL Framework, the Review Framework itself, and a brief Resources section.

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their living arrangement through the six initial arrangements studied and the ten pilot reviews. Michelle Stanton contributed to the Manual development.

EXAMPLES OF INDIVIDUAL SUPPORTED LIVING ARRANGEMENTS

A key part of developing the ISL Framework was following six ISL arrangements for 18 months over 2008-2010. A summary of each arrangement follows. They provide insight into what is needed to set up and maintain effective ISL arrangements.

Rob's arrangement

Rob is a man in his late 30s. He rents an inner-city townhouse together with two non-disabled people. This is sometimes called a 'co-resident model'. Rob's ISL arrangement began 14 years before we contacted him. His mother and a non-government organisation organised this together. It has been a stable home life for Rob. Rob's co-residents have not changed often. He is still friends with some of his former co-residents. Rob was involved with recruiting the first co-residents through advertisements, but there has been no need to advertise for new ones. They have come through Rob's social network which has grown over time.

Rob has moderate support needs. His needs were much greater when the arrangement was set up. The ISL arrangement has been rich and supportive. Rob's skills and wellbeing have developed greatly with time. In the beginning, expanding his social network was planned. Now it is growing in a loose and informal way. Rob's social network includes some close friends and many acquaintances. Rob has travelled around Australia and overseas. He is welcomed at many businesses in the inner-city and he has a range of work roles.

Rob's co-residents get a discount on their rent and bills by the organisation supporting Rob. They are expected to 'be there' for Rob. This means that a co-resident is there for the evening meal and overnight. Some day-to-day assistance is also provided. To make the arrangement more secure, the organisation supporting Rob holds the lease. They also arrange for support staff to come in for a few hours on weekdays, supporting Rob in a range of activities. While the organisation and support staff oversee the arrangement, this is done from a distance. Rob is also close to his mother and they spend a lot of time together.

Andre's arrangement

Andre is a woman in her late 30s. She rents a public housing unit in her own name. Andre is supported by a non-government organisation. Her parents are very close to Andre. They have fought hard to get services and funding to meet Andre's needs. They work closely with the organisation supporting Andre. They have worked together for about ten years. After trying different group home arrangements that were not right for Andre, they began setting up her own home. When we contacted Andre, she had been living in her unit for about three years. Andre needs a lot of support. This includes many areas of her day-to-day life. Communication and understanding what happens around her can be difficult. There have to be people who know her well to understand what Andre needs.

Different support models have been used and some did not suit Andre. The organisation now provides staff on a 'live-in' arrangement. This means that a staff member lives with Andre. There are two people who live with Andre. A staff member lives with her for a week, a second staff member another week, and then the first staff member comes back. When no support is available, Andre's parents help out. Andre's Nanna is also involved. She stays with her Nanna from time to time. Her ISL arrangement is now stable. Her lifestyle and general wellbeing are also settled. Andre's parents and the organisation supporting her are now looking at her connections in the community. This includes changing from a sheltered workshop to open employment.

Geoff's arrangement

Geoff is in his late 40s. He shares a home with a married couple in a large town in southwest Australia. This ISL arrangement had been in place for about six years before we met Geoff. Geoff has a significant developmental disability. 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. 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 live in southwest Australia. Geoff's brother is also his legal guardian. A local non-government organisation was approached and helped Geoff and his family to set up the ISL arrangement. Geoff's mother also moved to southwest 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 has his own room, bathroom, lounge, and television. He needs help with some self-care activities. He also has a few health problems. The local non-government organises day activities for Geoff. He is fully included in the social lives of the couple he lives with. They thought carefully about living with Geoff – making sure they had common interests and lifestyles:

"We had to ask [Geoff] how he felt about us. We also told him about our life to give him an idea about what we're like. Told him about our pets and hobbies. Realised we had the same interests. Camping and music. [Geoff]... is a real music lover and has music going quite often and it would be very difficult to live with people who didn't like music almost the whole time."

Jude's arrangement

Jude is in her early 50s. Her parents are farmers in southwest Australia. When Jude was nine months old, she began having seizures. These were difficult to control and were associated with a significant developmental disability. Jude's parents received support from their family, especially Jude's grandmother. Jude spent about a year at a specialist centre in the state capital. When she returned home, Jude and her family received support. Jude also had short stays in respite.

In the late 1980s, a government initiative began in their area 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. This was challenging. Jude's mother "threw him out of our house once!" Peter continued working closely with Jude and her family. This is how Jude's mother described Peter:

"He was lovely. ... Made all sorts of suggestions that Jude might be able to do this and you'd never be able to know. I thought 'Oh my goodness! This is too much.' I don't think we were able to get our minds on the future. We were so busy with what was going on right then that we couldn't look to the future. We needed someone else to do our thinking for us. ... Peter was persuasive and we became convinced that he was on the right track. We liked him. He was good. It's hard for a mother who had the whole thing to accept that somebody else could do it. ... The main thing I said to Peter... was that we wanted to be sure that whoever looked after her loved her and respected her as a human being. That was very important. And that's what we got."

Initially, Jude moved into a home with another woman with a disability. This was not suitable. An arrangement through a non-government organisation was then set up. Jude moved in with Kathy and her family in a nearby town. This arrangement lasted for more than 15 years. Then Kathy's family situation changed and Jude moved in with Kathy's sister. She had been involved in Jude's life, and provided occasional care, for about 13 years. Jude's circle of family and friends has been stable within these support arrangements for almost 20 years.

Now Jude's needs are changing. The aim is to support her in her own home. This will provide more security and be a more relaxed lifestyle. When we left Jude's arrangement, planning for this had been ongoing for about a year. This included making sure her lifestyle and relationships continue. Jude's mother reflected:

"The big step was letting her come down here in the first place because I was sure no-one could look after my daughter as I would. I found out there are wonderful people in the world. They're special. And so we were able to let go of her and we knew she was being treated with respect and love and cared for – and it was a relief."

Lisa's arrangement

Lisa is a woman in her mid-20s. She lives in a villa by herself. Lisa is the owner of the villa. This was arranged by her family when her mother passed away. Lisa has a strong family network.

Lisa has an active lifestyle. She takes care of most of her day-to-day life. She has a few hours of drop-in support each week. This support is provided by a non-government organisation. They help with diet, budgeting, mail, and other things Lisa needs a hand with. Lisa's lifestyle is quite busy. She travels independently to and from work, the shops, and to visit family. A

longer term goal is to get a normal job. This will add new challenges and opportunities to the lifestyle that Lisa enjoys.

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

Paul's arrangement

Paul is a young man in his early 20s. When we met him, he was living with his parents in his family home. Paul needs considerable support. His communication is limited. It is important to have people around who know him well and understand what he wants and needs. Because Paul's parents have worked hard for many years to set up a good ISL arrangement, we have included Paul's story. There is a lot to learn from this arrangement on how to plan. It also shows the important role his parents have in being leaders in setting up an arrangement.

Paul's parents have been working very hard to set up a good ISL arrangement. They have been in contact with people who know a lot about ISL. Some of these people are international experts. Paul's parents have arranged a social support network. They have also received funding for Paul. Paul's parents have set up what is called a 'Microboard'. A Microboard is a small group of people, usually family and friends. Microboards are non-profit community boards. The role of the Microboard is to make good decisions for Paul: what Paul needs, wants, and likes.

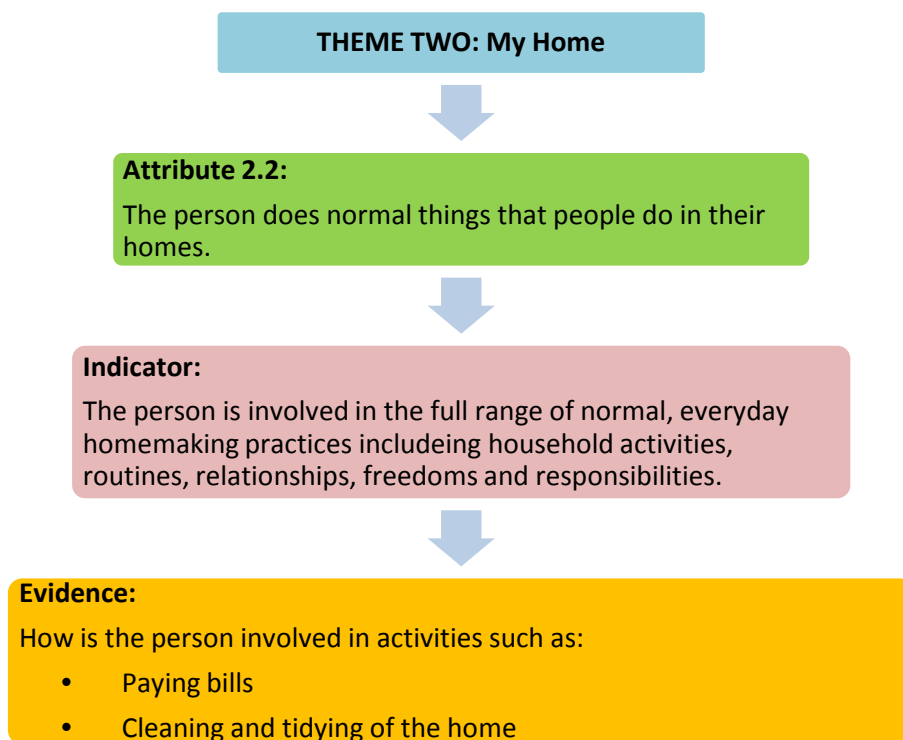
USING THE ISL FRAMEWORK

Structure of the Framework

The ISL Framework can be used to review or improve an existing arrangement or plan for a future arrangement. The ISL Framework identifies and describes **eight themes**. Each theme is an important area of ISL. There are two or three attributes in each theme, **21 attributes** in total. The attributes explain the important parts of each theme for ISL. 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. There are different sources for finding evidence. Evidence 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 structure of the Themes, Attributes, Indicators, and Evidence.



Using the ISL Framework to Plan an Arrangement

The ISL Framework can be used for planning in at least three different ways:

- Setting up a new arrangement.
- Reviewing an existing arrangement.
- Improving an existing arrangement.

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

- Continuous personal development, including community participation and development of relationships.
- Including significant people in the person's life in the process.
- Building on strengths and interests.

To plan for ISL, the person or people who know and understand the person well should be 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

It is crucial to protect what is working well and develop what can be improved.

Using the ISL Framework to Review an Arrangement

The ISL Framework can be used to review an arrangement in at least three different ways:

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

People participating in a review should read the Manual and the Framework and preferably 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 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 upon the person's wishes.

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

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 person participating in the review (review team members) to score each attribute individually and include notes to support opinions. In a group discussion, the whole review team can then come to an agreed (conciliated) score for each attribute.

Attribute Scoring

Each Attributes is scored on the following scale:

- | | |
|--------------------------|---|
| 1 Not Addressed: | There is No Evidence that the Attribute is developing. |
| 2 Underdeveloped: | There is Little Evidence to support the Indicator/s and most of the evidence suggests that the Attribute is underdeveloped. |
| 3 Developing: | There is Some Evidence to support the Indicator/s and most of the evidence suggests that the Attribute is developing. |
| 4 Strong: | Most Evidence indicates that the Indicator/s are being addressed and all the evidence suggests that the Attribute is developing. |
| 5 Optimal: | All Evidence indicates that the Attribute is well developed and strong, and cannot be improved. |

Deepening Understanding of ISL

Facilitated reviews require about 3-4 hours of group discussion.

The pilots indicated that reviews benefit substantially from facilitation. Facilitation helped to explain and clarify themes and attributes and also assisted the identification of what was working well within the arrangement and where improvements could be made. In this way, participation in a review can be a significant learning experience for review team members.

External reviews usually require more time because information needs to be gathered from a range of sources spread over time. When external reviews are carried out by a team, at least one team member should visit the arrangement. Each living arrangements is a person's home. People feel differently about others visiting their home. It is important to be respectful and understand what is OK (such as: 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 pilots 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. For the pilots, external reviews were spread over at least one week. Individual review team members scored each attribute individually based on information gathered prior to a conciliated scoring meeting. Additional information, for example from the person/s visiting the arrangement, was then provided at the meeting and a conciliated score agreed upon.

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

The Review Framework now follows.

REVIEW FRAMEWORK

The ISL Framework is underpinned by three key assumptions:

1. All people with the right supports can live in an ISL arrangement.
2. People with a disability 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, documentations, and observations should be consistent with these assumptions. The emphasis is on:

- The arrangement reflecting the person's support needs and preferences to enable anyone to live in an ISL arrangement.
- The arrangement not grouping people with disability together unless it is because of the person's own choice and preferences.
- The arrangement not requiring people with disability to live alone or independently unless it is because of the person's own choice and preferences.

Theme 1: Leadership

An ISL arrangement needs leadership. At least one person has clear and strong ideas. The leader or leaders are persistent. Anyone can be a leader, including the person with a disability, family members, and service providers.

'Leadership' has two Attributes:



Description

An ISL arrangement is shaped by what the person with disability and those close to him or her believe is a good living arrangement and lifestyle.

- It may take some years for the vision and ideas to become clear.
- Thought and effort goes into creating a clear vision and strong ideas.
- There is continued leadership to support the vision and strong ideas so that the living arrangement continues to develop.
- Trying new and different things learned from other supported living arrangements can be part of leadership.

For an ISL arrangement to be established and successful, **strong leadership** is needed. One or more persons will lead. The person/s will:

- Have clear ideas about ISL.
- Be able to influence others.
- Be important in establishing the living arrangement.
- Be important in the continued development of the living arrangement.

Anyone can be a leader. Leadership often comes from:

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

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

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

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 a single person with a disability. The arrangement will have:

- A clear vision for the person.
- A deep understanding of ISL.
- A set of assumptions, particularly those listed at the beginning of the ISL Framework:
 - All people with the right supports can live in an ISL arrangement.
 - People with a disability do not need to live together.
 - People in an ISL arrangement do not have to live alone or independently.

Indicators

- ✓ A clear and open vision 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 and the potential for him or her to have a good life and continue to develop.
- ✓ The vision and ideas have been clearly expressed.

Evidence

- How did the arrangement begin?
- How did the vision and ideas develop?
- How were the vision and ideas expressed? How do they continue to be expressed?
- The interests, needs, likes, and dislikes of the person are most important. What evidence is there that the arrangement is based on a clear vision and strong ideas about these?

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

Description

A number of leaders have been important to the living arrangement and still are. 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) has encouraged other people important to the arrangement to develop their understanding of ISL.

Indicators

- ✓ One or more persons stand out as important for the creation and/or 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.

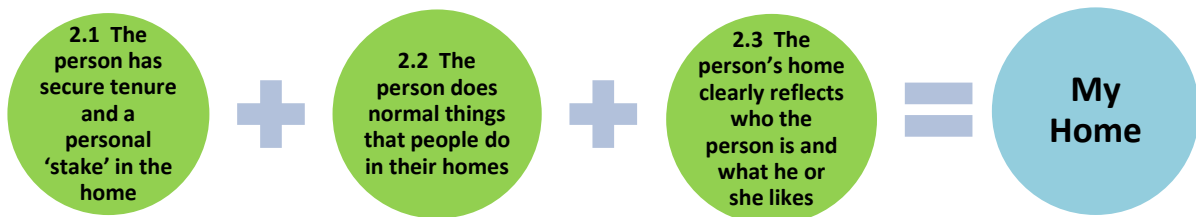
Evidence

- 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 was 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?
- What were the specific parts of the vision that the leader or leaders developed?
- What personal characteristics do the leader or leaders have? How did the leader or leaders show their leadership?

Theme 2: My Home

'My Home' means that the ISL arrangement creates the person's own home, not just somewhere to stay.

'My Home' has three Attributes:



Description

Many people dream about living in and owning their own home. A personal stake in one's home can bring a sense of ownership, responsibility, and empowerment. 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 home '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 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, and decoration, the location, and the style of 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 and a personal 'stake' in the home

Description

The person's living arrangement is secure in his or her home. The person cannot be moved from the home by someone else without the person's approval. Security is different in different forms of living arrangements such as home ownership, renting or leasing a property, and shared equity schemes. Owning the home in the person's name is usually the most secure tenure. If the 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.

Security also comes through the person having a personal 'stake' in his or her home. The person knows it is his or her home. It is obvious that it is the person's home and the person has made it his or her home – it **'feels'** like the person's home:

- The person is involved in running and making decisions about the home.
- The bills are in the person's name.
- The person has his or her own set of keys.

Indicators

- ✓ The person has a personal stake and secure tenure in his or her home.
- ✓ There are many indications that this is the person's home and not the property of someone else or an agency.
- ✓ There will be formal and/or informal measures within the arrangement that recognise and protect the person's security of tenure in his or her home.

Evidence

- The support arrangements are not intrusive and do not take away from the homely atmosphere.
- Is there respect for the person's natural authority and control in his or her own home?
- What measures provide security of tenure for the person?
 - Does the person have any formal ownership of the home?
 - If yes, what form does this take?
 - If rented, in whose name is the tenancy?
 - In whose name or names are the bills, e.g., for utilities?
 - How much control does the person have over the home environment?
 - How much control does the person have over the routines in the home?
 - Who has keys to the home?
 - Who makes decisions about the person moving from his or her home?
 - Who makes decisions about who shares the home?
 - How are these decisions made?

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

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. This can happen if:

- Support people have more freedoms 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

- ✓ The person is involved in the full range of normal, everyday homemaking practices including household activities, routines, relationships, freedoms, and responsibilities.
- ✓ The person has typical roles and responsibilities associated with their home.

Evidence

- How is the person involved in decision-making in his or her home?
- How is the person involved in activities such as:
 - Paying bills?
 - Cleaning and tidying of the home?
 - Preparing meals?
 - Entertaining friends?

- Gardening?
- Collecting mail?
- Contact with neighbours?
- Putting out the rubbish?
- Dealing with house-mates?
- Making a welcoming environment?

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

Description

A person's home reflect 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 past and history. The person's interests and preferences are reflected in the way the home is decorated, what is displayed, the music that is played, and entertainment such as television shows. The routines of the home, such as when and where meals occur and how people are entertained, reflect the person's preferences. The physical location and style of the person's home may indicate their choices. Visitors learn a lot about the person when they spend time with him or her in the person's home.

Indicator

- ✓ The person's home, the routines, and activities reflect who the person is and what he or she likes.

Evidence

- How does the home reflect the person's identity and personal preferences?
- What are things the person likes about his or her home?
- In what areas have the person's wishes been only partly met? How has this been addressed?

Theme 3: One Person at a Time

ISL arrangements avoid grouping people with disability. Each living arrangement is unique. It focuses on each person with a disability. His or her 'voice' is central. Each arrangement is centred on the person, based on personal knowledge of the person, and guided by people who genuinely like the person and always want to do what is best for him or her.

'One Person at a Time' has two Attributes:



Description

This theme is the one that most clearly makes ISL arrangements different from other supported living models. This is because arrangements are started, developed, and implemented around an individual person. The leaders and others involved will be wary of traditional models of grouped living. Their vision will include the idea of the person with a disability having a place in society that is full and varied like any other persons of similar age. With group living, the individual person's needs may be overlooked, difficult to address, or difficult to give priority.

ISL arrangements can include many different lifestyles. These are shaped by the person's own choices and the ideas of important others acting on the person's behalf. The person might live alone, with family, within a marriage or with a partner, friends, or other people.

A person with a disability living alone is not necessarily in an ISL arrangement. Living alone is not always good for the person. It may not be what the person wants. He or she may be isolated, lonely, and at risk of exploitation.

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

3.1 The arrangement is developed around the person

Description

Key people in the development of the arrangement know the person well. They can communicate with the person, and respond to the person's wishes, needs, and concerns. One person with a disability will be at the centre of the vision and the ongoing efforts of the arrangement. All decisions that impact on the arrangement will take into account the person's wishes and needs. Special attention is paid to ensuring that the needs and wishes of other people with disability do not interfere with addressing the person's interests in the arrangement.

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 a communication difficulty exists.
- ✓ Decisions (small and large) are based on the person's views. All decisions, especially major ones, are based on ongoing efforts to tune in to the person's point of view. These include decisions about the nature of the arrangement or 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 wishes? If there is a communication difficulty, how is this addressed?
- What examples are there of how the person's voice is central to this arrangement?
- How do the person and other key people feel that the person's voice is heard?
- Does the arrangement reflect the wishes and needs of the person in terms of, e.g., housing type, location, support, and activities?
- On what occasions have the person's voice not been heard?

3.2 The living arrangement does not group people with disability

Description

The thinking and actions of all involved are based on a determination that the arrangement is, and will continue to be, for the one person. Any form of grouping for reasons other than the person's own choice is avoided. Key people are very aware of the potential impacts of moving away from an ISL arrangement to any form of group living.

Indicators

- ✓ The arrangement avoids grouping people with disability 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 people with disability together, it is clear that this fits with the person's needs and preferences.

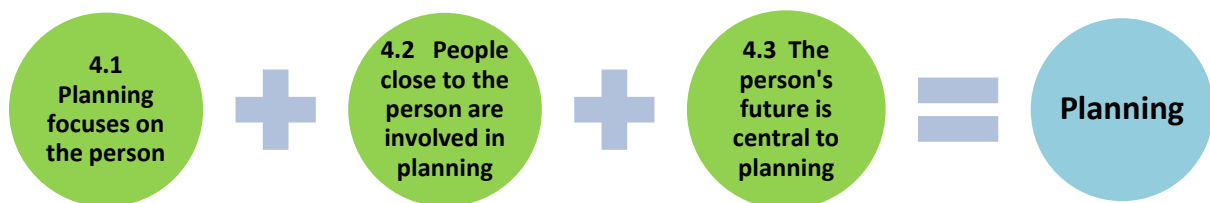
Evidence

- Who lives together in the arrangement and why?
- If some form of group living was considered, how was it resolved?
- What rationales were there for the arrangement that reflected the notion of 'one person at a time'?
- Where people with disability are living together:
 - Did they choose to live together?
 - Was it because of friendship or common interest?
 - Are they happy and/or fulfilled?

Theme 4: Planning

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

'Planning' has three Attributes:



Description

This theme is about both:

- Planning processes leading to the start of the ISL arrangement.
- Ongoing planning processes for the future of the person with disability.

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.

Within an ISL arrangement, 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 and the planned arrangement. It also recognises the preferences, strengths, and capacities of the person and does not focus on deficits.

4.1 Planning focuses on the person

Description

ISL planning focuses on the 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 the arrangement can meet the person's needs and wishes, not how the person 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 are addressed so that the person's 'voice' is heard. The natural authority of the person to represent his or her own interests is respected. Planning processes acknowledge the preferences and strengths of the person and reflect high expectations.

Indicators

- ✓ Planning is focused on the person.
- ✓ The person's presence and voice is obvious and influences 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

Description

It may be appropriate for the person's interests to be represented in planning processes by others who know the person 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 that is normal in most cultures. Planning processes are flexible and support the involvement of other key people, particularly when important decisions are being made.

Indicator

- ✓ People close to the person are involved in planning.

Evidence

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

4.3 The person's future is central to planning

Description

In an ISL arrangement, planning for the person's future and long term wellbeing is very important. To be effective:

- Planning includes a long term perspective.
- Planning includes safeguards to protect the person.
- Planning includes safeguards to ensure the ongoing quality of the arrangement.
- Planning includes reviews of the arrangement.
- Planning takes a lot of time and effort.

Planning in an ISL arrangement is ongoing. The aim is to maintain the vision for the person into the future. The planning itself may take different forms - such as a conversation, planning meetings, and evaluation. There is continuing renewal of the arrangement as required.

- What is working and what is not working?
- What can be done to make sure it keeps working well?

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 the person and the arrangement

An ISL arrangement is based on an awareness of vulnerabilities that the person may have that present risks to the person. For example, they may involve health challenges. Planning addresses these vulnerabilities and safeguards are built into the arrangement. There may also be aspects of the arrangement that are vulnerable. For example, an important support person may be moving on. Within the arrangement, there is awareness of the possible consequences of the loss of important relationships and safeguards are in place to identify and address these.

Planning includes reviews of the arrangement

Reviews involve a close look at how the arrangement is working. Reviews can be formal or informal. A review may involve an external, independent group that formally evaluates the arrangement. It also 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 the ISL arrangement. If need be, resources such as time and financial support are used to support ongoing planning.

Indicators

- ✓ Planning includes a long-term outlook.
- ✓ Major life changes are planned for.
- ✓ There is planning of safeguards around what is important to, and working for, the person, and what can be done to make this more likely to occur or to continue.
- ✓ There is planning of safeguards based on vulnerabilities and risks to the person.
- ✓ There is an ongoing process for reviewing the arrangement.
- ✓ Internally, people are involved in the review of how the arrangement is working.
- ✓ People with a more objective view of the arrangement are involved in reviewing or improving the arrangement.
- ✓ Considerable ongoing time and effort is spent in planning.

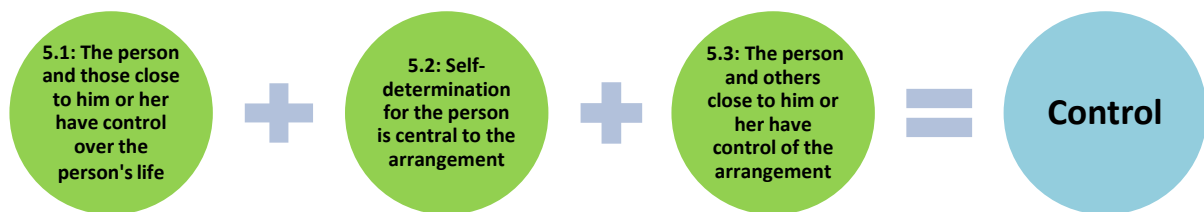
Evidence

- 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?
- What plans are there for addressing these transitions?
- What are the person's future plans/dreams/visions? How are these reflected in planning?
- Where is the person seen in two years time? Five years time?
- What are the things about this arrangement that work well for the person?
- What vulnerabilities and risks are there for the person and how are these safeguarded?
- Are there safeguards for things going wrong?
- How are arrangements reviewed? 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 where things are at and how they could be improved?
- Are these resources adequate? Why/why not?

Theme 5: Control

The person at the centre of the ISL arrangement, and others who are close to him or her, particularly family members, have a big influence on the arrangement. This may include hands-on management of the arrangement including its planning, development, and implementation.

'Control' has three Attributes:



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 substitute decision-making including formal means such as public advocacy.

The person and/or a legitimate decision-maker 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*, and *service business*, and *shared business*.

Where there is shared responsibility, partnership 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 about funding 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 have control over the person's life

Description

In daily life, the person, and others close to him or her, make decisions about, and control his or her lifestyle and personal affairs. This includes control over:

- Household matters.
- Relations with neighbours.
- Pursuing new ideas for a hobby or job.

The person is assisted in these areas as needed by others. They are not held back by rigid agency rules, regulations, or practices.

Indicators

- ✓ The person and those close to him or her, have 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

- To what extent does the person and those close to him or her, make decisions about and control his or her life?
- Can you describe an example of how the person and those close to him or her, controls his or her life?
- How is the running of the household decided?

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

Description

The arrangement emphasises and respects the person's capacities to determine his or her own affairs and make his or her own choices and decisions. People involved in the arrangement will know the person well, will assist the person to express his or her wishes, and will 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.
- ✓ 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 the arrangement?
- 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 others close to him or her have control of the arrangement

Description

Important parts of the arrangement will be decided directly by the person. If appropriate, this may also involve people in close relationships with the person. It may be in partnership with a service provider. Aspects may include the ownership or tenancy arrangements, funding processes, and support workers. Responsibilities are 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 appropriate people such as family, friends, or 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?
- What involvement and influence does the person, with appropriate involvement of those in close relationships, have over the arrangements and any changes?
- How have any disagreements about aspects of the arrangement been resolved?

Theme 6: Support

Support in an ISL arrangement comes from many people including family, friends, neighbours, advocates, and paid workers. These supports are both formal and informal. The ISL arrangement aims to balance formal and informal supports. The supports are flexible and may change as the person's needs change.

'Support' has two Attributes:



Description

The amount and type of support is flexible. It may change with the person's needs and wishes. Support includes:

- Direct support from formal workers.
- Informal support from friends, family, neighbours, and other people in the community.
- Indirect support such as through advocacy.
- Other people who may live within the support arrangement.
- Assistive technology.
- The location and nature of the physical environment that is part of the arrangement.

6.1 Supports are flexible and change as the person's needs change

Description

ISL arrangements use different types of support. Supports are adapted as required. The amount and type of support provided is flexible as possible. Contingency plans and back-up plans are put in place when the arrangement needs it. ISL arrangements change as the person's needs and wishes change. The arrangement will also change if the external environment changes. The ISL arrangement monitors the need for support changes. This includes changes in:

- The location and type of physical environment.
- People with whom the person may share accommodation.
- People who provide support.
- Any other aspects of the ISL arrangement.

The arrangement may operate under formal agreements such as regulations or funding requirements. These are adhered to creatively, acknowledging how they may undermine some ISL principles. Generally, rules and regulations are minimised.

Indicator

- ✓ Supports are flexible and change as the person's needs change.

Evidence

- How are supports arranged?
- How have needs changed and how has the arrangement responded to changes?
- What examples are there of how the support arrangement is flexible and creative?
- How has the arrangement maintained priority to the person's needs when formal requirements provide threats to that priority?
- How are formal requirements, such as regulation (e.g., occupational health and safety) and funding, managed?
- What rules are in place within the arrangement?
 - What happens when something unexpected occurs?
 - What back-up plans are in place, e.g., if a support person is unavailable?
 - How are changes in the person's routines catered for?
 - Are there enough supports to allow the ISL arrangement to be flexible?

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

Description

There is a variety of supports in place that suit the needs and wishes of the person. There is some informal, unpaid support. ISL arrangements see both paid and unpaid support as important. The arrangement is outward-looking. It actively seeks informal support and understands that this may be undermined by paid support.

Indicator

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

Evidence

- Who provides supports to the person inside and outside the home?
- What kinds of support are provided?
- What informal support is there?
- What paid support is there? How does it include or make a place for informal supports?
- How does this suit the needs and wishes of the person?
- What opportunities are provided for natural supports to exist and develop?
- How are people kept involved?

Theme 7: Thriving

ISL arrangements improve the person's lifestyle and wellbeing. They help the person to grow and develop. The person grows in independence, self-determination, skills, and valued roles in the home and community.

'Thriving' has three Attributes:



Description

This theme looks at some of the important personal outcomes of an ISL arrangement. ISL arrangements enable the 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 the ISL arrangement is focused on the needs and preferences of the person, this is more likely to result in the person's wellbeing and be reflected in a healthier, happier, and engaged person.

Valued social roles will come from engagement in the full range of roles and responsibilities associated with home and community. The arrangement will provide opportunities for experiences that will enable the person to develop relevant skills. There is 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 disability 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 the ISL arrangement that have contributed to those changes.

Key people involved in the planning stages of a new arrangement will have identified these outcomes as part of their vision for the person. This vision will provide an important reason for working towards an ISL arrangement over other models of support.

7.1 The person's lifestyle and wellbeing are better

Description

Lifestyle refers to the way a person spends their time day to day, week by week. It includes a person's interests, work, recreation, and relationships. 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 barriers to the person's wellbeing and will deal with these in ways that help the person to thrive.

Indicator

- ✓ The person's lifestyle and general wellbeing are better as a result of the arrangement.

Evidence

- How has this arrangement influenced the person's lifestyle?
- How has this arrangement influenced the person's wellbeing?

7.2 The person has valued roles

Description

Because of the support and opportunities provided in an ISL arrangement, the person will develop new and existing valued social roles at home and in the community. 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.

Valued roles at home include:

- Home owner or renter.
- Partner or friend.
- Neighbour.
- House-mate.
- Host.
- Cook.
- Decorator.
- Gardener.

Valued community roles include:

- Friend.
- Employee.
- Work-mate.
- Helper.

- Worker.
- Student.
- Companion.
- Consumer.
- Volunteer.
- Traveller.

Indicators

- ✓ The arrangement has helped the person to gain and keep valued roles at home and in the community.
- ✓ The key people in the arrangement know that valued roles are important and are determined to protect progress made.

Evidence

- Why are valued social roles important?
- What are the strengths and capacities of the person?
- What sorts of valued roles does the person have around the home and 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?
- How does the arrangement help the person to keep these roles going?
- What opportunities have been created for the person to develop and experience new roles in the home and community?

7.3 There are many opportunities for growth and development

Description

Having one's own home brings many opportunities for personal growth and development. The ISL arrangement will make the most of this. It will fully involve the person in all aspects of planning and actions to do with household roles and responsibilities. It will involve the person in typical neighbourhood and community roles. Support needs will be met in a way that encourages the person to accept as much responsibility as possible. The arrangement will ensure the approach is developmental and not over-protective of the person.

Indicator

- ✓ The arrangement provides many opportunities for the person's growth and development.

Evidence

- What opportunities are there for the person to learn, grow, and develop in the home? How involved is the person in household duties?
- What opportunities are there for the person to learn, grow, and develop outside 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 a year's time?
- What expectations are there for the person's development in five year's time?
- What assistive technology is provided to support the person to participate at home and in the community?

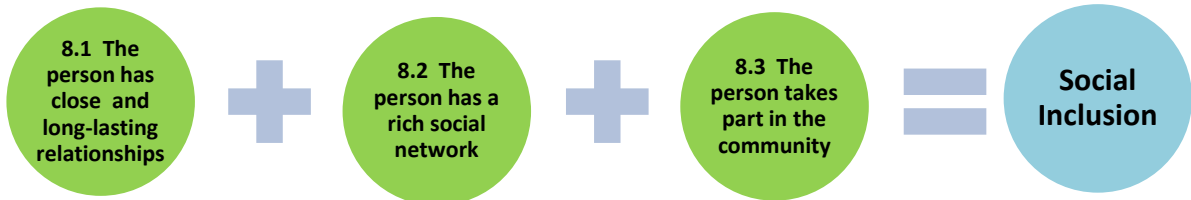
Theme 8: Social Inclusion

ISL arrangements build wider community inclusion in two ways:

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

For the person in the ISL arrangement, this means being involved in the community and being less isolated. The person is socially included. A key way this happens is through having a range of relationships with people. Relationships provide the necessary opportunities to participate and make connections with the community.

'Social Inclusion' has three Attributes:



Description

This theme looks at how the ISL arrangement helps the person to be included in the community. Social inclusion means:

- Being involved in community life, particularly through relationships with people.
- Spending time physically in community settings.
- Taking part in those settings through relationships and activities.

It is about the valued roles the person has by being a valued member of different communities.

8.1 The person has close and long-lasting relationships

Description

The ISL arrangement encourages and supports the person in his or her relationships with others that are close develop over time. The leaders know that these relationships are important. People supporting the arrangement 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.

Evidence

- With whom does the person have relationships?
- Which of these relationships are close and long-lasting?
- Why are these relationships important?
- How does the arrangement encourage and support the relationships?

8.2 The person has a rich social network

Description

Social networks are made up of the person's relationships. Relationships vary in terms of closeness. For example: from family and friends through to casual acquaintances. They also vary in where they occur. For example: in the family, the home, at school, at work, in social activities. This creates the link between relationships and social inclusion. A person in an ISL arrangement will have developing social networks both within the home and outside it. 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 people in the person's life.

Indicator

- ✓ The person has a rich and varied social network through relationships in various places that are helped and supported by the arrangement.

Evidence

- Who are the people in the person's social networks, e.g., family, friends, and acquaintances?
- Where are these relationships located?
- 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

Description

ISL arrangements enable the person to take part in a wide variety of community activities. Participation in the community provides opportunities for the person to develop valued social roles and to find new relationships. The person takes part in different communities: the neighbourhood, work, recreation, and education. Participation reflects the person's interests, likes, and capacities.

Indicator

- ✓ The arrangement creates opportunities for the person to take part in various community settings.

Evidence

- In which community settings does the person take part?
- 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?
- How does the arrangement support these involvements?

RESOURCES

The Centre for Research into Disability and Society at Curtin University has progressed the ISL Framework and Manual since 2007. The following publications may be of interest:

- Cocks, E. & Boaden, R. 2009. *A guide to developing personalised residential supports (PRS) for adults with developmental disabilities and their families*. Perth: Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, School of Occupation Therapy and Social Work, Curtin University. Available from: [http://otsw.curtin.edu.au/local/docs/Best Practice in Individual Needs Planning Report.pdf](http://otsw.curtin.edu.au/local/docs/Best_Practice_in_Individual_Needs_Planning_Report.pdf).
- Cocks, E. & Boaden, R. 2011. A quality framework for personalised residential supports for adults with developmental disabilities. *Journal of Intellectual Disability Research*, 55(8), pp. 720-731.

Additional publications and information may be made available at Centre for Research into Disability and Society's website: <http://otsw.curtin.edu.au/research/reports.cfm>.

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*. Perth: Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, School of Occupation Therapy and Social Work, Curtin University. Available from: [http://otsw.curtin.edu.au/local/docs/Best Practice in Individual Needs Planning Report.pdf](http://otsw.curtin.edu.au/local/docs/Best_Practice_in_Individual_Needs_Planning_Report.pdf).

'Independent Living' is a theme for the Academic Network of European Disability Experts (ANED). ANED has published National Report for different European countries which may be useful for some. Their reports and additional information can be found at: <http://www.disability-europe.net/theme/independent-living>.

We are continuing to developing the ISL Framework and Manual and are welcoming 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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