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Family &  
Community Services

# ILSI Training Manual

## Let the journey begin



November 2012

## **About this manual**

The Independent Living Skills Initiative (ILSI) training manual has been produced for the Program Coordinators, Facilitators and support workers who will deliver the program.

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# Independent Living Skills Initiative

**[www.ilsinet.au](http://www.ilsinet.au)**

## Table of Contents

	<b>Page</b>
Chapter One: Introduction	4
Chapter Two: The ILSI Model	12
Chapter Three: The ILSI team	23
Chapter Four: Person centred planning	36
Chapter Five: Working with families	49
Chapter Six: Making connections	64
Chapter Seven: Circles of support	79
Chapter Eight: Independent living skills	101
Chapter Nine: Making the transition	121
Chapter Ten: References and Appendices	129



# Chapter One: Introduction

## Introduction

This chapter introduces the Independent Living Skills Initiative (ILSI) and provides general information about:

- the Independent Living Skills Initiative
- person centred planning
- the development of the ILSI model
- background information, including:
  - the NSW government's commitment to Stronger Together (ADHC, 2006; 2008)
  - the *Up, Up and Away* program (Stevenson, et al., 2009)
- the purpose of the ILSI training manual.

### The Independent Living Skills Initiative

The ILSI service model was developed in partnership between the Department of Family and Community Services, Ageing Disability and Home Care (ADHC) and Down Syndrome New South Wales (DS NSW) in collaboration and consultation with two service providers, UnitingCare Disability (Metro South) and House with No Steps (Hunter).

The Independent Living Skills Initiative (ILSI) is a service response designed to enable people with a disability to live an inclusive life in the community. The ILSI model supports people with low to moderate support needs to transition from being solely supported by family, by teaching independent living skills, whilst either continuing to live at home or moving to an accommodation option in their community with drop-in support.



The development phase of ILSI targeted ageing parent carers, though the model has been developed with widespread applicability across a range of transition points, such as the Supported Living Fund, Leaving Care Program, post-school programs, and individuals wishing to transition from supported accommodation to more independent living. It also applies to those living with drop-in support who wish to increase their level of independence.

The program seeks to maintain or broaden people's long-term accommodation options in the community. ILSI supports include a focus on person centred planning, intensive living skills development, carer support and assistance in developing effective support networks.

The primary objective of ILSI is to help people with a disability make the transition from being dependant on others to living more independently within their community, with support from formal and informal networks.

We help people with disability move toward independent living within their community by developing living skills and building support networks. In this program, people with a disability are empowered to lead dignified lives in the community, with levels of community support that will allow them to fulfil their potential.

In the program, support staff use person centred planning to assist the person and their family to plan their day-to-day life, develop support networks and establish meaningful connections with their community. These ongoing supports within the community will be both formal and informal.

## Person centred planning

Person centred planning is about listening to the person with a disability and understanding their desire to be valued, and to contribute and belong to society. We then use this information to create a plan that will help each person to achieve these outcomes. Typically, person centred planning:

- keeps the person as its focus
- listens to the person
- takes the person's individual preferences into account
- focuses on the person's strengths
- looks beyond the services that are currently available from a particular service provider.

Person centred planning is not a new approach. Its practice, however, challenges us to consider the ways it can be put into place in a practical way and how it can be embedded in all aspects of an organisation's management and objectives.

The importance of person centred planning is central to ILSI. In ILSI, we are dealing with the transition stages in a person's life, such as when they are seeking to live more independently and are likely to move from the family home into community-based accommodation. Listening to the person and understanding their needs and preferences is essential during this time.





## Background

The ILSI program was developed in response to a change of focus in disability service towards a more flexible, person centred approach to accommodation supports. It also aims to provide a range of accommodation options that include early intervention and prevention as opposed to a crisis-driven accommodation system. The ILSI program was informed by the NSW Government's introduction of *Stronger Together* (ADHC, 2006) and the *Up, Up and Away* program initiated by DS NSW. The model is based on a combination of evidence-based research, service provider experience and knowledge gained from the action research component of the *Up, Up and Away* program (Stevenson, et al., 2009).

## Stronger Together

In 2006, in recognition of the need for change in the disability service system, the NSW Government launched *Stronger Together: A new direction for disability services in NSW 2006-2016* (ADHC, 2006). The Stronger Together report card (ADHC, 2008) stated change was necessary in a number of areas:

- The demand for services was increasing each year. More people with a disability live with their families in the community meaning that they, and their carers, need more support. There was a need to provide more services and also to find ways to provide services more efficiently.
- Services needed to be designed around the needs and circumstances of individuals and families, instead of a 'one size fits all' approach.
- The service system needed to be more flexible and responsive to people's changing needs as they moved through their life stages. It also needed to become more transparent and predictable with clearer entry and exit points.
- Accommodation options needed to expand to recognise people's life stages and the possibility that they might have differing accommodation needs over the course of their lives.
- There was need for innovation and continuous improvement in the way we support people with a disability in the community.

## Up, Up and Away

The *Up, Up and Away* program is run by DS NSW. During the initial consultation stages of the program, DS NSW staff asked young people with Down syndrome what it was they wanted in their lives. Many answered that they wanted to get a job, move out of home, see friends and help others. In other words they wanted to do the things their peers were doing.

In 2005, funding was granted to set up an action research project. Facilitators (later to be known as 'team coaches') worked with up to 16 young people and their families over three years (eight in the first year and eight in the second year) with the aim of supporting them to build circles of support to assist them in working towards and, perhaps, achieving some of their life goals.

DS NSW produced a DVD documenting the *Up, Up and Away* program. It is available free-of-charge to view online on Vimeo. See real people working with a Facilitator and a circle of support to achieve their goals and realise their dreams.

*Source: Up, Up and Away DVD (2009)*

### **ILSI builds on the Up, Up and Away model**

The ILSI model builds on the *Up, Up and Away* model and supports people with a disability to gain greater independence as they move from family-based living arrangements to more independent living arrangements. ILSI is comparable to *Up, Up and Away* in that the model is based on the following four core components:

1. the individual
2. families and carers
3. a Facilitator
4. formal and informal supports.

Each of these components has an important role. In the following chapter we will learn more about the function of each component and the relevant legislative framework.

The ILSI model is designed to provide:

- The development of a plan that assists people with individual goals and aspirations (person centred planning).
- Initial intensive skills development and training to assist with the transition to more independent living.
- Support to develop the person with a disability's own effective support networks (e.g. a circle of support).



### **The purpose of the ILSI training manual**

The purpose of the ILSI training manual is to familiarise Program Coordinators, Facilitators and support workers with how the program operates. It contains information about the relevant legislative and policy framework, including:

- human rights
- social justice
- person centred thinking and planning.

Written in an accessible format, it is designed to provide each ILSI team member with an appreciation of the knowledge, skills and expertise that will be expected of them in their role. Information on the following is included:

- the ILSI model
- the ILSI team
- person centred thinking
- working with families
- making connections in the community
- circles of support
- risk assessment
- reporting requirements
- disability rights, issues and choices
- “train the trainer” in supported living life skills development
- transition planning.

The manual has been designed to be read either as a whole or as stand-alone chapters.

Reference is made throughout to the current target group of ageing parent carers. However, the manual can be read in the context of potential for a broad range of target groups and applications within disability services.

For more information about ILSI please refer to:

- ADHC ILSI Fact sheet for individuals and their family/carer (Appendix 1)
- ADHC ILSI Fact sheet for Service Providers (Appendix 2)
- ILSI website [www.ilsinet.au](http://www.ilsinet.au).

### **Key points in Chapter One**

- The Independent Living Skills Initiative (ILSI) aims to help people with a disability with low to moderate support needs who have ageing carers and who have the goal of living in community-based accommodation.
- The transition process is supported through person centred planning, intensive living skills development, guidance and training in developing effective support networks, including circles of support.



## Chapter Two: The ILSI model

## The ILSI model

This chapter provides information on:

- The legislative and social context of the ILSI program
- The roles of each of the four core components of the ILSI model including:
  1. the individual
  2. families and carers
  3. a Facilitator
  4. formal and informal supports.

### Legislative and Social Context

#### **The development of a social model of disability**

The social model of disability defines and views disability in a strengths-based approach. Central to this view is the understanding that a person with a disability is a 'whole' and valuable person, equal to any other.

According to the social model of disability, it is not having a physical and/or intellectual impairment that disables a person but the social and economic exclusions that people with impairment face in society.

#### **The strength of the social model**

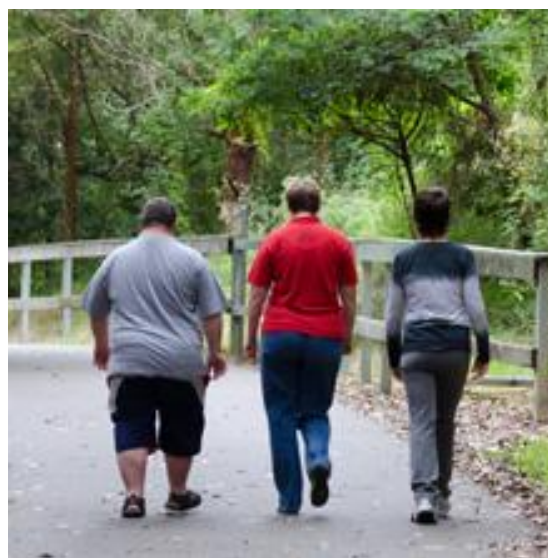
The strength of the social model is that it works to restore dignity and value to people with impairments. The concept of 'disability' is placed in the hands of society. It is society that needs to adapt to include people with a disability as valued members of the community.

Working with the ILSI program, you will be expected to be familiar with the social model of disability. In your work you will need to understand that your task is to focus on the growth and expansion of opportunities that encourage people with a disability to take part in the life of the community.

## **The United Nations Convention of the Rights of Persons with Disabilities (United Nations, 2008)**

The United Nations Convention of the Rights of Persons with Disabilities (United Nations, 2008) is an international document that outlines the way that people with disabilities can expect to be treated. It's important to note that this document is not part of Australian law or legislation. Instead, Australia has ratified the Convention, meaning that the Australian Government has signed and agreed with the principles in the document. The guiding principles emphasise respect for:

- dignity
- autonomy
- independence of persons
- non-discrimination
- full participation and inclusion in society
- respect for difference and acceptance of human diversity
- equality of opportunity
- accessibility
- gender equality
- respect for the right of children with disabilities to preserve their identities and for their 'evolving capacities' to be respected also.



## **The Disability Services Act, 1993**

The ILSI model uses a person centred approach that is governed by the *Disability Services Act, 1993* (New South Wales Government, 1993).

*“The Objects of the Act require service providers to enable persons with a disability to maximise their potential as citizens, and to increase their independence, employment opportunities and integration into the community. Person centred planning approaches support the Objects of the Act by maintaining the person at the centre of lifestyle planning.”*

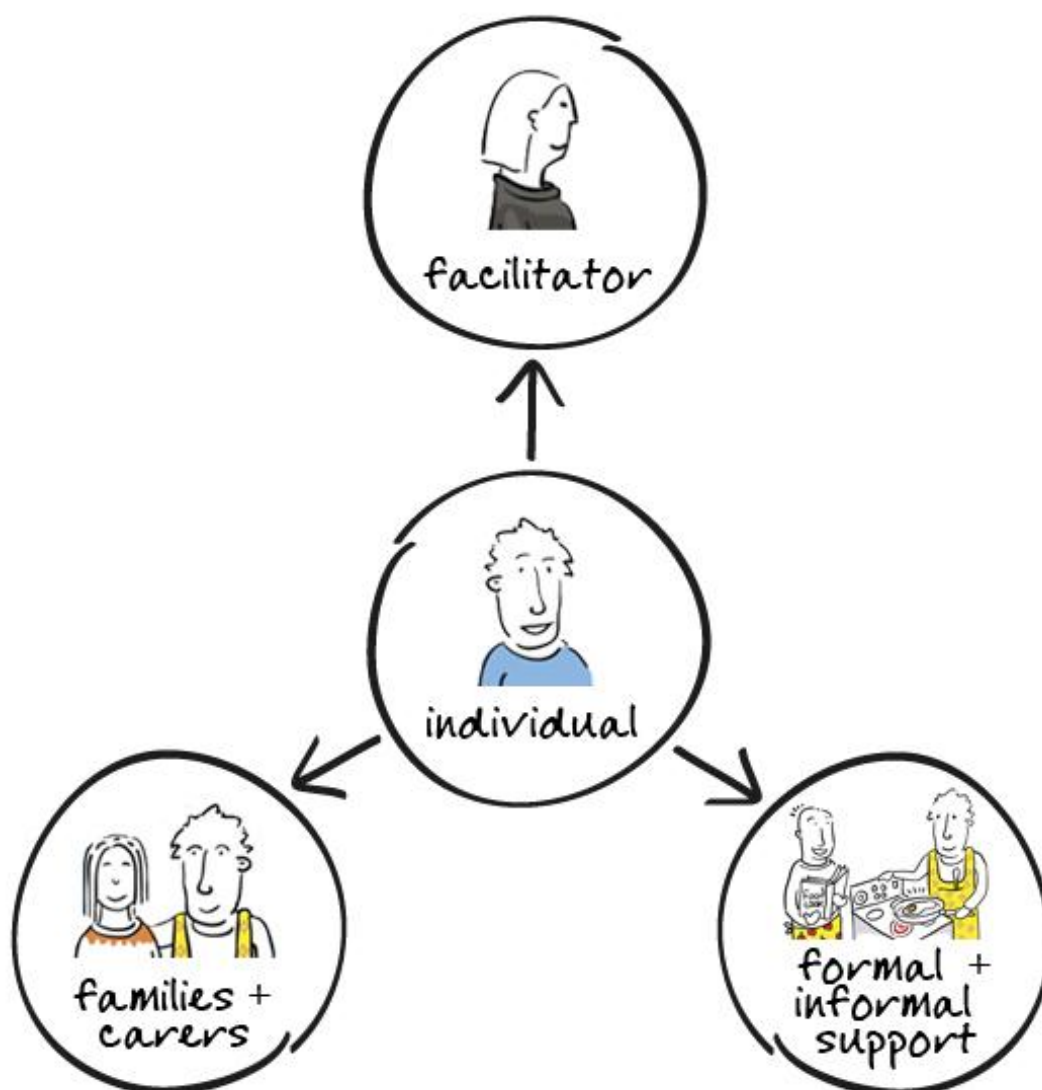
*Source: ADHC (2011)*

ILSI recognises the central importance of person centred planning, especially during the transition stages in a person's life, such as when they are seeking to live more independently and are likely to move from the family home into community-based accommodation.

### The key components of the ILSI model

The four key components of the ILSI model are:

1. the individual
2. families and carers
3. a Facilitator
4. formal and informal supports.





As a Facilitator it is expected you will be aware and understand the role of each of these components. This knowledge will help you in your role and build your understanding of how the model works.

## **Individual roles within each component**

### **Individual**

The ILSI program is suitable for people who:

- Have a disability with low to moderate support needs.
- Are between 18-64 years of age.<sup>1</sup>
- Have the capacity and potential to live more independently in the community following an initial period of intense training and skills development.
- Require no more than 35 hours per week of staff support and do not require overnight support (the amount of support provided will be decided based upon review of the individual's existing skills and may reduce over time).
- Have identified independent living as a goal or aspiration – usually with the support of their family to achieve this goal. The individual will have also identified access to suitable stable housing options such as the family home, a rented apartment or shared accommodation with a sibling or flat mate.

### **Families and carers**

Suitable families and carers are:

- Committed to working with the support provider/s to set the individual's community-based living goals and future aspirations.
- Willing to support the development of intentional connections, including the circle of support.

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<sup>1</sup> In the development phase of ILSI, participants were required to have an ageing carer. This transition model can now be applied to a range of target groups.

## Facilitator

The Facilitator is the primary formal support person employed by the organisation. There is information about recruiting Facilitators in Chapter Three.

As a Facilitator your role is to assist the individual and their family/carer develop a person centred plan that focuses on:

- personal goals for independent living
- learning independent living skills
- developing support networks
- building meaningful connections with their community.

It is expected in this role you will have:

- good communication and interpersonal skills
- experience with working with families and people with intellectual disabilities
- the capacity to be creative and show initiative
- the capacity to self-reflect
- planning skills
- an ability to work to plans and timescales and record work effectively
- an ability to work in a team environment and take part in group training sessions and evaluations.

It is also essential you have access to the skills training and resources required to achieve the objectives of the ILSI program. It is therefore recommended that you undertake training in:

- person centred thinking
- building relationships with individual and family/carers
- circles of support
- community connection
- risk assessment
- reporting requirements
- disability rights, issues and choices
- 'train the trainer' in supported living life skills development.



Because the overarching principle of the ILSI program is a person centred approach, the Facilitator will also be committed to:

- Supporting people to achieve their goals and aspirations by building on their strengths and support networks.
- Helping people to move into community-based accommodation.
- Tailoring supports to the individual, one person at a time.
- Focusing on what makes a good life for each person.
- Actively supporting social inclusion and contribution.
- Providing a mix of informal and formal supports.
- Being flexible and responsive to changing needs and situations.
- Ensuring families are supported as people move through the process.

### **Formal and informal supports**

Organisations will provide formal support to the individual and their family/carer. This support will be provided by Facilitators and support workers and will be capped at 35 hours per week. Formal support will include:

- Assistance in reviewing potential independent living options.
- Developmental work with the person on life skills, such as travel training, money and cooking skills.
- Support with the building of a stable support network in the person's life, including circles of support.
- The use of person centred tools to build on the person's strengths so that they can achieve their goals.
- Developing community connections.

The Facilitator will assist the Individual to develop their informal support, through a circle of support. Informal support may come from such persons as:

- family members
- friends and neighbours
- work colleagues
- community members such as a librarian, pharmacist or church members
- social acquaintances such as sporting coaches, teachers and club members.

## Community connectedness

To better understand the aims of ILSI and your role in the program, it can be useful to put yourself in the shoes of a person with a disability and their family and see ILSI through their eyes. For example, families attracted to the program are likely to answer the following questions positively:



Would you like help to plan your life, to achieve your goals and your dreams?

Do you and your parents or carer want to start planning now for your longer term living arrangements? Would you like to live more independently? Perhaps in your own home, shared accommodation or a granny flat?

*Source: ILSI (2011)*

## Case study: Kevin

**Person:** Kevin

**Facilitator:** Ben

**Hours of support:** eight hours with Ben (Facilitator). Up to 27 hours with support worker (dependent on plan).

**Background:** Kevin is a 35-year-old man who has an intellectual disability and lives with his 68-year-old mother Brenda. Kevin has two brothers that he has regular contact with, as well as many nephews and nieces. Family is important to Kevin and he has photos of his family all throughout his home. Kevin works three days a week in packaging. He is also part of a social group and goes on outings with this group on a regular basis. Kevin applied to ILSI as his mother is worried about what will happen to him when she is no longer able to care for him, and she wants him to have the opportunity to learn skills so that he may be more independent and eventually live by himself without family support.

**Circle of support:** Kevin has not yet developed a circle of support, but Ben, his Facilitator, is in the process of discussing this with him and his mother, and making a list of important people Kevin wants to ask to be in his circle.

**Accommodation plans:** Kevin lives in a granny flat at the back of his mother's house, which has its own kitchenette, bathroom, laundry, bedroom and living room. The flat also has external access from the backyard. The plan is for Kevin to remain living in his flat but to be less reliant on his mother for support.

## Case study: Miranda

**Person:** Miranda

**Facilitator:** Mary

**Hours of support:** 12 hours from Mary, Miranda's Facilitator. Up to 23 hours from support workers (to be determined).

**Background:** Miranda is a 33-year-old woman who has an intellectual disability and currently lives at home with her father, stepmother and brothers. Miranda's stepmother Stacey is her primary carer, as Miranda does not get on well with her father. Miranda works four and a half days a week in packaging. Miranda also attends a social drama group and a dance group on a regular basis. Miranda was referred to ILSI, as she is very keen to move out of home, and live in the community where she can have more freedom to make choices and live the way she wants to live.

**Circle of support:** Miranda does not have a circle of support at this time, and Mary will begin working with her in order to develop a circle of support. Miranda has a number of people she has already identified as important to her that she may want to ask to be in her circle.

**Accommodation plans:** Miranda wants to move out into public housing, but at this time is looking at whether she wants to live alone or with her best friend. Mary is working with Stacey as to whether this is a possibility, as Miranda's friend has never spoken with her family about it. No timeframe for a move has yet been set, and Mary is in the process of working with case management on application forms for public housing.

Feedback from ILSI Facilitators reminds us that community connectedness is integral to social inclusion. Facilitators constantly tell us how important it is to build relationships between people with disabilities and the communities in which they live. This provides people with the opportunities they need to lead active

and fulfilling lives. Formal and informal supports will be developed according to the needs of each person, their family and accommodation options chosen.

## Key points from Chapter Two

- The four key components of the ILSI model are the:
  1. the individual
  2. families and carers
  3. a Facilitator
  4. formal and informal supports.
- ILSI is part of the NSW Government's *Stronger Together* commitment.
- The social model of disability helps us use a strengths-based approach in working with people with a disability.
- Your role as a Facilitator in the ILSI model is to support individuals with a disability to live an inclusive life in the community, with support and skill development to enable increased independence.

## Questions for reflection

1. In what ways does the social model of disability change your understanding of your role?
2. What are the four main components and roles within the ILSI model?
3. What are the main features of a person centred approach to working with a person who has a disability?



## Chapter Three: The ILSI team



## The ILSI team

This chapter provides important background information on issues relating to the recruitment, care and support of staff. It includes:

1. the role and recruitment of the ILSI Program Coordinator
2. the role and recruitment of Facilitators
3. the Facilitator: essential and desirable qualities, skills and experience
4. interviewing candidates for the position of Facilitator
5. the ratio of Facilitators to people
6. matching Facilitators with people
7. supervision
8. team meetings.



### The Program Coordinator

The Program Coordinator is responsible for the daily operations and decision making to support the provision of the ILSI program.

#### Recruitment of Program Coordinator

For many organisations, the selection of the ILSI Program Coordinator will be an important first step. The selection of the Program Coordinator will establish and promote an understanding of the aims and objectives of the ILSI program within the organisation. It is desirable that the chosen Program Coordinator has commitment and enthusiasm, and is capable of transmitting and implementing the philosophy of a person centred approach to service provision. In addition, the Program Coordinator also needs to have excellent management, communication and recruitment skills.

### The Facilitator

The Facilitator will be the formal support person provided by the organisation. The Facilitator will assist the individual and their family/carer to plan their life, learn independent living skills and develop their support networks and build meaningful connections with their community.

## **Recruitment of Facilitators**

Program Coordinators will be expected to recruit Facilitators and support workers based on the number of ILSI places available. When selecting potential candidates, it is important to keep in mind that Facilitators are the primary formal support person for the person and their family. A large part of the Facilitator's role will be building a relationship with the person and their family. Facilitators will also be expected to work with any support workers and monitor the progress of the person's plan, goals and developmental work.

You'll find a job description template for recruiting Facilitators at Appendix 3.

## **Essential qualities, skills and experience**

- **Experience in working with families**

The theory and structure of ILSI is quite easy to grasp. However, the reality of working with people and their families in their unique circumstances is where the core challenges lie. People and families in the ILSI program are going to undergo a process of change that will be challenging on both a practical and emotional level for all concerned. Working in this context requires sensitivity, adaptability, an ability to foster discussion in groups, and ensuring shared decision-making. While some skills can be developed, not everyone is suited to or will enjoy this style of working. For this reason candidates must have some experience in working directly with families and must appreciate the complexity of the field.

- **Strong oral communication and listening skills**

Being able to speak clearly and confidently is essential. Equally important are good listening and observation skills. Patience is also required, as Facilitators will need to work at a pace that suits the needs of the individual and their family.

- **Literacy and IT skills**

Good literacy skills are needed to manage the administrative aspects of the program, including recording of contacts and writing plans. Being able to write clearly is essential. Competence in IT, including word processing, email, the internet and basic presentation software is essential, as these are key tools of the ILSI program.

- **Good organisational skills**

A lot of the work undertaken in ILSI will be spontaneous. It won't be routine or prescriptive. There will be a need to liaise with a wide variety of people and to organise meetings and visits to different places within the community. A



confident, conscientious and organised approach is therefore required to drive the transition process and generate trust on the part of the person and their family.

- **Character**

An easy-going, honest character with a good sense of humour lends itself to this type of work.

- **Willingness to undergo appropriate background checks**

Your organisation will have clear procedures for the employment of staff which will include background checks on staff. Because people with a disability are more vulnerable, it is extremely important that thorough background checks are undertaken in respect of all potential staff before they are employed. This includes checking reliable references and completing police checks.

## **Desirable qualities, skills and experience**

- **Experience working with people with a disability**

Feedback from ILSI staff tells us that, although it is not essential, prior experience working with people with a disability in a community setting is an advantage.

- **Experience liaising and networking with a variety of agencies**

- **An understanding of the services and supports available to people with a disability in the local community and within NSW**

- **Existing knowledge of ‘duty of care’ and professional ethics**

In the ILSI program, creative work needs to take place within a clear and expressed framework of professional codes and working practices for supporting the person, their family and any staff members.

## **Interviewing candidates for the position of Facilitator**

The interview process provides the organisation with the opportunity to evaluate potential candidates for the position of Facilitator. The interview itself is an opportunity to explore a candidate’s ability for thoughtful and reflective responses to planning and problem solving. Not everyone responds well to answering questions ‘on the spot’ as is often the case in classic interviews. One useful method is to supply a practice scenario and a list of questions approximately 30 minutes prior to the interview. Giving the candidate time to reflect and think will give a more authentic picture of a candidate’s experience and abilities. Carefully considered decision making is needed by Facilitators rather than hasty responses.

You will be required to do this within the requirements of your organisation’s policy and procedures manuals. It is also good practice to include people with a disability on the interview panel, as they are representative of the service user group of ILSI. Perspectives of parent representatives are helpful too.

During the interview process it is important you outline the basic training required. This includes:

- person centred thinking
- building relationships with people and their family and carers
- circles of support
- community connection
- risk assessment
- reporting requirements
- disability rights, issues and choices
- “train the trainer” in supported living life skills development.



### **Facilitator/individual ratio**

As already mentioned, we recommend organisations employ one Facilitator per two or three people. The reason we suggest this ratio is because of the time it takes to build the required trust and rapport with each person and their family. Recruitment of a number of Facilitators, each working with fewer families, is preferable to one Facilitator working with a large number of families. The existence of a small Facilitator ‘team’ within the organisation is also crucial in embedding a new culture and providing opportunities for team support.

### **Matching Facilitators with people**

People differ in the way they live their lives and it is important this diversity is respected and accommodated when it comes to matching Facilitators with individuals. Issues which will need to be addressed include, but are not limited to the:

- Individual characteristics and the skills which are required, such as the use of sign language.
- The type of support that an individual needs.
- Developmental work needed, such as travel training or money skills.
- Geographical location.
- Compatibility, such as cultural considerations and shared interests.

We’ve provided a matching tool at Appendix 4.

## ILSI in practice

Below is an example of organisational allocation of staff support for five funded ILSI places. Please note: because many organisations will already have other accommodation programs, the example below includes only a part-time ILSI Program Coordinator.

**1. Program Coordinator** – part time – 17.5 hours per week (from a base of 35 hours per week). The Program Coordinator will be responsible for supervision, support and training of the Facilitators and support workers employed and/or working in the ILSI program.

The Program Coordinator may also provide direct support to individuals and families/carers as required. The Program Coordinator will also have responsibility for ensuring that each individual has a person centred plan.

**2. Two Facilitators**, each working 35 hours per week. This is a total of 70 hours per week, based on a 35 hour week. One Facilitator will work with two individuals and their family/carers and the other Facilitator with three individuals and their family/carers.

Each Facilitator will work at least 24 hours per week directly (face to face) with their people. These hours may increase depending on travel time required.

The facilitation hours include time for:

- person centred planning development with people and their family/carers
- developing a circle of support
- implementing person centred planning goals, including developing living skills.

These hours are provided Monday to Friday between the hours of 7 am and 8 pm and may change weekly depending on each person's needs.

Each Facilitator will timetable at least six hours per week (hours will vary with individual load) for support facilitation such as writing up notes, program preparation for skills development training, person centred planning documentation, and engaging and liaising with support workers.

For individuals who require additional support hours to those provided by Facilitators (that is up to 35 hours per week), support workers will be engaged to provide this support. It is expected that the service will provide a nominated amount of emergency response hours per week (which will accumulate).

**Support workers** will be used on a casual basis at least initially while the individuals support needs are determined and through the living skills training period. The Facilitators will determine the support worker hours required based on the individual's person centred plan and will engage and liaise with support workers to implement the goals. Support workers will be used on weekends – and the budget and hours for this support will be organised by the Facilitator.

## Supervision

Regular supervision fosters understanding, accountability, staff care and development, and good planning. It is generally a hallmark of an ethical and healthy workplace. Supervision should be offered to all staff regardless of position or hours worked. ILSI Program Coordinators also need regular supervision. The following is a guide to supervision aimed at giving a basic framework and principles.



**Please note:** This format is different from clinical supervision, for example, where a psychologist or other therapist attends supervision with an experienced professional from the same field to discuss individual cases and practice in-depth, gain advice and identify issues which may be affecting them personally.

## **The purpose of supervision within ILSI**

1. To ensure the ILSI Project Coordinator is informed and has a general overview of each Facilitator's work and well-being in their role.
2. To discuss any workload issues.
3. To offer a safe space where, on a regular basis, Facilitators can receive support when they are struggling. Everyone has times when they are particularly challenged by life or are feeling vulnerable.
4. To ensure the accountability of each Facilitator to the Program Coordinator and the Program Coordinator to the Facilitator. For example, if a Facilitator has a significant and ongoing concern about any aspect of their work or the working environment, they have a professional duty to report this to their Program Coordinator. This can include feelings of stress, being over-stretched or problems within the team. This gives the Program Coordinator the opportunity to action a timely response. Likewise, if the Program Coordinator has significant concerns about the Facilitator's conduct or performance, the Program Coordinator has a duty to address this at an early stage without necessarily moving into a disciplinary framework, which can be distressing and counter-productive in workplaces. While some practice problems are significant, often Facilitators may just need to express their feelings and be heard in a safe space.
5. To address issues of ethical practice and development needs, such as training needs, and make plans to address these needs.
6. For staff to receive constructive feedback about their work.



### **Supervision guidelines**

It is recommended you follow your organisation's Human Resources (HR) policy and procedure manuals in relation to supervision. It is also suggested you have a broad standing agenda for supervision termed a 'Supervision Agreement'. This way both parties know what to expect in the supervision session. This normally consists of some of the previous points. An agreement should be drawn up at the first session and signed by the Facilitator and ILSI Project Coordinator. Both of you can keep a copy of this agreement and this can be reviewed and re-written, via negotiation between both parties, at any stage if required. A suggested template has been provided at Appendix 5.

### **Frequency and duration of supervision**

Supervision is usually set to occur on a regular basis at least every four to six weeks. Any longer between supervision sessions means that the ILSI Program Coordinator can get 'out of touch' with the Facilitator and problems can build up. Supervision is usually scheduled for one to one-and-a-half hours and both parties take responsibility for covering relevant topics. Facilitators should be encouraged to prepare for the session so that everything they want to cover is dealt with at the time.

### **Where to hold a supervision meeting**

It is important that supervision occurs in a relaxed setting where you can talk without disruptions and confidentiality can be maintained.

### **Recording a supervision meeting**

We recommend you follow your organisation's HR policies and procedure manuals for recording a supervision meeting. We also suggest the supervision is recorded by the Program Coordinator. The recording does not need to be too detailed – a brief summary (bullet points) will suffice. The document can then be checked and signed by both parties. A copy will be placed in the Facilitator's confidential file and the Facilitator is given a copy to keep.

**Please note:** Supervision records are highly confidential and must only be viewed by the ILSI Program Coordinator concerned, unless the Facilitator gives explicit permission otherwise, or a grievance or disciplinary process is invoked. This is to foster the establishment of mutual trust.

### ILSI team meetings

A key feature of staff support in ILSI is regular monthly team meetings with the Team Voice (this is usually an ILSI individual and is discussed further in Chapter Six) and the Program Coordinator. Sometimes, being a Facilitator can be stressful and isolating. The sense of belonging to a team is important for staff morale and support. In *Up, Up and Away*, Facilitators reported that they enjoyed their initial training but there was



no substitute for team support in the context of their work, especially while getting to know the individual and their family and being able to talk to the coordinator and the rest of the team about their experiences and ideas.

### Some pointers for conduct of team meetings

1. Decide on an agenda for the team meeting and keep the time to one to one-and-a-half hours.
2. Go around the group and listen to an update of each Facilitator's activity with the people they are working with. Make sure everyone takes a turn at talking, uninterrupted, about their work. Allow some time for sharing and the exchange of ideas.


3. Schedule other items for the agenda. These could include discussion about team training or information sharing. Talk openly about anything that impacts upon or concerns the whole team. Teams perform better when they feel well informed and valued. Sometimes team meetings can be extended to include training videos or presentations by invited speakers. Occasional team development days are generally well received.
4. Minute the meeting and make sure any plans for action are recorded as needing to be reviewed at the next team meeting.
5. Promote an atmosphere of continuous learning in the team. No question is a dumb question. No one has all the answers.
6. Promote an appreciation of the fact that all members of the Facilitator team are of equal value and each has unique gifts to offer.
7. Remember to organise some social occasions for the team to enjoy leisure time together outside of work.

### **Key points from Chapter Three**

- A successful ILSI team is one in which all the members have the aptitude to do their job, receive appropriate training and are positively engaged with the individuals and families with whom they are working.
- It is vital all ILSI staff feel valued and cared for by their managers and employers.
- If the above criteria are met, the chances of retaining an ILSI team who are continuously developing their skills and providing a service of excellence are greatly enhanced.

## **Questions for reflection for those involved in staff recruitment and supervision**

1. Think of a time in the past when you have dealt with a challenging personal situation, perhaps a situation that made you feel vulnerable. What qualities would you look for in a person who might assist you in dealing with that difficult situation?
2. Write a short scenario, perhaps based on a difficult issue you have dealt with yourself professionally. Think of some questions that might arise from this scenario in terms of practice. What might be good practice or poor practice?
3. What is the aim and purpose of staff supervision?
4. What might you find challenging about offering supervision to staff?
5. How might you deal with those challenges?



## Chapter Four: Person centred planning

## Person centred planning

The ILSI process draws on person centred approaches and tools in order to help individuals reach their goals and make the transition into more independent living. A significant strength of the ILSI model is that Facilitators work in a way that is not driven by crisis. There is time and space for the person, and their family and carers, to make plans and move on in a calm and well-prepared way. It is important to remember that the program is flexible in terms of timeframe and the methods used to achieve outcomes. This chapter looks at the initiation of the transition process, focusing on:

- person centred thinking and person centred planning
- engaging the person and their family
- the process of mapping.

### Person centred thinking and person centred planning

Thompson, Kilbane, & Sanderson (2008) define person centred thinking as a process of active listening with the focus on a person, their family and their friends in order to understand and work towards their present and future goals.

The person is always at the centre of the decision making process. Individuals, their family and carers and their friends are partners in the planning process. They work together in a way that focuses on the person's capacities and identifies community supports.

The plan is about identifying what is possible, not just what is available. Planning is a flexible, dynamic process that reflects each person's current situation. The person centred planning process is outlined through an abbreviated version of a document from Scottish Human Services (1995, as cited in Stalker & Campbell, 1998).

The five principles of person centred planning are identified as:

1. The belief that people with a disability should have the same rights and opportunities as everyone else in society. This is supported by the *UN Convention of the Rights of Persons with Disabilities* (United Nations, 2008).
2. An explicit value base that is based on universal needs rather than just clinical needs. For example, it includes housing, relationships and meaningful activity.
3. An attention to process. Person centred planning consciously addresses issues of process, such as who is involved in planning meetings, what questions are asked and how the discussion is managed and recorded.
4. Keeping an eye on the future. Using person centred planning assumes that people have futures, that their aspirations will change and grow and the pattern of supports agreed on is not forever.
5. Person centred planning encourages people to find new and different approaches to meeting individuals' needs.

Traditionally, arrangements have been made on behalf of people with a disability and may have involved living in larger accommodation settings and/or taking part in group activities. In the past, this type of arrangement has often occurred with little consultation with the people they are for. A person centred approach promotes a shift away from a situation where others make plans for people with a disability on their behalf, towards a position where individuals, assisted by their families and support network, make their own individualised plans and are in the 'driving seat' of their own lives. The following example briefly outlines the person centred approach.

## Case study: Juanita

**Individual:** Juanita

**Facilitator:** Laura

Juanita is a 38-year-old woman who lives at home with her mother. She attends a day program four days per week. She has been in this routine for four years. When Juanita attends the day program she engages in a range of activities which have been planned by staff. Although she enjoys some of the activities and thinks the members of the staff are nice, Juanita finds a lot of them tedious and not to her liking. There are also some attendees at the day program that she does not get along with and this bothers her.

Laura, Juanita's Facilitator, is conscious of this and arranges for the person centred plan to take into account Juanita's individual needs, wishes and feelings. As a result Juanita cuts her time at the day program to one day a week. Laura engages Juanita's circle of support (Laura, paid supports, family members and friends) and seeks out alternative activities based upon developing the specific independent living skills Juanita needs, making more connections in her community and doing the things that Juanita particularly enjoys.

## Getting to know the person and their family

### Meeting the ILSI Program Coordinator

It is a good idea for the ILSI Program Coordinator to meet with the individual and their family/carer prior to matching them with a Facilitator. The Program Coordinator thereby breaks the ice and can answer any further questions that the person or their family or carers have about the transition process. The Program Coordinator can also assess what kind of Facilitator may be suitable. The person and their family or carers can also put a face to a name and should be made aware that they are able to contact the Coordinator if they have any complaints or concerns that their Facilitator is unable to deal with.



## Getting started

It's essential for the Facilitator to spend some time with the person and their family and carers to explain the aims of the project and discuss what the ground rules are. Good ground rules can help to prevent misunderstandings and keep healthy boundaries in place between the Facilitator, the ILSI individual and family members.



Ethics and boundaries are covered in Chapter Five of this manual. These need to be understood clearly before the Facilitator starts to work with any family. It is extremely important for Facilitators to be clear from the outset about their role in the life of the person and their family and how they are going to be involved.

## Discuss the program

The way the program works and its aims are likely to have already been explained to the person and their family or carers during the application and acceptance process. However, it's a good idea for the Facilitator to go over these things again as people have busy lives and can become overwhelmed with information.

For a useful tool, see the guide *Being an ILSI individual* at Appendix 6. This guide is useful to leave with the person and their family so that they can go back to it when they need to, and they will also have the information to share with others.

Writing a simple 'ground rules' contract between the individual, family and Facilitator is good practice. Make sure that everyone understands why you are making the rules.

## **Confidentiality**

Facilitators need to explain, from the outset, that anything you are told by a person, carer or family member is confidential to yourself *and* your supervisor. It is possible that you will be told something that suggests there is a risk to someone's health or wellbeing. In this situation, you may be required to discuss the matter with other people, organisations or agencies. A decision may be made to take appropriate action. Be open about this at the start of the relationship with the ILSI individual and their family and carers.

## **Respect**

The relationship between the Facilitator and the individual is based on respect. It's a good idea to make a commitment to be honest with each other about how you feel about things. Encourage the person and their family to raise any worries or concerns with you as, and when, they arise. Explain the way to make a complaint to the Program Coordinator if people are not happy with how things are going.

## **Communication**

Communication can occur by telephone, email or face-to-face. Depending on the situation, and preferences of the person and their family and carers, different forms of contact may be used.

Keeping everyone informed of plans and developments is absolutely essential. Remember that families and carers are significant support people for the individual and liaising effectively with them is not only a key Facilitator skill, it avoids confusion and pays the family the respect they deserve.

## **Meetings**

Be clear about the type and frequency of meetings with the person and their family and carers. This includes formal planning meetings, visits to their home, support for the family and carers, and setting up a circle of support. Being clear about this in the beginning will prevent any misunderstandings and make

everyone aware of the commitment they need to make, as well as the amount of time the Facilitator will be in their home. This can be a real shock for some people.

## **Records**

Facilitators also need to explain to the individual and their family that records of their work are kept on file at the office, in a safe and secure place.

The ILSI journal is started at the first meeting with the individual and their family and carers. It will chart the person's journey through the process of transition. It can be called whatever the individual decides and can contain photos, drawings and thoughts written by the person and the other people in their lives. You might also agree that a note of the work that has been done each week is also made in the journal. An A4 ring binder and wallet file are useful as there will be lots of ILSI information and material, along with minutes of meetings, that can also be stored here. The use of IT equipment can also be discussed.

It is a good idea for you to bring binders, notebooks, coloured pens, pencils and paper so there are no delays in getting started.

## **The process of mapping**

Mapping describes a process in which people talk about who they are and where they are in their lives right now. In ILSI, mapping is expected to take a number of weeks and is combined with getting to know the individual and their family and carers. This is often an interesting process that allows you to learn a great deal about the individual, their life and their family.



It can also be a process of self-discovery for the person. Often it is by talking about ourselves that we learn about ourselves. Remember, however, that there is no pressure on an individual to share everything with the Facilitator, just the things they feel comfortable with. The person needs to have as much control as possible in every process. It's important to remember that everyone is different and has varying skills and strengths. You will need to be flexible about how mapping will work for you and the person you are working with. Most of this section is about ideas, rather than a set of rules for you to follow.

### The dimensions of the map

There are a number of tools in the appendices of this manual that might be useful to Facilitators in this part of the process. You can start by thinking about the people and organisations that are in the person's network.

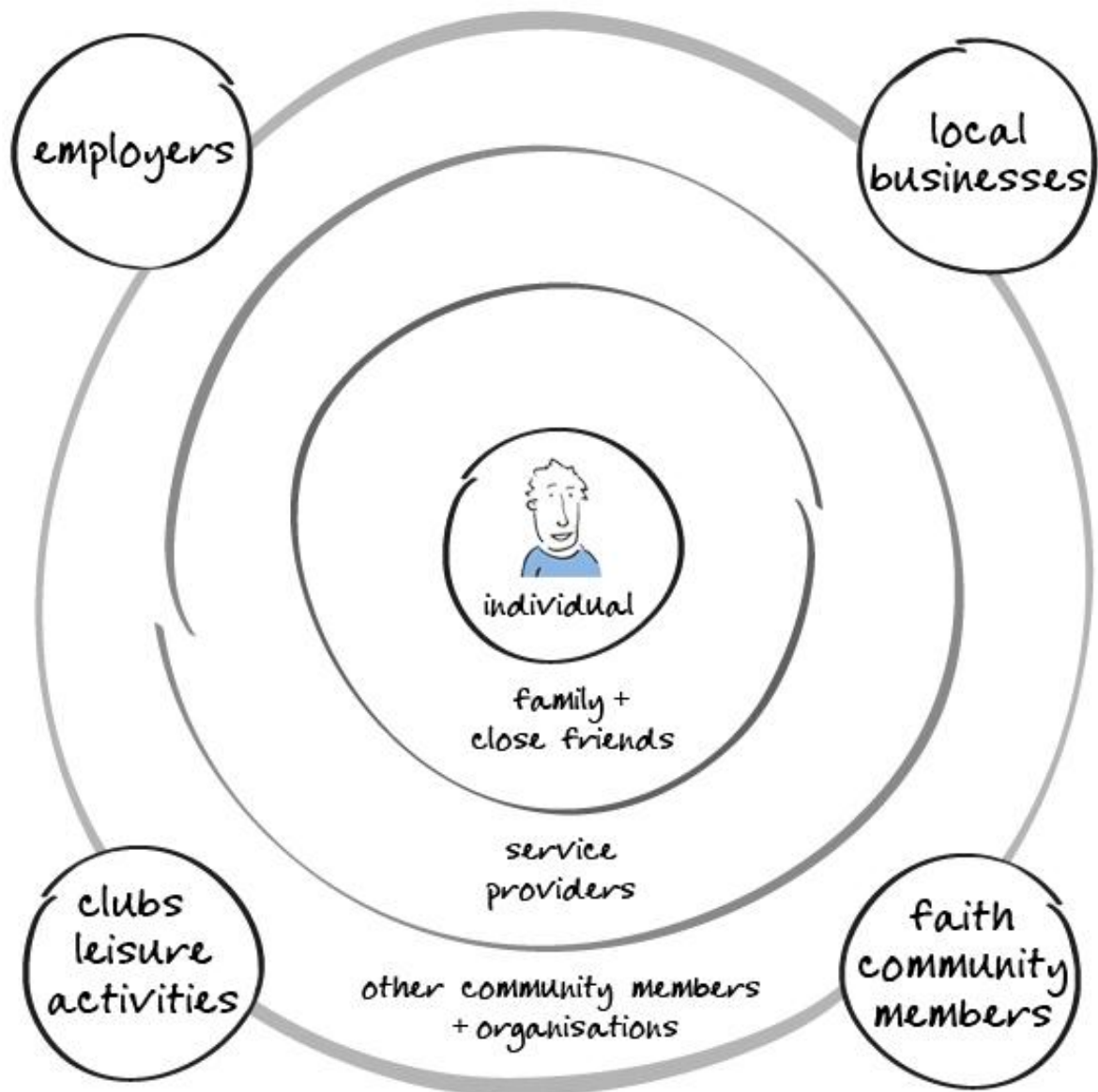


Figure 2

The person's network usually includes family and close friends, formal and informal supports as well as employers and local community members.

### Family and friends

List all the people close to the individual, anyone they could not think of living without. Looking through family photograph albums with the individual is a good idea – with the consent of the family of course! This is an activity that most people enjoy and is a great way to learn about someone and the people close to them. Talking with family at this time is also very helpful.

### **Service providers**

List any organisation or agency that provides a service or support to the person, such as a day program or respite service.

### **The wider community**

Make a list of people from social clubs, organisations, work, youth groups and faith organisations. This should also include people who provide services or support to the individual, such as medical and health professionals, hairdresser and local shopkeeper.

Completing this piece of work will be of great use further down the track when you are all deciding on who to invite to join the individual's circle of support – explained in depth in Chapter Seven.

### **Important events**

What are some of the important, happy or sad events that have taken place in the person's life? For the individual's history, you could think about drawing a life river or a simple timeline of events. Don't feel that you have to be 100% accurate in identifying dates and times. When you have completed the river or timeline you might want to check its basic accuracy with a close family member or carer.

### **Likes and dislikes**

What does the person like to do? What are their interests? What foods, TV, clothes, colours, music, films, sport and so on do they like? Also look at what makes them happy or sad.

### **Strengths and skills**

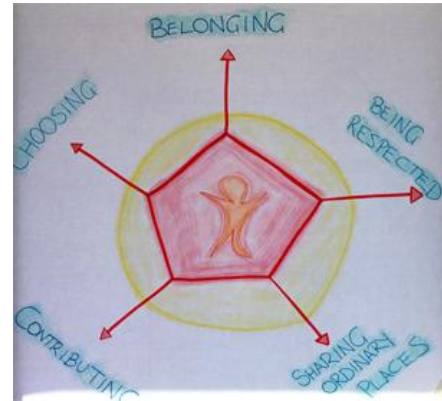
A person's strengths and skills can include anything from being 'good on the computer' and 'a good cook' to having a 'lovely kind smile' and 'making others feel special'. What are the strengths and skills of the person you are working with?

## Role models

Who does the person admire and respect? A role model could be a famous person, a family member, a person from the local community or someone in the person's everyday life. Identifying role models can help define the aspirations of the individual – who do they want to be? What do they strive for? What would they like to achieve?

## A personal perspective

It is crucial during mapping that the individual is able to express their personal perspective to the Facilitator. A person's ideas might vary from the perspectives of family members and others who sometimes speak for the individual.



If the individual can't express themselves verbally, consider using other methods to gather this information. For example, a trip to the local shopping centre can tell you a lot about a person from the kind of shops they enjoy going into and the items they are interested in.

Cameras can be supplied to some individuals if they wanted to take current photographs of their favourite people, possessions, pets, activities and so on. You could also make a video if a camcorder is available. Looking through magazines or books for images they are attracted to can also help.

Remember that this is important work. Recording some of this information in the individual's journal will provide a unique personal portfolio in many areas that might be of benefit when they come to making choices about their lifestyles further down the track.

Use visual representations of this work wherever possible as this makes the process interesting and easy to understand. Above all, however, make sure the process is interesting and fun.

Individuals and their Facilitators could produce a presentation of highlights of this work to share with their peers at a circle meeting or workshop (these are explained in Chapters Six and Seven). Some people use computer presentation software, speeches, collages and drawings that can be enjoyed by others. A microphone is always handy as well!

The mapping process generally takes about four to six weeks and, in many ways, continues throughout the entire relationship – people really never stop getting to know each other. Also, be open to discovering individual potential. As time passes and fresh opportunities present themselves, Facilitators will find individuals have many talents that even they were not aware of.

#### **Key points from Chapter Four**

- The early stages of building a relationship with the person and their family and carers is an important time. Undertaken carefully, it lays down the bedrock of trust and rapport between the Facilitator, the person and their family and carers.
- It is important to spend time being with the person alone and also with the family group to observe family interactions and relationships.
- The information and discussion during the mapping stage will assist the development of a circle of support and inform future planning towards transition.



### Questions for reflection

1. What are the key features of a person centred approach to working with people with a disability?
2. Practice the mapping exercise yourself. Draw a timeline and on it write down five important events that have happened in your life.
3. Using the circle diagram (Figure 2), draw up your own current 'circle of support'.



## Chapter Five: Working with families

## Working with families

The ILSI model can present both challenges and opportunities when working with people in the community. This chapter focuses on the major issues that you need to consider when working with people with a disability and their family and carers. It includes:

- ethics and boundaries
- core professional values – honesty, accountability and professional practice
- setting the ground rules
- issues facing families in transition
- cultural considerations.

**Please note:** this chapter is not exhaustive and is not a substitute for quality training by organisations in areas such as duty of care and boundaries, and the implementation of comprehensive policies and procedures around staff conduct.

### Ethics and boundaries

A code of ethics is essentially a set of rules and approaches to govern good conduct when working with people with a disability and their family and carers.

As a Facilitator you will quite possibly face situations that will challenge your professional and ethical boundaries, for example:

- Circumstances will arise where someone significant in the life of the individual will disagree with the choice an individual makes.
- You may be pressured to take sides as you mediate disagreements and try to find solutions.
- You might be offered a gift of money by an individual or family you are working with.
- You may learn that another Facilitator in your team has taken a gift of money from a family member.
- A family member may open up to you about a complex family problem that you do not feel equipped to help them with.

## **Where do you start?**

As you know, the goal of the ILSI program is for individuals to develop skills and make the transition to more independent living arrangements with the right amount of supports.



Your job as a Facilitator is to make sure you work towards this objective without crossing legal, ethical and professional boundaries and without alienating people. Ethical conduct is required for your own safeguards as well as to protect the individual. Furthermore, by knowing and working within clear guidelines, everyone will know where they stand, making you less vulnerable to criticism or allegations of misconduct.

## **The core values**

The core practice values for Facilitators are drawn from the Australian Association of Social Workers (AASW) Code of Conduct. The core values include honesty, accountability and professional practice. These are central to your work as a Facilitator and inform the following guidelines regarding best practice.

## **Place the individual at the centre of your work**

As highlighted in the previous chapters, ILSI Facilitators are expected to use a person centred approach. Person centred thinking is not a new concept. Its practice, however, challenges us to consider the ways it can be implemented – both on a practical everyday level when delivering services, and also the way it can be more broadly embedded in all aspects of an organisation's management and objectives.

For Facilitators, person centred thinking means positioning yourself alongside the individual you are working with and remembering that your prime concern is the best interests of the person. It is also important to be aware that many people with a disability have not always been involved in the planning of their lives in this way. They may need encouragement to express their wishes, opinions and feelings, and voice what it is they want for their future.

### **Comply with the law**

In all your dealings with the individual and the family you must abide by the law in every respect and have a broad understanding of the legislative framework within which you work. As mentioned in Chapter Three, the principle Act of the NSW parliament dealing with disability is the *Disability Services Act 1993*. It is suggested you take some time to familiarise yourself with the basic provisions of this as well as your organisation's procedures and policies.

### **Keep information confidential**

An essential part of building trusting, caring and respectful relationships with individuals and their family and carers is an appropriate level of confidentiality. Because you will be working intensively with the individual and their family, you will get to know a lot about them. However because the family home is usually a private domain, it is very important you respect their privacy and display sensitivity and discretion.

At the start of your relationship it is always good practice to tell the family what you will and won't share with others. It is also useful to alert them that if an area you are not clear about arises, you will discuss it with them first.

You also need to inform the person and their family and carers that you will be discussing your work with your supervisor who has responsibility for your work. You will also need to let them know that you need to pass on any concerns about safety or welfare affecting any person if they arise.

If individuals choose to share personal information with one another (at a workshop or in a circle meeting for example), this needs to be their choice.

You also need to explain that you will need to keep a record of your work and that this will be stored safely and securely.

### **Explain the complaints process**

Everyone involved in the program needs to be aware of your organisation's complaints process. Your organisation may have a leaflet or brochure that can be given out to explain the way the process works.

ILSI Facilitators have told us it is important to remember that even though some consider complaints are negative, they can bring about positive change. Knowing about problems will allow you to deal with them, ideally in a timely manner.

### **Know the boundaries**

Primarily, you are paid to work for an organisation – you are doing a valuable job of enormous significance. Your relationship with the individual and their family is therefore a working one and not a friendship. This does not mean that you cannot work in a warm and friendly way with individuals. It simply means that you have to be clear about the limits of your role.

Staying within the limits of your role means that you should not attempt to deal with issues that you are not trained and qualified to take on. All people and families have issues. In the course of your work with families, you may encounter family members with health problems, emotional or psychological problems and financial worries. As trust grows, family members may disclose such problems as grief, past abuse or marital issues. While non-judgemental listening is an important skill, and may be all the person needs, remember you are not a therapist.

If any person you are working with discloses a significant problem, take time to discuss it with your supervisor and decide on an appropriate way forward. After this discussion it may be that a referral for specialist counselling can be made. In respect of health, psychological or emotional problems, encouraging a person to see their GP is a safe and sensible approach to take.

### **Establish the ground rules**

Working with a person in the ILSI program places you in a privileged position to gain their trust, overcome practical problems, and help them build skills and self-confidence. In terms of boundaries, the two key concepts you need to know are:

- how to set basic ground rules
- how to be aware of your own emotional needs and get support when necessary.

**Please note:** it is also important you refer to the appropriate policy and procedure manuals provided by your organisation.

It is never possible to predict all the challenges you will face in terms of ground rules but below are some very basic ones to follow.

### **Do not take a person to your home or give out details of your home address**

An individual may have your work contact number (preferably a mobile phone number) and/or email address – with your consent.

### **Never take cash or offer to handle monies on someone's behalf**

Explain politely that you cannot manage or handle money as it is not part of your job. Report any gifts you might receive from an individual or their family to the ILSI Project Coordinator.

## Case study: Hannah

**Individual:** Hannah

**Facilitator:** Jenni

Jenni has been working with Hanna for 18 months. Hannah has enjoyed working with Jenni and has learned lots of new skills – her confidence has really grown.

At Christmas, Hannah hands Jenni a card and a parcel. Jenni opens the card which contains a warm message. Jenni unwraps the parcel and finds a gold necklace inside. Jenni is astonished and feels quite overwhelmed and emotional. She tells Hannah how beautiful the necklace is and how kind she is but gently explains that she cannot keep the necklace.

Hannah is upset and tells her that she wants her to have it for helping her. Jenni explains that she has been very lucky to work with Hannah and has enjoyed their time together greatly. Jenni adds that it is her reward that Hannah is doing so well. Later, when she finds a quiet moment, Jenni explains to Hannah's parents that she cannot accept their kind gift and they are very understanding.

The next time she is in supervision, Jenni informs her manager what has happened. Her manager is supportive, acknowledges the difficulty of refusing a gift and tells her that she has done the right thing.

The above example explains a difficult situation that was dealt with correctly and sensitively. Jenni's refusal of the necklace did upset Hannah and in many ways it would have been easier for Jenni to accept the gift, however, the acceptance of an expensive gift may well have compromised Jenni's professional relationship with Hannah. By refusing the gift in the way she did, Jenni respectfully maintained her boundaries with Hannah as her Facilitator and gave Hannah the credit for the progress she had made. Her Manager gave her appropriate support.



Always check with your organisation's policy and inform your program coordinator no matter what size the gift.

### **Communicate clearly and honestly**

Honesty and transparency are essential to trust. Make a commitment to discuss all plans with the person and their family and discuss any changes in plans with everyone concerned. Tell the family what will happen to information you gather about them.

If you don't know something, be honest about it. Don't feel you need to have all the answers all the time – there is no professional weakness in having to go off and consult with another party or find something out.

### **Make a commitment**

Change is generally a slow process and it takes drive and energy to happen. A motivated Facilitator is a key part of this process. If you make a commitment to visit the family or work with the individual at a certain day at a certain time, stick to this unless there are very good reasons not to. Give families as much notice as possible of changes in arrangements. Be reliable.

### **Challenge discrimination**

The ILSI project is about respecting the rights of people with a disability to live in the community and assisting them to make this transition. It is important you are aware that such a task may bring you face to face with various practices of exclusion including everything from employment opportunities, educational opportunities or recreational activities. You may also encounter other forms of discrimination such as issues to do with sex, race, culture, gender and class. In any situation where you witness discrimination, it is important you constructively challenge those who are discriminating and act in the best interests of the person.

### **Be accountable**

Keep a record of your work and let your Program Coordinator have a copy.

### **Pass on vital information**

If you receive any information about, or develop any suspicions about, abuse or neglect of an individual, you must immediately discuss this with your Program Coordinator.

If in your role as a Facilitator you meet with an emergency situation, contact the appropriate emergency service immediately, then inform family members or carers and your Program Coordinator.

### **Seek support when you need it**

Part of being a competent worker is knowing yourself and recognising situations where you need support. There can be many situations that will challenge your skills and abilities. Always feel that you can ask for support. Remember that everyone is on a learning curve and the various challenges that you face and the new information and skills that you will learn will contribute to your development and expertise as a Facilitator. If you have issues outside of work that you feel might impact on your practice, let your Program Coordinator know and discuss how you will both manage this.

### **Be sensitive about ethics**

This list does not cover everything and there are many ethically grey areas. If any matter arises which concerns and/or confuses you, record it and take time to discuss it with your Program Coordinator.

### **Issues facing families in transition**

Some families of a person with disability often focus on the specific challenges that they face, rather than the rewards and joys that such an experience can bring. This can lead to a negative perception of the experience of disability as a whole by others in the community that is far from accurate.



Research has shown that children and adults with intellectual disabilities are generally loved, valued and respected as family members and that the lives of parents and siblings are often enriched by a level of depth and meaning that would otherwise be absent (Grant & Ramcharan, 2001; Stevenson, 2011).

The stresses of the caregiver's role can of course have a practical and psychological effect on family members, but the nature and impact of this varies from family to family. It is important to understand how interpersonal relationships, support levels, financial considerations and personal histories have an impact on every family's experience. It is also important to note that family life, the path of care-giving, service provision and the course of a person's disability are also constantly changing.

Managing most of the care-giving issues facing families can be addressed by changes in the way disability is perceived in the community and how people with a disability are supported. Research by Knox, Mok, & Parmenter (2000) showed that many parents had little optimism for the future prospects of their son or daughter and were increasingly concerned about what would happen as their son or daughter with a disability grew older.

The concerns were wide ranging and included a lack of services for their children through their teenage and adult years, the probability of their son or daughter being on the fringe of society and a lack of planning for life when they are no longer around. Parents in the survey called for an expansion of services so that their son or daughter was not dependent on them as they aged. Parents also reported wanting to be equal partners in the service provision process and wanting to feel empowered to have a say in decisions that would affect them and their son or daughter. The ILSI model is responsive to the needs of parents of people with a disability facing the transition to more independent living.

## The impact of transition on ageing parents and caregivers

As a Facilitator, it is important you understand the implications of the experience of disability and caregiving on each family. This understanding will form the basis of your journey with the person and their family and allow you to be aware of some of the issues and obstacles that might emerge.



Issues to be aware of include:

- Most carers have organised their lives around meeting the needs of their sons and daughters. Families are often therefore particularly close knit and the role of the parents as caregivers has extended long into adulthood. The care-giving role, although stressful in some ways is one which many parents are attached to and (rightly) proud of.
- Parents generally become very knowledgeable about the disability service system and they often become skilled advocates. Helping their sons and daughters with a disability to live a more independent life may challenge the ongoing nature of the parental care-giving relationship with their adult child. The parental relationship with organisations in planning for their sons and daughters' futures is therefore critical (Grant & Ramcharan, 2001).
- In facing the fact that their sons and daughters are becoming more independent, many parents will experience a feeling of loss. Significant changes in their role can take place and this will have an emotional impact. Feelings of loss can be compounded; they may sense that control of their sons and daughters' future is being taken from them.
- Family members may also express fear or anxiety about their child with a disability moving towards independence.

It is therefore important for you as a Facilitator to:

- Be aware of the carer experience and that this is a challenging time for parents and carers.
- Actively listen to people's concerns and do not dismiss them as 'over-protective'.
- Gain the confidence of parents and carers through a committed approach to your practice with their son or daughter and ensure they share in decision-making.
- Ensure that the risks involved in any new activities are discussed with parents and recorded.
- Acknowledge the feelings of parents and carers in regard to the changes they face as a family and the ways in which this provokes anxiety.
- Give opportunities for mutual support and sharing with other parents/carers in the same situation. For example, you could encourage new ILSI parents to talk to parents who are further down the track with a son or daughter who has already moved out of the family home.

Generally, if the Facilitator's professional listening skills are well developed and his or her commitment and energy are evident, trust and rapport will grow between parents and Facilitators.

### **Cultural considerations**

Australia has a rich and varied tapestry of cultures and environments and it is not possible, within the scope of this manual, to discuss all issues that Facilitators need to work with in respect of this diversity. However, the following information gleaned from research provides a helpful insight.

In discussing the work of social or community workers, Johnson & Yanca (2010) coined the term 'diversity competence'. They argue that our work in the social and community fields needs to be delivered in a way that is consistent with the expectations embedded in an individual's culture.

Diversity competence covers all forms of diversity including culture, age, demographic considerations, disability, religion, gender and sexual orientation. We must all seek to learn and understand how to serve individuals in a manner which is respectful of their diversity. This knowledge might come from members of the community, experienced colleagues or from families and individuals themselves.



Developing diversity competence includes understanding the notions of self and societal influences, and putting your skills and knowledge into practice.

Because of its focus on the unique individual in their unique circumstances, person centred planning is seen as compatible with, and sensitive to, cultural considerations such as language and tradition. Person centred planning is about being open to the person's needs and aspirations. A one-size-fits-all approach is therefore not required.

As a Facilitator, it's a good idea to remain aware that communication styles can be different, as can the level of involvement each family wishes to engage in, or the level of personal information they wish to share. Different people may be comfortable with different levels of participation depending on their culture, age, gender or socioeconomic status. Being culturally sensitive requires a skilled Facilitator that asks questions in order to understand the individual and their family.

Hasnain, Sotnik, & Ghiloni ( 2003) argue that:

- there is a shortage of bilingual staff in the disability sector
- the demand for services from culturally diverse populations is far less
- there is pressure on culturally and linguistically diverse (CALD) families because of a lack of outreach efforts.

We also need to consider the fact that the notion of independence may not necessarily be valued by other cultures when compared to Western societies. We need to understand the person's culture on *their* terms, rather than on *our* terms.

Research conducted in Western Australia amongst Aboriginal communities (Disability Services Commission, 2006) raises some important considerations for Facilitators. In general, perceptions in Aboriginal communities were quite different from Western perceptions. In general, Aboriginal people with what we term a disability engaged with family and community in terms of how 'able' they felt. People with a disability in Aboriginal communities are often not distinguished from other community members on the basis of any perceived impairment. In fact, some communities had no name for 'disability' as such. Because of these cultural differences and, in part, due to the natural inclusiveness of many communities, Aboriginal families may not identify family members as having needs which might be met via established support and health services. The study also concluded that Aboriginal people, for various reasons, have less access to services and information about disability.

### **Tips for working with culturally diverse groups**

- The culture of the family needs to be considered when matching Facilitators to people.
- The Facilitator should be able to speak the first language used by the family.
- Wherever possible, it's a good idea to appoint a Facilitator who is of the same or similar culture to the individual. However, in some circumstances families are happy to have a Facilitator from a different background. They may even prefer this for reasons of privacy.
- Facilitators need to be fully aware that there is diversity *within* cultures and that an individual's cultural and religious traditions and practices can vary greatly. It is important not to make too many assumptions and instead address the unique circumstances of families.

Don't be afraid to ask questions. Most people enjoy talking and educating others about their culture. Be prepared to listen, research and learn.

- Just as we take a strengths based approach with an individual, we need to focus on the positive aspects of cultures when achieving transition. Support needs to work *with* cultural differences and draw on the strengths within cultural groups to offer appropriate support.
- Work carefully and respectfully to develop trust and understanding with families from diverse cultures. Many people from diverse cultural groups may have experienced discrimination in the past which may have left them mistrustful of government and non-government agencies in general.
- You are encouraged to get families together socially but do not separate people by race or culture unless there is a very sound and ethical reason to do so.

### Key points from Chapter Five

- Fluency in working with families/carers comes with practice and is almost impossible to teach in this sense.
- Many questions and challenges that arise will be unique to the context of each individual, family/carer and/or culture. This points to the need for supervision and team support for Facilitators.
- Good supervision from the ILSI Project Coordinator is important in the ongoing learning process, as is sharing with other Facilitators.

### Questions for reflection

1. What are the three core professional values endorsed by the ILSI model?  
Why are these values important?
2. Think of a time when you had to deal with a significant change/transition in your life. What, if anything, was positive about the process of change? What was hard about the process? What helped you to cope with change?
3. Imagine you are assigned to work with a family who have a different language and culture from your own. What do you see as the potential challenges to working with the family? How might you begin to overcome these challenges?





## Chapter Six: Making connections

## Making connections

This chapter discusses communication and networking strategies that can be used within the ILSI program to foster a sense of belonging as well as connecting with the broader community. It includes connecting people and their families with the wider community.



### Connecting ILSI individuals and families

Peer support is important to everyone at many stages of life; individuals and families involved in ILSI are no exception. The process of transition is exciting but can also provoke anxiety for some people. Getting together to network, make new friends, and share experiences, information and ideas can be very reassuring and productive for everyone involved.

One of the ways ILSI facilitates this process is to encourage individuals and their families to attend ILSI workshops. ILSI workshops are designed to provide a meeting place where individuals can get to know each other, develop a team spirit, learn new skills and share their experiences. The workshops are also designed to meet the needs of parents and provide families with the opportunity to meet with each other and share their experiences. Workshops can be held jointly (with both individuals and families together) or separately.

Past experience shows that ILSI workshops have had positive outcomes for both individuals and their families in connecting them to the program and to each other.

## Setting up workshops: guidelines and ideas

### Step ① **Check availability**

The first thing to do is check that individuals and families are interested in attending workshops. Explain the purpose, agenda and benefits for both the individual and their families and carers. Find out which day/s and times of the week they might be available. If anyone really does not want to attend, look at other ways to share the information and contacts with them.

### Step ② **Find a venue**

Finding a good venue is crucial. Travelling distance is a factor for most families, especially those living in rural and remote communities. Try to find a venue that is close to a train station or bus stop so that individuals can use public transport to get there. A venue that can provide food or has a café nearby is ideal. Some RSL Clubs have good amenities and can offer good room hire rates.

### Step ③ **Establish the frequency of the workshops**

Generally speaking, four to six weekly workshops are ideal. This offers frequent contact and allows relationships to develop among members of the group. However, if this number is not possible, even a few workshops are better than no workshops.

### Step ④ **Organise staff**

At least two staff are required to facilitate a workshop. It is good if each person can attend with their Facilitator who can assist them to take part in the workshop and be on hand in case of any issues that may arise.

### Step ⑤ **Prioritise safety**

Safety is of paramount importance. Prior to a workshop, you need to be aware of any health or dietary needs of everyone attending. It is also important to make sure any volunteers who may attend the workshop are trained in duty of care principles and practices.

### Step ⑥ **Arrange refreshments**

Provide water and snacks as an absolute minimum. It is important to have a break at least every hour. Individuals and families can be asked to bring some food to share or, depending on the venue, you may decide to make other arrangements, such as have a BBQ.

### Step ⑦ **Develop the workshop content**

It is a good idea to let the ILSI individuals decide on the structure and content of workshops. Some sharing time is important so plan for this at the outset. A good ice-breaker is for individuals to present some of the mapping and goal-setting work that they have done with their Facilitator in the form of a software presentation, a speech, a collage or a short film – whatever suits each person.

Depending on the time allotted for the workshop, the content can be very flexible but the focus on transition is important. Hold a brainstorming session with the group about what they think is relevant to them at this time in their lives.

Possible topics can include:

- relationships and relationship skills
- budgeting
- food and nutrition
- keeping fit
- safety at home and in the community
- first aid
- ‘Stepping back’ workshops for families.

Encouraging discussion about the shifting relationships with parents/caregivers is especially important in transition and this may include grief and loss.

### **Make it fun!**

Have some sessions which are light hearted and fun. Hold a dance class, celebrate birthdays with karaoke, or arrange a trip to the theatre or cinema. Some spontaneous social contacts and arrangements between group members can blossom from this approach.

### **Invite speakers**

New people are always welcome. Uplifting and specialist presenters can be brought in to lead sessions in their subject area if relevant to the topics the group are interested in.

### **Provision for parents**

As parents are also going through transition, it is important to consider their need for mutual support and encourage this. The setting can be formal, informal or both. Arranging a meal at a restaurant or a breakfast or coffee morning can often help to bring the group together. Feedback sessions from parent groups can be very useful in terms of informing and refining Facilitator practice. Such groups are also very useful for sharing information.

### **ILSI newsletters**

It is often useful for each group of ILSI individuals to be encouraged to produce a newsletter. The newsletter can be published every six to eight weeks and the individuals involved can use it to record their achievements and share their news with other members of the group and their families.

Facilitators can assist with this process by providing guidance and office space if necessary. It is also recommended the group choose one individual to be the Team Voice. The role of the Team Voice is to collect the information and produce the newsletter. This role can be rotated so each member has the opportunity to produce an issue. This is an excellent way for individuals to gain confidence in expressing themselves and connecting with other people.

### **Making connections in the community**

A significant part of the Facilitator's role is to steadily work with each person and their family to establish more connections in the community. This includes connecting with both people and organisations. The aim is to work towards positive levels of engagement for the individual in everyday life. Whether these connections eventuate from the 'circle of support' (see Chapter Seven) which meets regularly or through other means does not matter.



### **Where do we start to make community connections?**

Community connections are crucially important to successful independent living. We can learn from the past. For example, in Canada in the 1980s, many large institutions started to close and people with an intellectual disability moved to community settings. While the closure of the institutions was a positive move, little thought and resources were put into how to help people with an intellectual disability adapt to community living and lead an inclusive life. As a result, many people experienced problems of loneliness and isolation.

In 1988, Professor John McKnight started a project in British Columbia, Canada, looking at how to promote inclusion. In 1990, Professor McKnight gave us six principles that can enhance community participation:

1. Isolation from community life is the worst disability. People who have labels such as 'developmentally disabled' or 'learning disabled' are usually most disabled because of the effects of their isolation from the life of their community.
2. Every person has gifts to contribute to the community. No matter what label people might have, they have gifts abilities, talents and skills to contribute to their community and its people.
3. Communities grow stronger when all people can contribute. As all people contribute their talents, the power of the community grows and the disability of isolation diminishes.
4. A special effort from people within communities is necessary to open community life to isolated people. Some people will initially need to reach out and open the doors to the community, guiding the people with a disability to places where they can contribute their gifts.
5. Isolated people need to be introduced to groups in the community. Community is about the relationships between groups of people. As isolated people are introduced to these groups and offer their gifts, they will find that special relationship known as friendship.
6. Well-connected people are the most effective community guides. The most effective 'connectors' will be people who are well known and respected and active in community life.

This information has been adapted from McKnight (1990), please see the references section in Chapter Ten for more information about this project.

## Connecting with the local community

In terms of assisting community connection with the individual, the Facilitator needs to see this as an adventure full of possibilities. The following is a good example of connecting work by a Facilitator. As one of the goals he has set, Simon decided that he would like to be able to visit the local social club with his friend whenever he liked. In the following example his Facilitator, Sharon, talks about how she is helping him to connect with people there and, at the same time, build up his confidence and skills around managing money and using his mobile phone.





## Case study: Simon

**Individual:** Simon, aged 32.

**Facilitator:** Sharon

Sharon, Simon's Facilitator, explains the way she has been facilitating Simon's growing independence: "What we have been doing is going to the club. Simon is a member there and each week we sign in and have a bit of a chat with the person who is on the front counter to build up a bit of a rapport.

Once we go into the club, Simon does everything on his own. He gets his own meals and he communicates that really well now. He gets his own drinks and we go and sit down and watch the football together and then there is a meat tray raffle and he goes up and buys his own tickets, then at the end of the night we have started to use the courtesy bus.

What we are trying to do is build up his relationships with the people who are at the club, the local people. Since we have been going we have noticed people that have been there who always go for the meat raffle so it's just about building up his profile in the club so that people know who he is. Yes, building up those relationships so that he will be able to go independently. And one of the new goals is actually going there on the courtesy bus, catching it there and back home... as well as being able to send an SMS text – to initiate the 'going there', so it's not all organised through his Mum."

Sharon mentions 'building up' Simon's 'profile' at the club. Like everyone, Simon needs to feel comfortable, familiar and accepted in the area within which he lives and the best way to achieve this is if he is known to local people through regular contact.

Other activities that promote inclusion are going shopping at the local supermarket, having a haircut or calling in for a drink at the local cafe. Again, these activities can also be combined with building up skills which are defined in the transition plans. Establishing these local 'contacts' is important for another reason: they can help open up employment or voluntary work possibilities, as in Emma's story.



## Case study: Emma

**Individual:** Emma, 32 years old

**Facilitator:** Julie

Emma is a thirty-year-old woman with an intellectual disability who has always wanted to work in the hospitality industry but has struggled to find work. She wants to be in an environment where she feels she is helping others and is able to chat to people.

Emma and Julie, her Facilitator, started to call into the local coffee shop, often chatting to the staff and the manager. Emma told Julie she would love to work there, and said, "It was lively and friendly but not too busy." Emma's parents supported her aspirations and Julie discussed the possibility of voluntary work at the coffee shop.

Everyone agreed, so Julie visited the coffee shop alone and asked the manager Geoff, if he needed any volunteers, explaining that Emma was looking for work in the hospitality industry. Julie told him what Emma's skills were and how she might be able to help at the cafe. Julie also stressed she would be there with Emma to support her. The next step was for Geoff to have a meeting with Emma, her parents and Julie. At the meeting, Geoff interviewed Emma then talked about her possible role. He also talked about Occupational Health and Safety issues (such as hygiene and safe lifting) and Julie took notes and later put together an accessible sheet for Emma with illustrations to assist her understanding.

For six weeks, Julie attended at the cafe with Emma working to help open up on two mornings per week 9 am to 12 noon. Emma loved the work. At this point Geoff decided to pay Emma for her time as he thought it was fair and important. And after another meeting with Emma, her parents and Julie it was decided Emma could try a day a week working without Julie being present.

Six months down the track, Emma now works three mornings per week at the cafe making the return journey to work alone and working independently. She helps to open up and in addition, undertakes some waitressing duties.

This scenario illustrates some key features of good connecting practice:

- Being visible in the local community with good support builds awareness, acceptance and opportunities for people with a disability.
- The Facilitator was pro-active and thoughtful when she saw an opportunity for Emma in her desired field of work.
- The Facilitator initially talked to *both the individual and her parents* to ensure they were all on board with the idea. The communication with the family was consistent and clear.
- The Facilitator made the approach to the prospective employer on the individual's behalf. Obviously the individual can make the first approach if they wish and this needs to be respected, but a Facilitator approach is often a good way of avoiding unnecessary hurt feelings if the prospective employer declines. In this scenario, Geoff might have been placed in a difficult position and it could have marred his relationship with Emma who may have felt rejected.
- Aim small to start with, be conservative in your thinking.
- It is always better to start with a short term arrangement and fewer working days and hours and then build this up if things go smoothly.
- Make sure occupational health and safety issues are discussed from the outset.
- Have regular meetings and a strategy to deal with any problems that arise. Arrange meetings to review progress on a regular basis, that way the positives can be expressed as well as any problems.

Being well presented is important. Without being overly fussy, just like everyone else, people with a disability should be encouraged to be well groomed and well presented at all times. This helps to bring about confidence and a sense of well-being. As we all know, being well presented leaves a good impression on prospective employers.



Another way to make connections is to contact organisations directly. Many large organisations now have community engagement agendas and are happy to provide voluntary work, educational and experiential opportunities for people with a disability. There is never anything lost in picking up the telephone and asking about what might be available. Facilitators can often use their own connections to gain access to wider networks. If Facilitators are cold-calling organisations, talking to the people in senior roles is usually a good strategy as they often have the discretion and power to make decisions.

## Case study: Carina

**Individual:** Carina

**Facilitator:** Samar

Carina's brother and sister both graduated from university and often talk about attending lectures and doing assignments. Carina has always felt left out of this process and has been curious about what university is like. Realising this, Samar, Carina's Facilitator, asked if she would be interested in going to a lecture. Carina said yes.

Samar, a graduate in Nursing, then rang her lecturer, Dr Clark. Samar explained the situation and asked if there was an opportunity for Carina to join an undergraduate lecture. Dr Clark asked what subjects Carina was interested in and Samar shared that although Carina's main interest was animals, she would be happy to attend any lecture. Dr Clark suggested Samar contact Dr Brown, head of Veterinary Science at the university who Dr Clark knew well. Samar rang Dr Brown and mentioned that Dr Clark had suggested she contact her. Dr Brown was interested in the idea and suggested Carina and Samar come in for a chat.

Carina, her mother and Samar came to meet with Dr Brown at the university. Dr Brown had, in the meantime contacted the Community Engagement officer for the organisation. The group sat down and discussed some lectures that would be appropriate for Carina to attend and Samar wrote up a plan.

During the next semester Carina was able to attend three lectures on three different days at the university. Dr Brown had arranged for her to have a 'uni-buddy' – a student who accompanied her for the day, showed her around and took her for lunch afterwards.

The next time Carina met with her brother and sister at a family gathering, she was able to share this experience with them instead of feeling shut out of this part of their lives. Dr Brown wrote a letter of appreciation for Carina to keep, noting the lectures she had attended.

## **Key points from Chapter Six**

- In terms of the connecting role of the ILSI Facilitator, energy and initiative are needed. There are many ways of approaching community connection limited only by imagination.
- Community connection with individuals is a process that needs to be driven, it will not happen on its own.

## **Questions for reflection**

1. In what ways are you connected to your local community?
2. In what kinds of places have you met new friends and acquaintances?
3. What kind of social skills do you need in order to mix easily with others?



## Chapter Seven: Circles of support



## Circles of support

This chapter offers guidance about how to set up a circle of support and includes the following information:

- describing what we mean by a circle of support
- the benefits of a circle of support
- how to set up a circle of support
- how to run a circle of support meeting
- possible issues and barriers to overcome using the circle of support model
- maintaining the circle of support and reviewing progress.

### What is a circle of support?

The term 'circle of support' refers to a group of people who commit themselves to providing a person with a disability the tangible and holistic support they need to live a good life.

The aim of a circle is to provide support to the individual and their family and carers over many years. It is not just a short, time-limited event.

However, it is not expected that members commit for an extended period but rather that the circle is fluid and people come and go as the needs in their own lives change and the needs of the person with a disability change.

Circles of support are sometimes called 'support networks', 'teams of champions' or 'intentional networks'. Circles are now being used in many countries and communities around the world, and in different contexts. For example, they have been set up to support students with disabilities in mainstream schools with positive results.



In ILSI, the purpose of a circle of support is to provide support to the person with a disability as they move from family-based living arrangements to more independent living arrangements. As a Facilitator your role is to assist the person and their family and carers to set up a circle of support in order to expand and widen the number and variety of supports available as they move through the transition process.

### **What does a circle of support look like?**

When you think about it, most of us have our own circle of support – a network of family members and friends who give us practical and moral support throughout our lives. Some people are a constant in this process and others move in and out of our lives at different stages, according to circumstances and other commitments. For all of us there may be times when we have too much or too little support.

For a person who is participating in ILSI, their circle of support will look much the same and taking into account their age and life circumstances will usually include:

- family members
- neighbours
- friends
- boyfriend or girlfriend
- work colleagues
- paid support workers.



In general, circle members are there purely because they care about the person, want to provide friendship, give moral support, and help them overcome barriers to taking part in the community.

Usually the circle is a two-way street and members often find opportunities for new connections and possibilities. The circle makes its plans in consultation with the individual and the circle meets regularly to re-visit original plans, update and stay on-track with its activities. This will include decisions about the frequency and the type of contact, which might be through a formal meeting or a more informal setting. You can use other methods apart from face-to-face contact, such as telephone calls to individual circle of support members, or teleconferencing using the internet and Skype if that suits people in the circle.

*Source: Adapted from Stevenson, et al. (2009, pp. 2, Section 2).*

Not everyone needs a circle of support, and even those who do take up the idea might just have the circle when they need one. Members can move in and out of the circle as the years go by, new members join and others leave as people often have changing life commitments that take them away from the circle temporarily or permanently.

### **What are the benefits of a circle of support?**

There are many benefits to a circle of support, including:

- a network of people who can act as safeguards
- an increased sense of well-being
- the reduction of social isolation
- an enhanced capacity to plan for the future.

Many families also report a sense of relief and joy knowing the person with a disability is able to rely on a far wider range of supports than what they alone can provide. This is especially so for ageing parent carers who have fears for the future support of their son or daughter with a disability.

### **What does the research show?**

Research undertaken by Miriam Stevenson in interviews with parents of young adults with Down syndrome participating in the *Up, Up, and Away* program shows the benefits of circles of support. Following are a number of examples derived from comments from parents.

### **Supporting parents allows them to have higher expectations of inclusion for their sons and daughters.**

*"It's given me permission to be idealistic. I think I've always been accused of being idealistic or expecting too much." (Mother)*

*Source: Stevenson (2011)*

### **Supporting a family member with a disability can allow an individual to have focused discussions about their relatives who have a disability.**

The busy day-to-day lives of all families are generally very task orientated. Most of us just get on with the everyday challenges of life. The circle of support can help to promote time for reflection on plans and opportunities for their relative who has a disability. Circles can sometimes facilitate more communication between family members including siblings. Older siblings can become disengaged from their brother or sister with a disability, especially during and after adolescence. Being part of their brother or sister's circle can help re-engage siblings in the lives of the individual in a meaningful and purposeful way.

*"I think its brought us a lot more closer to each other because through the circle of support meetings and things like that, a lot of things have been discussed that we don't usually sit and discuss as a family....we have got more understanding of each other which I think is great." (Mother)*

*Source: Stevenson (2011)*

## **A circle of support can provide a structure for introducing more people into the life of the individual with a disability**

*According to one mother, the circle is “a tool for giving Heather the opportunity to have more people in her life than just the immediate family. And I'd like to think that those people who have been supporting Heather will be there long-term. Maybe going in and out and in and out depending on circumstances in their lives but I'd like to think that it could carry on with these people for all of her life. So that she's got more people supporting her in life and she is also learning skills to make her more independent. And at the same time she is making new friends and socialising.”*

*Source: Stevenson (2011)*

## **A circle of support can help others in the community to learn about disability**

People with a disability have not always been fully included in community life. For this reason there is often a lack of understanding and awkwardness on the part of some people. Some families feel that the circle of support is a useful device to help other people understand more about intellectual disability and what it is like for families.

*One parent explained how the circle process has raised awareness and hence built this kind of capacity into her community: “...even with the circle of support, not every one of them has had a person with a disability in their own life. So just coming here and listening to other people talk about disabilities, listening to Sandia herself, that is in some way ‘spreading the word’.” (Mother)*

*Source: Stevenson (2011)*

## **A circle of support can help parents to ‘step back’**

When parents and caregivers feel they have caring and trusting support from others they often gain greater strength and confidence in ‘stepping back’ and allowing their sons and daughters with a disability to try new activities and broaden their lives. Subsequently they learn more about their sons and daughters’ capacity to learn and grow:

*“I am learning to let go and I don’t find that easy at all... and I have learned more about Selina. I have learned that she is actually very capable and I do need to stand back”. (Mother)*

*Source: Stevenson (2011)*

## **The use of the circle for making plans and reviewing progress**

Circle meetings can also provide a useful forum for producing and reviewing plans as a group. Circle meetings are useful for discussing new activities and any risks or safety issues these might entail, and so are particularly helpful in a process of transition and change. The individual and their family can draw on the views and ideas of others, both in assessing risk and in looking at ways in which risks can be minimised.

## **How to set up a circle of support**

The mapping phase described in Chapter Four will have helped you to identify people within the person’s life who could have a role in the circle. Setting up the circle will be guided by the following principles:

- each person and every family is unique, therefore every circle will be different
- all planning at all stages must engage **both** the person and their family
- the idea of the circle is flexible and must respond to the needs of the individual and their family
- do not rush the process and manage expectation carefully – as long as the circle meetings are **safe, respectful and positive** experiences for all involved, nothing has been lost.

Anyone who plays a positive role in the person's life can be part of their circle.

### Step ① **Make sure everyone knows what a circle might be like**

At some point before initiating any circle meeting it is a good idea to watch one or more DVDs that feature circles with the individual and their family, including the *Up, Up and Away* DVD and *ILSI: Let the Journey Begin* DVD. You might like to have a discussion about it afterwards. This allows everyone to start thinking about what their own circle will be like.

### Step ② **Talk to the person**

Talk about the circle concept with the person. Explain what the circle is all about, how it can help them achieve their goals, and watch the relevant video together. Talk about what they might want out of a circle and who they would like to be in their circle. Make a list of important people together. Everyone is different so some individuals may want to identify a big circle and others a smaller one. Always explain that perhaps not everyone can come to the meetings but can be part of a wider support group. Also explain to the person that you will be discussing this with other family members as it affects everyone.

### Step ③ **Talk to the family**

Have a separate discussion with the family about the circle. What do they think, what are their feelings about the list that their son or daughter has provided? Do they have any views on membership, venue, and content? Remember that a circle of support is a huge step to take for some families who may see it as an invasion of privacy, or placing a burden on others through expecting them to make a commitment. They may also feel let down if circle members do not meet the commitments they might make. The way to deal with these fears is to take it step by step and start small if necessary.

## Step ④ Plan the first circle meeting

There are a number of different ways of approaching the circle meetings. Some families prefer a low key first meeting with family members and close friends. One ILSI individual had a cake iced with COS for his first circle meeting! There is no reason why it cannot be an unstructured and social occasion with the individual at the centre and where circle members can mingle and get to know each other. This is a good way to start when families are apprehensive. On the other hand, some families will be happy to start off with a more structured meeting. Make sure that you are aware of the style of the meeting that the individual and family want and plan around this.



At this stage you can decide what to include in the meeting. For example, does the individual want to stand up and speak to the group? Would they like to produce a presentation about their life? Do they want to talk about their goals? Do any family members want to speak?

A little later in this chapter you will find a suggested structure for the first meeting but the concept is totally flexible. What is not undertaken at the first meeting can be done at the second meeting and so on. Whether the first meeting is large or small, the main aim is to get the circle started positively. Decide on the possible date, time and venue with the person *and* their family.



## Step ⑤ **Send out the invitations**

A great rule of thumb from the very beginning is to put the individual in charge of arranging and running the circle as much as possible. Check the availability of the suggested circle members and then work with the individual to write out some invitations or send an email. Give suggested members at least three weeks' notice, ask for an RSVP and be prepared to send a reminder. Anyone who cannot attend (and this might include friends or family who are interstate or overseas temporarily, or even permanently) can be sent feedback by email.

Again, do not worry if there are not a lot of people available to be invited to the first circle meeting. A mistake that Facilitators often make in the beginning is to think that the initial group of people is the final circle, when this isn't the way it will work in practice. An important part of circle planning might be that the person decides they need *more* people in their circle. Indeed, this is often the case as people are seeking to make more connections within the community. As noted above, the circle shifts and changes over time. One of the initial tasks for the circle may be to start building contacts and social connections for the individual.

## Step ⑥ **Get ready for the first meeting**

The following is a plan for a structured meeting. It has been designed so no special equipment or tools are required. Where any structure is used, the golden rule is to aim for a positive and enjoyable meeting and to keep the meeting focussed. We suggest that the meeting is no longer than one to one-and-a-half hours in length with drinks and snacks available.

To prepare you will need:

- four sheets of butchers paper or big pieces of paper
- coloured marker pens
- adhesive to temporarily stick the paper to a wall (without causing damage!)
- pen and paper for names and contact numbers
- light refreshments for circle members to snack on in the meeting
- an agenda to pass around (this shows efficiency and helps you keep the meeting on track)
- the first big sheet stuck on the wall.

## Running a circle of support meeting

### Step ① Start the meeting

First, welcome everyone and thank them for coming. Then ask everyone to introduce themselves. Pass around a contacts list with a pen for everyone to record their details, especially their name, email and relationship to the individual.

Explain to everyone what the meeting is about and give out the agenda – it is great to involve the person in doing this. You want to encourage them to do as many of the meeting tasks as possible.

Talk about the importance of confidentiality. Ask that everyone respect each other and the confidentiality of the meeting. Explain you will need to write up and share the information with your manager but the information will go no further.

## Step ② Get to know each other

First, draw a circle on the sheet with the person's name inside (the individual may wish to do this). Next, go around the room and ask everyone to say who they are, what their relationship is to the person and to share one positive thing that the person has given them. This can be anything such as; "she has a lovely smile", "he has taught me to be patient", "he cooks a great curry".

As people say the positive things, write the direct quote on the sheet around the circle with the name inside. Make sure you also contribute.

Focus things a little more after this and ask the group to say what the person's strengths and skills are. Because you have taken time to get to know the person, you will also be aware of their strengths and abilities and can add to the list.

Some skills listed might be:

- good self care skills
- independent living skills such as money handling, household skills, food preparation or ability to travel independently
- inter-personal skills
- communication skills including the telephone, mobile or internet
- problem-solving skills.



It is worth also noting:

- Some individuals and Facilitators are very creative and draw symbols and signs on each of the sheets. This is great as visuals help to make the messages on the sheets more accessible and interesting for everyone. They may become more necessary if an individual does not have literacy skills. If this is the case, give some thought to this before the meeting.
- We human beings are generally not good at giving positive feedback to each other. However, positive feedback is very powerful and can be a wonderful boost to a person's self esteem. Some people will become very moved and emotional in this part of the meeting. Just acknowledge and celebrate this good feeling in the meeting!
- Some people like to reciprocate and say what they like about their friends in the circle. If they want to do this it is fine, but make sure the individual remains the focus of the meeting at all times.

### Step ③ **Record the person's hopes and dreams**

Put up the next sheet of paper. At this stage, the person may like to take over and do a presentation of some of the mapping work they have done and talk about their dreams and goals to everyone in the circle.

If you need to prompt the person, you could ask questions like: 'What are your long and short term hopes and dreams?' and 'What would you like to do with your life?' Get the person (if possible) to talk and write these in lots of big clouds on the sheet. Again, because of the prior work you will have done with the person, you will know some of these and be able to support the person in expressing their wishes. Discuss what the circle members think about these goals. What do they see as barriers, both practical and otherwise?

It is worth also noting:

- This stage requires discussion and needs careful and sensitive facilitation. You need to make sure that no one in the circle is dismissive of a person's hopes and dreams. Even if dreams are not practicable, the circle meeting is not the place to confront or challenge people.
- One controversial area for people with a disability is in the area of relationships, sexuality and having a family, which might include having children. Having a family is something that the majority of people wish for and there is nothing more natural. Many (but not all) parents and carers have anxieties about these issues and there needs to be discussion if possible to address such concerns in the right place, at the right time, with the right people!
- Do not hesitate to say "We can talk about this more outside of the meeting", if a contentious subject rears its head!
- Again, if you have done plenty of background work with the individual, you will have prior knowledge of what they might share with the group. You will be able to anticipate possible responses, and may even have discussed some goals and ideas with parents and carers previously.

#### Step ④ **Record short and long term goals**

Divide the sheet into two columns and name them 'short term' and 'long term' goals. Get the individual and their circle to decide what goes in each column. Short term goals might be: go out more, develop independent travel skills, use a mobile phone. Long term goals for example might be: to live independently, get married, travel overseas with a friend.

## Step ⑤ **Develop the action plan**

Write a broad action plan and keep it as simple as possible. Over time it will change. Simple goals are absolutely fine. They might include finding more supporters, or exploring options for jobs, leisure, housing and meeting people.

Discuss who in the group can take on specific roles. It's a good idea not to let circle members over-commit themselves or they might end up letting the person down. Some circle members might just say that they are there for friendship and support for the individual and that is fine.

Remember, as the Facilitator you will have some time to work on some of the goals identified with the person, so factor yourself into some aspects of the action plan.

Discuss how the group will communicate with each other – such as via email or phone.

## Step ⑥ **Provide feedback and close the meeting**

Go around the group and get everyone in the circle to say one thing that they really enjoyed about the meeting and one thing they will find challenging about being in the circle. Spend about five to ten minutes on this part. Finish with the individual having the last word. You can both thank everyone for coming and the family for hosting the meeting if this is the case. Make a date with everyone for the next meeting.

## Step ⑦ **Write up the minutes**

Afterwards, spend some time transferring the information from the sheets onto paper and give a copy to the person (and give them their sheets back!). This is valuable work that they should keep with their journal. Distribute minutes to the individual and the circle of support attendees. You might need to write an 'accessible English' version for people with a disability.

**Please note:** not all circle of support meetings are initiated like this but Facilitators who have used this format have said it was successful and helped to structure their work and keep the focus of the person with a disability central to the meeting. For more information on structuring and recording information during a circle of support meeting see Appendix 7.

And remember: stay positive! Don't rule out their dreams. In the *Up, Up and Away* program, one person got a fabulous job with a top Sydney accountancy firm, another recorded a song that she wrote at the Sydney Conservatorium, and another managed to make his own movie and win Australia's Tropfest... you just never know!

## Maintaining the circle and reviewing progress

### The importance of regular meetings

In the early months of a circle of support, regular meetings are really important to get established and embed the idea of the meeting and the support network. Regular meetings, even with a minimal number of members, are necessary to ensure that planning and reviewing is taking place. More significantly, the individual and their family and carers have joined ILSI on the understanding that circle meetings will occur. People need to be confident that a meeting will occur when scheduled, otherwise their trust and sense of support from the program could be damaged. Setting up and driving the circle is therefore a key responsibility of the Facilitator.

There will often be many reasons to put off or cancel circle meetings, generally around the availability of circle members. Even if a meeting occurs between the individual, a parent and the Facilitator, it is fine because the meeting is the place at which progress will be reviewed and supported.

The person should be encouraged to chair and establish control of the meetings. This is important for their self-esteem. It is good to introduce new ideas to keep

the circle fresh. Make sure that there is always a 'social' atmosphere and that the meetings are inclusive of everyone.

**Making progress: The 'Plan, Action, Review' Cycle**

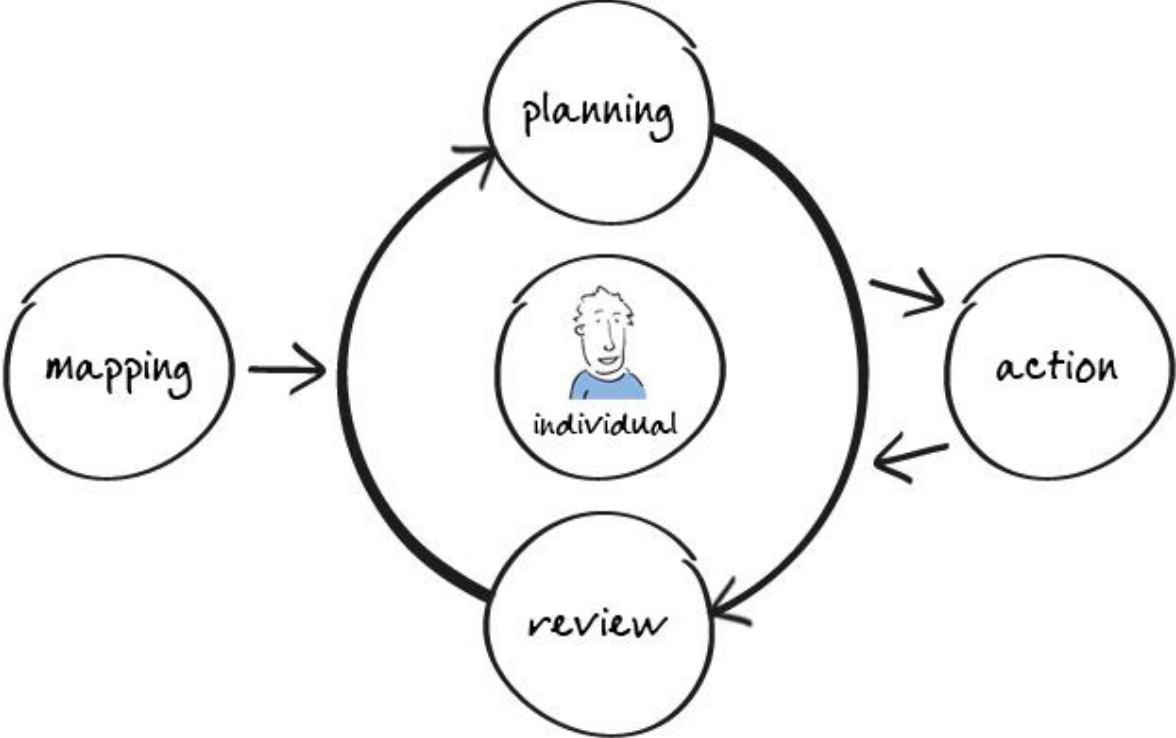


Figure 3

The above diagram shows the basic cycle of plan, action, review which is possible in the circle meetings.



## **Suggested structure for ongoing circle meetings**

- Ask all members of the circle to share their news since the last meeting, avoiding anything too personal.
- Look at the action plan created in the previous circle meeting and review what progress has been made towards some of the goals.
- Explore the things that have been good and that have been hard for the person. What are the barriers to achieving the goals? What has helped?
- Discuss any possible solutions to any problems and get the circle members to share their ideas.
- Using the Circle of Support Review Tool, create a new action plan including any new goals that the individual wants to set for themselves. Please see Appendix 7.
- At the next circle review the plans that you made at the previous meeting and so on and so forth.

It is important for the Facilitator to work to the person's positive achievements. Even where there are problems and pitfalls, these need to be turned around into learning experiences for everyone concerned. The Facilitator needs to stress that everything takes time to move along and getting regular meetings established is a good start.

## **Possible issues and barriers to overcome within the circles model**

While many families set up and run circles of support quite smoothly, more often than not the process is a challenging one. There can be personal, interpersonal and practical challenges to face for all involved.

If the Facilitator is not aware of some of these barriers, time can be lost or you can fail to build a circle completely, or in a sustainable way.

To manage some of these issues it is recommended you:

- Have access to good supervision with an appropriately trained and qualified manager.
- Understand some of the dynamic and current issues within the family before embarking on setting up the circle.
- Lay down some group rules – explain that this is purely a support group and that any significant relationship issues or disagreements need to be explored outside of the group.
- Set an agenda with the individual before the meeting and discuss it with the family and carers.
- Know resources where family members can be referred to for appropriate support.

Many people are used to having most of their everyday support needs met by their families, and families become accustomed to meeting the needs of their sons and daughters with a disability. Most parents have a very close and complex bond with their sons and daughters for this reason. Any challenge to existing family arrangements can feel uncomfortable so great sensitivity and care is needed when engaging in discussions about the future.

For most of us, our homes are our sanctuary. It can be very hard to invite people who are not well known to us into our home. If a family does not wish to hold circles of support in their own homes, seek an alternative venue. Privacy and comfort is an important consideration.

Some people do not hold a circle of support meeting because they feel they do not have enough contacts or people who would be willing to be in the circle. Most families have a strong sense of personal privacy and this is to be respected. Do not encourage people to share information that is not essential to the planning and decision-making of the group.

While the development of a circle of support is generally a very positive occurrence, negativity in groups, however unintentional, can have a damaging effect on individuals – whatever their role and position. The case study below highlights this.

### **Case study: Andrew**

**Individual:** Andrew

**Facilitator:** Zara

Andrew is 22 years old and has an intellectual disability. He lives with his father, David, his stepmother Dianne and two younger brothers Michael and Paul, who are from his fathers' second marriage. Andrew's mother, Susan, died when he was 15 years old.

Zara, Andrew's Facilitator, has been working with the family for ten weeks. Andrew talks about his mother a great deal. Dianne, his stepmother, is very sensitive to this and finds it upsetting. Dianne interprets this behaviour as Andrew not liking or accepting her as his father's second wife and, as a result, she has emotionally withdrawn from Andrew.

Andrew's behaviour has become extremely challenging in the household and he has made some disrespectful comments to Dianne.

David finds this situation very difficult. He increasingly feels torn between his feelings for Andrew as his son and Dianne as his wife. Neither David nor Dianne have spoken with Zara about the situation, although Andrew has told her that he does not get along with his stepmother although he thinks she is a great person and does a lot for him.

**Circle of support:** Zara sets up Andrew's first circle of support meeting involving his family. At this first meeting, Zara asks everyone to talk about something they really like about Andrew. All of the members of the group have positive comments to make about Andrew, except for David and Dianne.

Both David and Dianne say that they cannot think of anything positive to say and explain that they are very unhappy with Andrew's behaviour, which they think is getting worse.

At the end of the group Andrew breaks down and cries and tells Zara that he felt totally humiliated by his parents and he does not want a circle of support anymore. Zara felt that what promised to be a very positive meeting turned out very badly.

On reflection Zara believes that Andrew is still grieving the loss of his mother, and that he, David and Dianne would benefit from some family counselling. She suggests this to the family and they agree.

She also suggests it might be best if they discuss the difficult feelings the meeting has brought up with a therapist before resuming the circle of support.

During the counselling Andrew acknowledges his ongoing grief and Dianne realises she is reacting to and misinterpreting Andrew's grief as rejection. The counselling helps the family to move on. Later, Andrew and Dianne tell Zara they are ready to start their circle of support again.

It's important to remember that the ILSI Facilitator is not a trained therapist and the circle of support is not a therapy session. It is important to make this distinction, but how do we do this?

Facilitators need to be mindful that the purpose of a circle of support is to provide informal support for the person with a disability. Facilitators need to make sure all members understand there is an expectation the circle will be a safe, respectful and positive experience. Where individual people express personal needs that impinge on the primary purpose of a circle, the Facilitator will refer the person to more appropriate, dedicated counselling.

It can also be useful for the Facilitator to signal at the outset that if any personal issues do arise that counselling is available.

## Key points from Chapter Seven

- A circle of support refers to a group of people who commit themselves to providing a person with a disability the tangible and holistic support they need to live a good life. They focus on helping the person achieve their goals.
- Usually circles of support are a two-way process, with members often getting the opportunity to make new connections.
- Circles of support can act as a safeguard to support the person with a disability and their family to actively discuss any risky situations, problem-solve and reduce social isolation.
- Circles of support provide the opportunity to record and review progress.

## Questions for reflection

1. Who is in your own current 'circle of support'? With whom do you share caring, trusting and supportive relationships?
2. What different kinds of support do you receive from these people ?
3. Think of an example of where a person has helped you to achieve one of your personal goals.
4. What do you see as your personal goals?
5. What are your strengths and what skills would you like to improve upon?



## Chapter Eight: Independent living skills

## Independent living skills

This chapter focuses on developing an individual's independent living skills. It includes information on how to support the person with a disability to:

- develop the skills they need to live more independently
- apply this knowledge so they can take part in the community.

The more tasks a person is able to do independently, the more control they will have over their life.

The aim of development work is to teach the person to perform tasks independently, or more independently so that they require a lower level, or frequency, of support.

### Developing independent living skills

#### What do people need in order to learn how to do tasks?

In order to learn a specific task, individuals need to acquire skills and knowledge, and then be able to apply their skills and knowledge in the appropriate context. It is often as important to learn what to do if things don't go to plan as it is to learn the steps of how to do the task. For example, if a person is learning how to use public transport, they will need to know what to do if something goes wrong. They may get on the wrong bus or train, or there may be a disruption to normal services.



As a Facilitator, you will be supporting each person to learn tasks that will move them towards independence. The selection of these tasks will be informed by an assessment of each individual's particular support needs and the goals for independent living outlined in their person centred plan. Each individual will bring their own goals and areas of development need to the ILSI program.

## Goals for learning

The goals for learning are determined by the person with a disability and the Facilitator. This can be done using a variety of support assessment need tools. These tools can help you work out what an individual's long-term goals are, the level and frequency of support they will require to complete tasks at home and to take part in community settings.

Examples of independent living skills and tasks the individual may need to master as part of the ILSI program include:

- learning to cook
- cleaning, such as washing the floors
- safety skills at home
- budgeting and paying bills
- travel training
- doing the laundry
- acquiring the knowledge and skills required to take part in social and community activities.

Person centred planning prioritises the learning most important *to* and *for* the person. The learning most important *to* the person involves the individual's dreams and aspirations. The learning most important *for* the person includes the skills and tasks required to keep the person safe and healthy.

Of the 3.8 million people with a disability living in households, 61.5 per cent (2.3 million people) reported needing ongoing assistance because of their disability or age. People with a disability were most likely to need assistance with property maintenance (53.3%), health care (41.9%) and housework (39.5%).

*Source: Australian Bureau of Statistics (2003)*



## Instructional objectives

### What are instructional objectives?

An instructional objective lists the short-term steps towards the achievement of a goal or mastery of a task. The steps might be set weekly, fortnightly or monthly. They break a goal into achievable chunks and provide a means of monitoring an individual's progress towards each goal or task.

Instructional objectives should be ordered in a logical sequence and include the following components:

1. The specific behaviour to be performed. This needs to be written using words that describe actions you can see. For example, you can **see** 'cooks using a visual recipe', but you cannot **see** 'follows a recipe' as this could be undertaken as an internal mental process.
2. The conditions under which the learning/behaviour will be demonstrated. For example:
  - the context (in the kitchen);
  - how the information will be presented (from a visual recipe);
  - the level and type of support required (with verbal prompts).
3. The criteria for success/level of performance. For example, you may include the:
  - level of accuracy – the number correct, such as eight out of ten steps correct or the percentage correct, such as at 90% accuracy)
  - duration – how long the person will perform the task, e.g. for 45 minutes, or within a timeframe, e.g. within two weeks
  - latency – the length of time before responding, such as responding within 30 seconds
  - frequency – the number of times, e.g. four times.



### How is the level of success determined?

The level of success is determined by the task. If the person is learning to cross roads or travel by train, the level of accuracy required during the acquisition phase is 100% due to safety.

### Case study: 6 Nita

**Individual:** Nita

**Cooking skills:** One of Nita's goals is 'Nita will learn to prepare three hot meals independently in a period of three months.'

The first instructional objective will be for Nita to learn to cook one hot meal.

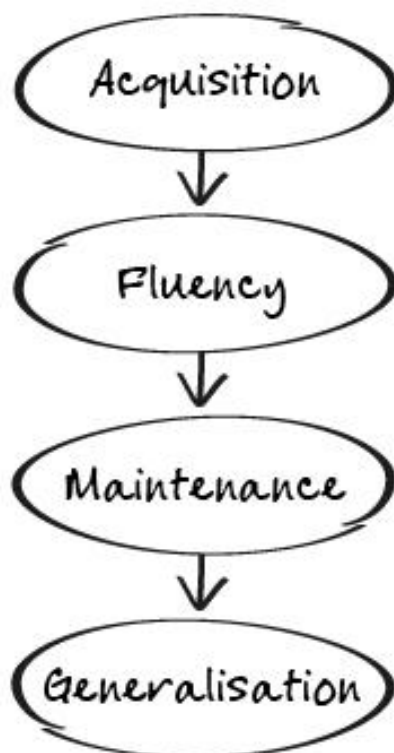
The components of the instructional objective are determined as follows:

Components	Example
Participant's name	Nita
Specific behaviour or task to be performed	will prepare scrambled eggs on toast
Conditions	when provided with a recipe with picture prompts
Criterion for success/level of performance	at 100% accuracy on three consecutive occasions

**Instructional objective 1:** Nita will prepare scrambled eggs on toast when provided with a recipe with picture prompts at 100% accuracy on three consecutive occasions.

## The phases of skill development

As people learn how to perform a task they will move through the four phases of learning. These are:



In order for a person to achieve a goal and be able to apply their learning in appropriate contexts, instructional objectives should be developed for each of the four phases of learning. This breaks learning towards a goal into manageable steps for the individual. Learning at each phase is supported by particular teaching strategies as outlined below.

### Phase 1: Acquisition

The acquisition phase is when an individual acquires knowledge and skills accurately with minimal support. In this phase, teaching involves:

- Supporting the person to acquire essential knowledge and skills by breaking the learning into manageable chunks.
- Demonstrating how to apply the knowledge in a sequence of steps that the individual responds to by imitating the behaviours.
- Providing support and aids where required, for example images or visuals.
- Providing repeated opportunities for practice.
- Providing feedback.

### **An example of an instructional objective in the acquisition phase**

When asked, John will select a \$1 coin from a choice of three coins *with 90% accuracy* on three consecutive occasions.

### **Phase 2: Fluency**

The fluency phase is when an individual is getting better and faster at applying the knowledge learnt and demonstrating the skills in a task with increased accuracy. In the fluency phase, teaching involves providing frequent opportunities to practise the task. Fluency is particularly important for tasks that must occur within a set time. For example, taking money out at the ATM, and crossing roads in response to a walk sign.

### **An example of an instructional objective in the fluency phase**

When asked, Nicki will select a \$10 note from a choice of three notes with 100% accuracy *within three seconds* on three consecutive occasions.

### **Phase 3: Maintenance**

The maintenance phase is when the individual is remembering knowledge and skills over time and demonstrating them with accuracy and fluency. In this phase, teaching involves reviewing knowledge and skills and practising them at planned intervals. At first, the review should be frequent, such as checking the persons' ability to do the task once per week. Over time, review will occur less frequently, dropping to once per fortnight, once per month etc. This will vary depending on the skill, the frequency of its use by the individual, and the risk to the individual in getting it wrong.



### **An example of an instructional objective in the maintenance phase**

When asked, Brenda will select a \$2 coin from a choice of five coins with 100% accuracy *within three seconds after one month*.

## Phase 4: Generalisation

The generalisation phase is when the individual applies knowledge and skills in different contexts and in different ways. In this phase, teaching involves creating opportunities for the individual to apply the skill or task in a variety of contexts and in different ways. For example, they may be able to use their new skill with a different support person, shopping in a different shop or catching the bus from a different bus stop.

People with a disability often have difficulty generalising information and skills to other materials and settings e.g. they may be able to recognise a bus stop in their street but not in an unfamiliar suburb.

*Source: Rosenberg & Westling (2010)*

### **An example of an instructional objective in the generalisation phase**

When asked, John will select a \$1 coin from a choice of five coins with 100% accuracy within three seconds after one month for a *variety of purchases*.

## Supporting learning

When teaching an individual a new task, you need to consider the adjustments, support and prompts that will help them to learn. Examples might include:

- Providing pictures of each step of a task, such as a visual recipe.
- Labelling or colour-coding equipment.
- Providing a visual or written routine.
- Using approximations and reinforcing attempts at getting the skill right. For example, when learning to write their phone number, a person initially traces it, then copies it, then writes it independently.
- Using assistive technology, including:
  - 'Apps' on an iPad or iPhone
  - text reader or word prediction software
  - YouTube clips
  - the internet.

It is important to note, however, that any artificial props or scaffolding are temporary and should be lessened as an individual becomes more successful or independent in undertaking a task. Scaffolding should be reduced in a gradual and planned way by changing the level of support provided to the person.

## Task analyses

Task analyses are used to break practical tasks into a sequence of steps that form the basis of teaching and learning. Once the individual has mastered all of the steps they will be able to complete the task independently.

### What does developing a task analysis involve?

Developing a task analysis involves the following six steps:

1. Develop an instructional objective for a goal, appropriate to the phase of learning, as described above.
2. Identify and record each of the steps in the task.
3. Plan the materials and assistance the person will need.
4. Plan your teaching and prompting procedures.
5. As the person undertakes the task, record the level of prompting required for each step.
6. Count the number of steps the person performs *independently*. This will allow you to monitor progress.

The person's progress towards doing the task independently is recorded and evaluated by the number of steps they are able to perform on their own. You may choose to focus on only a small number of the steps at one time, depending on how quickly the individual learns. This assists the individual to feel that what is being asked of them is manageable and that they are experiencing success as they learn new things. It is important to consider the phase of learning the person is at when determining the instructional objective.

These steps are outlined in detail in the section below. The following case study shows a task analysis that will help Teresa learn to wash her clothes independently.

## Case study: Teresa

**Individual:** Teresa

**Goal:** Teresa will learn to wash her clothes independently.

**Step 1:** Develop an instructional objective for the goal, appropriate to the phase of learning.

**Instructional objective:** Teresa will complete steps 8 to 13 on her own to do a load of washing on the normal cycle. The place on the dial is marked with a sticker and delicates and wool have been separated on two previous occasions.

**Step 2:** Identify the steps of the task (below). These are recorded in a table starting from the bottom so that progress can be graphed.

<b>Date:</b>							
13. When the wash is finished, takes the washing and puts it in the wash basket							
12. Turns the dial to the sticker that marks the normal cycle							
11. Pushes the cold wash button							
10. Closes the soap container							
9. Pours the contents of the measuring cup into the soap container							
8. Opens the soap container							
7. Pours washing powder into the measuring cup to the marked place							
6. Shuts the washing machine							
5. Puts one of the piles into the washing machine							
4. Opens washing machine							
3. Turns on washing machine							
2. Sorts clothes into whites and colours							
1. Takes clothes basket to laundry							

**Step 3:** Determine materials and supports required.

Materials may include the equipment or ingredients required. Or they may include the types of supports. For example visuals to assist the person in completing the task.

In the example above a sticker has been used to mark the measuring cup and normal cycle.

**Step 4:** Determine the teaching procedures (see below) and prompting procedures.

**Step 5:** As the individual undertakes the task, record the level of prompting required for each step.

**Step 6:** Count the number of steps the individual performs independently. This enables you to monitor progress.

## Teaching procedures

As a Facilitator, you will teach an individual the steps of a task in a sequence. This sequence is called a behavioural chain. It can be a forward, backward or total task chain. Whatever chain you use it is important to demonstrate or prompt the person for steps they are unable to demonstrate independently and over time the prompts are faded out.

### Forward, backward and total task chains explained

- A **forward chain** is teaching the steps one at a time from the first step. As each step is mastered, the Facilitator adds a step.
- A **backward chain** is teaching steps one at a time from the last step. You demonstrate the last step, then the last two steps, then the last three steps as they are mastered.
- A **total task chain** is teaching and doing the whole task each time.



### **Deciding how to teach a task**

Deciding on how to teach a task depends on each person's needs and how quickly they acquire knowledge and skills. You may assess this by doing the whole task with the person the first time and see how they respond to the prompts given. Backward chains

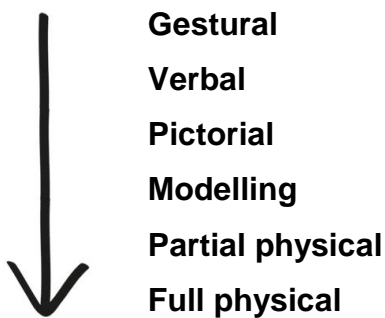


are useful for tasks that are difficult as they can support the individual's motivation by enabling them to achieve the final step each time.

### **Prompting procedures**

Teaching individuals any new task involves prompting. Prompts involve providing additional assistance to increase the number of correct responses. Prompts should be as weak, or as unobtrusive, as possible to enable participants to be as independent as possible. Only provide the level of prompting needed. This will be assessed during the first assessment of the task, as described above in "Deciding how to teach a task".

Use prompts from least to most:



Prompts must be reduced over time and should only be used as long as required. This will reduce the person's dependence on the prompts and move them towards independence in that task.

Prompting procedures might involve the following:

1. **Decreasing assistance** – systematically reduces the level of prompting as person acquires the step.
2. **System of least prompts** – used for initial assessment and once the task is starting to be acquired. This method starts with the lowest level of prompting and increases the level of prompting as required.
3. **Time delay** – involves using the same level of prompting but, over time, increases the time provided to allow the person to respond before prompting.

The above information is a basic introduction to task analyses and prompting procedures. Comprehensive information can be found in a number of sources including P. A. Alberto's, & A. C. Troutman's 8th edition *Applied Behavior Analysis for Teachers*. Please see the References section for more information.

## Concept development

### What are concepts?

Concepts are the categories we use to classify items, events, or ideas. We use common features or characteristics to do this.

Examples of concepts include developing an understanding of what certain words refer to, or what symbols represent. For example, recognising a 50c coin; understanding the concept of a friend; or understanding that the numbers before a decimal point represents dollars. Sometimes as part of a task you will be required to help the person develop a new concept or concepts.

Concept learning can be supported by:

1. Drawing attention to key features of an item, idea or event. For example a 50c coin has corners, smooth edges and is the biggest coin, a friend is someone we know well.
2. Linking existing knowledge to new material.
3. Relating things through diagrams, concept maps or mind maps.

4. Clearly explaining the meaning of words. For example 'terminating' means something will come to an end. On a train it means the train will finish its journey at the named station.
5. Providing examples to help the person recognise the contexts that apply. For example, you could explain the concept of a 'half' in relation to cutting sandwiches or measuring liquids in a measuring cup.

## Recording progress

When teaching new tasks it is important to gather information in relation to progress towards the instructional objectives and goals you have planned. The information gathered will help identify if the teaching, or instructional objectives, need to be adjusted to make the task easier. Or you might find that you have broken the task down into too many steps, so you may be able to merge some of the steps together. Sometimes only part of a task needs to be focussed on, as the individual may be able to do the other parts already. The information gathered may also provide the individual with a way of reflecting on their achievements.

You can gather information using:

- anecdotal notes
- checklists
- videos
- photographs
- graphs
- numerical data
- recording the level of prompting (which you do for a task analysis).

## Supporting learning using visuals

Visuals can be used to assist learning and can include pictures, words, photographs and catalogue pictures. Visuals can be organised in a variety of ways as described below. The decision about what type of visual system to use is based on the needs of the person and the learning it will support.

If the person cannot comprehend what a picture or word represents straight away, or shortly after being taught what it refers to, do not use it. It is better to use a representation the individual can understand with minimal effort.

When paired with other symbol forms (for example photos, pictures or objects), written words act as a guide to the person with whom the individual is communicating. The individual may also learn to associate the written word with what the symbol represents.

### **Single symbols**

Presenting one symbol at a time can be used to indicate what will happen next, such as a shower symbol to represent time for shower. Or, it can indicate the location of objects and activities, such as a picture of a knife and fork, representing the cutlery drawer.

### **Sequences**

Sequences of symbols placed in order are useful for representing routines and the steps in a task or activity. You can use the symbols in a horizontal or vertical sequence, depending on the routine or steps you need to describe.

### **Lists**

Visual lists can be a useful tool. For example, a list of symbols can be used for shopping. The symbols can be arranged in a set order (perhaps the aisles at the supermarket) or randomly assigned.

### **Books**

Books can be used when it is necessary to display a series of related steps one at a time. You could produce a book of recipes, for example, or group symbols according to category to describe feelings on one page and activities on another.

## Technology

Technology is increasingly being used to support learning and communication. New applications (Apps) are frequently being developed for ease of accessing or teaching information.

## Social relationships

Relationships outside the home are particularly important as they provide networks of social support. The Australian Social Inclusion Board (2010) explains, “visiting or meeting with family or friends can assist people to feel connected, cared for, and part of their community”.

*Source: Australian Bureau of Statistics (2009)*

Social skills involve a range of concepts and skills. Social skills are a less structured form of learning and involve decision-making and problem-solving in a variety of contexts and situations. Much social learning is best developed in context.



Learning can be supported:

- incidentally (i.e. on the spot as things happen)
- through explicit teaching, for example discussing problem solving or ways of keeping in touch
- through repeated opportunities to interact
- through role-playing
- using video.

Feedback from ILSI Facilitators suggests that the more people engage in interactions, the better their language gets.

*Source: (ADHC, 2011)*

The person you work with should be given regular opportunities to spend time with people of their choosing. It is important that the person understands the concept of a friend, for example:

- The characteristics that make friends different from other groups of people such as neighbours, carers and other people they meet.
- That friendships are reciprocal and involve give and take.
- Friends have equality within the relationship. This is important for the safety of each person in the relationship. Each person has an equality of power and the right to have a say.
- Friendships involve honest and open communication.
- Friends value one another and choose us and like us for ourselves.
- Friends have common interests.

People with a disability have fewer social connections outside family and service providers, and rely heavily on family. The structured nature of many human service settings, services, and programs do not lend themselves to the development of friendships.

*Source: McVillya, Stancliffe, Trevor, Parmeter, & Burton-Smith (2006)*

Friendships are of high importance to people with a disability and require a commitment from those supporting them. Friendships are essential:

- for intimacy, companionship and affection
- for shared experiences
- to gain an identity as an individual outside the family
- to feel valued
- to have the confidence to take risks
- for emotional support
- to assist the person to fit into settings and activities
- to prevent loneliness, isolation and anxiety
- for support in a crisis
- for physical and psychological health.

## Facilitating relationships

For friendships to develop and continue, individuals need to have an ongoing and consistent physical presence in each other's lives. This is developed through shared time when the friends are engaged in common interests.

As a Facilitator you need to ensure that repeated opportunities for social interaction are scheduled in the individual's routine. For some people, the focus will be maintaining and strengthening friendships. For others it will be widening social circles and opportunities for participation.

You can play a role in supporting the individual to develop and maintain social relationships by:

- prioritising social relationships as an essential part of the individual's well being
- creating opportunities for friendships to develop
- supporting the person to accept their disability and value what they have to bring to a friendship
- assisting the individual to advocate for themselves and problem solve
- teaching and reviewing social skills on a regular basis
- teaching the skills needed to plan an outing and travel to see friends or take part in community settings
- supporting the individual to stay in touch through other means such as emails, text messages, social networking and phone calls
- teaching safety skills.

Volunteering and membership of sporting and community groups are two forms of community involvement that are consistently associated with higher levels of social support.

*Source: Flood (2005)*

## Problem solving

Problem solving is an important part of all social relationships. Things to consider:

- The person may have difficulty recognising and naming their feelings.
- Sometimes people do not like to admit/share negative feelings.
- Many people with a disability are very reliant on other people. Sometimes this leads them to give answers that they think will please others (or not cause problems), rather than being open and honest.
- Some people with a disability are used to others doing the talking for them and are not given opportunities to talk about their feelings, dreams and what they want for their life.

You can support the individual in problem solving by:

- Acknowledging that negative feelings are OK. If you can read the person's body language, you could say things like: "That must have made you feel angry" or "You must be feeling disappointed."
- Reinforcing that nothing is so bad that they cannot tell someone.
- Acknowledging that mistakes are OK. As a Facilitator, it is important to set an example by acknowledging when you make mistakes, and talking through your thinking and strategies for improving the situation in the future.
- Modelling your thinking process. You could say things like: "I was thinking this but it was not working so I decided to do something different." People with a disability typically have difficulties with self-regulation, for example planning, monitoring and adapting the plan.
- Listening without over-reacting or acting hurt.
- Reinforcing that you cannot solve problems when you are angry, it is important to take time to calm down first.
- When you say 'No' explain why and acknowledge the person's feelings.



## **Intimate relationships**

One area that may cause conflict when working with families is the person's desire to have an intimate relationship.

People with a disability have the same diversity of sexual needs and desires as other people in the community. However, people with a disability often have limited opportunities for sexual relationships for a number of reasons, including a lack of privacy, other people's views on their readiness and being dependent on others for daily living.

Therefore it is important that individuals have opportunities to learn about intimate relationships as they may require assistance to understand the complexities of relationships and the rights and responsibilities involved in intimate relationships. Additional support and resources are available through a number of agencies, including Family Planning Australia.

## **Key points from Chapter Eight**

- The aim of living skills development is to teach the individual to perform tasks independently, or at a lower level or frequency of support.
- We want to provide the person with the necessary social skills to be able to expand and sustain their network of support.

## **Questions for reflection**

1. What sort of learner are you?
2. Is there any task you remember learning step by step? Try backward and forward chaining this task.
3. Do you remember learning a particular social skill? Think of how you might teach this to someone else.



## Chapter Nine: Making the transition

## Making the transition

A transition plan is a planning tool and a supportive framework that assists the person with a disability and their family to prepare for the move to more independent living arrangements in a coordinated way. This chapter includes information on the following:

- the transition environment;
- transitional issues; and
- transitional planning.



### The transition environment

Everyone's circumstances are unique. Financial, health, social and other factors will make a difference to the way a person moves from one place to another. In addition, some individuals will already know where it is they want to live while others may need some time to explore various options before they can identifying suitable accommodation.

In summary, each transition is different and each environment will shape the transition process in different ways. However, whatever the circumstances, it is important that a plan is created to provide each individual and their family and carers with a structure and a means by which to review their progress.

### Transitional issues

You can use the transition plan (described in detail below) to address some of the issues that may arise. We have explained some common issues and how to address them.

### Develop a solid relationship

Building trust is crucial if individuals, families and carers are to feel they can rely on you to provide support and assistance at each stage of the transition process. It is therefore recommended the lines of communication be documented in the transition plan at the first meeting and clearly understood by the individual, the family and the Facilitator.

This trust will enable the individual, the family and the Facilitator to handle the ups and downs of the transition process. For example, some individuals can experience a burst of enthusiasm at the beginning of their engagement with ILSI but then find the program confronting. They may even refuse to meet with either their Facilitator or support worker. This is not unusual and is often part of the process. It does, however, require a good working relationship between the family or carer and the Facilitator. If this connection is strong the family or carer can relax, secure in the knowledge the Facilitator will work patiently and innovatively to engage the individual. Additionally, the Facilitator can relax, secure in the knowledge the family/carer understands the process and will support them as they work to engage the individual.

Parents, carers and individuals can also find the process time-consuming and intrusive as the person develops more skills. For example, certain parts of learning living skills (cooking, laundry and general housework) are often carried out in the family home. In addition, parents and carers can find the demands of finding, organising and moving the person with a disability into their new accommodation tiring. For these reasons we recommend Facilitators make themselves aware of the needs of the family/carer and at all times negotiate a pace that suits them.

### **Develop a health management plan**

Any health issues need to be discussed with the individual, family or carers, and healthcare providers. A health management plan must be drawn up to be used when the individual moves out of home or becomes increasingly independent.

### **Address financial issues**

Planning around financial issues during the transition process is critical to long term success.

People who lack financial understanding may not be able to fully contribute to society, resulting in financial and social exclusion.

*Source: ASIC (2011)*

Discussions about finances need to begin early. In your role as a Facilitator, you will need to assess the financial literacy of the individual. You will also need to learn more about how the family or carers expect the individual will manage their finances once they move out of home.

These are not easy topics. However, the earlier the discussion begins the more time there will be to address any issues that may arise.

In the initial stages it is important you find out how the individual currently handles their money. Can they for example, use an ATM? Can they count change? Are they able to plan a weekly budget?

Some people may need time to adjust to any new financial arrangements. For example, some individuals may have little expertise or control over their money when they begin the program. Planning how to move forward could involve the family or carer addressing a wide range of issues including:

- what account will the person's money will be deposited in
- who will have access to the money
- how will they have access to the money
- how the mortgage or rent, utility bills and grocery shopping will be paid for
- risk management
- estate planning.

## Information storage and review

The person's file is a focal point that contains all the information about their life – whether logistical, family, financial or medical. It is therefore crucial it provide all relevant data about the individual so that you as a Facilitator, and the organisation that you work for, can deliver a service of excellence.

When writing files it is recommended you follow the policies set by your organisation. Information usually recorded includes:

- an individual profile, including family details
- communication needs
- regular activities
- employer details
- risk assessment checklist
- risk assessment profile
- health care plan
- medication
- medical appointment record
- person centred plan.

It can be useful to think of the file as not only a factual record but also a detailed account of the individual's 'story' as they progress through the ILSI transition process. The clearer the story, the less likelihood there is for misunderstandings or mistakes to occur. For example, if something important changes – such as an individual's health status, family situation or employment status – this needs to be clearly flagged so that anyone who is working with the person is immediately aware of any changes.

It is also useful to tell the 'story' about the support that the person receives as a way of monitoring progress and learning more about what works and what doesn't work, and what the person likes and what they don't like. As a repository of knowledge, the individual's story is likely to become more and more important as they age. With the passage of time there will be fewer and fewer family members who can be asked about the individual and their family history.

## Transition plan

The day the person moves out of the family home and into their own home is likely to be seen as the culmination of months and months of hard work and a source of immense pride – even perhaps some trepidation. For this reason it is important a schedule of all the tasks that need to be done before and immediately after the move is drawn up well in advance.



In general a successful transition plan includes:

- a list of the specific tasks that need to be done in order to make the move happen
- information on who is responsible for the completion of each task
- a proposed completion date
- a built-in review system.

The list usually includes information on:

- appliances and furniture required and how they will be sourced, delivered and assembled
- the connection of utilities
- removal plans
- keys
- food
- bed linen
- clothes
- medication
- money
- plans for how the first night will be spent.

In addition there needs to be an emergency contact list for the individual. This should include:

- emergency services
- family contact numbers
- maintenance contact numbers
- utilities contact numbers
- supported living contact numbers.

It is important the person is familiar with the purpose of each emergency contact and knows when or why to call each one. For example, they need to know what will happen when they ring 000. They should also be told they may need to be assertive and that if they believe they need urgent assistance, they may need to insist on speaking to someone who understands their needs.

There should be several copies of the emergency list, including a portable copy that the person can carry with them, as well as one clearly displayed at home. Numbers should also be stored clearly in their mobile phone contacts list. Furthermore, each copy should detail the number in full for each contact in case the individual is not able to access their mobile and/or speed dial.

Moving is stressful for anyone. However, the more you plan and think ahead the less stressful it will be for the individual and the family.

Once the move is completed it is important you ensure that all services and relevant organisations are notified of the person's new address. This may include their employer, Centrelink, Medicare and the Australian Electoral Commission.

It is also a good idea to assist the individual to create a weekly schedule detailing any support visits – including the time, date and purpose of the visit.



## Key points from Chapter Nine

- Successful transition planning takes time and trust.
- Expect hurdles, obstacles and surprises – and reassure the individual and family you will support them throughout the entire process.
- Planning for the week of the move is part and parcel of the transition process.
- In general a successful transition plan includes:
  - a list of the specific tasks that need to be done in order to facilitate the move
  - information on who is responsible for the completion of each task
  - a proposed completion date
  - a built in review system.

## Questions for reflection

1. Think of one big transition in your life and make a list of the steps you needed to take during the process. How straightforward was it? Did a list help?
2. Have you ever assisted someone during a transition in their life? Think about what you did that was useful and what was not quite as useful.



## Chapter Ten: References and Appendices

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# Appendices

## Appendix 1: ADHC Fact Sheet – ILSI Participant

Ageing, Disability and Home Care (ADHC) is working, together with Down Syndrome NSW (DSNSW), on a program called the Independent Living Skills Initiative (ILSI). It will look at the support needs of people with a mild to moderate disability, who live in their family home and have ageing parents or carers.

### What is ILSI?

If you have a disability with low to moderate support needs the Independent Living Skills Initiative (ILSI) is a program you may find useful. ILSI is a support program that can assist you and your ageing carers plan for your longer term living arrangements so you can live more independently and be more involved in your local community. It offers training in living skills to help you achieve this goal.

ILSI also helps you establish a group of support people called a circle of support to be there when you need some help. All of this is done using an approach called 'person centred planning' to help you make a plan about what you want to do and how your goals can be met.

### What will ILSI provide?

There are a number of activities the ILSI program can help you with. Being involved in the program means you and your family will be supported to think about your longer term living arrangements. You may want to stay in your current home or move into a flat or house with friends or relatives. The program will provide you with training to help you get the skills you need to live more independently. Skills could be anything from cooking, money management, personal health, or communication, to name a few.

ILSI will also help you develop effective support networks around you. The ILSI program calls this a circle of support. Of course you may already have some good support people or groups that are your own circle of support. Apart from your support group, you will be able to use up to 35 hours per week of support from trained staff. How many hours you get will be worked out after your existing skills are reviewed. Of course this means that as your skills develop, the support needed will be less and the support hours may reduce.

Person centred planning is also used to help you look at your long term goals and the steps needed to achieve them. Taking a person centred approach means focussing on your skills and what you would like to achieve in your life. Basically it's about placing you at the centre of what you want to get out of life and supporting you along the way.

ILSI won't provide the housing for you but the program will help you to think about what you would like for your living arrangements in the longer term.

### **What about the family and carers?**

As parents, brothers or sisters or other carers, the ILSI program will suit you and the person you care for if, together as a family you want:

- to plan for the future of the person with a disability;
- the person you care for to be provided with the skills and supported to shop, cook, and look after themselves in their home and be involved in their community;
- to build support networks to help the person you care for move toward more independent living; and
- the person you care for to live independently either at home, in a granny flat attached to your home, or into a place of their own or with a friend.

## **Who is eligible for ILSI?**

We are looking for people who:

- have a disability with low-moderate support needs;
- are between 18 and 64 years of age;
- have an ageing carer who is over the age of 60 years. For Aboriginal or Torres Strait Islanders carers the age is 45 years or over;
- are a resident of NSW;
- have the potential and most importantly, wish to live more independently after a period of intense training and skills development in things like managing money, shopping cooking, washing, personal safety;
- do not require more than 35 hours per week of staff support and do not require formal ongoing overnight support; and
- together with your family, are prepared to work with support staff to set and work towards your independent living goals.
- are able to identify their long term housing goal within the first three months of the program (i.e. to continue living in your family home, renting a flat or house, or sharing accommodation with a friend or relative).

## **How do you apply for the ILSI program?**

The first step in applying for the ILSI program is to complete the short Expression of Interest form. After that, you and your family will need to complete the application form.

This will be done with your support coordinator or case manager who can assist you in putting together the information required. If you don't have a case manager or support co-ordinator, ask one of your other support services such as your Occupational Therapist, your work program supervisor, your doctor or another support worker, to assist you in completing application forms.

After the forms are complete they will be submitted to an intake group that will review all applications and prioritise them for acceptance into the program.

The program may be expanded in the future, so if you are unsuccessful this time, you may be considered next time.



## **Appendix 2: ADHC Fact Sheet – Service Provider**

### **What is ILSI?**

The Independent Living Skills Initiative (ILSI) is for people with a disability with low to moderate support needs that can assist people to more independent living and be more involved in their local community. It offers intensive training in living skills to help people achieve their goals.

ILSI helps people to establish a support network that people call a 'circle of support' using a person centred approach to help people make a plan about what they want to do and how their goals can be met.

### **What will ILSI provide?**

There are a number of activities the ILSI program can help with. Being involved in the program means the person and their family will be supported to think about their longer term living arrangements. People may want to stay in their current home or move into a flat or house with friends or relatives. The program will provide people with training to help them get the skills they need to live more independently. Skills could be anything from cooking, money management, personal health, or communication, to name a few.

ILSI will also help people to develop an effective support network or circles of support. People may already have some good support people or groups that are their own circle of support. Apart from the support group, people will be able to use up to 35 hours per week of support from trained staff. How many hours people will receive will be worked out after their existing skills are reviewed. As people's skills develop, the support needed will be less and the support hours may reduce.

Person centred planning is also used to help people look at their long term goals and the steps needed to achieve them. Taking a person centred approach means focussing on people's skills and what they would like to achieve in their life. It's about placing the person at the centre of what they want to get out of life and supporting them along the way.

ILSI won't provide the housing for people but it will help people to think about what they would like for their living arrangements in the longer term.

### **Leigh's story**

Leigh is a 34 year old man and lives in Newcastle with his mum, step-dad and brother. Leigh works three days a week as a doorman at the local bowling club, where he enjoys his favourite hobby, lawn bowls. Because Leigh has Down Syndrome, some people may think this would be a big barrier to achieving goals like getting your driver's license, living independently and gaining your dream job as a public presenter.

Through the Independent Living Skills Initiative (ILSI), Leigh has overcome many barriers and has been working hard with his support staff to develop his independent living skills and social connections. Leigh currently receives an average of 25 hours per week. He is very keen to move out of home and have his own space.

Leigh has established a support network, which helps him work towards his dreams and goals for the future.

Leigh loves public speaking and was MC at his brother's wedding, mother's 60th birthday, the launch of the ILSI documentary at Parliament House in July 2012 and will speak at the House With No Steps annual gala dinner with Wendy Harmer in November 2012.

When Leigh has spare time, he helps promote ILSI through presentations to ADHC and regional service providers. Leigh's presentation can be seen at the ILSI website [www.ilsinet.au](http://www.ilsinet.au).

### **Who is eligible for ILSI?**

ILSI may be suitable for people who:

- have a disability with low-moderate support needs;
- are between 18 and 64 years of age;
- are a resident of NSW;
- have the potential and most importantly, wish to live more independently after a period of intense training and skills development in things like managing money, shopping cooking, washing, personal safety;
- do not require more than 35 hours per week of staff support and do not require formal ongoing overnight support; and
- together with their family, are prepared to work with support staff to set and work towards their independent living goals.

As part of ILSI, people must also be able to identify their goals for long term housing within the first three months of their involvement in the program. Long term goals can include continuing to live the family home, renting a flat or house, or sharing accommodation with a friend or relative.

### **How are applications made for ILSI?**

People may self-refer or be nominated by their family/carer, Case Manager or other service providers. If they wish to nominate themselves, they can contact their regional ADHC Intake and Referral Team and ask to be considered for ILSI.

### **For more information**

People can contact their regional ADHC Intake and Referral Team to enquire about ILSI or other Drop-in Support options. Phone numbers for regional offices can be found online at [www.adhc.nsw.gov.au/contact\\_us](http://www.adhc.nsw.gov.au/contact_us).

### **Appendix 3: ILSI Facilitator job description – suggested template**

1. To give people with disabilities a chance to think and talk about their future and define their aspirations around living independently in the community.
2. To work alongside the individual in developing their independent living skills.
3. To bring together a circle of support around each individual that can support the individual to develop skills and achieve their transition into independent living.
4. To support the circle through training, facilitation, ongoing contact and by providing relevant information.
5. To identify barriers to individuals achieving transition and to be aware of and discuss any risk/safety issues involved.
6. To ensure that the goals identified by each young person remain the focus of work for each team.
7. To contribute to workshops.
8. To receive regular supervision from the ILSI Program Coordinator
9. To attend regular Facilitator team meetings.
10. To undertake any other duties as appropriate within the role, via negotiation with the organisation.

Appendix 4: ILSI Facilitator /participant matching tool



## Appendix 5: Workplace Supervision Agreement

This is a suggested template.

Supervisee name \_\_\_\_\_

Supervisor name \_\_\_\_\_

The following supervision structure/agenda has been agreed upon by the above parties:

1. Update on work related issues – anything that is impacting on work at present.
2. Any work related matters arising which need to be addressed and discussion as to how these will be addressed.
3. Manager feedback to staff member.
4. Identification of any training needs and how these will be addressed.
5. Any other business to be discussed.
6. Action plan with timescales (if necessary).

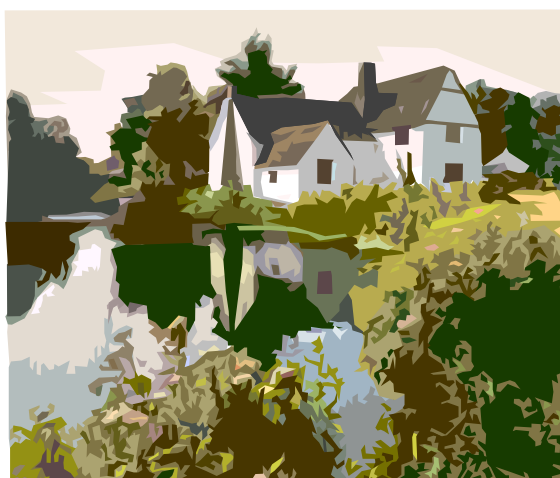
Signed \_\_\_\_\_ Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Signed \_\_\_\_\_ Date \_\_\_\_ / \_\_\_\_ / \_\_\_\_

## Appendix 6: Being an ILSI participant

### Being a participant in the Independent Living Skills Initiative

# Independent Living Skills Initiative



This is the plan . . .



First, you will spend time getting to know your Facilitator.

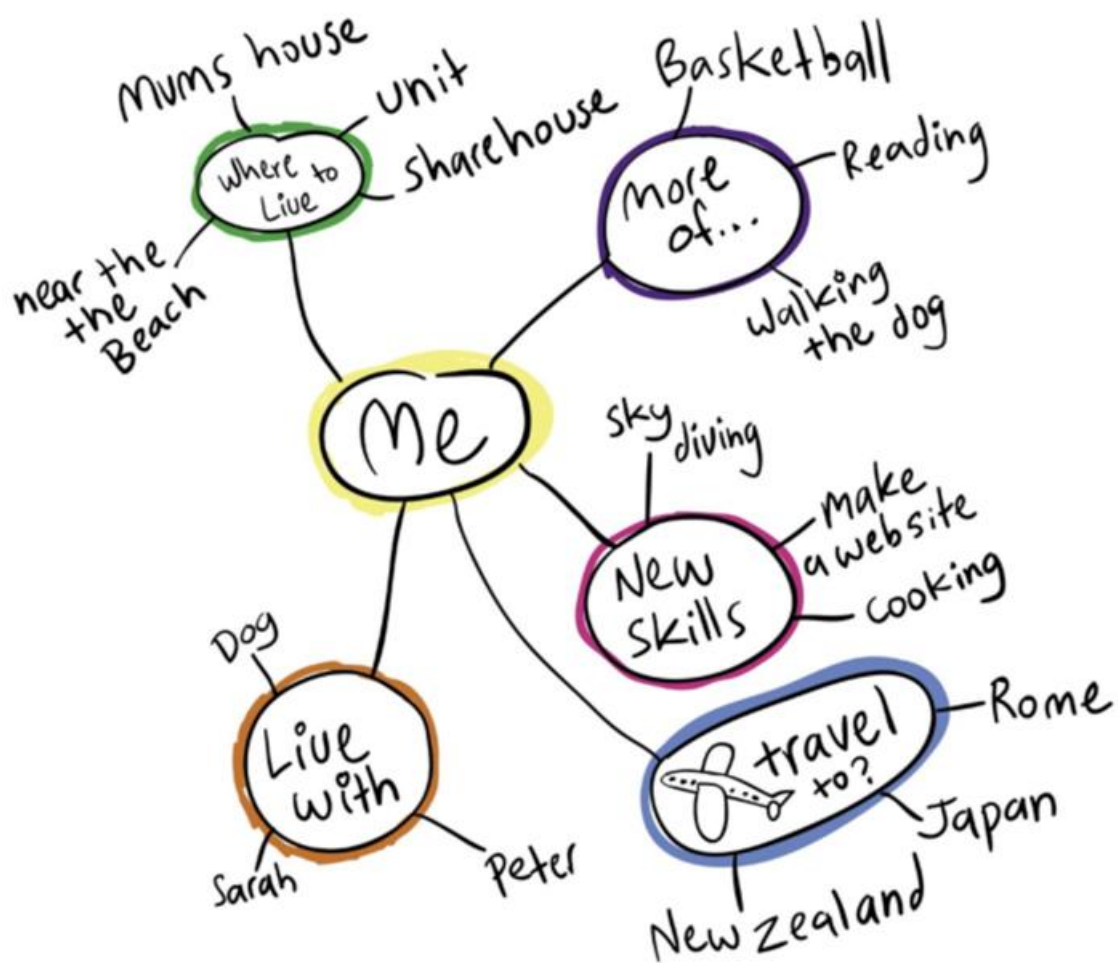


Mapping is where you talk about your life, your family and your friends. You can also talk about the stuff you enjoy doing, what you like, what you don't like . . .



Then you go on and talk about your dreams and goals... think about what you would like your life to be like now and in the future.

Where would you like to live? Who would you like to live with?  
Would you like to learn any new skills? Would you like to travel?  
Would you like more friends? What are your dreams?



After this you can think about your circle of support. Who can assist you to reach your dreams and goals?

Your circle of support can include your family, your friends, people you work with, people from your faith community, neighbours... anyone you want.





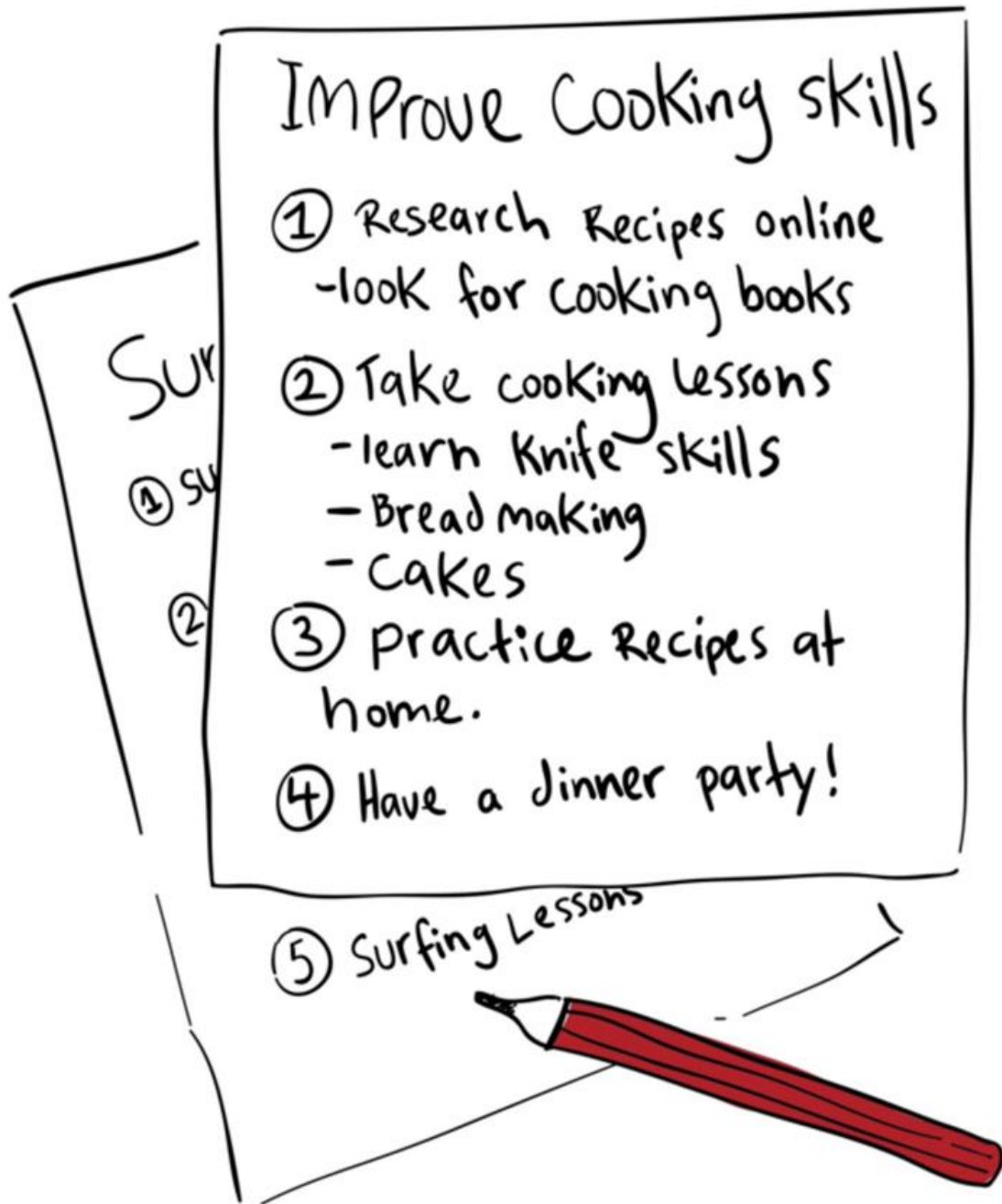
When you have decided on the people who can help you, your Facilitator will help you to call your first circle of support meeting.

At the meeting you will be able to talk about your dreams and goals and make an action plan. You might not be able to reach all of your goals very quickly, but you can make a good start in working towards them.

Some goals you can achieve more quickly. For example, you can talk about the skills you need to build on for independence.



You will make a plan on how you can action the goals, and then start work on them.





You might want more travel skills, computer skills, money handling skills, cooking skills, first aid skills or you might want to learn to sing and dance, you might want more social activities...

Your circle of support will do what they can to help you achieve at least some of your goals and plan to increase your skills for the future.



The circle will meet up regularly to look at what progress has been made and make sure you are happy with your work.



Your Facilitator will work directly with you to support you to achieve some of your goals as well.

You will have the opportunity to meet up with other ILSI participants and share your experiences with them as well!





**Remember:** Ask your Facilitator about anything you don't understand.





# Independent Living Skills Initiative



Illustrations by Paul Summerfield  
[www.ageofwonder.com.au](http://www.ageofwonder.com.au)

**Appendix 7: Circle of support review tool – a suggested template**

**Review of Action Plan**

**To be completed monthly – at Circle of Support meetings if possible**

Date of Circle of support meeting: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Name of participant: \_\_\_\_\_

Name of Facilitator: \_\_\_\_\_

List which other Circle members are at the meeting and/or who have been consulted prior:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

### Action Plan from previous meeting

	Points (in brief)	What has been achieved?
1		
2		
3		
4		
5		
6		

**Review of goals**

Progress report on goals and any other relevant issues:

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## Appendix 8: Graphing personal plans

Person centred planning focuses on making a positive difference to a person's life through acknowledging the person's dreams and supporting the choices that are important to them.

The person's ideas must be listened to and kept at the centre of the planning process. To ensure people are actively involved in expressing ideas, making decisions and putting their plan into action, it is important planning happens in a way that they understand and can follow.

Recording the plan in an accessible way – one that reflects the person's learning and communication styles (Grove & McIntosh, 2002; Dick & Purvis, 2005) is vital if individuals are to be engaged with the process. In other words if participants can read their plan, understand it and share it with others, it is more likely it will be put into action.

Graphic facilitation (Sibbet, 1997) is an effective technique for recording planning in an accessible way. It is particularly useful for those people who are visual learners. Some people may have difficulty with literacy, they may have learning difficulties or disabilities, or English may not be their first language. Graphic facilitation provides an alternative to the typical typewritten black and white plans that are not often distributed until sometime after the meeting.

### What is graphic facilitation?

Graphic facilitation uses the power of visuals to help people see their thinking. Graphic facilitation uses large charts, graphics and text to capture and communicate key ideas. It works on the principle that graphics are more quickly and easily understood and remembered than words alone. Graphic facilitation involves recording and organising a person's and/or group's ideas with clear and colourful graphics, symbols, icons, and words on large sheets of paper or charts. These charts create a rich picture of the planning conversation enabling people to discuss specific detail without losing track of the purpose of the conversation. Spoken words and ideas are easily forgotten, however graphic facilitation creates a permanent picture record. In this way ideas are not lost and it easier to refer back to ideas for elaboration or clarification.

Graphic facilitation takes place in *real time* - as the conversation is happening. The chart created provides a permanent reminder or summary that can be referred to and followed. The chart motivates people to talk, brainstorm and reflect, encouraging the person and/or group to move forward.

A major strength of the graphic facilitation process is that the person can take his or her plan with them immediately after the meeting. There is no lapse of time waiting for the plan to be written up and distributed. Taking a digital photo of the plan enables the plan to be photocopied or emailed to participants and distributed promptly. The immediacy of receiving a copy of the plan is affirming and increases the likelihood that the plan will be implemented.

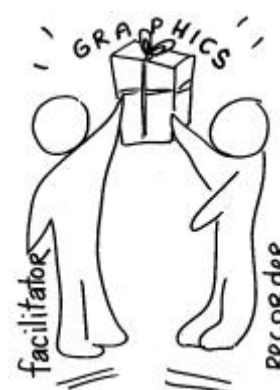


### Using a process and a Graphic Facilitator

Graphic facilitation works best when there are two Facilitators - a Process Facilitator and a Graphic Facilitator (or graphic recorder).

The Process Facilitator works with the person and/or group to draw out ideas and keep the conversation focused and moving forward. The Graphic Facilitator records the conversation – literally drawing the ideas as they are expressed, enabling participants to ‘see’ the conversation.

The Graphic Facilitator uses marker pens and large sheets of paper to develop a picture of the conversation as it evolves. Through careful listening and being fully present, the Graphic Facilitator turns the thoughts and ideas expressed by the person or group into colourful symbols and graphics. It is important that the graphics are kept simple so they can be easily understood and recognised. Clear graphics assist the recorder to keep up with the ideas as they are shared.





Don't try and record everything you hear. Instead focus on the key ideas and feelings – with the flow of the discussion.

Person centred planning approaches use creative ways of recording the conversation. The Graphic Facilitator uses a template for organising the thoughts expressed during the conversation. This may be a pre-designed template such as those used for PATH (Pierpoint, O'Brien, & Forest, 1993), MAPS (Vandercook, York, & Forest, 1989) and 4+1 questions (Sanderson, 2007) or it may be a personalised template that the Graphic Facilitator designs specifically for an individual or a particular meeting.

It is important to:

- be present and focussed
- have effective listening skills – listening for the key ideas, messages and feelings
- quickly understand and follow information, organising it onto the chart in a logical format
- have an imaginative and creative spirit
- record the key ideas with simple graphics, images and words
- retell and summarise the conversation at appropriate times.



Remember to prepare yourself:

- warm up and focus
- make sure you are fully present
- think about the possible content and graphics.

Remember your materials:

- make sure you have a variety of pens
- make sure the room is well set up and the chart is visible to all participants.

## What you will need

- *A room.* Thought must be given to the room where the planning meeting will be facilitated. The room and its furnishings must be comfortable, private and reasonably free of distractions.
- *Graphing space.* Graphing space is particularly important. A flat, smooth graphing space, ideally at standing height and within hearing and seeing distance of the participants is required.
- *Good quality paper.* Good quality paper is important, as the chart becomes the record of the planning conversation. The paper must be durable so that the plan can be relocated and revisited. Good quality paper will reduce the risk of ink from the pens seeping through onto the graphing space behind. Paper of 80GSM is recommended and rolls of 841mm x 50m x 2" core are available from Art Supply shops.
- *Marker pens.* A selection of marker pens, pencils and crayons are required to capture the mood and content of the conversation. Pens with fine tips, blunt tips, vivid colours and pastel colours all help to give texture, feeling and interest to the graphic.
- *Tape.* Some way of attaching the chart to the wall or surface is required. The tape must have strength and durability. You do not want the chart falling down during your recording. Masking tape works well as it does not damage the surface when you take the chart down.
- *A digital camera.* At the close of the meeting take a photograph of the chart. Take two – one of the chart and one of the participants standing in front of the chart. The digital copy can be emailed directly to participants (it will be on their computer before they arrive home or back at work) or photocopied, for participants to take away.

## Getting ready to draw

Forget about those nagging thoughts *I can't draw* or *I am not creative*. The secret is to listen to conversations – you will be given the ideas. When people often speak informally they often use very graphic language. People talk about being *on time*, *on the ball*, *at 6's and 7's* – when such descriptive language is used it is easy to conjure up appropriate images.

Choose five words, ideas or phrases that are commonly expressed and create a simple graphic to represent them. It is like learning a new language. Listen for these words and ideas and draw them (either physically or in your mind) whenever you hear them. Gradually build up your visual language, five and then five more and then five more. It won't take long to have a strong visual vocabulary.

Look around – we live in a very visual world. There are graphics and symbols everywhere. Some organisations have large budgets for branding and promotion; many businesses for advertising; publishers pay significant fees for illustrations for books and magazines; children produce art every day. Look out for these ideas. Jot down graphics from these resources and develop your personal visual dictionary. By practicing a few simple and easily learned graphics regularly on a large piece of paper using some straightforward templates, and a variety of coloured pens, you will be drawing in no time.

### Learning about graphics

- Take a walk around the local shops and neighbourhood – look at signposts, signs, billboards, notice boards
- Go to a magazine stand and watch TV advertisements – note the colour, spacing, wording, and graphics.

### Graphing in action

Think words, colour, lines, squares, circles and triangles – it's as simple as that. Graphics are made of combinations of these basic shapes.

### Words

Words are important in a graphic, as the graphic must be *readable*. Accompanying words with a simple graphic can help explain them.



To do this think of the feeling or message associated with the word, practice writing words in many different ways to reflect this – in script to give a flowing effect, in upper case to give prominence, in block letters to give dominance. Then, add some colour and watch them transform.

## Colour

We live in a colourful world. Studies have shown that people have similar reactions to colour and that we associate certain objects and feelings with certain colours. The careful use of colour is a powerful tool to add to your graphic toolbox. Colour will have a dramatic impact on your graphic.

Think of an idea, thought or concept that is sombre, happy, nurturing, sad, exciting, developing, dull, solid, and fluffy. What colours might you use to represent these ideas that will add feeling to the graphic.

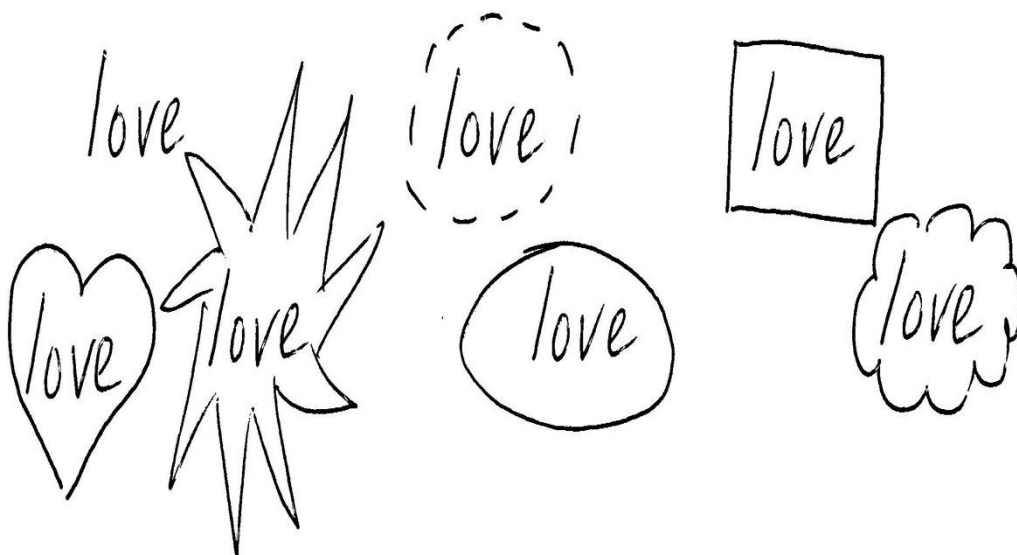
- Use bold, strong, dark colours for important or main ideas.
- Use yellow or fluorescent colours for highlighting.
- Use a specific colour to represent different groups of people, for example, draw the focus person in purple, the family members in green and friends in blue.



## Lines

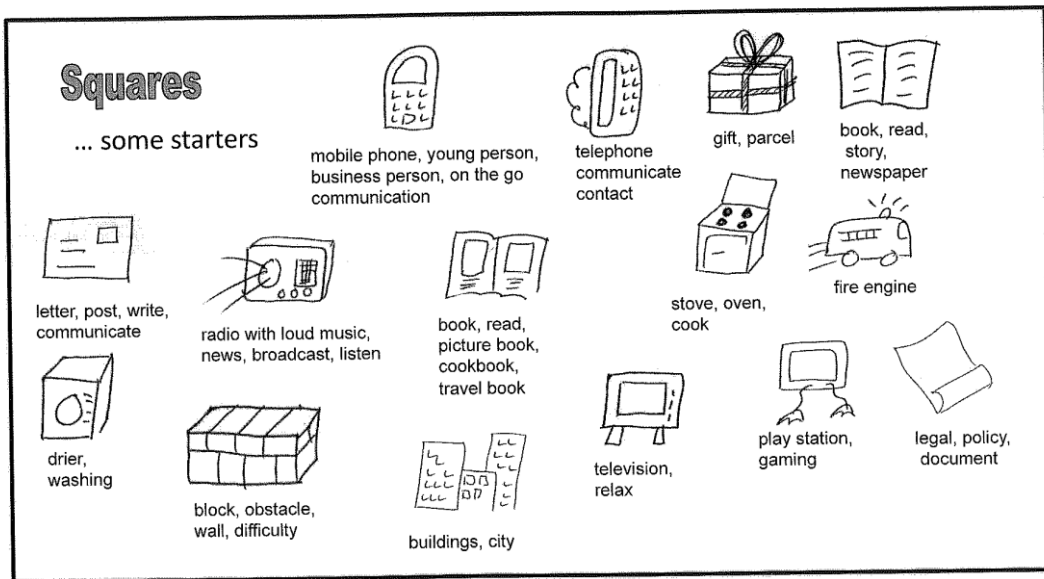
Lines come in many different forms and go in many different directions. Practice drawing a straight line, a wavy line, a jagged line, a curved line, an arc, a spiral. Practice drawing a variety of lines – and think about the feelings these different lines might imply.

Lines can be used for emphasis, for borders, as connectors or to convey a feeling. Consider the word below – does the border make a difference?



## Squares

The square is formed by two vertical and two horizontal lines. Draw a square slowly and deliberately and then very quickly. It may change from a square to a rectangle, or the sides may not be even, straight and exact. Is there a different energy suggested between the two? Is there a different feeling? The basic square forms the basis of many everyday items and concepts. Here are a few to get you going – add your own.

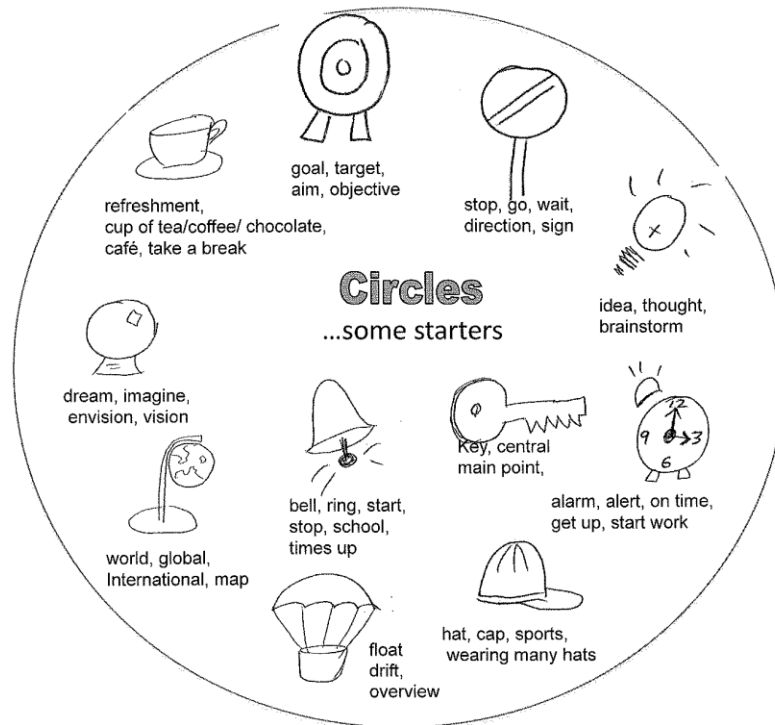


Draw some of your own here:



## Circles

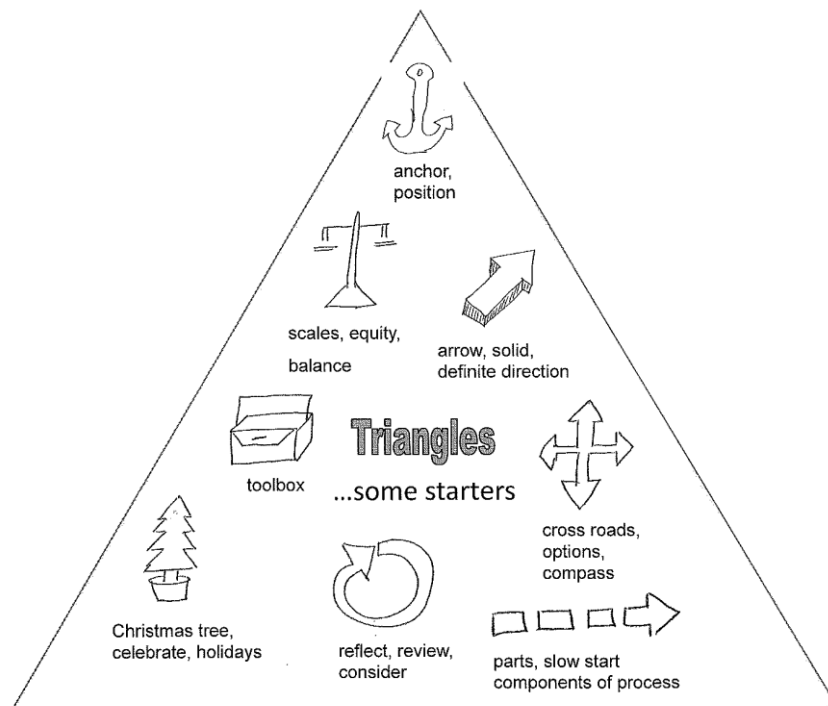
Practice drawing circles – use the freedom of your arm. Circles can be formed by many different types of lines. Look around you wherever you are – what circular shapes can you see? Here are some circular shapes to start you off.



Draw some of your own here:

## Triangles

The triangle consists of three connecting lines; again they can be of a different type. Triangles are used often as they form the spearhead of an arrow. Arrows point and give direction – forward, backward, reflective, multi-directional or uncertain – and so are common features of many graphics. They are connectors as well as indicating direction. Here are some triangular shapes.



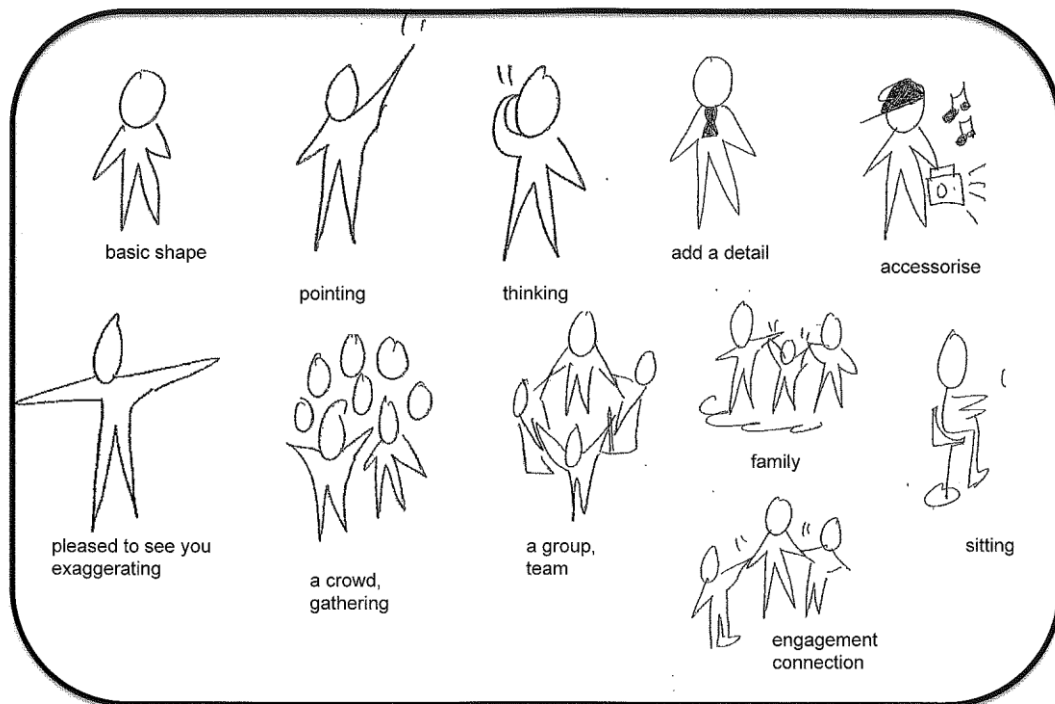
So that's almost it – words, lines, colour, squares, circles and triangles. Put these shapes together with your creative energy and you can create any graphic.

Remember – keep it simple, less is more.

## People

Your graphic will almost always include people – individuals and groups. You might choose to draw a stick person or the star person. The star person has the advantage of a body onto which you can add a little detail to personalise it and give added meaning.

When drawing people, think about what the person is doing. Where are their legs? Where are their arms? What are they holding? Where are they standing? Combine your person with some of the graphics you have already mastered. For example a person might be standing under a tree, beside a blackboard, on top of the world, on an arrow, on a skateboard or holding a fishing rod.



- Practice, practice, practice
- Create opportunities to graph:
  - the main points of the next meeting you attend
  - the content your favourite television program
  - the words and feelings while listening to songs your thoughts while listening to music you enjoy.



Graphic facilitation is not about creating a pretty picture. It is about creating a meaningful picture of the planning event. The chart will provide the details of the plan, the goals and specific actions towards achieving these. It will also identify support. The chart will show the process of the planning as well as the agreed upon outcomes. The chart must make sense to the people who will refer to it as it will be the blueprint for the person's life over the next short while.

## Summary

Graphic facilitation should:

- be accessible for most people
- engage people
- promote diversity and understanding of viewpoints
- encourage and capture the creative ideas of participants
- take people along – starting with a blank chart and a template and building a visual picture
- encourage interaction and participation – and be fun!
- inspire action as everyone can see any agreed actions
- generate ownership
- inspire teamwork and collaboration
- promote a common understanding
- clarify commitments and accountabilities.

**Appendix 10: Discussing risks and promoting safety form**

**Discussing risks and promoting safety**

Please complete this form to help the individual and their family think through the safety issues in starting a new activity such as travelling somewhere new independently.

Name of participant: \_\_\_\_\_

Name of Facilitator: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

What is the activity you would like to do?

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What will be good about this activity for you?

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What safety issues or problems might you face if you do this activity?

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How would you tackle these problems? Do you need any support? Do you need some more skills? Record your decisions and action plan here:

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Ageing Disability and Home Care  
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Family &  
Community Services

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