

Building Community through Circles of Friends

A practical guide to making inclusion a reality
for people with learning disabilities

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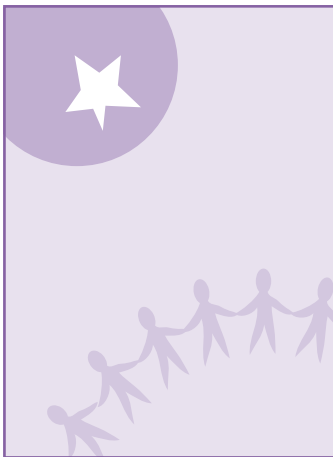
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INTRODUCTION

No man is an island, no man stands alone
We need one another, so I will defend
each man as my brother
each man as my friend

Unknown

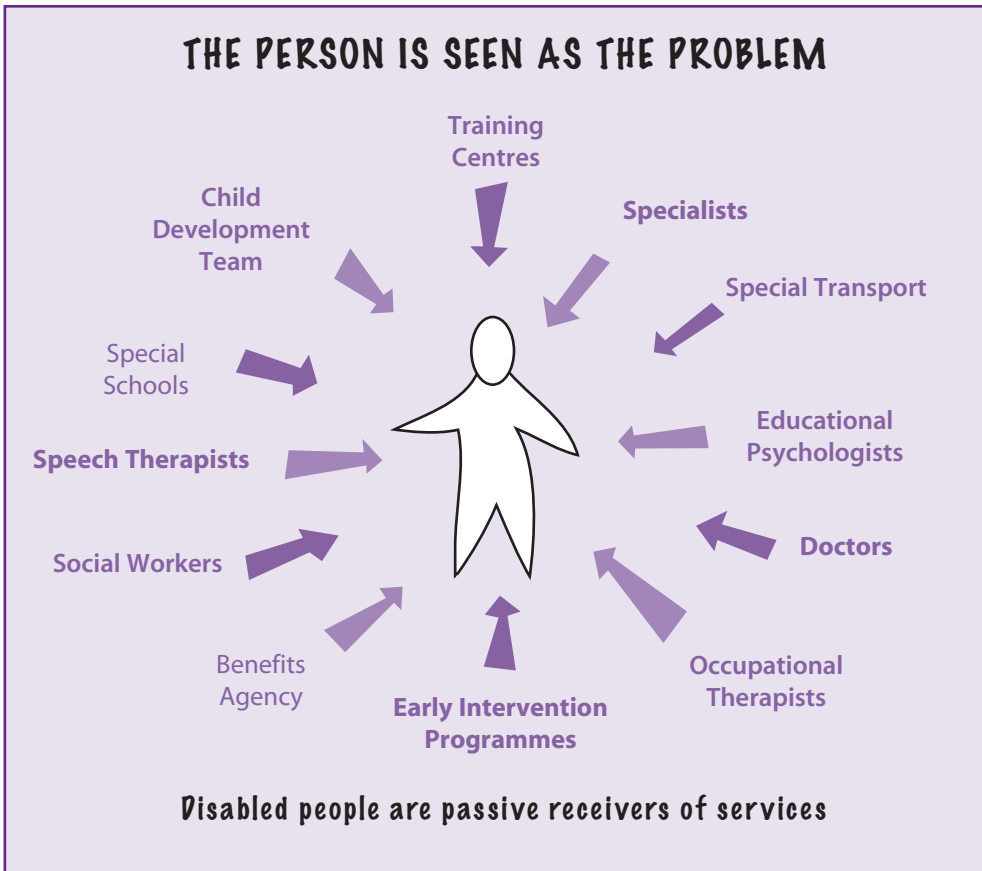


The need to belong is a fundamental human characteristic found in all societies. It is described as part of being human - a need as strong as the need for love or water. For most of us this need is expressed in terms of our family, our friends and neighbours and our involvement in a range of community activities in our neighbourhood. But in this age of world communication and travel, 'community' and 'neighbourhood' are perhaps not so easy to define. Many people still talk about the loss of 'neighbourhood' - a place where they felt they belonged - a part of a group called community. The old understanding of neighbourhood offered the idea of a grouping of caring relationships based on friendship, mutual support and belonging.

The fact that people with learning difficulties have for so many years to a large extent missed out on this feeling of belonging and being part of a neighbourhood has long been recognised. Services for people with disabilities have changed considerably over the last 30 years in efforts to reverse the negative impact of institutional care and isolation on people's lives.

Pioneering thinking and practice in the United States included Wolfensberger's normalisation principles¹ and John O'Brien's five accomplishments². In the UK, the publication of 'Better Services for the Mentally Handicapped' (1971)³ followed by the development of the 'an ordinary life' principle⁴ resulted in people being able to move out of institutions and into more ordinary homes in the community. The influence of other pioneering work in the States by people such as Beth Mount, Judith Snow, Jack Pearpoint and Marsha Forest has had a major impact on making services more responsive to individual needs and emphasising the rights of people to live in their own communities like other citizens. A significant part of this development has been the idea of circles of support, and in the UK we have seen how, through circles, people are able to gain more control over their own lives and start to have more natural community relationships.

The Medical Model



The Social Model



More recently, in the UK we have had the Community Care Act which went a long way in supporting the end of institutionalisation and segregation, and now we have 'Valuing People'⁵.

Underpinning all these movements has been the aim of supporting people to lead a full life within the community. John O'Brien's 5 Accomplishments became a central part of many organisations. Yet people remained isolated and lonely. It has taken us some time to realise that 'community presence' (John O'Brien's first principle) alone would not achieve inclusion: people found themselves living in the community but not part of it. Could it be that these honourable principles became systematised because they were not fully rooted in the values of inclusion? Perhaps we did not recognise how entrenched the 'medical model' was in influencing our thinking and practice.

We have come to realise that one of the reasons for our slow progress in achieving real inclusion for people is services making decisions that are service-led and finance-led rather than being directed by what people want for themselves as individuals. Sadly, there is a danger of history repeating itself. Some homes in the community have become mini institutions. We find ourselves discussing how we can stop colleges becoming the next generation of day centres. Unfortunately this situation is unlikely to change unless we have more action at policy level to ensure that services are firmly rooted in the principles of inclusion.

Valuing People - a way forward

'Valuing people' brought great hope for the development of better lives for people with learning difficulties. It introduced the idea of mainstream lives and led to a renewed surge of interest in working with people as individuals. The focus on person-centred planning and the development of a team that would ensure partnership and create an environment for change was far-reaching. For the first time, inclusion is stated as a main principle.

Yet even here there is need for a clearer definition of inclusion – what it means to be involved in the mainstream of life. This lack of clarity means that services still define segregated practice as inclusive. The more specialist segregated services we have, the more we are likely to perpetuate an environment where people are isolated, rather than being part of and supported by an inclusive community.

There is a danger that this welcome renewal of enthusiasm and energy is being focused on the 'tools' and ways of planning – for example, person-centred-planning – rather than being focused on creating inclusive lifestyles for people. Achievements are claimed in the name of person-centred planning, when in fact the services remain the same and there has been no real systems change. We seem to be experts at sustaining the status quo whilst implementing new ideas. Could it be that there is too much invested in systems and our livelihood to accept real change?

'Valuing People' offers us the way forward for policy change that has the potential to revolutionise services and support systems. However, it relies on good partnerships between special and mainstream services at all levels. It requires strong leadership from commissioners right through to managers at the coalface, and an on-going dedication and commitment. Evidence suggests that this is only happening in limited ways across the country.

A Rap in response to peoples Dreams

*So why cant I have the same as everyone else on this date
All people do is sit back laugh and discriminate
So is this the reason why im getting so irate
Is this the way it is or is there another way
Coz all I wanna do is work for my pay
Get in my car and drive up the highway
Relax on a cruise or a 2 week holiday
Be able to swim get on a plane and fly away*

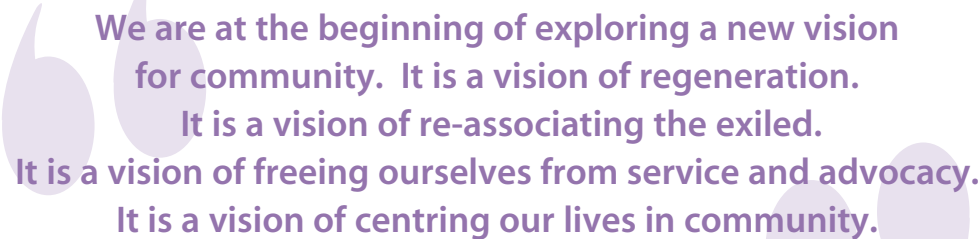
Darren Attard
Bournemouth Theatre in Education

It is not always easy to connect people and there are some people who are in circumstances that make it extremely difficult. This book is dedicated to all the people struggling with this question. It describes ways that have been found helpful in supporting people to become connected, illustrated with real life examples. It considers the practical steps to developing a circle of support that will result in long-lasting friendships and on-going connections in a person's local community.

**Getting on
with the job**

It is a resource to help understand the values that need to underpin the process of person-centred-planning. It reminds us why things are the way they are now and why so many people still lead lonely and isolated lives with not much control over what happens to them. It reminds us how services can end up 'disabling' people but also the positive role they can play in supporting people to gain a richer lifestyle.

If we want to achieve a world where difference is respected and everyone is included, we must focus on building inclusive lifestyles based on the principles and values of inclusion. The following chapters describe how some people have been supported to do just that. Their stories are rich in learning and show us that we can change people's lives from being disempowered and isolated to being rich with friendship and community.



**We are at the beginning of exploring a new vision
for community. It is a vision of regeneration.
It is a vision of re-associating the exiled.
It is a vision of freeing ourselves from service and advocacy.
It is a vision of centring our lives in community.**

John McKnight – The Careless Society.

Four O'Clock in the Morning

*I'm up high and awake, it's four o'clock in the morning
The night is still young, I'll always be the Ellen I ever was
Trouble I remember from my school days
I'm telling the truth with a fag in my hand
I love you, the boy that loves me*

*People around me, that want me to be happy
I know smoking kills, I say it straight from my heart
Rules are there to be broken, I'm friends with the big guys now
I'll never stop dancing the night away
Through the night, I want to get on one tonight*

*Nothing and no one can hurt me, I'm friends with the big guys now
I'm Ellen the melon forever, feel safe and secure
I feel sexy, just for you
Kiss me Mr DJ kiss me, kiss me good
I love you, he's one of my guys*

*It's five o'clock in the morning, the birds are about to sing
The sun rises to shine
There's a party all tonight, singing happy birthday
Give me a pint or two
I feel like a princess when boys come around
To lift me high, I'm friends with the big guys now
I'm friends with the big guys now*

Ellen Goodey



FRIENDSHIP



When Toby knocked on the door and asked to play with Andrew I was totally dumb struck. I could not believe that this was happening and let him in, wondering whether this was just a dream. Toby has now been Andrew's friend for 11 years. He is getting ready to go to university but I know that he will always be there. Andrew's mum

Throughout history mankind has chosen to live in communities, be it extended families or tribes. Our relationships with one another are what give us meaning in our lives. Our friends are vital to the quality of our lives and we know from all the research done on friendship, what an impact it has on our well-being.

So what does it take to make friends? Do you remember what it was like going to school or even nursery school for the first time? How did you meet those who have become your lifelong friends – probably some of the most important people in your life? The likelihood is that they were part of your extended family and network of friends with whom you grew up.

Friendship fulfils a fundamental human need to belong. Yet this need has been ignored in most support systems for people with learning disabilities and many studies have indicated that they have few friends and are often lonely and isolated. Research also demonstrates the adverse effect of loneliness on our mental and physical health (Count us in⁶, Making us count⁷, Wall 1998⁸). Now we find ourselves looking at how we can reverse this situation and support people to build friendships and become connected in the community.

Today's lifestyle does not make this task any easier. Gone are the days when we knew everyone living around us. Life is so much busier. Our technology-driven society, for all its benefits, has made it possible to live 'separated' lives, unconnected with our local neighbourhoods. We do not need to leave the house to work, shop or play. This can make 'connecting to our community' very difficult for some of us, particularly those who are elderly or disabled.



Mary had not been out of her house for over a year. She had support from human services but no connection with anyone else. Her meals arrived in the morning by a different driver each day. She had someone to help with her housework twice a week. Her community nurse dropped in to check on her. And that was it. She had no family, no children and no friends. Her dream was to be able to go to church sometimes, particularly at Christmas. Such a simple dream, yet no-one had thought to try and make this happen.



She used to be a frequent member of her church community and they were horrified when they realised they had neglected to find out where she was or what had happened to her. Several people offered to be part of a rota to pick her up and take her back home after the service. She now joins in some activities and has a new group of friends that have brought meaning to her life. Just bringing the local priest back into her life changed the pattern of her existence. But should her connection to the church have been left to a chance meeting with a stranger who bothered to ask why?

So how can we tackle this problem? Indeed, can we 'create' friendships?

In recent years many 'friendship schemes' and one-to-one volunteer programmes have been set up, but as a general rule these have not resulted in many long-lasting friendships and connections with ordinary members of the community. People still find themselves leading a largely service-centred life with most of their companions and supporters being staff and other service providers. In spite of every good intention, too often these schemes did not foster the natural processes for forming friendships, perhaps because of a lack of understanding – a need for more careful consideration of how friendships are formed. Friendships cannot be forced: they can only be encouraged by developing and nurturing opportunities that will create possibilities for real sustained friendships.

John O'Brien and Connie Lyle O'Brien (In 'Members of each other'⁹) point out that we have to break down the barriers to making relationships that exist in community. We have to overcome the perception that people may not be able to belong - that they are 'better off with their peer group'. Even though more and more examples of true friendship are being recorded and are 'visible' in the community we still find many people who are challenged by the idea of ordinary friendships between disabled and non-disabled people, motivated only by friendship and enjoyment of each other's company. That is not to say that we do not value friendships between disabled people, rather that ordinary friendships are also to be supported.

Personal relationships are vital ingredients in the quality of our everyday life. It is how we do things together as neighbours, friends, colleagues, family. Relationships are our 'connections with people' - people we trust - people we share experiences with and have fun with. They are there through the good days and the bad. Relationships are important because they offer us support, they

Developing relationships

help us grow in confidence. They are there for mutual benefit - we learn and grow with each other. They help us belong to a social group.

For most of us these various types of relationships and 'connections with others' are freely given. In the 'inclusive world' we are aiming for we would want this to be the case also for people with learning difficulties. Sadly, it is not so. Too many people with learning difficulties still find that most of the people they spend most time with are paid to be with them.

Barriers to building unpaid relationships

Professionalism

Professional training tends to promote a distance between professional and client. We are taught to maintain boundaries. It is considered bad practice to allow close relationships to develop. A concentration on people's 'deficits' instead of their abilities has fostered a lack of belief in people's capacity to build relationships. Disabled people have primarily played a subservient role and have 'learned' to think of themselves as somehow deficient and not equal citizens. In addition, too much emphasis on duty of care and risk assessments fosters a service-centred culture that limits people's development as individuals.

Segregation

Systems of support keep people apart in segregated activities – even though these may take place within the community. People are 'present' in the community but not included. This makes it almost impossible for relationships with non-disabled people to be built. The result is that 'non-disabled people' are unsure how to behave with disabled people, perhaps fearful, with stereotypical notions of what disabled people are like. They tend to have low expectations of them and doubt their capacity. This is particularly true when they find themselves with someone who has additional physical disabilities or has unique communication with or without words. The feeling of inadequacy makes people shy away particularly if they feel that it would need a lot of time and commitment to get to know the person.

Lack of valued social roles for disabled people

Relatively few disabled people occupy roles of social or community importance. Few are perceived as employer, friend, spouse, student, parent, lover, leader. To get inclusion right we need to see disabled people as potential contributors to society - not a drain on resources.



On the face of it, Lyn 's life seems to be so much better now that she lives in the community. She has a room of her own and lives with fewer people. Yet there is something missing. She does not like the people she lives with and is generally bored by the constant monotonous calendar of activities put together to keep her occupied and busy. Lyn wants a special friend that she can share a flat with. She wants to be able to look after her own flat and do things as and when she wants to - even stay home now and then and do nothing.

In 'Community Building in Logan Square'¹⁰ Mary O'Connell describes how she found that the most successful way of including people and encouraging valued social roles happened when ordinary citizens took on the responsibility to guide excluded people out of services into community life. This project addressed important issues around community building and regeneration. It brought disabled people out of the role of clients and into a new identity as citizens.

Any community is stronger for having active citizens rather than passive clients. Mary O'Connell

It is easy to make friends with people we feel are our social peers. It is more difficult to choose friendships outside this category. It also encourages the belief that people with learning disabilities should only be friends with each other. Reversing this perception and creating an atmosphere of mutual growth and friendship is the message of this book.

Developing opportunities for people to lead an inclusive lifestyle within the mainstream of life is something that needs to be taken seriously by politicians, planners, families, citizens and service providers alike. Addressing the barriers that maintain segregation and prevent inclusion will start to build a society based on friendship, respect and partnership – where difference and diversity is part of the fabric of life and all are equal. In this vision of society ALL people whatever their differences or disabilities are using the same mainstream systems of support, education, work, leisure and social life.

I think that when you don't have real friends you can't experience real life because real life is how you get on with people. I can't do anything on my own so I am completely dependent on people helping me, so if I am not going to be surrounded only by personal assistants, I have got to find a way of making friends. Maresa Mackeith

CONNECTING WITH COMMUNITY

What is community?



Creating opportunities for community connections

Being there as a human being not a human doing.
Be there when no one else is
Be there sometimes at your own expense,
It may not be to do anything but be

Communitas poem

Community is a much-used word with many different meanings and interpretations. Essentially, it is where 'home' is. Where we belong - where our friends and family are - the people who know and care about us. But, particularly in our modern world, it can have broader meanings. In 'Friendship and Community'¹¹, Kennedy, Sanderson & Wilson (2002) define community as having three parts: community as geography, community as a local social system, and community as shared identity. In 'Ties and Connections'¹² (King's Fund, 1988) community is defined as being part of or belonging to a network of relationships due to association, interest, neighbourhood, family or friends. It goes on to say:

"People describing 'my community' may be thinking of very different kinds of things. Yet people seem to have a pretty strong sense of what their community is and what makes it work or not work for them. Some people have ties and connections with others that not only stretch across the world, but are of many different kinds, including family, culture and religion. There are 'communities of interest' of a thousand different kinds - of commitment to particular causes or groups, work, leisure and learning."

When community cuts itself off from people who are disabled, it also denies part of what it is to be human. A community that has no place for those who cannot speak, or walk, or do higher mathematics is finally impoverishing itself

The Gift of Hospitality - opening the doors of community life to people with disabilities.

Mary O'Connell 1988

Opportunities for connections can be created by exploring places in the community where people spend time together. Leisure centres, churches and other religious organisations, libraries and other public places are all rich sources of activities and people. Even supermarkets now often have a café - another 'space' that people can spend time in and use as a resource.

Many people go to be with others because of common beliefs, interests or gifts - joining in or helping with community events and having fun with others. Going to the cinema can be a great night out but joining a film club is more likely to result in conversation and getting to know new people. Shared interests create a feeling of togetherness, a chance to let go of preconceived attitudes and see a person as just another person who shares the same interests. Shared interests are the 'ice breaker' in relationship-building.

Taking part in organising the Best Garden event brought Jane in touch with other organisers as well as garden lovers. She is now known as a valued community member rather than that disabled girl who lives down the road.

Sometimes connections can be made by creating an opportunity for one person and then opening it up to the whole community.

Supporting Sally to develop her interest in yoga called for creative thinking. Sally was 53. She joined the local adult education college but was still isolated. There were few activities for over 50s in the area. Meeting a yoga teacher created the opportunity to build community for Sally. We offered the yoga teacher a free venue at a local church. For the priest, it was an opportunity to develop yoga for over 50s in his church, thus building his connections with the community. For the yoga teacher, the 'deal' included giving Sally a lift to and from the class and accepting her help as assistant to collect a donation of 50p from each participant. The priest enrolled the ladies committee to make tea and sell it, thus making a bit of extra income for the church. We printed fliers and distributed them. Over 40 people aged 50+ enrolled. Sally had a positive role as assistant and as fellow learner of yoga. She started to make connections, offered her support to the church and helped with tea at other church activities.


Volunteering

Creating opportunities for volunteering can also result in friendships. Supporting the Friends group at the local hospital, joining a political association, or a tenants' association, can open up a whole world of working together to create change.

Jaheed has volunteered to be part of a campaign to keep canals clean. He goes with a group who clear litter from the canal paths, making a safe and pleasant place for the community to use. Nurturing friendship within the group becomes a possibility.

Jobs


Many people develop relationships with co-workers and others they come into contact with at work. Having a job is a dream of many people with learning difficulties but still comparatively few people are gainfully employed.

 *Tracy works in a library. Professionalism in doing her job, coupled with her great gift for making friends, has made her a respected colleague. She loves work and the friendship it offers her. She belongs. It has given her great confidence in all aspects of her life.*

Building relationships is something that a lot of people do naturally in everyday life. It is a skill we learn as children and internalise. We are not aware of how we build friendships. Helping to build friendships for others takes time and the way to support this varies from person to person. You cannot be certain about how potential friendships will develop. Sometimes the most unlikely person will turn out to be a 'successful' connection while someone who seemed a certainty will not. Give people a chance. Do not rule out anyone. There is no magic formula or guarantee that doing everything you think is possible to bring others into a person's life will yield the results you hope for. With some people many non-paid relationships will be built. For others we may only be able to create opportunities for connection and hope they will in time lead to relationships.

Keeping people connected

When people find themselves in crisis, the sequence of human service events often results in the person being plucked away from their community.

 *Rachel was moved to an outer borough placement when her dad died. Trying to build community for her was difficult as there was nobody in her life apart from paid people. When eventually we learned her history we had a conversation about her dad and where she used to live. She talked of her dad's friend the Rabbi. Contacting him was the starting point for reconnecting her to old friends. The Rabbi was delighted to find her and introduce her back into her community who received her with great love. They helped her move back to her borough of origin and her life changed dramatically.*

Re-thinking the role of staff

Organisations need to fight the temptation to systematise relationships, by for example, introducing training and procedures on how to build relationships. The emphasis should be on supporting staff to use and enhance their own natural skills. It is about keeping a natural process - not creating a 'formula' for it to happen. Staff who seem to have a special gift for making connections should be encouraged. They will be valuable role models for other staff.

One of the biggest dilemmas for staff is balancing their professional role with their personal relationship with someone they support. They will often feel a conflict between their 'duty of care' and their desire to encourage people to try new things and have a richer lifestyle. Managers have a key supportive role to play here and organisations need to produce clear guidelines and policies that will give staff the freedom to develop new opportunities for people within a framework of taking risks safely.

Janet is visually impaired. She likes to go to church and got on very well with two women she met there. One of them offered to come and visit for a cup of tea once a week and read with her. Staff at the house where Janet lives found this very difficult. They felt they needed to recruit her as a volunteer, do a risk assessment and undertake a police check. They failed to see that this contact would have taken place in the house where Janet is never on her own and – most importantly – that this friendship would have greatly enhanced her life. Playing 'gatekeeper' in her life, they made it impossible for this to happen.

A world of disconnectedness

Current interventions from nearly all professionals and service providers have the effect of breaking natural relationships between disabled people and everyone else. When this happens in early childhood, the consequences are devastating both for the child, and for society as a whole

Micheline Mason, Incurably Human¹³

Helen's circle is a success and meets regularly but apart from her circle she has nothing else. She is still isolated and lonely and struggles with keeping life going. A sense of a 'community life' is difficult to find where she lives. It is a residential area where most people are out working during the day and there is little community activity. Helen is in her 60s. Such older persons' groups that are available, Helen finds boring and inappropriate. There is no low-cost place where people generally can go and spend time reading a newspaper or a book and have a cup of tea or eat their packed lunch.

Helen would like a companion who could live with her at a low rent in return for spending time with her. However, this would affect her housing benefit and place her in a precarious position. There are no resources locally that would allow some funding to support her to gain access to community life.

Bridge Builders

A bridge builder introduces new people and places, initiates conversations, helps to show what people are really good at and nurtures friendships and relationships. A good bridge builder will use his/her own networks and connections and watch out for opportunities to make new ones which will further the focus person's dreams and ambitions.



Joe moved to a house of his own in the community. He went to the same pub regularly and had some other activities but never really got to know anyone from the community where he lived. Wanting to change this situation, his support worker started by thinking about Jo's gifts. She realised that what he was really good at was listening and story telling. Jo enjoyed listening to the radio and often told her about the stories he heard. Then she thought about their nights at the pub and realised that sitting at a table, though pleasant enough, did nothing to introduce Joe to other people. So the next time they went they sat at the bar and introduced themselves to the publican, whose role after all is to know all his customers. They made it a point to talk about the Soaps that Joe was so familiar with. This became a regular pattern of conversation. The publican was happy to join in and gradually involved others. He became a great 'advocate' for Joe, helping him to get to know new people who in turn grew to know and enjoy being with Joe.

Joe's dream was to have a job. Thinking again about Joe's love of listening to the radio, his support worker thought about where else in the community the radio was used a lot: answer - the emergency services. They got in touch with the fire station and Joe offered his time to help to listen to the radio for alarm calls and do other jobs round the station such as making tea for the staff. Joe now has a voluntary job that he can talk about at the pub with his new friends.

This story illustrates well what it takes to be a good bridge builder. The bridge builder not only makes introductions but follows up, thinking creatively of how to nurture relationships in order to strengthen and sustain them. It is a sensitive task that requires thought and planning and the patience to stick with it, even when progress seems slow.

Bridge builders need the support of managers who understand what they are trying to do and organisations prepared to adapt their ways of working to enable the bridge-building to be successful. For example, ensuring that the same member of staff can support someone at an activity on a regular basis will make it easier for new connections to be nurtured.

Sally is supported to go to church by the same two members of staff. Their organisation has had to change the way it works in order to make sure that Sally is well supported to participate in the life of the church and make friends. When she first started going she was ignored and got strange looks when she joined in the singing. She has a unique way of singing! Her 'bridge builders' introduced themselves to the priest and offered their time as volunteers. Sally now gives out the prayer books at the start of the service and her natural talent for welcoming people has endeared her to the congregation. The two staff keep in touch with news of forthcoming church events and make sure that one of them is on duty to go with Sally to take part. At a recent fund-raising event Sally took along a cake and helped with making tea. They are also encouraging a friendship between Sally and two elderly ladies who are particularly friendly.

STEPS TO BECOMING CONNECTED

-  **Focus on the importance of friendship, hospitality and fun in people's lives**
-  **Create opportunities for advocacy and empowerment**
-  **Listen deeply beyond words (intuitively using all our senses not just listening to spoken language)**
-  **Think creatively to achieve imaginative solutions**
-  **Value and promote the unique nature of each individual regardless of disability or difference**
-  **Focus on individuals by always using a person-centred approach**
-  **Provide a range of learning opportunities focused on furthering social inclusion**
-  **Support individuals, families, organisations and communities on their journeys towards inclusion**

Community is a complex concept and yet it is rich with opportunity and full of people willing to take part who are just waiting to be asked. Experience has given us many examples of generosity and friendship.



Albert is 65 Years old and for 63 of those years he lived at home with his disabled mother. They were both heavily involved with the church. When his mother passed away, Albert was placed in a supported living home but his friends and family have kept in contact with him and are a major part of his life.

Albert goes to two church services on a Sunday, being given a lift there by one group of friends in the morning and another group in the evening. He is regularly invited to dinner at his friends' houses and he occasionally takes along Angela, a friend who lives with him.



Grace lives in a group home with three other people. She has few words but a wonderful smile. She loves shopping and often visits the charity shop in her high street. Her support worker happened to go to the charity shop on her own close to Christmas and was surprised when the shop assistant asked: "Where is Grace? I have a Christmas present for her."



When John left school he was faced with the prospect of going to the day centre but he and his family were unhappy about this. His sister met the person-centred planning co-ordinator and told her about her brother's dream to have a job and friends. They got together and talked about his dreams and how they might help him achieve them. His social worker suggested applying for Direct Payments and the co-ordinator helped to put a support system in place to stop this being onerous for the family. John now has support to go out. He has a job at the local pub two days a week collecting the glasses and is also doing photography. He has made new friends and is growing in confidence.



Sam and her dog wait at the same time each day for her neighbour to come by with her dogs and they go walking together. They have become close friends. Sam often goes round to her friend's house and they just sit and talk. The neighbour joined Sam's circle of support and has become her strongest advocate. She challenges circle members when she feels they are trying to get Sam to do something she knows Sam does not want. She also challenges Sam and it's great to see the banter between them. Sam is hoping to get a job soon and is planning for the future.

Sadie's Story

I went to the Person-Centred Planning course. I can remember doing a lifestyle shield and then I worked on a plan for my life. Some were big things, some were small.

Mike, my social worker, was on the course as well. He arranged a meeting to talk about my plan. I invited Margaret and Pat so the four of us went out to coffee. We talked about a circle for me.

When I went to the hairdressers in Cromer I saw Freda my old school teacher. She invited me to tea at her house. She was interested in what I wanted to do with my life. I told Mike about Freda and her husband Terry and they are now in my circle. My first circle meeting was on 3rd November.

My dream was to move from where I was living into a bungalow which I could share with two other people. Mike said he would help me with this.

I wanted to be more independent and be more confident in what I do. I wanted to practise being out and about in Cromer and decided I wanted a mobile phone so I put this in my plan. I talked to Mark my carer. He said I had enough money and his wife came with me to buy a phone. Mark and his wife and staff at the Centre have all helped me to learn how to use it. It's useful and it's fun to have.

At the end of January 2005 my big dream came true – I moved into a bungalow with 2 friends Janet and Cindy. We had a lot of fun choosing the furniture and had a day off to be at home when it all came. I enjoyed choosing furniture and nice colours for my bedroom. My friend Freda came with me to buy my curtains and bed linen. I have been there nearly a year now and I love it. I am now doing more for myself like hoovering and general things around the house. Our support worker works with us and together we cook our meals. Now we have settled in we do not have support workers on Saturday or Sunday mornings and not at night. It was a bit of a worry to start with but we have people we can telephone if we need to. I think we are getting used to it.

There is a lot of work to do in the garden. We will need some help but we want to do some of it ourselves.

I am very happy about what is happening in my life now.

Sadie McKail
December 2005



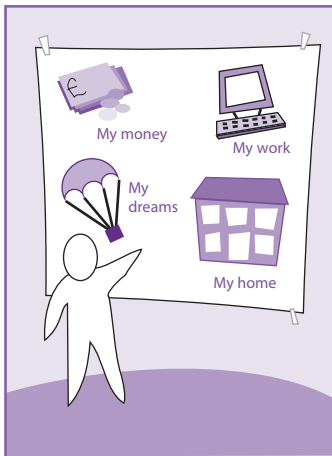
BEING PERSON CENTRED

Walking with someone means accepting the person where he/she is presently at, walking at the pace the person wants to walk, working in partnership with, rather than doing for or trying to fix or control the person.

George ducharme 1991 (Communitas)

In essence, what we now call person-centred planning is a meaningful conversation with another person about what they want from their life now and in the future, coupled with action that helps the person make their own decisions and have more control over their life. The 'average' family has done this for generations without the need to name it or use any tools or technology to make it happen. However, where people with learning difficulties are involved, the situation can often be very different. We have come to realise that all too often it is services and organisations that define the way people live their lives, and this needs to be changed.

Numerous excellent publications are now available that describe how to 'do' person-centred planning and the very valuable tools that have been developed to support this process (See Recommended Reading). So this chapter concentrates on how person-centred planning helps to change the cycle of dependency, segregation and powerlessness that many experience within service systems.



Focusing on the positive

Person-centred planning focuses on people's strengths and interests. It creates a 'can do' culture that fosters teamwork and a shared image of the future. It is a non-judgemental, inclusive way of working that respects what the person says and what they want in their life. It is a way of moving power and control into the hands of the individual.

Planning itself is not sufficient to change a person's life but it does give a focus for direction. It is a way of identifying gifts, interests and passions as well as identifying areas where a person may need help in order to make the best use of these qualities. Planning is not a magic formula that will mean every dream and goal in the person's life will be achieved. Some people's dreams may seem on the face of it, to be quite impossible. But we must take time to think creatively about the dream – 'unpack' it to see what it really means - and take action that gets as close to the person's dream as possible.

Belief in 'giftedness'

Discovering a person's gifts is a fundamental part of person-centred planning. Focussing on a person's gifts and potential is very likely to change our perception of the person. It helps us develop a positive outlook, discovering possibilities and solutions rather than focussing on risk assessments and the constraints of service systems. This in turn develops our own creative thinking.

Interdependence

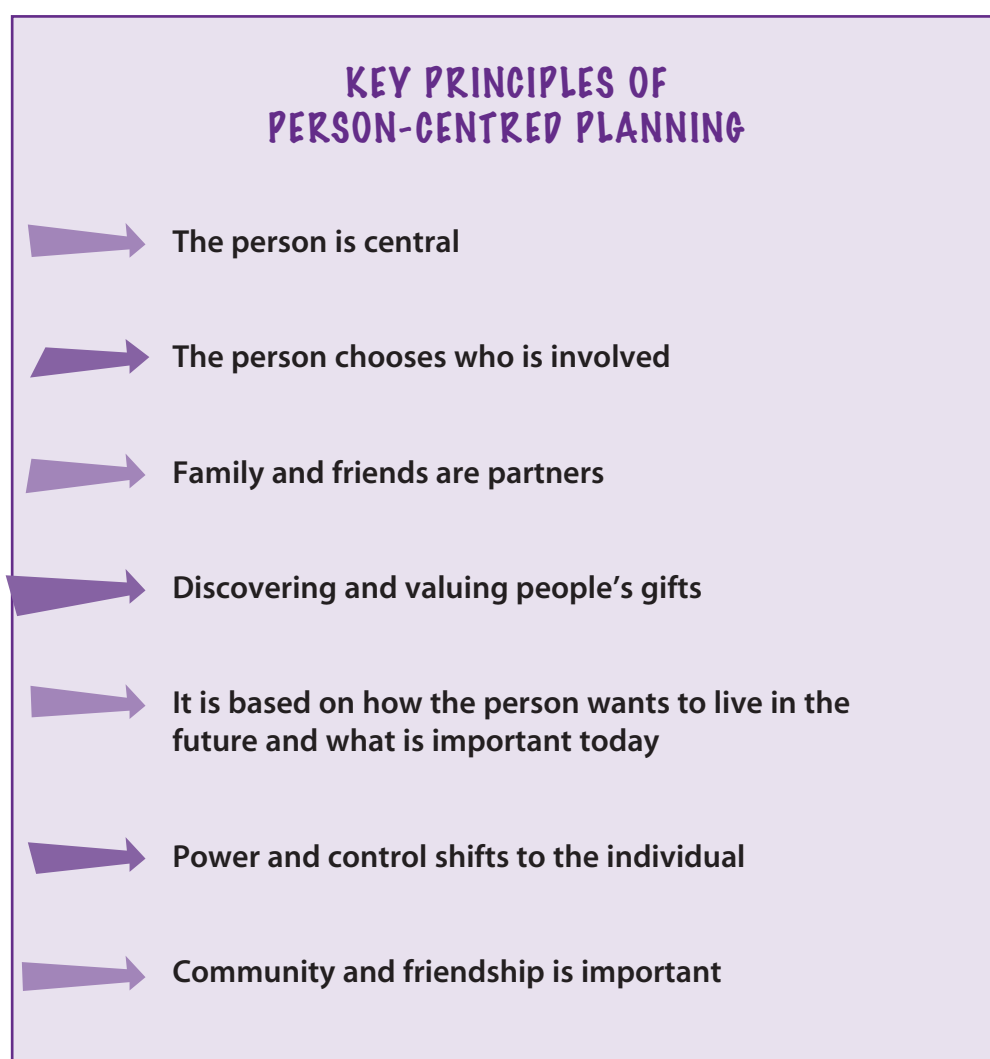
Person-centred planning brings together people who can and will act to support a person in what are sometimes life-changing decisions. It is not about doing things on your own, or taking all the responsibility alone. Person-centred planning gains strength and power from people supporting each other – people being interdependent – as they work to support the person to achieve their chosen life.

THE VALUES OF INCLUSION

- ➔ All people have a right to live and be a part of the community**
- ➔ All people should have the opportunity to lead ordinary and valued lives**
- ➔ All people have dreams and aspirations**
- ➔ All people have capabilities and qualities**
- ➔ All people should have power and control over what they do now and in the future**
- ➔ All people need friendships and independent relationships: a natural support network**
- ➔ The whole community can benefit from embracing diversity**
- ➔ Everyone has a voice and the right to be heard**
- ➔ ALL MEANS ALL!**

Getting beyond 'the plan'

Too many people have focused on the word 'planning' with the result that many individuals have a plan – but not much change in their lives. This is a serious mistake: thinking of the plan as the goal, rather than remembering it is just a tool to aid the process. Shortening and systematising the process by having 'a one tool for all' approach also makes it easier to turn person-centred planning into a technology that is 'done' to people rather than a process that we live 'with' people.



The plan should be an ongoing developing tool that changes as the individual changes. So services must have the flexibility to change also. Services should be tailor-made to each individual's wishes and not what the system determines is cost effective and manageable. Individualised flexible budgets are a solution for the future. Simplifying the bureaucracy around managing direct payments would greatly enhance their use. It is not acceptable for someone to have to complete a 7-page document for a 3-hour domiciliary care package, for instance.

We need to remain focused on the true meaning of person-centredness, remembering the values and beliefs of inclusion that underlie everything we do in person-centred planning. The plan may be important but it is the 'walking with' the person to discover who they are and what they want that helps to change the person's life and promote inclusion. If we do not want person-centred-planning to become 'just another fad' then we need to remind ourselves regularly of the values and beliefs that underpin this work.

IF WE ARE BEING PERSON-CENTRED WE:

- ➔ Explain how decisions are made
- ➔ Tell people about other places they can get help
- ➔ Do not 'fit' people into services they do not want or need
- ➔ Respect people's beliefs and cultures
- ➔ Help people to discover and celebrate their talents and abilities
- ➔ Do not label people or their families
- ➔ Keep people at the centre of all things about them
- ➔ Listen carefully but not just to words
- ➔ Value the knowledge that individuals and families bring
- ➔ Help people to get included in all things about themselves in a way that is helpful to them
- ➔ Meet together at times that suit the person
- ➔ Give clear, easy to understand information

Collecting information

This is the next step in getting to know the person. It can be an exciting and revealing journey of discovery to find out who they are; the people and influences in the past as well as the present, that make them who they are today. Many people find this journey of collecting information valuable in itself.

“For the first time I believe in myself and feel that things are possible.”

It is about collecting information from the person and those who know them well to work out what is important to them now and what their vision for the future is. The amount of time this takes varies from each individual. With some people it is very quick – one or two mapping sessions may be enough. With others it will take a lot of time as you work out different ways of communicating with them and learning about them and their lives.

It may mean spending time with the person in the different environments and activities where they are involved. Using technology such as multimedia profiling is helpful in order to observe and truly listen to how a person communicates. Watching his video, one man could be seen making the slightest movement of the mouth to indicate displeasure. This was enough to start the journey of supporting this person to make choices.

People have recorded different sounds a person makes to show how they communicate and to show others what their favourite things are.

At the Circle meeting

Listen deeply, beyond spoken language, to what the person and the group is saying. Be aware of body language. Always check with the person that it is ok to record what is being said. Write down what people say in an organised way and make sure you write their actual words. Do not use jargon. Use simple English and words people understand.

Always record points in a positive way. For example, someone may comment: “He takes forever to do something.” You would record it as “He likes to think about something before he does it.”

Check with the person and the group that what you are recording is accurate. Keep the group’s attention and interest by summarising from time to time what they have said, and asking new questions that move them on.

Make people feel comfortable - maintain eye contact and a friendly manner.
Be aware when people are getting tired and need a break. Remember informality and energy is important.

Also remember that you need to keep them focused on the job in hand. So bring them back and move things on to achieve the action plan.

Leanne's Poem

Yes, so what!

I have a disability

I am tired of society always judging me

Tired of being scared to leave my home 'cos of the hurtful things people say

I want to be more independent

To do more on my own

I find it hard to do things you can all do alone

People laugh at me because I'm different

But in my heart I'm just the same

Instead of judging me by what you see

Why not rejoice

In my individuality

Ind/divid/uality

Leanne Theresa Purvis



GIFTEDNESS, DREAMING, LISTENING

Hope is not a guarantee of complete satisfaction.
It is a kind of inner power to believe that life can get better,
not perfect, just better than it is..

Lewis B. Smedes One candle power.1989

Dreaming, listening and a belief in giftedness are crucial in supporting change in people's lives. If we do not have these three elements as part of our value base we will not be able to achieve person-centred, quality lifestyles for the people we support. Technologies, tools and systems on their own will not result in rich, satisfying lifestyles. What must be added is a belief in the worth and capacity of each person, the ability to 'listen deeply' to someone's dreams and a commitment to 'walk with' the person to achieve those dreams.

Giftedness

Judith Snow, for whom the first circle of support was formed, offers us valuable insight into giftedness:

A gift is anything that one is or has or does that creates an opportunity for a meaningful interaction with at least one other person. Gifts are the fundamental characteristics of our human life and community.

What's really worth doing and how to do it. Judith A. Snow. Inclusion Press, 1994.

Judith goes on to say that there are two simple gifts that all people have and that every other gift depends on. The first is presence. Since you are here you are embodying the possibility of a meaningful interaction with someone else. Secondly you are different from everyone else. This means that human interaction arises from presence and difference. Our presence in the world is a fundamental gift we bring to community. Our very difference enhances community.

Community depends on giftedness for its existence – it is both the context and the creation of giftedness. This is more than just being idealistic or sentimental. Giftedness is strategic, and understanding giftedness is fundamental to achieving full inclusion in community along with active, valued participation and strong networks of relationship.

All human beings are gifted: it is up to us to discover those gifts. The ethos of person-centred planning and circles of support teaches us is that people are defined by their gifts.



Working with people's gifts helps us to understand who they really are. When we think about what a person is really good at, we start to see the human being – not just the disability. In turn, that person listening to others defining her/him by their gifts, not their deficits, starts to change their perception of themselves, leading to greater self-esteem and confidence.

Rania's circle was meeting for the first time. It was hoped that Rania would join the circle but she found it very difficult to sit still for long or even to stay in the same room with other people. She enjoyed drawing so an easel with pens and paper had been set up in a separate room so that she could go in and out of the circle meeting room as she wished.

This was also the first time that members of her family had sat down together to talk about Rania's life. The circle discussion started with Rania present. At one point she got up as if to go out but then came back. To her family's amazement she stayed for the whole of the meeting. Afterwards, they said they thought it was because, somehow, she sensed that people were saying good things about her – she was the centre of attention in a positive way – and this was different from her previous experience.

**I have a dream that all men are created equal.
I have a dream that my four children will one day live in a
nation where they will not be judged by the color of their
skin but by the content of their character.**

I have a dream today.

Martin Luther King

Dreaming

Dreaming is an emotive word that means different things to different people. Some may view it as 'airy-fairy' - not to be taken seriously: something that is in the realms of fantasy that we cannot reach in our life. But dreaming is important in our lives. If we do not listen to our dreams or even think about them, how can we ever hope to achieve them? Dreams can give us direction in life.

Many innovations in history started with a dream. Out of Martin Luther King's dream was born the civil rights movement. From dreams spring ideas, and from ideas come innovation. Dare to dream and create a vision for the future and see

what a fertile mind can do. Dreams tell others our wishes for ourselves. Once we know the dreams we can start to think about how to reach them.

Dreaming, combined with the spirit of giftedness and fun creates a powerful atmosphere that is rich, creative and full of possibility. Dreaming inspires creativity. Then you need time, persistence and commitment to carve your journey to the dream.

Dreaming is a process of communication that all human beings participate in. Dreaming will tell you where exactly a person wants to go with their life.

Judith Snow

If we become good at listening to what a person's dream is we become good at supporting them to find their way of life.

Generally our dreams are related to our experiences in life. People with limited life experience are likely to have limited dreams. Some people find it easier to start with their fears and nightmares, and from these emerge the dreams. Thinking about dreams helps to carve a path on how to achieve them. The journey is as important as achieving the dream because on this journey we are likely to encounter opportunities to try new things, meet new people and make new connections.

The dreams that people with learning difficulties express most often are not extraordinary. They are usually just what the rest of us take for granted in our lives – to have a job, get married, have children, have a home of their own, choosing who they live with and who supports them. Yet, despite progress in thinking, such dreams are still often described as 'unrealistic' – often in the same breath as 'unaffordable'.

★ *David's dream is to maintain what is happening in his life now. He wants to keep the same people supporting him in his life as this gives him a sense of safety and security.*

★ *Robert wants to be with people who understand him and can help him keep the boundaries that help him make sense of the world.*

★ *Gwenda's dream is to move from where she is living and get a job and make friends.*



Sally's dream is to be a long distance lorry driver. This was a challenge for her circle as Sally's physical disabilities make it difficult for her to control her wheelchair, let alone a lorry! But they decided to explore what being a long distance lorry driver meant for Sally. Was it the lorries, the long distance travel, going away from home, the drivers? So a couple of circle members started to go with Sally to the café stop on the edge of the motorway where long distance lorries parked while drivers had a meal. They found that the same drivers regularly stopped at this café and they gradually got to know them. Sally absolutely loved being there. She loved the noise, the smell, the drivers, the lorries - the whole experience.

One driver often stopped to talk and they told him about her dream to be a driver herself. He then made an offer they could hardly believe. He said he drove to and from Birmingham and this took a day. If they could safely fix Sally's chair in the cab and both supporters went along he would take them for the trip. Sally might never be a long distance driver but she now has experienced what being one is like. In the process she met many people and made important connections that could lead to friendship.

Understanding what the dream is about is important.

When David says he wants to be an astronaut you discover that he likes stars and also an astronaut has power and is independent. Going to the planetarium and the science museum may be an option, as well as exploring ways that he can gain more independence.

Wendy said she wanted to fly in Concord. But this was a far too expensive option. Her circle talked with her about what this dream meant for her. She wanted to travel like everyone around her and to have positive stories of holidays and having fun. Concord was not the important factor although there was a desire to see one and fly in one. Since Concord is no longer around, finding out more about it and buying a book about it was important.



Getting as close as possible to the dream is important. You do not stop looking at the ultimate but you reach as far as you can.

Discovering the dream

With some people, particularly those with unique communication, it will be important to ask those closest to the person to help think about what the person's dreams might be. To help ensure it is the person's dream – and not

that of their contact – it is vital to understand how the person communicates and know as much as possible about their likes and dislikes.

This can take a lot of time, patience and creative thinking.

How do you discover what someone is saying? It could be that the first dream is to 'be with people that understand what I am saying and what I am communicating'. Here again, technology can help. A video was used as a communication tool for a man who responds to sounds. It has the voices of people he likes, shows his favourite things and what he likes to do generally.



Louise shows her dreams in her behaviour. She spends all her time talking about clothes and makeup and from the moment she walks into the house she is talking about what she will wear to her next activity; or she gets hold of the TV guide and talks about the Soap she wants to watch.

Her dream is to have fun with people of her own age, to go out with boys and to have a boyfriend. She wants to have nice clothes and make up and to see her family when she wants to. We know this through her actions and words. She is not always interested in her circle. Her main interest is in going out. She goes upstairs and dresses, puts her makeup on and comes down with her handbag, asking what time the bus comes. In order to be able to engage in real conversation with Louise, her circle has had to be particularly careful to arrange circle meetings at times when she is not busy.

The dream of Louise's family is for her to get a job, be independent and eventually move into a flat of her own with a friend. But is this Louise's dream too?

By getting to know her well you see clearly where her passion is, the essence of who she is and what her dreams are. You get to know her gifts, her motivations and what she really wants for herself. Taking her dreams one at a time, you can ask her questions and get to know her true choices.

To find out where she wanted to live, we drew a picture of her in the family home and another showing her in another house. She pointed to her family home. More drawings – of Louise with one other person, two other people etc. – reveal that she wants to live with one other person. Her first choice would be with her boyfriend. However, this was not his dream and we had to think again.



With Philip we learned most by listening to those closest to him. But we noticed there was one word he always shouted on the phone – “Mum”. Discovering what was behind this, we found the clue to his dream. Staff discovered his mother was ill and in a nursing home. His brother had decided that it was in his best interest if he did not see her any more as it would be painful for him to cope with her eventual death. The staff contacted the nursing home and asked if it was ok to send his mother a card: she liked the idea. So Philip sent her a card. She replied and after a second card they arranged for him to visit his mum. It was a very emotional meeting. (The member of staff accompanying him found he had to go outside to regain his composure.) Philip got into bed with his mum and they cuddled each other and cried with happiness.

Philip’s mother died a year later. His brother’s attitude had not changed and he refused to let Philip go to the funeral. Later, the staff organised a memorial service with the priest so Philip had the opportunity to say goodbye. Philip has stopped calling “Mum” on the phone: he knows she is dead and has moved on with his life. His brother attended the service and has kept in touch.

Philip’s life is quiet but happy. He is doing what he wants with the people he likes. For the first time in many years he has his brother in his life. His brother has started to see a different side to Philip and appreciates his strengths.

Philip recently had an exhibition of his art at the local library assisted by his circle and they are considering other opportunities for him to become connected, either through his art or his passion for rug making.

Yes it hurt. It is very painful to lose someone you love, but we all have the right to say goodbye. The question should be how we support the person to go through the pain of bereavement and not how to protect them from it. When supporting Philip it was important to work with people who knew him best. He would not join in his circle meeting. He would sit outside, but clearly listening to what we were saying. Or he would carry on making his carpet that was on his table. I felt that I was failing when by the third meeting he was still not included or ignored me. However, when I arrived for the next circle meeting, to my astonishment he answered the door and received the gift I brought for him. He took my paper and led me to his table. He moved his rug and opened my paper and asked for tea from staff. When we finished drinking this he took two pens and gave me one and proceeded to draw at the top of the page waiting for me to start the meeting. It felt that he knew that we were there for him and he started to see changes in his life that he associated with his circle meeting.

The people who are paid to support Philip have changed their working practices to create a truly person-centred environment. The house he lives in is his home and feels like his home. The way this staff team works is a shining example of what is possible even when someone is wholly reliant on services for support.

Listening

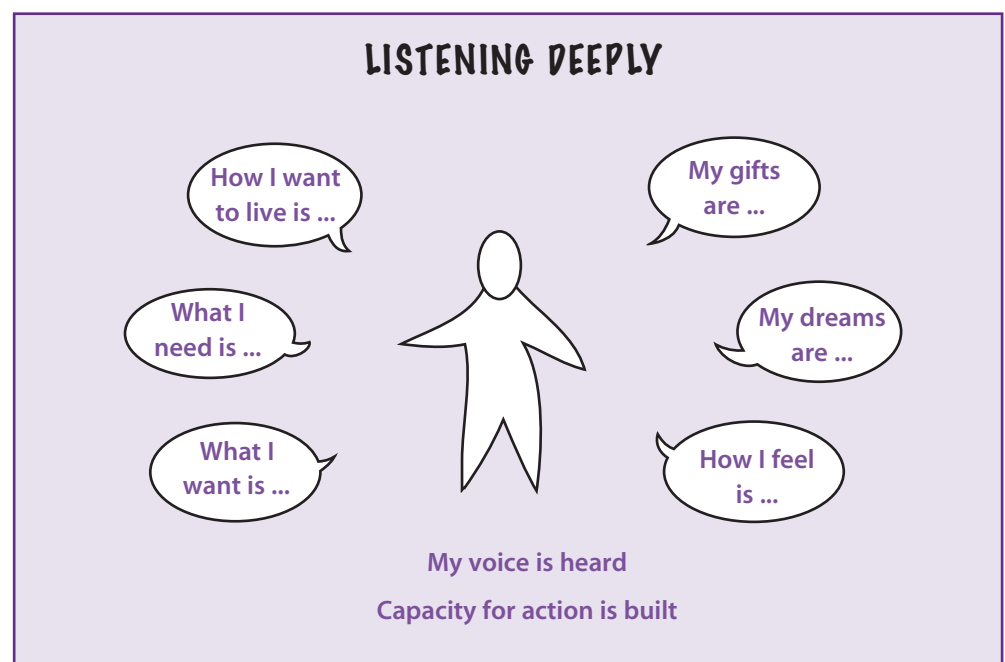
Listening is an important part of getting to know someone well: listening deeply to a person, not just their words but also their behaviour. Listening with all your senses is the greatest tool of person-centred planning. As John O'Brien says, it is listening with your heart. (1997)

Listening should be non-judgemental, with no preconceived notions about the person's capabilities.

Listening together feelingly, intuitively, thoughtfully and with each of the senses leads to a shared glimpse of the person's dream:

The threads that animate this person's particular contribution to our common life; the threads that glow when this person is passionately engaged. A glimpse of someone's dream organises and motivates efforts to help that person to establish the living conditions and develop the opportunities necessary to allow the person's identity to unfold.

John O'Brien 1997. Members of Each Other



John O'Brien⁹ talks of 3 dimensions of listening required for successful listening:

Where we listen from

This is where you stand with a person and are willing to accommodate his communication. Too often, we stand over people and communicate with detached objectivity. We listen at times and places suitable to us, we use questions and planning methods that give power to the system we operate. We do not listen in order to let the person know that we care what they think and feel - that we are on their side. We may not be able to help but we want them to know that what they want matters to us.

What we listen for

We listen best when we encourage people to have a voice. Listening is not about granting wishes but about attending to the details and dreams that disclose a person's identity and their desire to participate and contribute. As their voice develops, self esteem increases and confidence grows.

How we listen

We listen best when we listen, not with pity but with a desire to discover who the person is and how they want to live their life; acknowledging their fears and disappointments and seeing their point of view even if it may not be ours.

Effective managers promote listening. They listen to their staff with respect and encourage them to stand alongside people, challenging policies if necessary. They encourage organisational openness. "Leading an organisation of listeners requires the wisdom to develop the capacity to take direction from the people the agency exists to serve." John O'Brien.

Listening involves giving total attention to another human being. This respectful giving of attention is what makes it possible for the other person to be released from the constraints placed upon them by years of being disempowered within systems. It helps the person to start thinking for him/herself; to believe and feel they have things to say and that what they have to say is important.

Listening with respect implies that you are listening to an equal, someone without labels and limiting perception. It requires you to see that person as a human being with intelligence and gifts. Intelligence not measured by IQ but

the belief that all human beings are intelligent and gifted. This is something that needs to be learnt by both the listener and the listened to.

Good listeners wait and give people time to think. They do not jump in with advice. When they have heard the person's ideas they may use questions to help the person think through other ideas. They hold back from giving answers too readily because they believe the person knows what the problem is and has some idea of the solution. A good listener does not interrupt, gives good eye contact and treats the person in a respectful 'adult' way.

N. Kline, in 'Time to Think'¹⁴, gives the following guidance for listening:

Do

- Listen
- Ask incisive questions
- Establish equality
- Appreciate
- Be at ease
- Encourage
- Feel
- Supply accurate information
- Humanise the place
- Create diversity

Don't

- Take over and talk
- Know everything
- Assume superiority
- Criticize
- Control
- Compete
- Toughen
- Lie
- Conquer the place
- Decide difference

Creating a group of people that can help a person think for themselves is one of the factors that make circles so effective. A good facilitator knows how to create a thinking team. They give everyone respect and uninterrupted time to speak.



Zilla's circle was not listening to her and was focussing on 'negatives' only. Her facilitator started the next meeting by getting everyone to focus on what Zilla was good at – her gifts – the positive things about her. This resulted in an atmosphere of creativity. She then explained that one of Zilla's dreams was to own her own house and she wanted to know what people thought about this. She helped Zilla describe what it was like living where she lived and why she wanted to move. She then invited each member of the circle to speak, explaining that they would each








get time to say what they thought without being interrupted. The circle needed to know that their thoughts were important to Zilla and would be valued and respected.

The group gave a lot of positive ideas but some fears were also expressed. Zilla's mum was upset and tearful. She voiced a lot of her fears about Zilla moving out of her group home. Listening to her nightmare gave people a new understanding of why she had appeared to be overprotective. The facilitator then asked the group to say what they thought about those fears and how they could be overcome. This process made it possible for the circle to help Zilla come up with a plan that met her needs but also took account of safety issues that were so important to her mother. As for Zilla's mother, the circle experience made her feel she was listened to with respect, that the group valued what she said and helped by focusing on each point and planning for it.

Circle members felt valued and connected to each other. They felt enabled to achieve a lot for Zilla. They felt comfortable and happy to come again.

What helped

-  The promise to give everyone equal, uninterrupted time to speak.
-  The promise to listen in a non-judgemental way.
-  Focussing on the positive aspects unleashed creativity that shifted thinking from problems towards solutions.
-  Allowing people to express feelings - listening to pain
-  Making sure that circle members knew their ideas mattered.

If thinking does not flow try putting people into pairs and getting them to listen to each other, and then feed back to the whole group. This also helps people who may need more time to think and are shy of speaking unprepared in a big group.

What is needed

- ➔ Listen respectfully
- ➔ Discover the message of the conversation and what the person's question is.
- ➔ What is blocking them to find their own solutions.
- ➔ Ask a question that points to the block.
- ➔ Ask them to write down the block.
- ➔ Think of what was positive.
- ➔ Consider using the process of a thinking circle.

THINKING CIRCLES

Allow 15 minutes for this and prepare the group by explaining the process. Identify a time keeper, a graphic recorder – someone who will write down/draw what is being said at each stage, and a facilitator – someone who keeps the process going.

- ➔ **Step 1** (5 mins)
The problem presenter speaks uninterrupted about the issue they want some creative ideas about.
- ➔ **Step 2** (5 mins)
The group speaks uninterrupted about what they heard. The problem presenter does not speak. The group say what they thought about what they heard, pose questions and give ideas as to what could be done.
- ➔ **Step 3** (5 mins)
The problem presenter answers the questions raised and talks about what the group had said. He/she then considers the suggested solutions and says which of these made sense. The problem presenter is then asked to say what s/he will now do and is supported to draw up an action plan.

This is a positive structure that supports creative thinking. It is a useful tool to use with circles, teams and committee meetings.

**Until we are free to think for ourselves
our dreams are not free to unfold**

N Kline 2003

Our dreams remain dormant until the right conditions come along that will entice them to awake.

The facilitator is the catalyst, they do not need to have the answers but perseverance to keep going and supporting the group until they find the answer.

Tim wanted to be independent and do more. He lived with his mum who was 80. He did not want to leave home he just wanted to do more. His mother was reluctant and would not allow any of the suggestions from the circle. Finally, after many circle meetings, Tim's sister challenged his mother. She told her that Tim wanted to do more, that there was no suggestion that he should leave home and that they would make sure he was safe. Gradually Tim's sister felt able to stand up for his wishes and so strengthen his voice within the circle.



CIRCLES OF FRIENDS

The more we dream about personal and social change, the more we need people around us to sustain the dream and support us during times of struggle and disappointment. The more people around us, the greater the dream and our sense of hope. The greater our sense of hope, the more we can change the world.

Beth Mount. *Imperfect Change.*

What is a circle of support?



A circle of support is the intentional building of relationships around a person who may have become disempowered because of disability or difference. It is a group of people that care and come together at the request of the individual (or focus person) to help them think about their life. Circles of support are based on an understanding of the importance of relationships in our lives and our need to belong in a community.

This is a natural process for most of us. When we are in trouble we call on our family and friends. We share our pain with them and celebrate our happiness. But many disabled people do not have this natural network. Many families become isolated because day-to-day living is so difficult they have no energy for anything else. 'Ordinary citizens' keep their distance because they don't know what to say or do, or through fear of getting too involved. For whatever reason, this intentional building of connections – the circle of support – is a valuable tool for creating networks of friends and relationships and promoting empowerment and inclusion.

A circle of support has a person-centred ethos. It focuses on the person as an individual with gifts and capacities, someone with their own views, beliefs and opinions; someone with the right to self-determination and a lot to offer to the community. It takes an individual's vision/dream seriously and helps them to become connected with people who can support them to achieve that vision.

The circle is made up of people the focus person has chosen. Each circle member needs to believe in the person and believe that they can achieve an ordinary life of their choosing. Circle members nurture relationships and create opportunities for the focus person to develop real friendships. Circle members build bridges into the community seeking like-minded people with gifts needed in the circle. They develop an action plan of how they will achieve change. This may mean taking on 'the system' - challenging policies and red tape.

The first circle

The story of Judith Snow is well documented in many publications including 'From Behind the Piano'¹⁵ (Judith Snow, Marsha Forest, Jack Pearpoint). This is a book everyone should read.

Judith's struggle to survive in her fight to be allowed to lead a life outside the institution brought her close to death. Five friends rallied round, took on the system and became her advocates at this moment of crisis. Judith called them her Joshua Committee. Eventually she was able to move into an apartment with round-the-clock attendant care. This was co-ordinated by the circle until she was well enough to take the lead herself.

Circles bring together those that care about the person and bring in others when they need extra skills.

A family were preparing a formal complaint to the education authority and realised that the circle did not have the skill or experience to write the report. One of the circle members had a friend who was married to the education adviser from another authority. He joined the circle for one afternoon and helped with the development of the report.

In the world of circles there are many stories of success. Sometimes the results are so profound they can seem almost magical – to have happened with little effort. However, there are often many struggles on the road to success: with some circles these are immense. The most difficult can be fighting 'the system' - bureaucracy, inflexibility, people with closed minds, people who still believe in the medical model. These situations can drain the energies of circle members. They feel ineffective and powerless. This often requires great effort and energy from the circle's facilitator to help the group sort out the problem and find a way forward.

Power of a circle

When no-one would listen to Mary the circle decided to arrive in force at the next care managers' meeting. They worked out a plan to enable Mary to speak up and stand her ground. The group experienced the negativity of the meeting at first hand and then supported her to lodge a complaint with the director of social services. This was investigated and Mary got her package of direct payments.

Planning circles

Planning circles have evolved from circles of support but are different in some ways. Like circles of support they bring benefits and involve ‘...a group of people who meet together on a regular basis to help a person accomplish their personal goals in life’ (Wertheimer, 1995¹⁶). However, circles of support operate outside services, free from any conflicts of interest and are mainly made up of friends, family and ordinary citizens. Planning circles on the other hand are instigated by a service and are primarily made up of staff working with the individual.

In an ideal world, everyone would have a circle made up of friends, family and ordinary citizens. However for many people with learning disabilities, services have been their life. They have never played an active part in community and have nobody in their life but paid people. Hence the need to mobilise staff to help change this pattern of isolation and bring ordinary citizens into people’s lives.

Planning circles bring together all staff working with an individual, combining their efforts and sharing information, rather than working in ignorance of, or opposition to, each other.

This has proved to be a valuable way of not only helping individuals achieve better quality lives and greater involvement in their community, but also making an important contribution to changing the culture within a service.

Circles as a Trust

A circle can be set up to help with legal issues. By setting up as a Trust, with a trust deed registered with a lawyer, the circle gains legal status.

Such trusts have been successfully used to support the development of home ownership, shared ownership, gaining a mortgage, or managing support through direct payments.



Malcolm was not happy where he lived and his mother was perceived as a trouble-maker. She decided to develop a circle for her son in order to gain support in thinking about how she could help him achieve a different lifestyle. The circle looked at what Malcolm wanted in his life. They realised he was not interested in the other people he lived with, he was more interested in going out and having his own space. He adored his mother and asked for her often. He loved water and the seaside. He liked car drives.



The circle felt that direct payments might be a solution for Malcolm. They helped his mother by organising themselves to manage the direct payment. They discussed what good support looked like for Malcolm and helped him interview and choose his supporters. They chose someone who Malcolm knew well and really liked to be the lead officer who would manage the other staff. This lead person would be a circle member and the circle would manage the finance. This made it possible for Malcolm to have a flat of his own and the support he needed to be able to do the things he liked.

Having a circle at work can help to ensure that a person is well supported and able to be independent at work. It helps with making work a pleasant place to be. Hanifa Islam has a circle at work and this is what she says about it.

A circle in the workplace

My present job is a Support Admin Officer for the Foundation for People with Learning Disabilities in central London.

My job includes:

Helping reception staff with post.

Helping marketing and fundraising teams with their mail-outs.

Helping the FPLD by advising on easy to read documents and typing.

I work 16 hours a week. I travel by myself on the tube.

I have a circle of support at work. It is a good time to talk things through with my colleagues and to know there are people to support me if I need help.

I like my circle. It is good fun and I have made good friends. My friends from my circle come to my house for dinner and we go out to the pub or shopping. My friends Marie and Jill came to see me dance at my dancing club.

I love my work and all the friends I made with my circle.

Hanifa Islam



Setting up a circle

Good planning and preparation is important to make sure the circle is a success. The first step is to get to know the focus person well and how they want to live their life. Think carefully about what sort of preparation will best support the focus person and/or the family. Decide with the focus person what process will help to achieve teamwork and action. Find out where the focus person is most relaxed and at their best. It might be at home, or in a café or pub, in a library, or a place of worship such as church, synagogue or mosque. If possible, it should not be at a 'services' venue.

Invite the circle

Help the person decide who will attend. Help them to think about the people that know them best and those from services that may be able to help.

Help the person to phone, speak to, or write to circle members. Letters on official headed paper do not create the right spirit for the meeting. It should be clear that this is a personal invitation to each circle member. Keep it informal and fun.

Informality is the key

Create a friendly, hospitable, welcoming environment. (a pleasant, comfortable place - flowers, sweets, drinks)

Provide refreshments.

This type of informal environment does not happen by accident. Just like having a party or organising a youth group activity you make sure that you set up the room and have all the 'props' set out in a way that encourages everyone to feel relaxed and happy to be there.

At the circle meeting

Ensure focus person is in charge

Support the focus person to lead and speak for him/herself. Be there as their assistant, ensuring that they are in control. Prepare materials that they are familiar with and that will act as prompts for them. For example if you are going to use a person centred planning tool such as PATH, (see appendix), have a different part of the process on different sheets of paper. This will help the person follow the process and keep the circle members involved.

If the person has unique communication make sure that the people who are closest to the person, for instance their family, are in the circle. Address your questions through the person and make sure that they are the focus at all times.

Finding out what the focus person wants from his/her life and knowing how they make choices and decisions is fundamental to making sure that you are able to protect their wishes. Make sure your approach sets the scene that will give the focus person respect. Set ground rules that will make sure that the circle will listen and respect all contributions.

Help the group to search for solutions

Support the circle to focus on the reason they are there - to find creative solutions to the focus person's wishes. Get them to focus on the positive, the 'can do'. Starting with gifts and dreams helps this process. Ask the group to think of their own gifts that might be useful when seeking solutions. For instance the focus person wants to learn to cook and you have a good cook in the group or the person wants to gain direct payments and needs help with payroll and you have an accountant in the group. Be creative yourself and lead by example.

Record the process

Make sure that the important points are recorded visually. This ensures no decisions are forgotten and also releases creativity.

From time to time, summarise what has been said – to check everyone agrees and to add things people feel were left out.

Keep it positive. Always record points simply and in a positive way – avoid labels and jargon.

Develop an Action Plan

Make sure the group decides some actions - you do not want it just to be a talking shop. Be careful not to allow only service solutions. Find community based solutions using non-paid community members. The whole point is to get the circle members working together to make things happen. Encourage people to volunteer for action.

Notes

Send out a summary of the notes to make sure that action is followed through.

Closure

Ask the focus person and the circle members to say how the meeting felt for them.

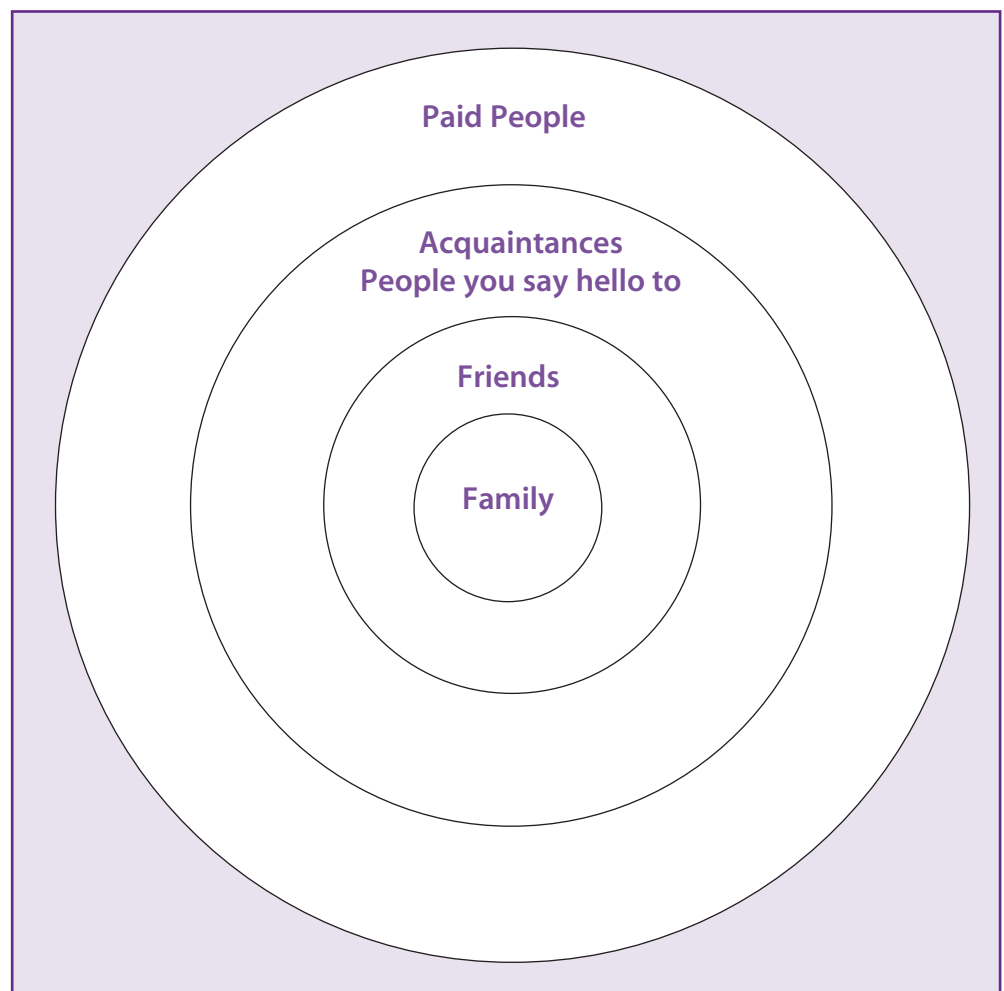
End on a positive note. Perhaps, reflect back on the dream you are all working towards.

Choosing circle members

Some individuals are clear who they want in their circle, others may need some help. Using relationship maps is helpful. Start with listing everyone the person knows in Map 1 (below). Then if necessary use Map 2 to get a better idea of which people the person feels closest to: these are the people who will usually be in the circle.

Spend time on this: ask questions to bring out who the people in the person's life are and how important they are to the person. This will give you insight into the person's life and the type of relationships they have. Are most of the person's contacts professionals or 'paid' relationships? Who are his/her friends? Does he/she know the neighbours?

Relationship Map 1



Some people decide not to include the very people who might seem to be their closest allies. As a facilitator you need to support this. However, it is also part of your role to ensure the person is making an informed choice. Explore why the person does not want these individuals to be in the circle. Explain how they might be helpful. Are there other ways they could be involved without losing their support? It is then up to the focus person to make the decision.

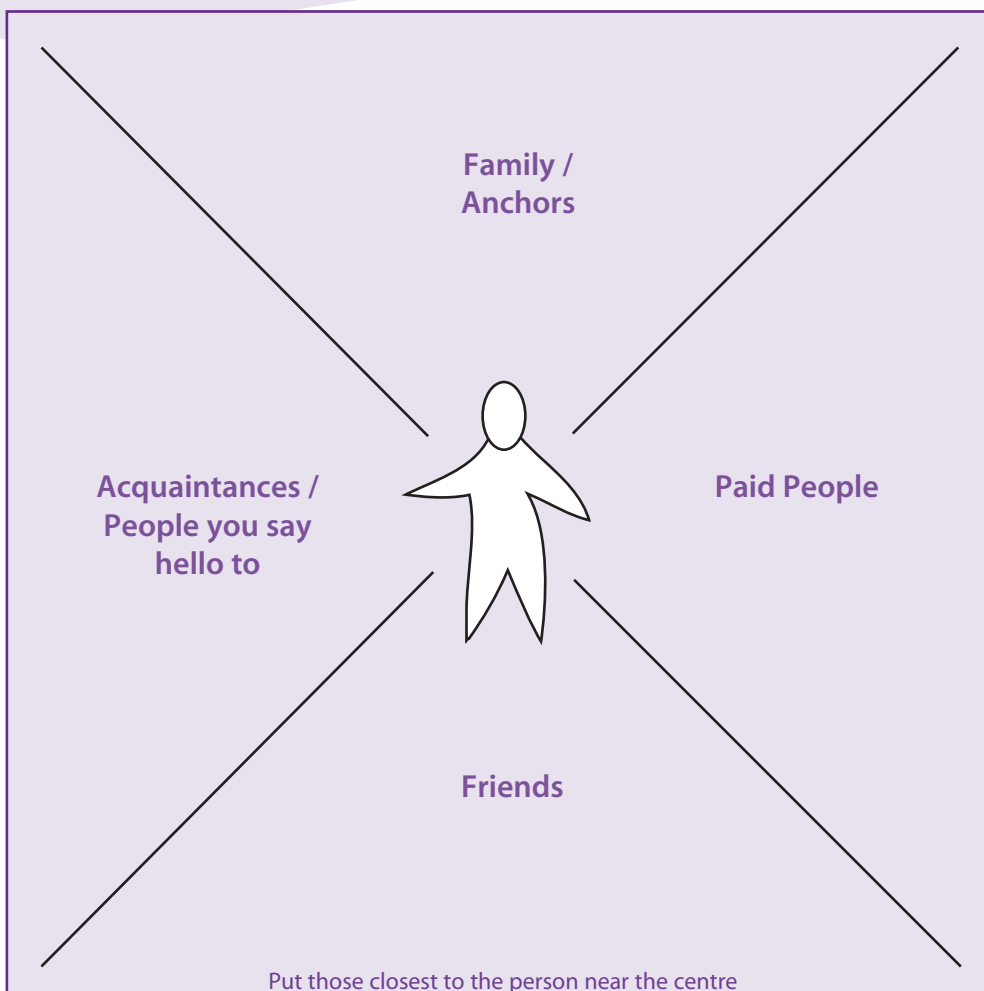


Kay decided not to have her parents in her circle. However, after thinking it through she decided to include her mum but not her dad or brother. Helping Kay to focus on who was the person who was always there and made things happen for her, helped her to realise that her mother should be in the circle as she was her greatest ally.



Helen feels that her parents don't have a role in her circle as she is an adult. She sees their role as part of her family, to consult when she needs too. They understand and respect this.

Relationship Map 2



Family as circle members

Parents, grand parents, brothers, sisters and other family members bring important information about the person, particularly about their background and life history. They are the people who have been there through thick or thin – for the good days and bad.

Some people feel that family members are a hindrance and stop the person doing what they want. But there is a need to take time to question why a family seems to be blocking progress: to understand what struggles they may have been through in the past. They may have felt let down by services. They may have been left to pick up the pieces when something went wrong. They may feel they've had to fight for everything the person has.

Its best if you do not go down the road of social care. This is a sure way for my daughter to become labelled and trapped in the system and that is the end of inclusion. (Mum)

Often fear is what generates overprotection. It is important to explore the nightmare for the family and to find ways that will guarantee the safety of the individual whilst trying new things. This can often be a transforming turning point in a circle.



Staff's view of John's mum was that she was overprotective and stopped him from becoming independent. They were unhappy with the fact that he was not allowed to do much at home. What they did not see is the fact that mum was told by the doctors to never leave him alone particularly in the kitchen as he was in danger.

There may well be times, however, when family members insist on imposing their own wishes on the individual. The same can be said about others in the person's life - paid or unpaid. These situations can be very difficult. You have to trust in the process and the ethos of the circle, allowing the circle to take charge and challenge each other in order to ensure that the person's wishes are paramount.

Friends and acquaintances as circle members

Friends and acquaintances bring a different perspective from that of the family and should be seen as just as valuable as the family. Like the family, they bring

knowledge and understanding of the person and see them in different ways and in different situations. They can often see different possibilities and expand the person's dreams and ideas of what they can do. They often become strong advocates for the person.

"I don't think this is what Claire wants. She is saying she wants to work but not in a sheltered workshop - she would be wasted there. She is saying she wants to work with people in a café or something. And anyway she wants to move away from home."

(Claire's friend)

"I don't understand why you think he cannot do this. He is very capable and does a lot for himself. What I want to know is what are you, as paid staff, going to do to help him do all the things he wants, rather than us meeting over and over again and nothing happening? And also what is your fire evacuation procedure here? I don't think Andrew can get out of his room if there was a fire and I am very unhappy about this." (Andrew's friend Yiasin)

Staff as circle members

Often members of staff are the only people in the person's life and the only people that know the person well. Staff can be creative and often know a lot about the person's dreams, wishes, likes and dislikes.

Bringing all the staff in a person's life together and finding out what they know about the person throws up new information and possibilities. Strange as it may seem, staff in different parts of the person's life often don't get the opportunity to talk to each other and share information.

"I started talking to his key worker at his house and do you know we were trying to do the same things. He would have ended up with two person-centred plans. How confusing. We now work together and share the job. His life is now different and we are having such fun at the circle. I really thought it would be a chore and now I can see all the things he is doing that make him happy and it's all worth it."

(Day service worker)

Staff can often help the circle process move along more quickly. They can link up with other professionals more easily and may have time allocated for them to

put plans into action. However, it is important to maintain a balance as the circle could easily become service-centred. The 'non-paid' members of the circle may feel they have no role and stop coming. It is important to encourage everyone to contribute ideas and time.

Advocates as circle members

Sometimes a more formal advocacy is necessary. This role can be taken up by anyone paid or unpaid. The role is one where the advocate supports the focus person to have a voice and make informed choices around their rights. The advocate is someone who is able to put their opinions on one side and support the person in a non-judgemental way to make an informed choice.

Formal advocacy is a sensitive role and should be carefully planned and supported so as not to stop others in the circle also taking an advocacy role. The advocate needs to know when to step back and let others learn what the person is saying, without making circle members feel threatened or unimportant. A circle can take up this role collectively offering collective advocacy and can prove to be a very powerful tool for the person to use when required.

Challenges in choosing circle members

There may be instances where choosing circle members becomes problematic. Circle members need to ensure that someone is there for the right reasons and not there for personal gain. They need to make sure that safety is paramount to ensure that the focus person is not placed in a vulnerable position and open to abuse of any sort.

Managing this has to become part of the role of the circle as a whole. The focus person needs to be assisted to make an informed choice as to whether the person remains in the circle or not. There is an argument that the focus person as an adult has the right to this choice. Similarly as a paid person you have a duty of care to make sure the person is safe. The dilemma is great and there are no simple answers.

Planning the first meeting

Choosing a venue

The focus person needs to choose where they would like to have their meetings. Think about where the person is at their best. Perhaps the person's home will be where they would feel most comfortable.

Some community places, like places of worship such as halls in a church or synagogue or leisure centres are happy to let you meet free of charge. Make sure you find a quiet area to respect confidentiality. Some people choose to meet in the pub or a restaurant such as a pizza place or café. One circle chose to meet at the café in the Royal Festival Hall only to discover another circle was meeting four tables away!

The choice of venue for a meeting can support the development of a more person-centred ethos in planning. Having the meeting at a services venue may give the message that the planning is owned and led by the service.

Paul lived in a house with others and his family found it difficult to get on with staff there. However they decided to invite everyone to their house for Paul's first circle meeting as they, along with the facilitator, felt that this was where he was at his best. It took convincing to get the staff to accept the invitation but to their surprise the family welcomed them hospitably into their home. They were also surprised to see how relaxed Paul was. He sat on the sofa next to his dad with his shoes off - feet on dad and dad massaging his feet. They had always believed that Paul did not like personal contact and were totally surprised to see how different he was in his parents' house. Also, he had a reputation of not wanting to be involved and not staying in one place for long. Yet he sat there for most of the meeting and when he got tired his parents suggested the circle take a break. Paul went into the garden with a basket of tools and dug a little and then came back and resumed his place with his father.

Hosting the meeting

Decide who will host the meeting and arrange for hospitality and a welcoming environment.

Discuss with the person how they want the meeting planned. How they want the seating arrangements. How long the meeting should be. What they want your role to be. Is it to facilitate the meeting, or to support them to facilitate the meeting, or together - if so how.

Is there anything they do not want to talk about with the group and things that they definitely want to consider?

Practical matters

Can you put things on the walls? If yes, work out how not to damage the wall. Use a backing sheet to protect pens from going through to the wallpaper. Use washable pens.

Is there space for using large sheets of paper? Flip chart paper will do or use art paper or roles of lining paper.

Plan how you will present information on the page and use light pens that you can then go over with a neater design later.

It is amazing how successful the graphic process can be. One mother said: "Seeing things on the wall like that makes me able to see things so clearly". It helps people focus and be creative with solutions and ideas. Colour is important too. This process helps not only people who may not read words but helps everyone see the whole picture of the discussion.

Starting the meeting

Welcome everyone as agreed with the person whose circle it is. Introduce yourself and the focus person and explain your roles. Ask everyone to introduce themselves and say what their relationship to the person is.

Explain why circle members have been invited. They are people that the individual feels close to and believes can help them with planning about their life. They are invited to contribute just as much or as little as they can offer in terms of time. Don't scare people off by making them feel they are being asked to make a big commitment if they do not feel they can offer it. Explain that they can ask questions at any time.

Keep things flexible. The type of introduction you do will depend on the number of people in the circle and how well they know each other. Explain the process and the values that underpin circles. This is a new way of planning with people based on respect for the person's choices and the belief that people should have a lifestyle based within the community.

Establish ground rules

It is important for people to know what the process for the circle is and how we are all going to work together. It helps people know where they stand and how to react. It establishes equality for each member right from the start.

Start with dreams

It may help circle members to understand 'dreaming' by talking a little about dreams and explaining that it is ok to think of an ideal life. If we do not dream of a desired future we are less likely to reach anywhere near it. Support the person to express their wishes, dreams, and aspirations for now and in the future. Think about the big and small things.

Getting to know the circle members

What are the group's dreams and hopes for the person? Ask family members first. In the past their contribution may have been ignored or at least not fully valued. They may have felt over-ruled by professionals or services.

Circle members may object to a dream or state a solution that they insist is for the best. You need to find out what is behind the objections – what they are worried about. Often talking about the nightmare helps to clarify what the dream could be. You need to give people time to express their fears, and respect what people are sharing with you, but then keep things moving on in a positive way.

Setting goals

Help the circle set goals from the dreams and prioritise them. Consider any barriers and how they can be overcome. Don't reject ideas but build on them and encourage creativity.

This leads to the action plan. It is important at this first meeting, to decide on some action and who will take it. It establishes momentum and gives the circle clear goals and purpose. This keeps people interested and builds trust in the process. Having some early 'wins' will motivate everyone.

Make sure it is fun. This is a serious business and the responsibility of supporting someone to change their life is enormous, but it need not be dull. Encourage friendship. This will help to develop the social aspect of the circle.



Amanda's Story

Our daughter Amanda was a happy child and teenager. However, at the age of 16 years both Amanda and our family went through a very difficult time without support. We wondered if we would ever get through it and were so afraid about what the future would bring.

We wanted to help our daughter as much as we could so in 1990 we formed a small circle of friends to help Amanda get a better life. This was a turning point and one that was to set us on a new journey that has lasted to this day.

We worked together to make sure Amanda could get further education and we contacted the local Speech and Language Therapist to support us to develop a communication system with our daughter who does not use spoken language. With the help of some thick card, velcro and photographs we were able to support Amanda to make some choices in her life. This meant that she did not have to get so upset and frustrated when other people could not understand her. We ordered photographs of the menu from our favourite restaurant and pretty soon Amanda was able to choose her own food when we were out. We discovered just how many fantastic things could be done without spending lots of money.

Some years ago Amanda was successful in getting an increase in the Independent Living Fund money. Having a person-centred plan really helped this as we could all see how she could be supported to be more independent. Today our daughter has personal support at a small daytime service that has helped her so much. She also goes out most evenings and has more people in her life who are closer to her own age.

Over the years some people have left the circle, but others have joined. We thought about the future and drew out a PATH to help us make our dreams for Amanda come true. We are still working on most of these things and life has been hard at times. However, when we look back Amanda has come such a long way. We have more happy times again and look forward to birthdays and other celebrations with our friends. Amanda has been a bridesmaid, travelled to Spain and France and continues to show us what she can do.

We want Amanda to have a life full of happiness, where she is able to have more of the things she enjoys. Amanda will have her own home and we are looking into shared ownership at the moment. None of this would have been possible without the circle of friends. We have known each other for such a long time and have shared our lives together. We are all good at different things and when we get stuck we invite people to join us who can get past the problem. There is now a light at the end of the tunnel – of this we are sure.

Iris and Brian Sell

Amrien's Story

My planning circle was started by the people who know me well. It was initiated as a direct result of my changing physical health needs which were dominating my life.

My planning circle challenged the medical practitioners and other professionals in order that my voice be heard. Throughout this difficult period of emotional adjustment I managed to develop my plan into a multi-media format which I have actively been involved in constructing. Doing this helped my circle to look at what I wanted and needed in order to be healthy and safe.

My plan gave me time to adjust to my changing physical needs and helped me to understand what was happening to me. It enabled my voice to be heard – I have limited communication and my plan explicitly outlines my dreams, my nightmares, my needs and action.

My plan has enabled me to be acknowledged as a person who has complex health issues but has clear views on how future care package should be delivered.

What next

Showing the people who make decisions about my future my plan and letting them understand why it is important to hear my voice and my wishes when they make decisions about my future. I want to make the decisions that matter to me and my family.



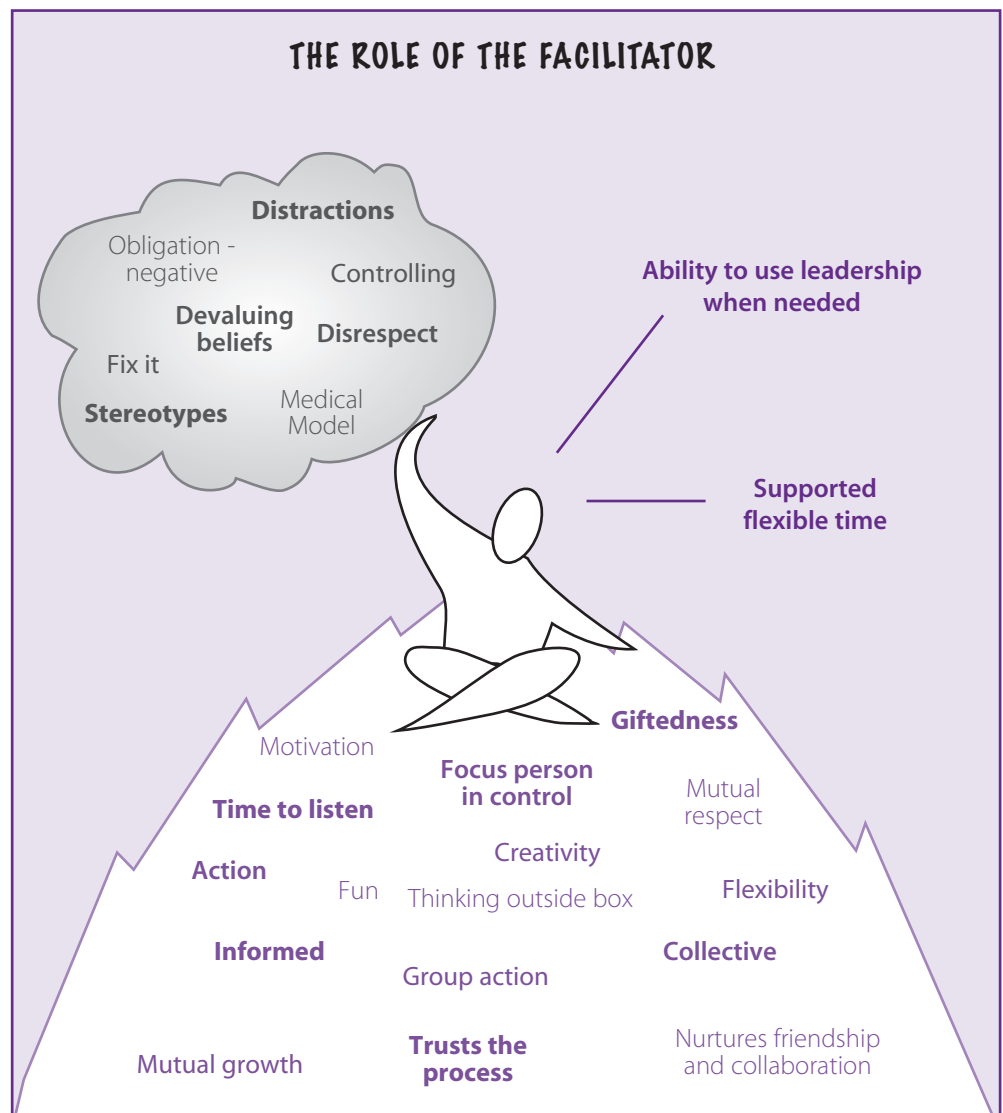
Written with the permission of Amrien Javed
Supported by Susan Spencer (facilitator)
Redbridge & Waltham Forest Learning Disability Partnership

THE ROLE OF THE FACILITATOR

Someone who has stopped to listen and cared enough to want to make a difference to someone's life.

C. Ludlum 1993. Tending the candle.

A facilitator is anyone who helps another human being to make changes in their life and gain power and control over their life. They can be individuals with a learning difficulty, disabled people, family members, carers and paid people. A facilitator brings people together and helps make it possible for the focus person's voice to be heard. They nurture relationships and support the focus person to name their dreams, wishes and hopes for a positive future. We use the skills of facilitation in many parts of our life, at work, home and social life. It is these skills that we need to bring to our work with individuals who are disempowered.



Thoughts before you start

You cannot plan with people unless you put your whole self – your whole person - within the planning process. You need to use your heart not just your mind. It is a good idea to get someone to do a plan for you and your life in order to understand what it takes to trust another human being to come into your life in this way.

Ask yourself why you are supporting someone to plan his/her life. Are you clear about the values that underpin person-centred planning? Putting values at the forefront of your mind each time you start the process of getting to know someone will help you remain person-centred.

Be clear about your role and honest about your commitment. How much time will you give? What are your boundaries? For example, will you be directly supporting the person to build community connections or will you be asking circle members or paid people to do this? It is important to agree your boundaries with the focus person at the outset. This avoids embarrassment or misunderstanding.

How will you support the circle to develop its independence – ensuring it is not service-led?

How will you plan your exit?

A good facilitator is able to see the bigger picture and share the person's vision and dream. He/she helps the circle understand who the person is and what is important to them and defends the focus person's wishes.

A facilitator needs to be a good listener, learning to be comfortable with silence and spending whatever time it takes to understand what is important to the person, particularly people with unique communication. Informality is the key: this is not a formal interview or an assessment or a review meeting. You will need to walk with the person at their pace in the places that are important to them and pick up on what they are communicating. It is this walking with the person that helps you be sure that what is being expressed are genuinely the person's wishes – and not your own or someone else's wishes for the person.

Good facilitators are creative and build positive energy that supports the persons voice to be heard. They enable action through creating a strong

Facilitator's gifts, skills and qualities

collective advocacy within the circle. Good facilitators know the right questions to ask and do not feel they are the ones who have all the answers. They do not give advice but guide the circle to focus on possibilities and positive solutions. They develop caring, friendship and good relationships between circle members, but are able to challenge others when need be.

Facilitators are agents of change. They are neutral agents but biased on an agenda of inclusion that challenges stereotypes and negative beliefs about the person. They are biased towards building intentional communities based on building on people's capacities.

Facilitators have flexible styles of questioning in order to ensure that they are not leading the person. Keep in mind the well-known problem of a person always answering with the last thing said: "Do you want red or blue?" "Blue." "Do you want blue or red?" "Red". Use different techniques in order to be clear about what the person is saying. Graphics and pictures often help. Give people time to think about things. We all have a different style of learning and thinking and some of us need time to reflect before we give a considered response. Spend time with the person and get to know them in the different environments that make up their daily life. Be clear how they communicate in order to be clear as to what they are communicating.



Ming was supported to make choices by being shown pictures of people in her life. She pointed to her mum's picture and gave a big smile. The circle gave her two boxes – one with a lid for things she did not like or did not want to think about; and an open box for things she wanted in her life, things she wanted to see and do. The circle was not sure this would work but it did.

The facilitator keeps the circle moving when it is stuck or loses momentum, aiming to create a listening environment filled with energy and creativity.

The circle should always focus on developing long-lasting natural supports and community connections. Ideally, this will result in a person or people from the individual's natural support network taking on the facilitation: they are more likely to be around for the long term.



Uncertainty and lack of confidence can make us fall into the trap of relying on familiar systems and tools. However, it is important to focus on your belief in the person and your belief in inclusion - not the techniques and tools you are going to use.

Focus on the person not the tool

There are a number of very useful tools and techniques available (see recommended reading) and you need to be familiar with these and consider how they can be helpful to you in different situations. But always remember that first and foremost it is your commitment to the person that counts along with three straightforward action steps:

- ➔ Get to know the person
- ➔ Find out what they want
- ➔ Help them work out how to get it

Also think about how you are going to build community connections and nurture friendship.

Getting to know the person

Facilitators start by getting to know the focus person well - their wishes, their dreams, how they communicate, how they make choices, their likes and dislikes, where they want to live and with whom. Then they find out who is in the person's life and whom they would like to invite into their circle – people who will respect and believe in their vision for the future and be committed to keeping it alive. Working in partnership with people who know the person well will help you get to know the person more quickly.



One man's circle was considering what they knew about him. They found it difficult to build a picture of him as they felt that he could not communicate. He was described as a 'man who rocked'. Then a nurse who knew him from the institution joined the circle and explained that actually he did not just rock. She said: "He rocks side by side when he is happy or you give him something nice to eat. He rocks front to back when he is unhappy or he does not like his food." This information helped to 'unlock' him as a person and the circle was able to work with him to make choices about his life.

Start to get to know the person by spending time with them. Go for a drink or coffee or a meal. Spend an evening or part of a day together. Try to get to know them in different environments and give them time to get to know you. Build a relationship based on the principles of friendship. They will not open up and share their hopes and dreams unless they grow to trust you.

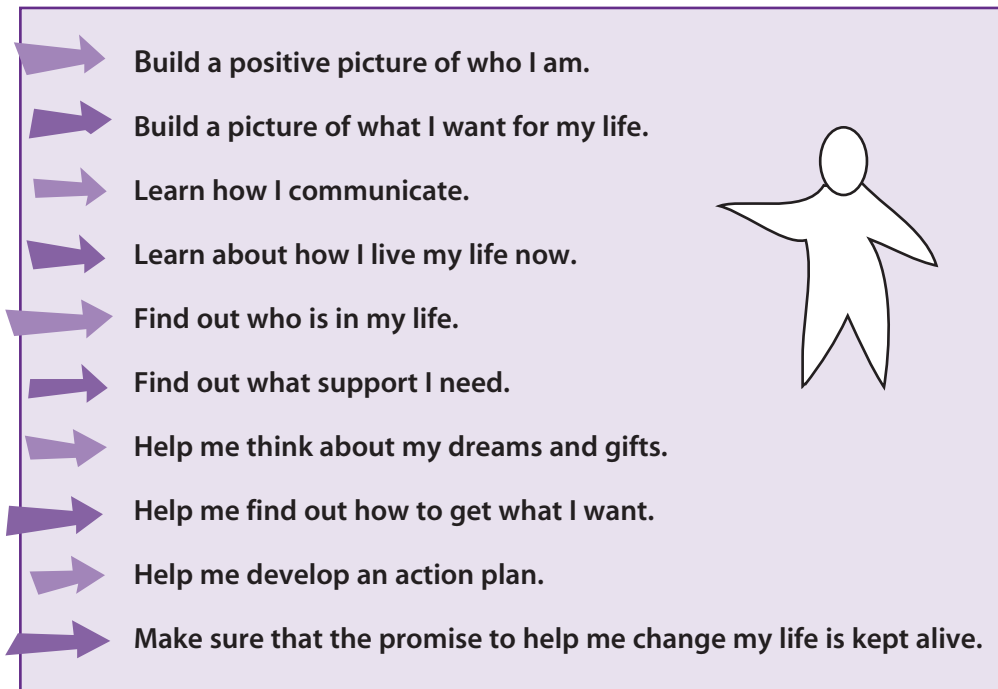
Finding out what the person wants

Take time to understand the person's questions and their dreams. What are the things that do not make sense to them? For example, one man's question was why he had to live with six other people. You need to know what the person is going to say about their dreams so that when it comes to the circle meeting you can protect the person's wishes.

It is important to discover the dream, (see chapter on dreaming), and be clear what the person wants and how they want to change their life.

The person needs to feel confident that you have a commitment to them and their dreams. You may have your own ideas and dreams for the person but these need to complement the person's dreams, not replace them. If you cannot support the person's dreams then you should not be that person's facilitator.

Steps that help



- Build a positive picture of who I am.
- Build a picture of what I want for my life.
- Learn how I communicate.
- Learn about how I live my life now.
- Find out who is in my life.
- Find out what support I need.
- Help me think about my dreams and gifts.
- Help me find out how to get what I want.
- Help me develop an action plan.
- Make sure that the promise to help me change my life is kept alive.

Often circle facilitators find it difficult to share power and control. This does not help the goal of empowering the focus person and prevents the circle from developing its own skills and capabilities. It encourages the circle to look to the facilitator for all action, suggestions and solutions, rather than taking on these responsibilities themselves. This in turn limits the circle's creativity and ability to work together and leads to loss of purpose and commitment.

This lack of sharing power and control is a particular danger when the facilitator is paid. It reinforces the notion that people with learning difficulties always need paid support and cannot survive without them. It is true that many people need paid support but they also need other ordinary relationships in the community to ensure a balance between services and community life, based on interdependence, safety and sharing of roles.

Many people have never had the life experiences to know how they really want to live their life. Creating opportunities and motivation to take part in those opportunities is a crucial part of a facilitator's role. Then the person will start to realise that their choices are respected and so they will grow in confidence and take more control of their life. A good facilitator learns to present opportunities at the person's pace and on their own terms: not offering too much at once but helping them to choose for themselves. This approach helps people change from being passive recipients of services to active participants who choose what they want to eat, wear, do and eventually decide how they want to live their life.

Power and control

Family members as facilitators

Family members acting as facilitators need to make sure they know the person's wishes, even if they don't agree with them.

The circle needs to know that you value their views and ideas – that they can safely challenge you - particularly when there is a difference of opinion about your relative's wishes.

Creating a climate of partnership is vital if you are going to build something that will last beyond your lifetime; a group of people that will be there for your relative through thick or thin.

Facilitating your own circle

If you are facilitating your own circle you need to be clear what you want from your circle. You may need someone you can trust to share the job.

Have the meeting in a place that is comfortable for you. You are the host/hostess so you need to welcome the circle members. Offer refreshments and make people feel comfortable.

Paid facilitation

People often ask whether facilitators should be paid. There is no easy answer. Circles of support should be natural support systems that develop community connections and long-lasting, mostly 'unpaid' relationships. Ideally facilitation would be unpaid and carried out by individuals in the focus person's natural circle of unpaid people. However, in reality many people have no unpaid relationships.

Paid facilitation can be complicated. The organisation the facilitator works for can affect the nature of the relationship between him/her and the focus person. The facilitator may leave that employment and so the relationship is severed.

Paid facilitators should consider seriously what their role is and what their commitment to the individual is going to be. Their commitment might be to get the circle going and find an appropriate facilitator. Sometimes a natural facilitator emerges from among the circle members but more likely these skills will need to be discovered and nurtured. This is an important goal for the paid facilitator as it is vital that the circle does not become so reliant on the facilitator that it comes to an end if the facilitator leaves.

Sharing the facilitation role

It doesn't need to be just one person who takes on this role. Some circles share the role on a rotating basis thus ensuring that there is not over-reliance on the one person. The circle needs to agree some ground rules on how this will work in order to avoid lack of continuity or action that is not followed through. This can foster good teamwork and offer everyone the opportunity to try out the role. However it could also end in chaos - with no meetings organised, no clear understanding of the role, and ultimately disappointment for the focus person.

It is important to specify the extent of the role and spell out the duties. For example who organises the meetings, who will organise hospitality, who reminds people about action, who ensures notes or other record of the meeting is distributed.

KEY INGREDIENTS FOR FACILITATION

- ➔ **Develop commitment for change.**
- ➔ **Understand the person's vision for their life.**
- ➔ **Develop person-centred thinking in the circle.**
- ➔ **Be committed to inclusion.**
- ➔ **Move toward a person-led life rather than service-led.**
- ➔ **Ensure action is taken.**

A facilitator is a person that is there for as long as the focus person needs them to be there to help discover the things they want to do, develop self-determination and support them to design and manage their own life.

Facilitators find themselves in awkward situations and having to manage many difficult dilemmas in their pursuit of helping the focus person get the life they want. The following are some of the questions often asked with a brief outline as response in an attempt to be helpful.

Often asked questions

Handling conflict of interest

Trust in the process is vital. As relationships grow the circle members become a closer team in friendship and action and start to be able to manage conflict amicably. Be focused and 'protect' every member of the circle. Most importantly make sure the focus person is able to make their own wishes clear. A facilitator may need to bring in an advocate at this point or someone else who will stand up for the focus person. This will make it possible for the facilitator, at least to a certain extent, maintain an impartial role.

There are many examples where patience and time yields a desired outcome. When a mother was voicing opposition to what her son wanted it was her daughter and daughter-in-law who provided a resolution. They expressed an alternative view and explained what their brother truly wanted. Had the paid facilitator taken that stance, there may well have been a different and less desirable outcome.

Sometimes the family and focus person are on one side and paid staff on the other and there seems to be no solution. The collective advocacy of the circle needs to be trusted. They – and the facilitator – may need to be prepared for a long, drawn-out struggle. Be brave. Sometimes this is the only thing that will help. In the end, you may need to support the focus person and their family to lodge a complaint.

This type of situation can become exacerbated if the facilitator is a paid person. Then the facilitator may need to pass on facilitation to someone else.

When one circle tried to resolve conflict with the care manager they found that they were being marginalised by the service and an attempt was made to remove decision-making from the family. The circle decided to attend a meeting they were not invited to – all seven of them along with the focus person and their parents. It was a difficult situation for all. But the circle stood strong and expressed their disappointment calmly and in friendship. They explained that the focus person did not want to move from their flat to a residential home; that they did not feel they were being unreasonable to ask for some direct payment to ensure the person was successfully supported to lead an independent life with support. They relied on the other paid people, who had been invited by the care manager, to bring logic and sense to the discussion and a compromise was reached.

What if the person does not trust you?

Sometimes a member of staff is just 'appointed' to be the facilitator. They do not know the focus person or their family. But the facilitator must be someone the person chooses or is happy with. So the first task is to build trust with the focus person and their family. Sometimes it is vital to keep trying – to 'keep the door open'. Families have heard it all before and many have endured empty promises. Listen carefully - show that you are different and that you do not have ulterior motives. It may take a long time and many calls to say 'hello', or just dropping in for a cup of tea. If you are a paid facilitator, this will mean taking off your 'professional hat' and truly listening to what the family is saying.

Where do I get support?

Evidence shows that where there is good support for facilitators there is a better chance of successful outcomes in the circle. You may be able to find another facilitator for mutual support and to share experiences. Facilitators need to be open to learning new ideas and ways of working. Having your own circle and plan gives you great insight and is a step that cannot be ignored. It is this building of intimate knowledge and experience of the process that gives you the most support. If you are a person with learning difficulty facilitating your own circle, you may need to choose someone who will help you to remain strong at times of conflict or disagreement.

Keeping focused and not burning out

Organising good support for yourself is vital as your role may be crucial to the success of the focus person getting a better quality lifestyle.

Keep a diary for yourself of what is happening in the circle - the life of the person, action agreed, issues of concern, the time it is taking. (This would be in addition to notes kept for the circle and focus person's use.) This is particularly important when you are planning with a number of people. It helps you keep track of where you are with each person and keep the action on-going.

Try to be aware of your own capacity. It is important to be able to say you can do no more. Be careful to ensure that you are not trying to 'take control' of the circle. You may need a mentor to help you think this through and work out ways to relinquish control and pass on facilitation to other circle members.

Trust the circle and trust the process. Build allies that can help to achieve change rather than trying to do everything yourself. Making the circle a good 'working team' will help stop you burning out.

Who is the focus of the circle?

The chief focus of the circle is the person whose circle it is. However at times the whole family is the focus as their needs and hopes may be totally enmeshed with the focus person. This is particularly true where the family is the main carer, often the case with older family carers. (See Recommended Reading – ‘Working with Older Carers’ – FPLD, 2005)

How do you support people who do not like meetings?

Find out what works for the person. Is it a picnic, a walk, a meal at a restaurant, a drink at the pub? How and where the ‘meeting’ is held is not the most important matter. The objective is to listen and talk and to agree some action steps that will change the person’s life. If all else fails, you may – particularly at the beginning - have to meet with each circle member separately and agree steps. Remember too, that experience shows that once the focus person realises the circle is truly there for them and their interests, their attitude towards ‘conventional’ meeting arrangements can alter dramatically.

How do you support people with unique communication in circle meetings?

The first task is to find out how the person makes choices and how they communicate. We need to find out what the person wants in whatever way suits them. Sometimes you have to rely on those who know the person best, linking this with what you know about the person, to try and make sure that the choices made are actually what the focus person wants. This is where the tools of person-centred planning are particularly useful because they help us look in detail at what the person wants.

Where does the circle stand when there is a dispute about who has legal responsibility for decisions?

This is one of the most difficult issues to resolve. When a person’s capacity to choose or to make decisions is disputed you need to bring in every possible ally to help work out the steps that everyone would be happy with in order to resolve the issues in question.



Gerald's mother and care manager do not feel he has capacity to make decisions for himself so it is vital to include other allies in his life to help with the decision-making. He hates where he lives and says this in words every day. He clearly expresses his desire to live alone with support. He now has a job and is looking for legal representation to help him with this issue.

This is another instance where independent advocacy may be crucial in order to find a resolution. Building advocacy through the circle is important as it may be this commitment that will ultimately lead to positive outcomes for the person.

What about risk and duty of care?

The issue of risk is of major concern to families, staff and the individual. They worry that things may go wrong and they will be blamed.

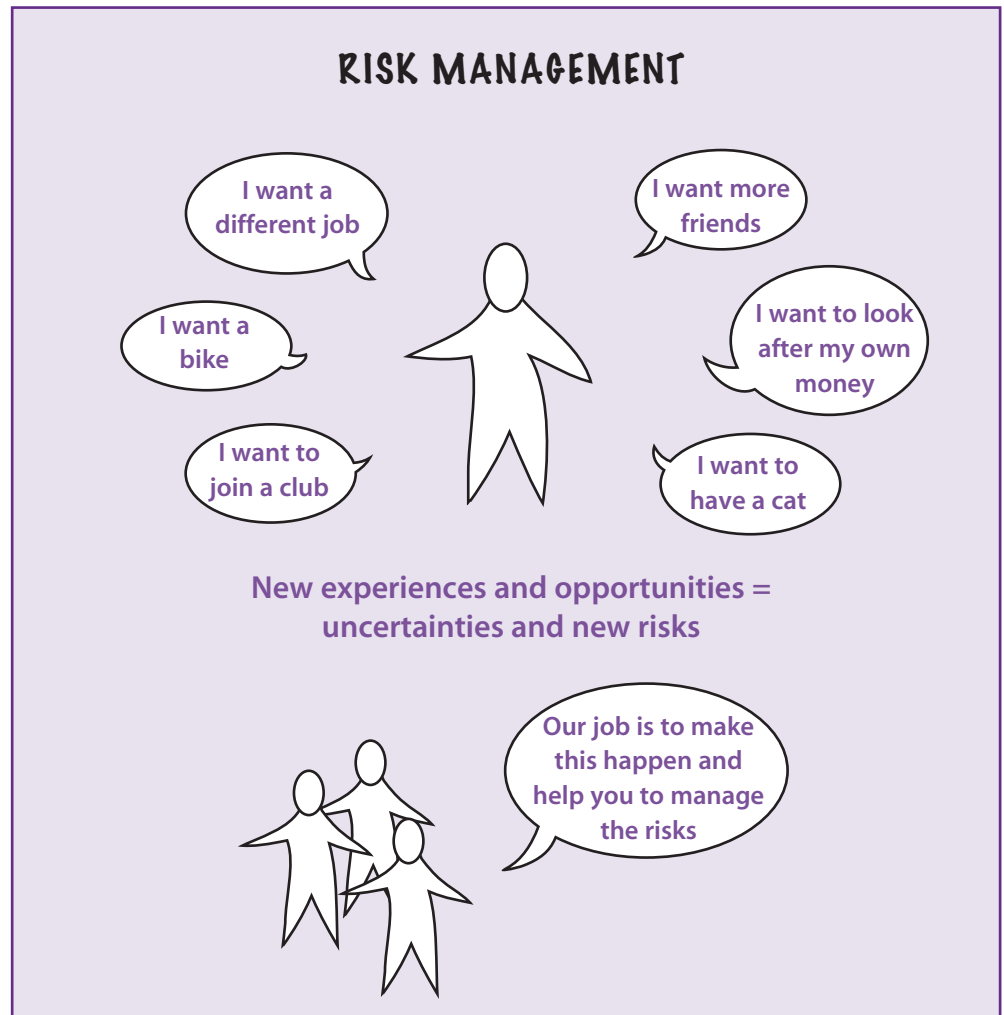
Staff would not lift Gale. They were worried that because of her brittle bones they would hurt her and her mother would blame them. Her mother gave official permission for them to learn to be with Gale and how to lift her and she reinforced this in the circle, verbally and in writing, that she would not apportion blame. She knew it was important for Gale to have companionship.

It helps to have an official risk management policy as long as this is supported in practice so that risk is managed and does not prevent the person doing what they want. This will give staff more confidence to try out different ideas and help people achieve what they want.

A HELPFUL POLICY EMPHASISES:

- ➔ The benefits of new experiences and opportunities for people
- ➔ That risk taking is part of daily life
- ➔ That managing risks needs to be an integral part of everyday work
- ➔ The need to ensure beneficial things happen as well as ensuring that negative things do not
- ➔ The need to take an individualised approach – to look at risks specific to each person
- ➔ The need to empower people so they can make their own informed choices
- ➔ That decision making lies with the person and their planning circle
- ➔ The need to manage risks for individuals in ways that do not compromise the lives of others
- ➔ The importance of careful planning, monitoring, review and action learning

Risk management is integral to the empowerment of disabled people. An organisation that aims to empower people through person-centred planning must support its staff to manage risk effectively.



How can we get staff to change their practice?

Person-centred planning helps because it does have an impact on people's lives. It makes staff concentrate their effort on what matters most to those they are supporting, and on improving lifestyles. It presents challenges to staff and the organisations they work in and needs sustained support in order to achieve change in people's lives.

Much more will be achieved through person-centred planning when organisations develop more flexible ways of organising and using the immense resources at their disposal. As long as person-centred planning stays focussed on people and achieving their life goals it will create a culture of learning and

empowerment, and change will happen. However, if it is perceived simply as a technology that staff have to introduce, it will become just another hoop for people to jump through and very little benefit will result.

What happens if nobody turns up at the circle meeting?

This is a risk we have to take. To minimise the risk, ask people to RSVP or call them in advance. It also helps if you make the circle meeting a pleasant activity that people will want to come to. However, if it is just the two of you, you can still enjoy the activity and each other's company and think of the next steps together. Remember that whereas before the person may have been on their own, they now have you.

How much time will person-centred planning / developing a circle take?

This is a difficult question to answer because it can depend on so many different things. But it is a real issue when someone has limited time available and/or many other people to support.

Particularly in the early stages, it will take quite a lot of time getting together with the person/family, organising and being present at circle get-togethers. From the beginning, you need to make it clear to the person and the circle how much time you can offer and what degree of commitment you will be giving to the group. It could be that you are there to start things and then someone from the circle would be assisted to take over facilitation.

That is why it is important to start with one person at a time: don't try to support everyone you know to have a plan all at once. You need to recognise that it will take time to support a person well. This varies from person to person but particularly in the initial stages, it will require time and informal meetings possibly outside work schedules to get to know the person well. It is a big commitment but it is a person's life we are talking about so it is important.


You can judge roughly how much time will be needed as you get to know a person and know the action that will be required. This will determine the frequency and number of meetings in the initial stages and help you plan your time. Be realistic about how much time is going to be needed. This is particularly important if you are seeking management support for this.

Conclusion

Facilitators hear people's dreams and hopes and create a climate where mutual respect and collaboration is built up with others as allies so that the person gets the life they want and choose to live.

The facilitator is someone who understands the importance of the process of developing opportunities for growth, learning about life and making choice; the journey towards gaining empowerment and self-determination - moving away from a life that is defined by services.

Facilitators are active agents of change that learn the skills through practice on themselves. They understand the importance of the role and the skills required to listen to someone's dreams and joys, vulnerability and pain. It takes imagination, love, creativity and commitment. It requires much thought as it may well determine whether an individual is successful in achieving a meaningful, self-determined lifestyle.



In essence, listening and sharing vulnerability. It is sharing life, sharing power, giving up control, encouraging interdependence and getting to what really matters to make someone's life not perfect, but meaningful. It is about nourishing the humanity and gifts in every one of us.

Lets call it an art. Let's give it colour, passion, power, emotion, magic, skill and the talent it deserves. Peace and justice will not come by us wishing it. It will come with sweat and tears that real change always entails.

John O'Brien - A little book of person centered planning 2000



The real voyage of discovery is not in seeking new landscapes, but in seeing with new eyes.

Marcel Proust



In Praise of Subjectivity

*I know what I know
Because I have lived it
Smelled it, heard it,
Felt it, seen it.*

*I know what I know because I held hands
Witnessed the stories,
Felt the pain, wiped up the blood,
Cried the tears, with others,
Many others.*

*I know what I know because I have reflected
On all these stories
Talked about them,
Laughed about them,
thought about them,
Drawn conclusions,
Tried things out,
Made mistakes,
Tried again.*

*You know what you know
Because you have read it,
Attended the lectures,
Written the essays,
Passed the exams,
Gained professional status
Distance and
Objectivity.*

*Your word is sought out,
Trusted and valued,
Handsomely paid.*

*Mine is ignored,
Silenced,
Starved of resources
Dismissed in my
Subjectivity,
My passion, tears and rage.*

*Thus
Those who know (but think they don't)
Are condemned to be controlled
By those
Who could never know (but think they do).*

Micheline Mason

(Taken from 'Let It Be Us and other poems' www.michelinemason.com)



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About the Foundation for People with Learning Disabilities

We use our research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people's lives now and in the future.

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