Family Futures

AN INTRODUCTION TO PERSON CENTRED SUPPORT – 2 DAY COURSE

Course pack written and produced by

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ABOUT THE FAMILY FUTURES PROJECT

Thank you for making the commitment to take part in this course. You will be helping the Family Futures Project achieve its goal to build a national infrastructure of skills and experience in person centred planning with children and families. This course is for staff from NCH Gilmerton Road Project and is funded by the Family Futures Project.

The Project is a partnership between SHS Trust and six organisations working directly with children with special educational needs. The partners are; SenseScotland, Aberlour Childcare Trust, NCH Action for Children (Gilmerton Road Project Edinburgh), Barnardos West Lothian Project, Fife Education Services and Capability Scotland.

The Project is funded by the Scottish Executive Special Educational Needs Innovations Grant and runs to 31 March 2002. The two and a half year project involves training and coaching in facilitation skills for staff of the partner agencies, school-based staff, volunteers, interested family members and young people, and facilitating plans between children, families and friends and the range of professionals and agencies involved in their lives.

Family Futures aims to train and coach 90 people as person centred planning Facilitators. We hope to work with around 400 pre-school, school age children and young people in transition with special educational needs as a results of emotional or behavioural difficulties. Project staff will also work with around 20 children throughout the Project.

At the end of your training, you will be asked to consider becoming involved in the Family Futures Project. This will entail joining a network of support, ongoing learning and mentoring set up under the Family Futures Project to enable you to work together in pairs to facilitate or support plans locally or in other areas of Scotland. To make this possible, financial support is available for parents and volunteers, along with a modest remuneration.

For more information about the Family Futures Project and the Family Futures Network of Facilitators call Dawn Shield, Family Futures Project Co-ordinator at SHS Trust. Mobile number 07803 649017.

DAY ONE

10.00	Welcomes, introductions and names
10.20	Agreeing group groundrules
10.35	Rites of passage
11.20	BREAK
11.40	Values of inclusion
11.45	Power status and kinship
12.00	Power in society
12.30	Levels of inclusion
12.35	Serviceland and Euphemism Park - person centred planning addresses universal needs
12.45	LUNCH
1.45	Rituals and routines - introducing non-negotiables and lifestyle choices
2.45	BREAK
3.05	What makes a home a home?
4.00	End

DAY TWO

10.00	Welcome back - share one non-negotiable that was met this morning
10.15	Vicious circles
11.00	Lenses and reinterpreting reputations
11.15	BREAK
11.35	Giftedness posters
12.05	Principles of person centred planning
12.25	Overview of tools
12.40	LUNCH
1.40	Facilitation roles and dreams
1.55	Working on individual panels
2.55	BREAK
3.10	Practice brainstorming
3.15	Looking at the possibilities
3.50	Summing up - recap of key concepts
3.55	Evaluations

AGREEING GROUP GROUNDRULES

why

To give the group an opportunity to agree groundrules for how they will work together in an inclusive and empowering way. This is also an opportunity for individual participants to check out any concerns they have at this point about the course.

how

We will give you between 5 and 10 minutes in small groups to agree groundrules. To help you come up with groundrules, it might be useful to think about the kinds of things the trainers and other participants would have to do to make you feel at ease and part of the group.

Another way of doing this is to think about the things the trainers or other participants might do which would make you feel uncomfortable and anxious - and make sure we all know not to do them.

It is also worth giving some thought to additional supports individuals on the course might need and how we organise this - someone might need a lift to and from the venue, someone might need help with taking notes or writing up their learning log, someone may be shy and need support to speak out in the big group.

Someone in the small group will have to take a note of the groundrules your group agree and report them back to the big group. You can take a note of the final list of groundrules agreed on the next page.

OUR GROUP'S GROUNDRULES

1 ______________________________

2 ______________________________

3 ______________________________

4 ______________________________

5 ______________________________

6 ______________________________

7 ______________________________

8 ______________________________

9 ______________________________

10 ______________________________

RITES OF PASSAGE

why

To understand the physical and social barriers which make social inclusion difficult for children and adults with disabilities.

how

We divide the room up into teams to look at different age ranges, for example from before birth to 5, from age 6 to age 10, from age 11 to 15, etc....We ask participants in each team to brainstorm "rites of passage" which are important for someone growing up in this culture. For example, 'first birthday party', 'first day at school', 'first time having a friend over to stay', 'first night away from home', 'first kiss', 'first drink', 'first crush on someone', 'leaving school', 'eighteenth birthday', 'passing your driving test', etc.

When people have brainstormed their ideas, the facilitators will write these up on a long strip of wallpaper with ages from birth to 25.

The teams will then go back to their lists and look at the factors which make it difficult for children and young adults to either experience these rites of passage at all or at least at the same time and in the same way. These factors should be grouped into three types of barrier:

- 'intrinsic barriers' - i.e. those which are difficult simply because of the person's disability
- 'physical barriers' - i.e. those which are difficult because of access problems - for example, other people's houses are inaccessible
- 'social barriers' - i.e. those which are difficult because of other people's expectations and attitudes.

The facilitators will then discuss which barriers are the most significant and difficult to tackle. The facilitators conclude by asking people to reflect on the fact that while people may be 'born in', experiencing these and similar rites of passage is a key part of staying 'in'.

THE VALUES OF INCLUSION

Every one is born in

we are all born as equal citizens and part of a community, we are only later excluded

All means all

everyone capable of breathing, even if breathing requires support, is entitled to be included - no-one is too difficult, too old, too poor or too disabled to qualify

Everyone needs to be in

if people are physically excluded, they have to be physically included. Judith Snow talks about presence being the first criteria for inclusion - if you're not there, no-one will know you're missing

Everyone needs to be with

being there is necessary - but being with takes time and effort. A community is not just a locality - it is a network of connections and relationships. We have to help people be part of and belong to communities, not just be lonely residents within them or day visitors to them

Everyone is ready

no-one has to pass a test or meet a set of criteria to be eligible - everyone is ready to be part of community now and it is community's task to find ways of including them

Everyone can learn

we believe that everyone should be given the opportunity to try new things, grow as individuals and develop to their full potential

Everyone needs support – and some need more support than others

no-one is fully independent and independence isn't our goal. We are working towards interdependence and differing degrees and kinds of support at different times

Everyone can communicate

just because someone can't or won't use words to communicate doesn't mean that they don't have anything to say - everyone can communicate and we have to work harder at hearing, seeing, understanding and feeling what people are communicating to us and communicating back

Everyone can contribute

each person has their own gifts and strengths - and each person has a unique contribution to make. Our task is to recognise, encourage and value each person's contribution - including our own!

Together we are better

we do not believe the world would be a better place if everyone is the same. We are not dreaming of a world when all differences are eradicated and all disabilities are cured - we believe that diversity does bring strength and that we can all learn and grow by knowing one another

POWER, STATUS AND KINSHIP

People's quality of life, their sense of identity and their safety is closely connected to:

- the power they have
- the formal status which society confers on them

  and

- the strength of their kinship network.

This lecture explores the meanings of these terms and the reasons why some people are particularly vulnerable in society.

In British society, there are huge differentials between the status and power of individuals. By status, we mean the importance which society accords to them. By power, we mean someone's capacity to make things happen, to control events in their own life and influence the actions of others.

Status and power are associated, but are not the same. For example, Rupert Murdoch has more power than Stephen Hawking, but probably lower status. Nelson Mandela may have higher status in Scotland than Donald Dewar, but less power.

Clearly, someone's status and power can change dramatically during their lifetime. Churchill was sacked by the government in the 1914-18 war; 25 years later he became Prime Minister at a critical point in World War Two.

Status – where it comes from

People's status may derive from their membership of particular groups; from their roles and responsibilities within particular contexts; from their talents, integrity, courage or personality; from particular actions or achievements, or from their conduct over a long period.

Adults can have status within one setting but not another. Someone can be head of a large organisation, but seen as the duffer in a local darts team. Some children may be regarded as the cleverest child in the class, but ridiculed by the other kids because they aren't cool. Someone may be seen as a freedom fighter by one group and a terrorist by another group. Someone may have high status within their own small community, but be unknown outside. Tony Blair's status in England is very different from his status in Scotland, although he is Prime Minister of both countries.

People can acquire status through their individual efforts, qualities, characteristics or achievements, or they may derive it from their membership of a particular group. Someone who is related to the Kennedy family in the United States will start off with high status - although they may lose it later. Similarly, some people start off with low status because of their family background, where they live or many other factors - and they may achieve high status despite this.

Power – where it comes from

People's power may derive from their physical strength, their control of resources (money, organisations, facilities), the people they know, the legal authority invested in them by the state, their particular skills or the force of their personality. Someone may have great power within their family, but no power at work, or vice versa.

Three 'bands' of status and power

The 1% - Our society can be seen in terms of three unequal 'bands' of people. There is a small group of people - perhaps 1% of the population - who have very high status and/or very high power. Government ministers, sporting heroes, company bosses, top civil servants, judges, media people, top academics, landowners, famous lawyers and doctors ... their status and power puts them in a position where many other people look up to them or are directly influenced by their decisions. They are the people for whom other people wait, the people whose words other people pay attention to.

For someone with such very high status or power, the role or talents or achievements from which their status and power derive 'drown out' almost everything else about them. Individuals become their public persona. They can afford to be no good at plenty of things because they are so famous and powerful in one or two roles. Richard Branson's hot air balloon can blow away before his world record attempt, but no-one questions his ability to manage Virgin's many business activities.

The 90% - There is a large group of people - maybe 90% of the population - who get by. Within this group, there are big differences of wealth and health. Some people will have significant authority at work, or will have a highly respected profession, while other people are unemployed or in low-paid jobs. Some people will have loads of money, others are scraping by. Some people will live in mansions, others will be tenants in poor housing. Some people will have many talents or be members of prestigious organisations, others will have much quieter lives. However, all the people in this group are seen as citizens, customers, consumers, voters, community members. They are seen as part of society, as OK, as the great British public.

The 9% - Finally, there is a band of people with such low status, or such little power that they are at risk of being marginalised or excluded. Within this band there are people who are homeless, people who are permanently unemployed, people who are old and ill and very poor, people who have long-standing major mental health problems, children and young people in the care system, children and adults with sensory and physical impairments, and children and adults with significant learning disabilities.

Not everyone with these characteristics will end up 'on the edge' like this. Some will achieve enough status or power to see themselves and be seen as people who matter. But people 'on the edge' are seen by society as unimportant and have little capacity to take control of their own situation. They become the people for whom nobody waits, whose words nobody hears.

These people get a worse deal from society. They are likely to receive a smaller share of the society's resources, to have to accept lower standards, to live shorter and harder lives. The more unequal a society, the greater this difference of treatment, and the more this difference is seen as acceptable.

Kinship

Kinship is concerned not with formal roles and responsibilities, but with personal ties and connections between people - friends and family to rely on, colleagues at work, neighbours to swap favours with, mums and dads and grannies who take care to spoil us.

These are the people who introduce us to new people and new opportunities, the people who include us in things they are planning, the people who keep in touch and who think we matter.
These friendships and relationships are also a vital safeguard against abuse and neglect, and a source of solidarity and support in taking on the system. They are especially important to children and young people to help them develop into confident and secure individuals.

Some people who are at risk of exclusion have strong family connections, but only with a small number of people. They may be very close to their mum, or daughter, or partner but know very few other people. Sometimes the whole family is at risk of exclusion because nobody in the family is well-connected with the wider world.

A crucial role of services is to support people in building up and maintaining their networks of kinship and acquaintance. Again, however, services can operate in a way which destroys people's existing networks and cuts them off from opportunities to build new ones. Sometimes services lock people into being entirely dependent on one caring relative or paid carer.

The challenge for those of us who work in services is to act in a way which enhances people's status, allows them to take greater power and creates new opportunities for kinship.

Why most disabled people have low status and power

Disabled people, like other people, acquire status in two ways. As an individual, their personal characteristics, talents, roles, activities, contributions are regarded as desirable or undesirable. But also, as a member of the minority group 'disabled people' they have a particular status attached to them.

Similarly, travellers, or Asians in Britain, or older people, or teenagers, have a particular social status as a group - and individuals from that group have to start with and work from that point. The social status of these different groups does change over time, for a variety of social, cultural and demographic reasons.

The beliefs which are commonly held in society about disabled people as a group make a frame through which we see and judge disabled individuals. The way we then treat disabled people tends to keep us within this frame, and to confirm rather than challenge the judgements we make.

Group status

In our competitive society, any impairment or inability is regarded as a problem - people are supposed to be young, beautiful, thin, employable, independent, quick, and smart.

So being a member of the group 'disabled people' gives people a poor reputation to recover from.

On top of this, there are widely held views about disabled people as a group.

They are seen as like children; innocent, naughty, less important, to be protected from bad news, easy to please. Disabled adults may be expected to enjoy children's games, activities, films, plays and music and may be mercilessly 'entertained' by primary school choirs.

They are seen as sad, pitiful, objects of charity, rejected. There are still charities which circulate black plastic bags to households and ask us to fill them with our unwanted goods 'for the disabled'. Disabled people living on income support are asked to get involved in raising money to give to charities to pay people to help them. Being someone else's good cause is a bad place to be.

The way we organise services tends to reinforce negative assumptions about disabled people as a group. By providing separate schools and facilities, by batching people together on the basis of their disability, and by organising strange activities and imagery around people, we create a cultural apartheid in which disabled people are seen as separate and unequal.
Someone's disability may be seen as the most interesting and important thing about them in other people's eyes. Their disability obliterates differences of gender, age, class and ethnicity as well as personal qualities and characteristics. People are assumed to have more in common with other disabled people than with anyone else - even their own family.

As disabled writer and researcher Jenny Morris points out

> *"One of the biggest problems for disabled people is that all these undermining messages become part of our way of thinking about ourselves and/or thinking about other disabled people. This is the internalisation of their values about our lives."*

People whose membership of this group is lifelong and starts in early childhood are at a greater disadvantage. Many people work very hard to escape from, or not to be drawn into, this disability net, because they feel that the damage caused by negative status and reputation will outweigh any benefits from getting access to 'services'.

At the same time, some people are laying claim to a positive identity as a disabled person. Like women, black people and gay people in their struggles against oppression, some disabled people are proud to be part of a cultural minority which they believe has a unique value and role within society. They argue that society needs to get better at tolerating diversity and accommodating difference within a stronger framework of equal civil rights.

This distinct minority culture is most developed in the deaf community. Maggie Woolley writes:

> *"Among these disabled people and among deaf people, there is a feature that can be found in all liberation movements - pride. They are proud to be disabled. They are proud of their culture and language as Deaf people. They are proud to be who they are."*

People in the 'radical' wing of the disability movement may argue for separatism. For example, some deaf people see integrated education as an erosion of identity and argue for separate deaf schools. Some disabled people want organisations providing services to disabled people to be 100% managed and staffed by disabled people. This is a healthy challenge to non-disabled people, and gives them some sense of how it feels to be on the outside and dispensable. This strategy is common in many liberation movements and is often essential to the development of a sense of value and pride. However, as we know from past experience, if used as the movement's only strategy, it may to lead to marginalisation rather than power.

Individual status

People can achieve things as individuals which reduce or even cancel out the negative reputation they inherit from their 'group identity'. By holding down valued roles in society, they can be recognised as individuals with a place and a contribution to make. So, for example, people can become classmates, members of youth groups, householders, partners, parents, actors, writers, designers, scientists, lawyers, managers, employers, councillors, MPs, ministers.

All these formal social roles help to create an alternative status and identity for this person as an individual, so they can be seen as someone in their own right. However, even high status people like David Blunkett and Jack Ashley may be better known for their disability than for what they actually say or do.

Individuals with a significant disability, particularly those born with an impairment, have to work harder to achieve some of the things which give people status as individuals. Special schools generally give people a poorer academic education. Universities are traditionally poor at accommodating disabled students, and there is still widespread discrimination by employers. Without personal and/or technological assistance available on and off the job many disabled people simply can't get to work on time or physically get the work.

Power

Disabled people tend to have less power than other people of a similar age and social background.

Some of this disadvantage is to do with people's formal and legal powers as citizens. Children with a disability do not have the same entitlement to attend a regular local school. Adults with a disability may have to prove their legal capacity to be a tenant or a homeowner, to refuse unwanted treatment, to have and bring up a baby. In all these ways, disabled people are second-class citizens.

Some disabled people are in situations where they have none of the typical powers which other citizens would take for granted. They have no power to change the people they live with, the clothes they wear, the food they eat, the time they go to bed or get up.

Disabled people are also at a disadvantage in the personal power they wield. They may have little money, and often no control over the money they do have. They may have no control of their own living arrangements, or of the staff who provide assistance to them. They may have limited powers of communication and self-expression. They may have restricted mobility. They may have little self-confidence or experience of making decisions and giving instructions.

Clearly, it is possible for people to extend their personal power and control, and to regain the crucial sense of being in control of their own life and managers of their own time and space. Again, however, services frequently operate in a way which reduces rather than extends people's power.

POWER IN SOCIETY

why

To enable participants to think about different levels of power and control and who has them

how

Each small team is given a set of cards with examples of power. The floor has been marked out with 3 zones:

1. The Super Power Zone - very high levels of power and control, often over others
2. The Standard Power Zone- typically expected levels of power and control
3. The Minimum Power Zone - basic power and control over day to day life

Each team is given 3 minutes to allocate all of their cards to the different zones. Then, as a big group we travel from zone to zone hearing about the powers you can exercise in each zone. As we travel through the zones, we try and get a sense of the kinds of people who exercise these different levels of power in our society.

When we are in the Minimum Power Zone we will consider how we would feel if these were the only powers we had. If we had to give up some of these basic powers, which ones would it be? If we could hang on to just one of these powers in the minimum zone, which would it be? What if we had to give up that final power? What if we were zoneless?

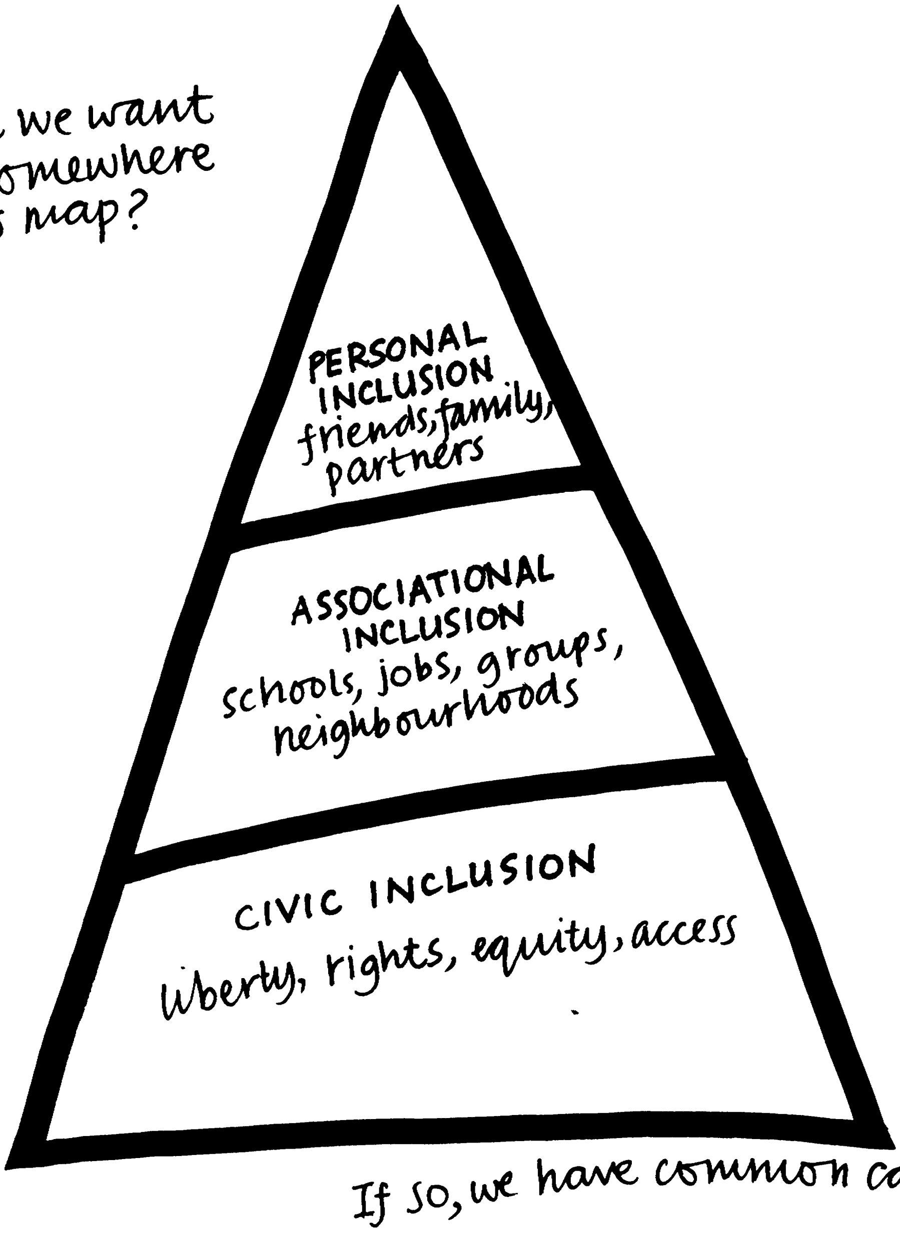
-EXAMPLES OF POWER

- I am a Police Constable and I can arrest people
- I am an army general
- I own my own house
- I can invite people back to my house
- I can order the bombing of any country
- I can fly anywhere in the world in my own jet
- I can lend members of my family money
- I am Leader of the ruling Labour Group on the Council and have a key role in setting the Council budget
- I can hire and fire staff in my organisation
- I can drive anywhere I want to in my own car
- I can employ people to carry out domestic chores for me
- I can decide whether or not to have a baby
- I decide what I eat
- I can have a cigarette when I feel like it
- I can walk out the front door when I want to
- I decide what I am going to wear every day
- I can influence the share price of any medium sized company
- I have a key to my front door
- I can bring down a cabinet minister by telling people what I know
- I can get someone beaten up
- I supervise 4 members of junior clerical staff
- I decide what other people eat and drink
- I am chief executive of a multi national company
- I can choose who looks after my children
- I am a bank manager and I can authorise overdrafts
- I can complain about ill treatment without fear of reprisals

- I can decide who sees me naked
- I have a phone
- I am a member of the National Lottery Charities Board
- I can decide who has sex with me
- I decide how to spend my money
- I can refuse medical treatment
- I am a senior social worker and I can take children into care
- My brother is a local councillor and is on the housing committee
- I am on the central committee of the European Central Bank
- I manage a premier division football team
- I can change my doctor
- I own a national newspaper
- I have a bank account and a credit card
- I have security of tenure where I live
- I am a GP and I write prescriptions
- I am a senior manager in the Benefits Agency and decide who gets grants from the Social Fund
- I have somewhere to keep safe the things which are important to me
- I decide what drugs or medication I take and when

DIFFERENT LEVELS OF INCLUSION

Is what we want to do somewhere on this map?



If so, we have common cause..

SERVICELAND AND EUPHEMISM PARK

We use the concept of 'Serviceland' to try and understand the way in which society has segregated people with certain labels. Regardless of whether an individual is labelled as an older person, someone with learning difficulties, someone with poor mental health or a young person in care, the services on offer to support people are designed on the same model and have common features.

Serviceland is a separate place to the rest of the world. Like Disneyland it often has big gates and open land that is fenced off from the rest of the world. On appearances it is a 'special' place incorporating special schools, special training centres, and special activities. However, the 'specialness' of Serviceland is not apparent in the buildings and spaces of Serviceland which are used to congregate people according to a medical label. The organisation of Serviceland ignores all other factors- you will only meet people who have the same medical diagnosis or share the same labels as you.

Serviceland provides some entertainment for people who have social needs. For example some day centres have social evenings so that all the people who congregate there during the day can see each other in an evening too. Sometimes a befriender will come from the real world and take someone bowling, to the cinema or to a pub in the real world. What the real world calls hobbies or interests are called therapies in Serviceland. For example, swimming is hydrotherapy, playing musical instruments or listening to tunes is music therapy, drawing and doodling is art therapy and for children there is play therapy specially designed to help them express themselves. Of course, all therapies need special teachers.

Inhabitants of Serviceland do visit the real world. There are special buses which are yellow or white with the name of a charity written on the side which take groups of 'residents' of Serviceland into the real world for visits. Serviceland does have buildings in the real world. They are noticeable because they are unlikely to look like the surrounding houses and some have a sign in the front garden so that neighbours know that the people who live there are special. A mini-bus is likely to arrive every morning to pick up people and take them into Serviceland or another Serviceland building in the community- such as a resource centre on an industrial estate. A mini-bus will also be at the Serviceland house in the evening to drop off people. Inhabitants of Serviceland rarely experience the real world as anything more than tourists.

Some aspects of Serviceland mimic the real world, so that we can easily think that the people who live in Serviceland have the same experiences and opportunities as people living in the real world. Euphemism Park exists to exemplify the progress made in Serviceland. In the past, some Serviceland inhabitants lived in hospital wards, were physically restrained and worked for pocket money. In contrast Euphemism Park is modern, and residents live in units or houses. These houses are shared between eight people and some of them have four bedded bedrooms. In Euphemism Park there may eight or more houses in a complex and so everyone knows their neighbours so there's a real community spirit. It has spacious grounds with an administration building where decisions get made.

Euphemism Park has many facilities including a hydrotherapy pool, physiotherapy equipment and its own bus. Someone of the residents may have 'tenancies' which allow them to agree that the owners of Euphemism Park provide their housing and their day to day support. They may go to work at the Park's training centre, where they are trained in crafts which will help them find a job. Basket weaving and knitting are among the most popular crafts being trained. Euphemism Park has a hotel department offering short breaks to visitors. This enables visitors to the Park to have a rest away from their families and offers them the opportunity to do something different.

It is quite obvious that although this description is tongue in cheek and exaggerated in places Euphemism Park is not really that different to long stay hospitals, it just uses different words to describe certain things. However, such euphemisms disguise and hide the true nature of an establishment and can make us think we are progressing towards inclusion much faster than we actually are.

Person centred planning is about planning with people in the real world. Person centred planning addresses people's everyday needs focusing on the person as an individual with likes, dislikes and interests rather than their medical needs and deficits. John O'Brien talks about universal needs. These universal needs are:

- growing in relationships
- sharing ordinary places
- making choices
- developing abilities, and
- being treated with respect and having a valued social role.

These five universal needs are addressed through person centred planning- it is planning to get people a life in the real world where universal needs are met, and if necessary, finding the support to enable this to happen.

RITUALS AND ROUTINES

why

To assist participants to understand the importance of basic routines to their own quality of life, and the difficulties they would experience if they had no control over their regular rituals and routines.

how

One of the facilitators interviews someone about their morning routine and records the information in significant detail on flipchart. Participants then work in pairs or small teams and take turns to interview one another about their typical weekday morning routine, from when they first wake up until they get to work.

They must fill in times, detail the order of activities (do they wash their hair first, when do they brush their teeth, etc.) and they must give specific information about their preferences. They should include details about the speed and atmosphere of their routine and give information about noises and smells which are important. They should summarise the most crucial element to their routine and think about what might happen if this requirement is not met.

After the interviews, each person sticks their own flipchart on the wall and stands facing the flipchart with their marker. Then everyone moves round five places to the right and studies someone else's routine. They give it an overall score out of 10 - how would they feel if they had to go through this new routine every morning.

Then each person has the chance to say why they gave their 'new' routine that mark - the factors that they would enjoy and the things they would find unacceptable.

As a large group we then discuss why some routines got high scores, and some low scores. What were the key areas that lost people marks - in doing this we should pay attention to details like pace, times and timing, noise and tone.

We need to support people in the way that suits them. We will discuss the impact of going through your day when people who support you just don't get it right- they bring you tea with milk in it, or put your clothes in the drawer unfolded. This is not just a matter of people being fussy, wilful, ungrateful etc.!

WHAT MAKES A HOME A HOME?

why

Participants develop their home-grown quality assurance tool, and use it to compare the quality of their home life with the life of someone they know in their service.

how

Each person individually lists up to 10 aspects which for them makes a home a home. Then, in groups of 4, people have to agree jointly a list of up to 10 aspects. Each group puts up their flipchart with their list and the whole group has to agree on a final list of 10 aspects which make a home a home.

The group as a whole then agrees weightings for these 10 aspects such that the combined weights add up to 100. Foe example, they may give each aspect 10 points or they may give 15 points each to 5 major aspects and 5 points each to 5 more minor ones.

Each person then rates their own home life on this agreed scale and these scores are charted. Some people in the group are then asked to think about a person with very high support needs, and some people to think about someone with relatively lower support needs. Ask people to work in pairs to rate the home life of two people they are thinking about.

Chart these scores along with the groups own scores and discuss. Is there a difference between the staff scores and residents scores? Is there a difference between resident scores? If so, are the differences an inevitable result of people's learning disability?

VICIOUS CIRLCES AND NEGATIVE REPUTATIONS

why

To give participants an opportunity to understand how reputations can develop and begin to think about the impact of reputations on our understanding of people

how

Working with wallpaper and the big group, the trainers ask each person to think of one thing other people do which drives them crazy, really winds them up. This can be anything which personally annoys them, from people leaving wet towels on the bed to people talking on mobile phones when driving.

The trainers write up these details on the wall.

As a group we then imagine what it would be like to live somewhere where all these things happen every day, all the time. How would we be feeling in such an environment?

The trainers lead the group through imagining what it would be like to live in such an environment for different periods of time, say one month, or one year. They ask how people would be feeling after these periods of time and what they would be doing - how would they be behaving, where would they be in this place, how would they be coping.

Once we have a sense of how people are in this future environment, we then ask people how they are perceived by the rest of the group - what kind of reputations have people gained in this environment.

We then debrief the participants and talk about what we have learned about behaviour and reputations.

REINTERPRETING REPUTATIONS

why

To assist participants to look again at negative reputations and to try and see the person from a different perspective.

how

When thinking about reputations there are three different kinds of things to think about:

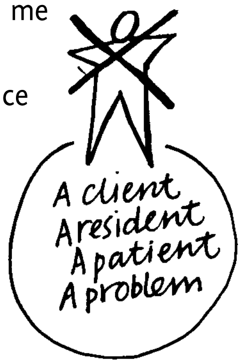
1. Sometimes people have qualities and traits which other people dislike or which can be seen negatively in one context, e.g. someone may be described by some people as ‘pigheaded’ or ‘insecure’ or ‘selfish’.

   These same qualities might be seen differently by people who like the person or people who know the person in a different context. They may say that the person is ‘committed and determined’, or ‘keen to please’ or ‘good at making time for themselves’ or ‘clear about what they want’
2. Sometimes the way someone behaves can be seen as a diagnosis rather than a symptom - the person is described by others as having ‘challenging behaviour’ or being ‘attention seeking’ or ‘self isolating’ This description is seen as part of their ‘medical condition’ rather than a response or reaction to a set of external factors. If the people around the person see them in this way, they can end up trapped in their reputation.
3. Sometimes the way someone behaves is misinterpreted or taken out of context , and the reactions and responses based on this misunderstanding in fact make the person’s behaviour worse. Situations can go on like this for some time, with every new behaviour seen as further evidence.

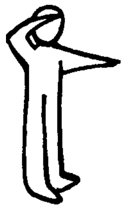
In some senses when we are thinking about reputation we are trying to see through a new set of lenses. Some of us can imagine sitting in the optician’s chair while she slots in different strengths of lens in each eye until we can see things in focus. Part of this work is about changing some of the lenses commonly used.

For example we are trying to move from

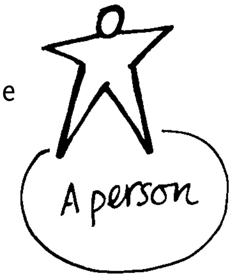
what other staff say - anecdotes stories	labels descriptions used	environment grouping imagery	not like me genetic difference



and move to



sense of justice and decency	recognition of wounds	seeing another context	appreciation and understanding of difference	benefit of the doubt belief people can change



In the large group discuss some of the reputations we had earlier and think about how they might be reinterpreted. We may also talk about some of the reputations we have in our own lives or some of the reputations the people we support have to carry.

WHO ARE WE AND WHAT'S IMPORTANT TO US

why

To learn to see people rather than labels, and realise how much we and other people have to offer.

how

After the trainers have modelled the process first, in pairs take pens and a piece of flip chart paper. Coach each other through the 4 sections of the gifts poster.

- Identity

  This is really all the important roles that you have in your life. It can include information about your age, relationships, gender etc. It can also include positive reputations that you may have, such as being the office agony aunt, the van driver etc.

- Hobbies, interests and passions

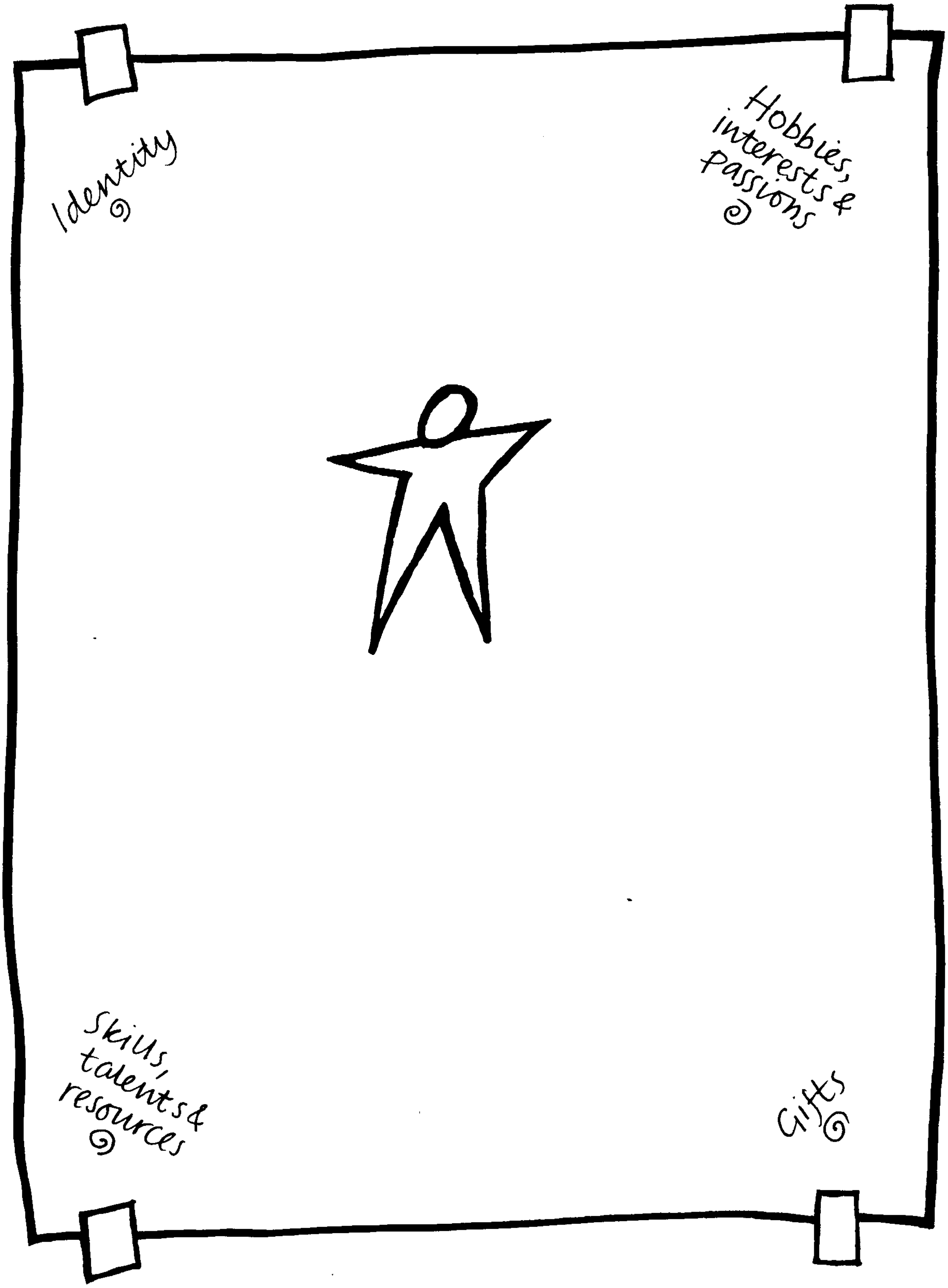
  This should list all the areas and interests that the person has. Remember you don't have to be good at something in order to be interested in it or enjoy it.

- Skills, talents and resources

  This is everything that a person can do or is good at. It also includes all the useful people that the person may know and all the resources and equipment they have access to.

- Gifts

  What do people who like them say about the person, when the person has done something well what positive things do people say.


Identity
Hobbies, interests & passions
Skills, talents & resources
Gifts

KEY PRINCIPLES OF PERSON CENTRED PLANNING

We are spending time during the course thinking about how we can plan for the present and the future in a more person centred way with people, where they are seen as having rights and control over the services they receive and the lives they lead. We are also looking at different ways of providing support for individuals we know in a person centred way.

All person centred planning processes share a number of key characteristics:

- the locus for the plan is the real world, not service land - person centred planning is about getting someone a life, not getting them a service
- the focus is on the person and their whole life - the planning meeting is not to discuss the difficulties the service or the professionals may be experiencing or the constraints they are working within
- the control is with the focus person and their advocates and the person and the people who love and care for the person are the primary authority
- the professionals are there to provide specialist advice, knowledge, and support - but it is not their meeting
- universal needs are as important as medical needs
- the focus is on individual gifts and aspirations, not individual needs and deficiencies
- there is a future orientation,
- there is a commitment to address conflict openly and honestly
- there is a commitment to reach a consensus for action
- there is a willingness to come up with non-traditional, sustainable solutions

When person centred planning works it builds a desirable future for the person and engages the energy, commitment and ingenuity of others to make that future happen.

When used with integrity and an understanding of the values which underpin the process, it is an inclusive method for achieving inclusion.

It is culturally coherent means to reaching a culturally valued goal.

Person Centred planning is a method, not a formula; a process, not a pro forma.

The process of the planning is as important as the steps of tool being used - what is happening in the room and in the minds of the people who are contributing towards the plan is often as important as the words being written down in the formal document.

The process also seeks to build commitment to change and the development of creative solutions to long term problems, not just analysis. By its very individualistic focus, it does not produce standardised and predictable outcomes. Everyone's plan will be different and unique to them.

USING DIFFERENT TOOLS

There are a number of different person centred planning tools. In this course we will provide an overview of:

- PATH developed by Marsha Forest, John O'Brien and Jack Pearpoint
- MAP developed by Mary A. Falvey, Marsha Forest, Jack Pearpoint and Richard L. Rosenburg
- ESSENTIAL LIFESTYLE PLANNING developed by Michael Smull and Susan Burke Harrison

We will not have time to explore these tools in any depth or provide an overview of PERSONAL FUTURES PLANNING developed by Beth Mount. The book 'People, Plans and Possibilities' available from SHS describes each of these processes in detail. You should not use any of these planning tools on anyone else until you have experienced them for yourself. Only then will you have the insights to use the processes with the skill and humility which they require.)

If it is your plan, you are referred to as the focus person.

The people who guide you through the planning process are called facilitators. For Map and Path there are two facilitators - a process facilitator and a graphic facilitator. For Essential Lifestyle Planning there may be only a process facilitator, but we think it works better to have two facilitators working together.

The graphic facilitator records the information on large sheets of paper. The process facilitator manages the planning process.

If it is your plan, you may also have a group of people around you - your support team - who you want to be there to help you plan. This support team can include members of your family, your friends and, if relevant, some advisors or other professionals who you think might be useful.

The tool you choose, the type of facilitation you need for your own plan and the people you suggest the facilitator speaks to when they are gathering information vary - depending on the context:

- sometimes you need to identify the most important area in your life you need to change before you can work out which planning tool can help you change

- sometimes you need to improve the day to day level of physical care or emotional support you receive
- sometimes you need help from others to move on from where you are now
- sometimes you need assistance from others to help you safeguard what is good in your life now
- sometimes you need help from others to work out how the future might be different

When we are facilitating planning for other people we have to know that different tools have different strengths - Map and Path are good at creating compelling images of desirable futures and inviting others to join with the person in making these futures happen.

Essential lifestyles planning is designed to help us catalogue specific details about how best to support individuals and this is particularly important when people have complex physical and medical support needs and do not use words to communicate. Essential lifestyles planning is also good at highlighting what makes sense in your life now and what needs to change.

Some tools are good at exploring ways to connecting people to communities and other tools are good at helping us work out individualised and specific support packages for people. Once you have practised using different tools, their specific strengths will become obvious.

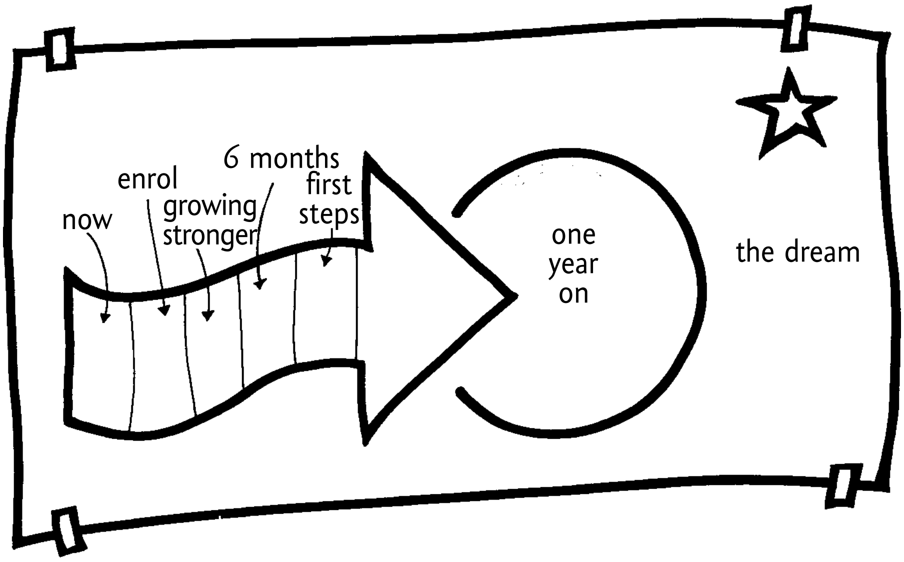
THE PATH PROCESS ~ AN OVERVIEW

The Path process was developed by Marsha Forest, John O'Brien and Jack Pearpoint. Jack Pearpoint and Marsha Forest are based in Toronto and work world-wide as advocates and campaigners for inclusion. They are founders of the Centre for Integrated Education and Community in Canada. John O'Brien has been working around the world for the last 20 years as a teacher and philosopher in the field of social inclusion.

The Path process uses some of the same elements as the Map process which we will look at in more detail on the third day of the course. Like the map process, there are a number of key criteria which must be followed for the process to work:

- the process happens in public - the person who is the focus of the plan invites the key people in their life to the meeting and the facilitators work with the whole group
- there are two facilitators - one to manage the process and one to work on the graphic record, and the graphic is an immediate and agreed record owned by the group
- the two facilitators should be external to the group of people who are participating in the path. If you are someone's key worker or their best friend, you can not facilitate their path - but you may have been invited to the meeting as a contributor to the process
- any conflict within the room has to be dealt with openly and it is the process facilitator's task to bring to group towards a positive consensus for action

There is a very clear visual graphic to accompany the process. This is usually drawn on a large sheet of wallpaper (say 15' by 4') before the meeting and it looks something like the illustration on the next page.



The steps and sequencing in the process are very important and should be followed. However, anyone using Path should be aware of how powerful Path can be - you should never facilitate this process if you have not experienced being the focus person in your own Path. Anything can happen and the facilitators need to know when to push ahead with the process and when to abandon it and do something different.

Before you start, be clear who the path is for. It should be for the focus person who has requested it, not for the service or for other people in the person's life. The service may need a path, and someone's parents may need a path, but their path will need a separate meeting.

Finally, as with all person centred planning approaches, the guiding principle should be DO NO HARM.

We will now describe the process from the point of view of the facilitators. Remember that you can not facilitate your own Path and you can not facilitate a Path for someone who is very close to you - you should be with them, supporting them in the Path if they want you to. The steps of the process are as follows:

1. The Dream

After you have welcomed everyone to the meeting and explained your role, it is often worth talking through the process with the people in the room and explaining how long you think it might take. Putting a timescale on the meeting is always worthwhile. You usually need between 2 and 4 hours for a Path. (An organisational Path takes longer, usually 6 hours)

Path starts with the Dream - You may therefore need to do some warming up work with the group before you start asking the focus person about their dreams. Asking people to tell you their name and describe their perfect, favourite place is one way of helping people relax and get them into the frame of mind for the dreaming section.

As the process facilitator, you will have to work out whether you have done enough work with the group to enable them to open up in the Dreaming section - for some people this is very easy and for some it is hard to imagine a dream.

This is our chance to imagine a perfect future - it should be inspiring and energising and it should engage the imagination and mood of the people in the room. It's content will vary enormously - for some people it may seem completely out of reach, for others it may sound like a list of limited aspirations. Some people apologise because their dream isn't very realistic - you can remind them that that's the point of dreaming. This is the one point in the process when we are asking people not to be realistic.

Dreams vary over time and on different days - a dream may be to have your own house, but once you have your own place you will move onto a different dream. Dreams changing over time should not be viewed as an organisational obstacle - if we are working with people in a person centred way our goal should be to raise their expectations and enrich their dreams.

The key thing is to LISTEN to the dream and record it - particularly when, as the facilitator, you think the dream sounds far fetched or out of reach for the person. As the process facilitator your job is to draw out the essence of the dream - what is the person trying to tell us, what clues are there, what is important and essential to them, what do they really want...

Remember - the seeds for the future are in the dream.

The graphic facilitator has to draw the dream - in addition to trying to "picture" the big ideas in the dream, it is important to get down the words and the emotions the person is expressing. It is often important to start writing up key words right away - the focus person may be very anxious at the beginning of the path and this will let them know you are listening and feel more confident that they are saying the right things. Save the space around the star icon in the dreaming section until you are sure you are getting closer to the heart of the dream.

Sometimes the nightmare creeps into the dreaming section - sometimes people can tell you what they don't want very clearly. As the graphic facilitator it is often important to record this information - but try to keep it on the lower half of the paper. The graphics near the star should all be positive.

The graphics facilitator checks back the dream throughout this section of the Path to make sure they haven't misinterpreted anything or missed anything out. The focus person has to know that they can tell the graphic facilitator if they've got it wrong or they missed something out or need to change something.

The icon of the Star is symbolic of the North Star - the star which allows us to chart where we are going. Whatever else we do, we must be working towards the dream.

2. One year on

Once people have built up the dream, you have to bring them back to some form of reality. We use this section of the path to help people keep in their mind the best elements of the dream and imagine what would be positive and possible in a year's time. As facilitators you have to talk the group into the future - in terms of the process we need everyone in the room to be "remembering" the last 12 months as if they really did happen.

Although this may sound fanciful and contrived, it is an important part of the process. If you can get people to imagine what happened and tell you the story, you know they have begun to believe that the story is possible and that they have started to engage with their role in the story.
Earlier we spoke about person centred planning creating a compelling image of a desirable future and inviting others to make it happen - this is exactly what you are doing at this point in the process.

When you are facilitating this section you have to help people talk through what happened, when it happened, how it happened, what the weather was like when it happened, what they were wearing, how it felt...anything which makes the story feel real. People in the group can work together to create the stories - and you must always check back with them whether it felt positive and possible.

By the end of this section you should have built up quite a few ideas for the next 12 months. The graphics facilitator has to check back the information with the focus person and the people they have invited to the meeting. The focus person must feel positive about the scenario you have built up - you need to check whether anything important is missing and whether anything undesirable has been included. It should feel like a year worth having - if there is no energy in the room at this point you may have to consider whether or not to go on with the process.

There are situations where 12 months is the wrong timescale - sometimes people need to go 18 months ahead and sometimes 6 months is the best period. We will discuss on the course situations where you would change the timescale here and why. There is also a tension between checking for reality and over challenging people who may be experiencing a lot of pain in their current life. We will also discuss this during the course. The key guidelines here are - be sensitive and do no harm.

3. Now

We now have to take people out of the desirable future and bring them back to today. Quite often this can be quite hard work because the people in the group may well want to stay with the dream and the one year one sections- they like it there.

When we say "now" we don't mean now in the meeting, we mean now in life generally. We need to get words from people to describe how things feel now - adjectives, feelings, phrases which sum up for them how life is now.
You can use this section to get different kinds of information - how does the person feel, how do the people around them feel, how do others view the present time. There may be differences of opinion which highlight important issues which have to be addressed.

You are essentially measuring dissatisfaction at this stage - if people think things could be a lot better than they are now, there will be some energy for change. If people are complacent or happy about how things are, there will not be any energy for significant change.

You have to sense the tension between the now and the dream and one year on sections and check with the group whether they think there is enough energy to move towards the dream. People in the room may feel low during the now section and it is important to reconnect them with the dream to help them focus on the future again. There are various techniques for reconnecting people with the dream and the one year on scenarios at this point and we will demonstrate them during the 3 days.

4. Enrol

You have completed the Now section and you have a sense of how big a stretch it is from the Now in the Path to the Dream and the One year on panels. If there is a big stretch this can give us the energy and urgency we need to do something. If people are content with the present, there will not be enough energy to do anything differently - if this is the case, you may need to abandon the Path at this point and use a different planning tool.

If there is enough energy, move onto the enrol section. This is the invitation to people to sign up to help the person reach their dream. Obviously the focus person has to enrol and this is another way of checking that we have got it right so far. After the focus person, other people who have been invited to the meeting are invited to come forward and put their names up.

During the enrol section the graphics person should put the pens down and leave the space for the participants to come forward and write their names up. Don't hang onto the pens - it can be more difficult for the participants to take the pens out of your hand than pick them up. If someone needs help to put their name up, one of the group should do this. The enrol section can be a very emotional and energising part of the process and the act of signing your name empowers the group to take ownership of the paper - it is as if it physically becomes the group's path from this point onwards.

It is important to be clear about what people are enrolling for. We are asking them to enrol for the dream and the one year on we have just created - not just the person and the future they previously or separately wanted for that person. When they enrol, ask people to clarify to the group what they are enrolling for - if they have one particular thing they want to assist the person with, they should say so at this point.

It is also important to be clear about who the people are enrolling to - the process facilitator has to make sure each of the people signing up speaks directly to the focus person and not the process facilitator during this section. We are really handing over the Path to the focus person and their team of supporters during this part of the process.

People in the room may not be able to enrol and this is an important part of the process. In many situations it is better for people to be honest than say they will do something which they can't or won't do. People may have to be given their chance to say why they can't enrol - it may be a positive contribution to the process.

In addition to this being a possibly reaffirming time for people who have know the person for a long time, it is also a chance for new people to come into the person's life and for some old acquaintances to see the person differently.

As you can imagine, this can be a very stressful part of the path process - if no-one signs up, nothing will happen. As the facilitators are generally external to the situation, they should not be signing up to assist the person with the changes they need to make - they have to invite the people in the room to contribute. If there is tension and uncertainty in the room at this point, the facilitators have to hold this and deal with it in a sensitive and honest way.

Often the wider the group of people who have signed up, the more likely it is that something will happen. If one person takes on all the tasks, then it is generally less likely that everything will happen.
Sometimes you need to list additional people who aren't present who have to be enrolled in order for the dream to come true. When you do this, check out with the group who how they will do this. If there are a lot of people missing, it may be worth stopping the process and rearranging the meeting to finish the path when these people can be present.

You should try to avoid a situation where the focus person is beginning to feel disempowered because they are sitting inventing people they think might help who aren't there. Remember that the act of engaging people to help someone's life improve is a key part of the whole process - if the focus person has not been supported to invite the right people to the meeting, they can feel very lonely here. As a facilitator, if you have not explained the importance of this section of the process to the focus person, you have let the focus person down here.

5. Growing stronger

If people have signed up to assist the person, you can move onto this section. The people who have signed up have to agree how they well get stronger - how will they work together and keep one another motivated to assist the focus person.

We can also think about what the people in the group need from one another, for example "I need you to phone me on Sunday evenings at around 8pm to let me know where we have got to" or "I can't be chased up about this on Saturday afternoons because I am out with my kids".
This section must never be used to make up a list of things that the focus person must do in order to qualify for the dream - it is about what the group of people who are supporting the person have to do assist the focus person reaching their dream and experiencing some of the things highlighted in the one year on section.

6. Charting Actions

We then move to the arrowhead of the graphic and we pick out the key areas where we need to take some action. This is essentially the beginning of the action planning phase of the Path. Once you have identified the key areas where people need to do something, you need to get them to brainstorm what and how they might do it. You can keep them in a big group or divide them up into smaller groups around specific areas - as facilitators you will have to decide what feels right for the group.

7. Six months, three months and one month on

It may feel right to do these more detailed sections - it often depends on what people need to do and what has to change. Often it is useful to have some kind of deadline agreed by the big group as this helps people focus and think about when they need to meet again.

8. First Steps

We like to end the Path meeting by making sure that everyone is clear about what they have to do after the meeting. It is vital that everyone who will be contributing to the action plan has identified their first step - if they don't do anything within two to three days after the meeting, there is less likelihood that they will do anything at all.

As facilitators, try and make everyone sign up to something and make sure that they are checking up on one another to make sure they have done it. You may need to remind them about the things they said would make them stronger as a group.

Closing the Path meeting

At the end of the Path, you have to agree when you will meet again and you have to agree who will be the keeper of the Path - who is going to keep the wallpaper. This is often the focus person, but they may want someone else to keep it for them. The ritual of rolling up the paper and presenting it to the keeper of the path is significant - it is about the facilitators formally handing over the control to the focus person and the people they trust.

People sometimes take a photo of the Path and circulate this around the group. Someone may want to draft a written version of the action planning section to help the group work together when they meet again. The original path should be rolled out again and reviewed at follow up session. If the graphics person has been doing their job, they will have made the Path look beautiful - they should feel proud to hand it over to the focus person and they should feel exhausted!

It is also really important to remember at this point that what went on the in the room during the Path is as important as what went on the wallpaper. Path is a process for engaging people in another person's life and inviting them to help that person get what they need.

Last words

Remember that people may need different Paths for different things - they may need a Path to help them work out where and how they want to live, they may use the Path to work out what kind of work they need to do, they may use if to help them work how to get through a difficult time in their life. Like dreams, you don't just get one for life.

Be aware - Path is dramatically different from traditional forms of assessment. If you have assessed people using traditional methods, facilitation of a path should feel uncomfortable. Your role of facilitator is completely different from your role as assessor. If you don't feel uncomfortable, you may not be doing it right!

Be warned that a Path for an individual is very different from a Path for an organisation - different issues come up in an organisational Path and we can discuss these during the course

THE MAP PROCESS – AN OVERVIEW

Jack Pearpoint and Marsha Forest are based in Toronto and work world-wide as advocates and campaigners for inclusion. The are founders of the Centre for Integrated Education and Community and the Map process was originally developed as a way of planning with children with disabilities who were being integrated into mainstream school.

The key criteria for this process to work are:

- the process happens in public - the person who is the focus of the plan invites the key people in their life to the meeting and the facilitators work with the whole group
- there are two facilitators - one to manage the process and one to work on the graphic record, and the graphic is an immediate and agreed record owned by the group
- any conflict within the room has to be dealt with openly and it is the process facilitator's task to bring to group towards a positive consensus for action

We will go through the steps in the map process from the point of the view of the facilitators. Please read the section on Path before this part of the pack as much of the information given there is relevant to Map. Like Path, Map is an emotional and potentially volatile process and the facilitators need to know when to push ahead with the process and when to stop and do something different.

1. What is the MAP for

The first question in any planning process should always be "why are we planning now?". The opening section of the Map process allows us time to focus on why we have brought everyone together and why this is an important time to plan with the person. Who is the Map for and what is it for - where is our desired destination.

Like Path, you would want to welcome everyone to the meeting and help them relax before starting the story section. Also like Path, it is worth talking through the process and explaining what we will be doing and how long it might take.

2. The story

You are trying to get the focus person to tell you their version of their life. It is not the authorised biography - it is their version as they see it at that time in their life. You can help the focus person talk about the key events in his or her life - the clues you discover here will inform all the work you do later in the process.

Your aim here is not to scrip a chronologically accurate and detailed record -your aim is to give the focus person, their family and the people around them a chance to tell the story of the crucial events, both negative and positive, in the focus person's life. It may be a revelation to many people in the room, it may be angry, it may be emotional, it may be sad.

You have to make sure people have enough time to tell their story, but not dwell too long on the negative sections. You must never put the focus person under pressure to give you details they don't want to share. It may be sufficient to write up "this was a bad time" and move on. Once you have shared your own story with others you will be very aware of how emotional this panel of the map process can be.

The purpose of this section of the Map process is to set the scene, build empathy and support around the focus person and let people hear what their story felt like from their point of view. It is not voyeuristic - the focus person decides what to tell and how to disclose the information.

If you think their may be difficult part of the story you can go through this with the focus person before the meeting and agree with them how they tell their story in the room in public. You should be very sensitive to what people decide to share - it is their story.

From the point of view of the process and graphic facilitators this can be a very difficult section - you have to completely hear the story and feel the story - your job is not to counsel or console the focus person - you are standing alongside the person listening and you can not go out of this role. You are witnessing the story - and this can be very emotional for you as a facilitator.

3. The Dream

This section is crucial to the process. Everyone has dreams (even if they only feel like aspirations or ambitions at the moment). This section of the Map gives us a chance to focus on a desirable future - if we could get everything right for this person, what would it look like? We may need to use much of the information we gathered in the story to help us think about how to get things right. Sometimes this is very like the dream section in path, sometimes it is less intense. "What would it look like" is a different question from "what are your dreams" - you have to judge how deep you want to go.

The picture we draw here, whatever its content, should be energising and inspiring - it should engage the people in the room. It's content will vary enormously - for some people it may be having a room of their own, for others it might be owning their own business. Its purpose is to act as a North Star to allow us to chart whether we are working towards or away from the dream.

For the process facilitator this can be exhausting - you have to change mode from listening intently to the story section to engaging the focus person in the dream. You have to work out whether the nightmare is easier first and you may have to put a lot of energy back into the room for the dreaming section. The focus person often welcomes the dreaming section and the mood of the meeting can completely change at this point.

4. The Nightmare

Sometimes it is easier to do this before the dream - we are often much more familiar with the nightmare scenario and it can give us a base to work from in the dream. The key question here is - if we were doing all the wrong things for this person, what would their life look like? By this stage in the process you should know whether the person's life at the present time is much more like the dream or the nightmare.

5. Who is this person

Ask the people in the meeting to describe the person to you as they would describe a friend. In this section we try and get some idea of the person's identity, their status, power and personality - i.e. 23 year old man, a 30 year old daughter, a 19 year old athlete - this gives us a benchmark for comparison. The sense of identity you build up here is very important. The focus person may have a negative self image and this section should work to overcome this view.

This should be a warm and empowering experience for the focus person. They have to listen to what others want to say about them. It may be the first time any one has heard anything this positive.

6. What are their gifts, strengths and talents

Ask the participants to highlight what they like about the person, what hooks them into this person, what's different/distinctive about them. This section highlights what the person can do, not what they can't do. The qualities listed here don't have to be "gifts" in the British sense of the word - they are qualities and attributes which draw others to the person - from their smile or laugh to their memory for train timetables, etc... We can include phrases and words people who like the person use when they talk about them.

If the focus person is isolated, the information in this section will give us some clues about how we can introduce the person to new people and begin to build a supportive community around them.

If there is a lot of negativity in this section, it is good indication that the person is surrounded by people who do not, or can not at this point, love or care for them. This may mean that one of the first steps which has to be undertaken is to move the person out of their current environment or help them build a new group of people around them. It is also a chance to help people see the person differently - if there are some traits which are viewed negatively, we can think about a different context where this trait might be useful and describe it differently. For example being described negatively as "strong willed" and "determined" in one context can be viewed positively in another - both qualities are very useful if you need to advocate on behalf of others.

If the right people are in the room, this can be a very powerful section. The words written up on the paper can often be less important than the process going on in the room. When we are asking people to talk about the gifts they see in the focus person, we are inviting them to align themselves with the person. In doing this, they give permission to others to align themselves.

By stating you think the focus person has a brilliant smile, you are telling other people in the room that you like the focus person. This may change their perception of you and your relationship with the focus person. For parents it may be the first time they realise that their son or daughter is surrounded by people who like them - this can dramatically change the dynamics in the room.

7. What does the person need now

Taking into account all the information we have gathered to date, how is the person doing? Is their life more like their dream or their nightmare? Is there scope for working towards the dream and how can the person and the people in the room contribute towards this? What do we have to do to help the person avoid the nightmare and work towards the dream?

If little is known about the focus person or the focus person does not use words to communicate, we may need to find an expert witness to help us work up a picture of the best options for the person - the best person to provide information about what an 18 year old boy wants to do over the summer, is usually an 18 year old boy, not their mother.

8. The plan for action

Here we highlight and work out what needs to change and who is going to help achieve that change. We also need to clarify deadlines for actions and ways of working together to increase the chances of success. This may be one small telephone call or a major change in the way the person lives their life.

A more detailed description of the Map process is detailed in "All my life's a circle" by Mary A Falvey, Marsha Forest, Jack Pearpoint and Richard L Rosenberg. (Inclusion Press, Canada, 1992)

ESSENTIAL LIFESTYLES PLANNING ~ AN OVERVIEW

Using the Essential Lifestyle Planning process
This tool was developed by Susan Burke-Harrison and Michael Smull as a way of discerning what was important to people in their everyday lives and cataloguing this information in a way which enables service providers to deliver the service in a consistent and respectful way.

It was developed originally as a means of supplying service providers with as much relevant information as possible about individuals who were leaving long term institutional care. It is also used widely in residential care settings as a way of ensuring that all staff provide the service in a way which suits the person.

Preparing an essential lifestyle plan requires a range of skills:

- Interviewing skills to gather as much useful information as possible an encourage people to open up and trust you with important and often sensitive information
- Analytical skills to assist you in making sense of and organising the information you have gathered into a shape other people can understand
- Writing ability to ensure you can communicate clearly and coherently on paper - an essential lifestyle plan is a written document
- Facilitation skills to enable you to manage the meeting with the focus person and their supporters and others and ensure that an action plan emerges.

We would always recommend two facilitators rather than one. If two of you are gathering information you can share interviews between you or assist one another in taking notes. You can check information and impressions out with one another and you can better facilitate the action planning sessions.

Phase 1 – Undertaking interviews and gathering data

The focus person and the facilitator for the plan identify the key people who are most important to the person and who can contribute to the plan. The facilitator starts with the focus person and then talks with each key person, trying to build up as rich a picture as possible of the focus person and the things which are important in that person's life.

The method for gathering this information is very important. There are no check lists - the facilitator's success in building up a rich picture relies very heavily on their ability to ask open questions and draw out stories about the person, the things they like and dislike and their rituals and routines.

Open questions are designed to open up the conversation and encourage the person you are interviewing to talk. "do you like the person?" is a closed question - it encourages a yes/no kind of response. But "what do you like about the person? encourages the person to tell you as much as they want to. The kind of information they give you will let you know whether they like the person or not. If you sense that they don't like the person, they are unlikely to be a good source of information. People who like the person will give you much more useful information - spend more time with them.

Some examples of the kind of questions you might use are:

- how long have you known the person?
- how much time to do you spend with the person?
- what do you like and admire about the person?
- have you had a good time with the person recently? what did you do? what happened? what make it enjoyable...
- what are your favourite stories about the person?
- have there been any bad days recently? what happened? what made them difficult days?
- how do you know the person is in a good mood or bad mood?
- what does the person like to do in the morning/ evening/ getting up/ going to bed

- what rituals and routines are important to the person?
- can you describe these ritual and routine in detail?
- what kind of things do you do that the person likes?

etc...

As you start to talk to the focus person and the people they have asked you to talk to, you will begin to build up your own repertoire of questions. You may ask some of the people you are interviewing to tell you their version of the person's story - what was the person like when they first met them? How have things changed over the years? What were the best times? What were their happy memories?

The main thing is to keep the questions open - encourage the person you are interviewing to talk as much as possible. If the process is working well, the person being interviewed should be enjoying the process and they may be realising things they hadn't been conscious of before.

As the facilitator it is crucial that you stay in phase - you are gathering information at this stage. You are not judging or analysing the information. All the information is useful at this point - you must not begin to make sense of it yet. If you make judgements early on about what is important or what is "correct" information, you may well miss extremely important bits of information.

If we asked a range of our friends these questions about us we would gather a wealth of information. Contradictions don't always mean that one person is right and the other is wrong - those people just see us differently and experience us differently. Both views can exist at the same time - people are not caricatures, they are complicated.

Finally, some of this information might have to be very detailed - if the focus person requires a lot of physical assistance, we may need to get very specific details about to provide this support from someone who is good at providing this support. The way this person provides support can be used to inform others who may have to provide the support both now and in the future. This is when closed questions become more useful - "is that cafedirect with one brown sugar or two?"

During this phase of the process - keep an open mind. Write everything down - don't decide in advance what is going to be important.

Phase 2 – Checking back, clarifying, prioritising and sorting data

Having completed your interviews, you now have to begin to sort out the data you have collected. This can often be like looking at a "magic eye" picture - you have lots and lots of dots and only by standing back and looking at the whole picture in a new way, can you begin to see the real picture coming into focus.
The sections of the plan - an overview
In essential lifestyle planning there are a number of different sections for the information and you have to begin to see the important patterns and crucial details. We will go through each of the sections or panels in detail, but here is an overview of the kind of sections you want to sort the information you have gathered into:
It is crucial to remember in essential lifestyle planning that the essential, important and likes panels are written entirely from the person's point of view. If the person likes smoking it must go down here. If there are health issues around smoking, this can be dealt with later in the "to keep the person healthy and safe" section - but we can not delete the fact that they like smoking because there are health issues.

If the person hates being out in the rain, it must go down here even if there is no way we can guarantee dry weather for the rest of their life. We might put a bit in the "to successfully assist" section about how we support the person to be outside in the rain when we can't avoid it.

There may well be issues and contradictions between these three panels (essentials, important and likes) and the later sections of the plan. The planning tool is designed to ensure these contradictions and issues are highlighted - if the person hates being placed in a hoist or using a shower, we need to know this.

If we have to put them in a hoist for health and safety reasons or use a shower because there is no alternative, we need to know we are doing this against the person's wishes and preferences. This should make us look at the issue and do some action planning to change the situation where we can. If we don't include the person's view because we don't think we can do anything about it, we are not writing their essential lifestyle plan - we are censoring the truth and we may simply be describing the constraints and limitations governing their life at the present time, not their preferences and wishes.

The sections of the plan in detail

Positive Reputation

Our introduction to the plan is the person's positive reputation which may start off with the sentence "people who love and care for Mary say she is....." Like the "who is" panel in Map, this section should include positive and affectionate descriptions of the person, details about their age, identity and self identity. It should be a positive, inviting and empowering description of the person and the people who know the person should be able to recognise the person they know from the description.

This section should not include clinical descriptions, such as "expresses anger inappropriately" or "can eat independently", or "needs to be the centre of attention". We should use language which we would use when describing our best friend. If the focus person has a very negative reputation, most people involved in the plan will already be familiar with this - they don't need it written down anywhere. We also want to challenge this negative view and build on the person strengths.

It is important to remember that essential lifestyles planning was designed specifically to assist service providers to support people the service found "challenging" and difficult to support. If there are issues around behaviour which contribute towards a negative reputation, we can deal with these in the "to successfully assist" section of the plan. (see later section)

Essentials, important, likes

The information is sorted out into three main categories:- the essentials (or essentials) , the things which are important (or strong preferences) and the things the person likes. We are beginning to build up a picture of the people and things which must be present or absent in the person's life in order for them to achieve their preferred lifestyle.

When we think of ourselves and the people very close to us, it is easy to make up a list of essentials or essentials - for example, my son must continue to see his grandmother once a month, my mother must be allowed to knit as many cable patterned jumpers as she wishes, my aunt must be supported to attend church every Sunday morning. The things listed here must be really essential to the person, even if some of them seem trivial. I must have a cup of tea in the morning - if I don't have one I begin to become very irritable by 10am...

In addition to asking us to highlight the key areas, essential lifestyle planning asks us to be specific and quantify volume and frequency. The essential lifestyle plan relies heavily on the facilitator's use of language. The facilitator is writing the plan for people who may not yet know the focus person. Don't take if for granted that everyone knows the person well and that they will know what you meant. If the details in the plan are vague and ambiguous, they can be very damaging.

To say that someone doesn't like strangers may mean that they never get to meet anyone new for the rest of their lives. Be specific and say what you mean - you may mean that someone must not be assisted to wash by someone they have only just been introduced to. This is a much more useful piece of information. To say that someone does not like a lot of noise may mean that they are never taken to the pictures again - you may mean that they do not like a lot of noise when they waken up in the morning, so talk softly and don't turn the radio on; or you may mean that they don't like the sound of other people shouting...be specific, it makes a huge difference.

We then categorise other areas and requirements as either important (or strong preferences) or likes. Again this can include a whole range of information, from the vital to the seemingly trivial, from spaghetti and Star Trek programmes to a favourite activity or person. It is useful to include both positives and negatives, i.e., "it is important to Mary that this happens...that this does not happen"; "Mary likes...Mary dislikes..."

If we are not sure about the validity of the information we need to make this clear. Anyone reading the plan will initially assume that everything written in this section is correct - if you are guessing it is important to say so in order to enable other people to check out your assumptions. You can add in sentences like "we think Mary likes...dislikes" or "from our conversations, it appears that Mary must have..."

Remember - these sections reflect only what is important to the person, not what other people or the service consider to be important or essential.

Overview of the support panels

Before you start writing the support panels, check that you have a clear and positive sense of who the person is from the previous panels. Make sure their personality influences everything else you write.

Many people who are critical of person centred planning say that person centred planning is great at describing the person positively but fails to deliver a full and true account of the person and their support needs. They say it leaves out all the negative information.

If the following sections of the plan are not written correctly, this can be a fair criticism. The following sections of the plan should aim to provide as much specific and useful information as possible about how best to support the person. All the negative and positive information should be taken into account, but we must not label the person - everything we say must be in context.

For example, if there are issues around behaviour, it is very important to describe the behaviour and our understanding of it's cause and its consequences. We must not label the person. If someone is labelled aggressive this can be very damaging. If we explain what we think causes the behaviour and how best to support the person during it, we are creating a very different picture.

For example, to simply say that I am nervous and irritable is completely different from explaining that I am frightened of flying and may become distressed during take off. Explaining the context for the behaviour helps other people empathise with it and work out how to support it

Remember, when we describe someone's behaviour, we must also supplement the description with our understanding of why and when we think it happens and then describe what support people should do in that situation.

For example, if someone needs a lot of reassurance because they haven't made many decisions, if we just write "Shona has very little experience of making decisions" this does not give the support person any advice about how to help. It might be better to write "Please bear in mind that, despite the fact that Shona has had little opportunity to make her own decisions in the past, she is keen to make her own decisions now. Like everyone, Shona appreciates both encouragement and reassurance when she is trying to make the right decision for her."

To be Successful in Supporting

This is the section where you include information about important rituals and routines in the person's life. It should detail the kind of support the person requires, when they require it and the manner in which that support is to be provided. It can also include information which would assist us in finding the right type of person to provide support.

If there are high support needs, it is sometimes useful to work through a day, describing everything from the way the person wakens up in the morning to their preferred bedtime routine. We should be highlighting preferred rituals and routines and building on successful practice. Every plan is completely different depending on the person's individual situation, but possible headings might be:

- successfully assisting Mary to get ready for work
- successfully assisting Mary to eat breakfast/ dinner/ tea...
- successfully assisting Mary in the supermarket
- successfully assisting Mary to walk/ travel/ swim/ sit...
- successfully assisting Mary to get to bed

We have to be specific and detailed - "Mary needs assistance to eat" and "John needs help to dress" is hopeless - we need to know exactly the way in which we successfully assist Mary to eat - what kind of cutlery, what kind of plate and cup, what form of physical intervention, how long does it usually take, does the person like a drink with their meal or after it, etc. The people who serve the person well know this stuff - we have to ask them to write it down for the new person on the Saturday morning shift who doesn't have a clue.

Sometimes it is useful to use photos. For example, they may help illustrate the way someone should be positioned in the chair. Sometimes it is useful to identify people who can demonstrate the best way to assist the person - if a particular intervention is complex you might add "ask Pat to demonstrate the way she assists Mary to dress before attempting this".

People with power and control

If the person has very low support needs and they have a lot of control over their life, they can sometimes dictate this section to you by simply telling you what they want you to do. If the person is able to explain the support they need clearly, let them. An alternative heading for this section might be "if you are going to support me - get the following things right!" Don't fall into the trap of trying to psychoanalyse the person here - just ask them what they want support staff to do.

People with little power or control

If the person has little control over their life we have to be very careful not to just log down current practice, particularly when we know the person is not being served well. The way we write this should be trying to transfer power to the person. Sometimes, in situations where people are served by a large number of different paid supports in one week, it is important here to ensure consistency in the quality of the physical and emotional assistance provided.

It may be necessary to increase awareness of the methods and approaches which appear to be most successful with the person - this is vitally important when the person does not use words to communicate and is at risk of being misunderstood or overlooked.

Different kinds of support

It can be divided into different sections and it is important to remember that there are difference kinds of support:

- there is emotional support and encouragement - i.e. "Mary is anxious about walking into a room full of strangers and may need some reassurance before she enters the room and when she has entered the room"
- there are styles and approaches which people are more likely to respond to - i.e., "Mary hates to be rushed - always give her up to 25 minutes to respond to any requests to get ready to go out and go somewhere"
- there is physical care and assistance - i.e. "to assist Mary to eat her lunch, cut the food into small bite size pieces. Mary can use an ordinary fork and can eat the food herself once it has been cut up"...

Remember that this section is written specifically for people who are going to provide support and we need to give them the best chance of success. It the person is likely to respond negatively to certain situations or types of people, we need to give this support person information about how to avoid or manage these situations or encounters.

For example, I hate flying. It is useful for anyone coming with me when I'm having to get on a plane to know that I will become irritable and find it difficult to concentrate in conversation. When the plane is taxiing down the runway - hold my hand if I want you to, and let me read my book or magazine. Tell me it will be OK but don't try and have a conversation with me...I will be OK when we get in the air!

As with all of the plan, always try to write down the information in sentences and put the information in context. Try to be aware that the way you write things can create exactly the wrong impression.

For example, if you write "when Fred says no, he means no, so don't contradict him" this could inadvertently create the impression that Fred is a violent person and may become aggressive. The people who wrote the first sentence were trying to say "In the past, Fred has often not been listened to and his opinion has been regularly ignored. When this happens, Fred tends to withdraw. Please bear this in mind and make sure that you both listen to what Fred is saying, take his opinion seriously and act on it". It is better to write a paragraph trying to say what you really mean than to leave a bullet point which is ambiguous and misleading.

To keep the person healthy and safe

The inclusion or length of this section of the plan varies with the focus person. Sometimes you don't need this at all, sometimes this is very detailed and vitally important.

This section may contain details about:

- Specific health issues or diagnosis
- medical treatment - dosages and frequency, side effects and warning signs
- aids and adaptations - why they are required, how often they are used, what happens if they are not used
- information about risks to the person or other people.

The purpose of this section is to ensure that anyone supporting the person - from a regular member of the person's support team, to their sister when they go home for the weekend, or a member of day centre staff - would know what to do if the person was in ill or in pain or would be aware of how to react if the person's condition suddenly deteriorated.

Specific health issues or medical conditions

We should include here information about any specific condition or diagnosis the person carries but we should not label the person. For example, to say the person has spina bifida is not particularly useful, as people will make their assumptions about what this means. To say that the person's spina " affects them in the following ways:-" (then list) is much more useful. It might say "Laura uses a wheelchair but she can transfer herself from the chair into a car seat unaided and walk for up to 10 minutes with the aid of two crutches."

medical treatment and specific conditions

We should list when and how any medication is to be provided. Staff and family members alike often find it useful to know what the side effects of medication are, i.e. is it likely to make the person drowsy or agitated. We need to be able to recognise symptoms which might indicate pain or harmful reactions.

aids and adaptations

This section can also be used as a user friendly guide to technical aids and supports used by the person in order to ensure that any aids and adaptations are being used properly and appropriately. The person should not be being put at risk because someone in their family or in staff team does not understand why they have to do something in a certain way.

We should also detail the use and frequency of use of any aids or adaptations which have been provided for the person - i.e. if someone has to have their arms in splints - what purpose do the splints serve, how long should they be worn, during which activities is it most useful to wear them, when is it advisable to remove them and what damage is likely to occur if they are not used.

We also need information about the types of mobility aids used - and supportive guidance on positioning and comfort.

If special training is required for any areas of support (i.e. lifting, rectal valium) this should be detailed.

A check list on how to deal with any emergencies would also be useful - what easy steps should be followed and who do we call in the event of an emergency.

gathering information for this section

This section of the plan is not a replacement for the medical notes for each person - they will remain the property of the GP concerned. This section is to empower staff and other people around the person to provide safe and effective support and care.

Useful questions might be:

- Can you outline for me the kind of medication Susan receives and the likely affects of this medication on her behaviour and physical condition?
- What are the main things we have to be aware of - how are we likely to know that something is wrong with Susan?
- What symptoms should alert us to the need for intervention?
- What kind of things can go wrong and what should we do when they do go wrong?
- Can you clarify for me what kinds of aids and adaptations Susan uses?
- What are they for and how should they be used?
- How much flexibility is there?
- What guidelines do we need and what happens if someone doesn't stick to the guidelines?
- When was the equipment she uses last reviewed?
- How do you rate it's effectiveness?
- Is there any thing you think would be more helpful?
- If we wanted to improve the kind of care and support she currently receives, what would be the more useful thing we could do?

Again you are trying to have a conversation, not an interrogation. You are trying to have a structured conversation and you should follow up on things the person says, not just follow the script. We all need the best information possible to prevent the person being at risk.

Sometimes there may be a section entitled "to keep others healthy and safe" which could contain details about specifically dangerous conditions or situations.

Communicating with the person

This section may be very important if there are issues around communication. If the person does not use words to communicate, there may be completely different interpretations by different people around them of their preferences and views. We may also be making incorrect assumptions about how much the person understands.

Here we are cataloguing specific details about how best to understand and communicate with the focus person when they have communication support needs. The focus person may not use or understand words and in this section we try to gather and make sense of all the information and views we have about the ways in which the person communicates and ways in which we can help them understand language.

Many people do not use verbal communication and they may be being supported by a large number of staff who do not have any common vocabulary about methods and approaches which might useful. Some staff have lots of clues about individual people, but this information is not shared in any systematic fashion.

As with all sections of the plan, we should always speak to and about the person respectfully and treat the person with dignity. We should never discuss the person over their heads as if they weren't there and we should always talk about them as if they fully understand what we are saying - even if we assume, often incorrectly, that they don't. We must always be conscious of the fact that verbal language is only a part of communication - we also communicate with out eyes, faces, gestures, tone and body language.

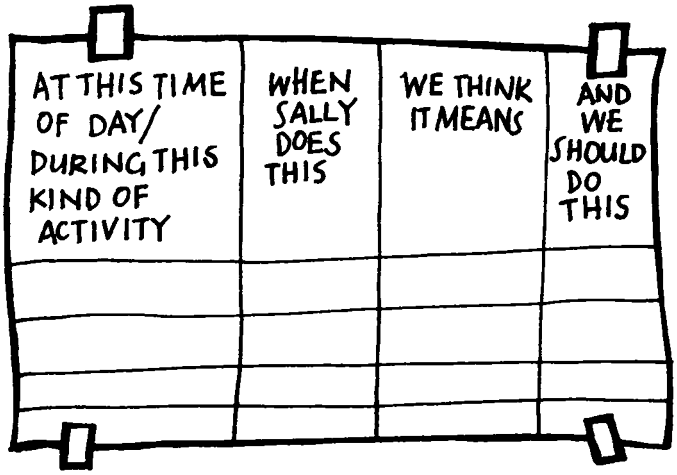
Some people have very obvious speech and language difficulties - they may not use words to communicate for example. Other people may use some language, but have difficulty understanding all or some of what is said to them. As this is less visible than speech difficulties, it can often be underestimated or overlooked.

Meaningful inclusion of the focus person in this process is more than just having them sit through the meeting. It may demand a lot of effort on our part to support the person's understanding of what is happening and what is being said. Simplifying language, using gestures or signs, showing people objects, photographs and symbols will help their understanding of what we say and enable the focus person to make a real contribution. List techniques that you know help the person understand what is said and express their preferences.

We should list any equipment currently used by the person and describe how it works. The equipment could be a highly technical communication aid. However, for most people, objects, photographs, pictures, symbols and signs are vital pieces of equipment for aiding their understanding and expression.

We should describe any ways in which the person attempts to communicate and our understanding of how they express preferences. If we don't understand the ways in which the person communicates, we should say so and not list untested assumptions as if they were fact.

If the person does not use words to communicate, we have suggested using a communication grid as one way of pooling our understanding of the ways the person expresses preferences. Sometimes we have a number of alternatives and we might have to list the options. The communication chart used in Essential Lifestyle Planning is one approach.



AT THIS TIME OF DAY/ DURING THIS KIND OF ACTIVITY	WHEN SALLY DOES THIS	WE THINK IT MEANS	AND WE SHOULD DO THIS

Authors note - we were assisted in writing this section by Rachel and Helen from the speech and language therapy department of Greater Glasgow Primary Healthcare NHS Trust.

Unresolved issues

There may be areas where you are unclear about the person's preferences or how best to support them. There may be major contradictions between the views of the person themselves and the people who support them - these can be listed here for more details discussion at the meeting.

Phase 3 – What makes sense, what doesn't make sense and action planning

Ways of checking back the data

There are different ways of checking back the data with the focus person and the people who have contributed to the plan.

You can do this one-to-one with the focus person and write the plan in language they are happy with

You can do this with the focus person and their support team to check that we have the details correct - we may be trying to log best practice at the time of writing or we may be trying to dramatically change current practice and we need to give people who have contributed a chance to clarify any inconsistencies or discuss any contradictions

You can do this at a big meeting involving everyone who had contributed to the plan and amend the details in public through consensus

You should be clear whether the key purpose of the meeting is to check and clarify the content of the plan or to essentially engage people who like the focus person to support them in making changes in their life - or both. We will talk about the facilitation skills required for these different tasks during the course.

You need to discuss the situation with the focus person and sort out with them what they are happy with - they have control over whether there is a big meeting, who is there and what information is shared. The focus person may be happy to talk about the key things which are important to them with people they like, but they may not want the personal details of their physical care and support shared with their friends and colleagues.

Having a meeting to check back the data

If you have a big meeting to check back the data, after welcoming people to the meeting and outlining the process, the facilitator should say who they have spoken to and then present the sections or panels prepared so far to the group.

The facilitator may have written this information up on sheets of flip chart and have stuck them on the wall. However, it is often better to prepare the sheets in public with the focus person and the people who know them well. In order to do this the facilitator will have their notes from the interviews and will have done some preparation for this meeting. The facilitator will lead the discussion, but they will check all of the information back and reach agreement with the focus person about what is written down and how it is written down in public.

Generally at this meeting you would focus on the first four panels

- People who know and care about Mary say...
- The following things must/ must not happen in Mary's life
- The following things should/ should not happen in Mary's life
- Mary likes/ dislikes the following things.

These panels may be the ones the focus person is willing to share in the group - they may not want a detailed discussion about their personal, health or communication support needs. Alternatively, if there are issues around the support and care they receive, they may want to use the meeting to state their preferences and views. As a facilitator, think through the situation with the focus person and their supporters before you work out the best way to proceed.

If the facilitator has done a good job the focus person will learn something about themselves that they didn't know before and they have a chance to work out their priorities for their life now.

What makes sense, what doesn't make sense

Up to this point in the process we have had data. If the person is supported in exactly the way they want to be and they are content with their life at the moment, you may not need to work out what makes sense and what doesn't in a big meeting. You can help the focus person reflect on their current situation and change what they need to on a one to one basis.

However, if there have been a number of issues raised about the quality of support and the quality of life the focus person is experiencing, you need to get people who like the person together to help them work out how to change things in the person's life.

Such a meeting is really the start of the plan for change. This is chance to check out whether any of the important things in the person's life are happening and to see whether the person has any power or control over the kind of support and assistance they are receiving.

At this meeting, present the key information the people attending the meeting need to help them work out what is making sense in the person's life now and highlight the areas which do not make sense.

Action planning

The focus person then need to do some action planning - this might include action planning to:

- safeguard the good things that are happening in the person's life now
- stop and change the bad things that are happening in the person's life now
- start exploring and doing new things which make sense to the focus person

Some of these changes can take effect immediately, some of them can happen in the short term and some of them will be in the long term. It is important to help the participants in the planning see the things they can change immediately because they are within their control and may not need any extra resources. The focus person and their support team need to have some immediate sense of achievement.

The participants will then need support to think creatively about how they change things in the long term where they do not have a great deal of control or require additional resources. In essential lifestyle planning we use a lot of brainstorming to come up with creative and non traditional service solutions. We do the brainstorming in stages and work through the following sequences:

- What can we do

  Having highlighted an issue and described the current situation, the facilitator gives people time to brainstorm as many things as they can think of doing to improve the current situation - 5 to 10 minutes is usually enough. When people are brainstorming, the facilitator must write everything down and write down everything. They can't judge or veto any ideas and they have to encourage people to be creative and, if necessary, wacky!

- How can we do it

  Once we have a sheet full of ideas, the facilitator reads out all the ideas and the people in the meeting chose the best ones - which ones appeal to people there and sound like good bets. Taking each idea in turn, the facilitator asks the people at the meeting to brainstorm ways of doing it - what could we do and how would we do it? The facilitator has to time manage this process and get as many ways as possible of achieving the desired outcome. Probably restricting it to 5 minutes per idea is useful. You need to help people in the room be energetic and creative - give them breaks when they are tired!

- Who can do and when can they do it

  Once we have a number of ways of doing some of the best ideas, we need to check whether any one in the room can do any of them and, if they can, when they can do them. If no-one in the room can do it, then probably nothing will happen. As a facilitator you have to help people to work out the easiest way of taking action.

Closing the meeting and working on the plan

Check out that everyone know what they have to do next then agree with people when to meet again to review and update the plan. The panels of the plan agreed at the meeting should be amended and updated as a result of the meeting, dated and circulated to the people who need to use this information.

The action planning has to be noted and needs to be referred to in the follow up meeting. The action taken as a result of the meeting should have an impact on the content of the panels written so far - in this sense the plan is in constant revision and is never static. The content therefore has to be reviewed at the next meeting and again updated.

A more detailed description of the Essential Lifestyle Planning process is contained in "Supporting people with severe reputations in the community" by Susan Burke-Harrison and Michael Smull (available from the National Association of State Directors of Developmental Disabilities Services Inc., USA 1992).

ROLES AND TASKS IN PERSON CENTRED PLANNING

Process and graphic facilitation

Roles and responsibilities

One of the key questions in person centred planning is 'who are we in your life?' Unless the people involved are clear about their own roles and responsibilities in the process, there is a danger of drifting into poor ways of working.

There is no one list of roles to be divided up between the different actors. Rather in each situation there are a number of roles to be adopted, responsibilities to be recognised and tasks to be undertaken.

For example:

- Someone may have to help organise the process with or on behalf of the person
- Someone may have to spend time helping the person tell their own story and prepare their own account of what they want
- Someone may have to spend time finding out about the person because no-one knows them well
- Someone may have to gather together perspectives from different people to create a picture of the situation that everyone will recognise
- Someone may have to facilitate the discussion in a meeting where people have very different perspectives
- Someone may need to give technical advice about how to help someone control a computer, buy a house or employ staff
- Each of these tasks can be done in many different ways. Some people may take on several different tasks and roles during the planning process. The important thing is for people to be clear about their roles and boundaries as this allows other people to take up their own roles more effectively.

So, for example, a care manager may have taken on the role of gathering together different perspectives and facilitating a meeting. The care manager should be careful not also to take on the role of 'knowing the person well' unless there really is no-one else in the person's life who knows anything about them. Stepping back allows other people who do know the person to contribute and work together. Another common situation is where the person wants to invite a member of staff along to the meeting as their friend. The staff person has to be clear with the person and with themselves what being a friend means. If they are the person's friend, they have to walk out the door and come in again, out of staff role and in their own time. Otherwise they have to be there as staff. People need friendly staff as well as friends.

There are some roles in person centred planning which are definitely different from the roles in traditional assessment practice. The roles of family and friends, and the role of clinical and professional staff are seen in a different way.

Most person centred planning will involve someone taking on some form of organising role, and/or someone taking on some form of facilitating role. Even where the person is able to manage both these roles themselves, they may well invite a friend or relative to take on one or both of these roles. Person centred planning sees interdependence - giving and asking for help - as part of community-building, not as falling short of independence.

The role of family and friends

Often it is family members who know the person best. They care about the person in a way that is different from everyone else and they will probably be involved in supporting the individual for the rest of their lives. They bring a huge commitment, energy and knowledge to the table.

Family members see the person and the situation from their own perspective. They may well have been let down time and again by services. They have probably had many experiences of not being heard unless they shout. They will probably have had professionals smile knowingly when they talk about their son or daughter and will have seen those professionals discount or ignore what they have to say. They will have had experience of being told nothing, of being passed from pillar to post. They will also have legitimate concerns about safety and security that have to be acknowledged, respected and addressed.

Person centred planning starts from the assumption that families want to make a positive contribution and have the best interests of the person at heart, even if they understand those best interests differently from other people. In person centred planning families are not caricatured as one dimensional - either 'over protective' or 'not interested'; instead they are invited to tell their side of the person's story with the richness of detail which can provide the clues for change.

Sharing power with families means seeking their active involvement and building a partnership. This has to be based on families and professionals getting to know each other well and building up a personal trust.

The role of clinical or professional staff

People with disabilities need good expert advice, information and specific help from skilled professionals - not just nurses, doctors, therapists and social workers, but also lawyers, housing specialists and people who know about money. What they don't need is for those people's opinions to come first, to be the only basis for decision-making.

In person centred planning clinical or professional staff move from being the owners of the process, centre-stage, to being backstage technicians, the people who know what is technically possible and how to make it happen.

'Information gained from technical assessments of the person can be helpful, but only in the context of a knowledgeable account of a person's history and desired future. Subordinating professional-technical information to personal knowledge turns the typical agency decision making process on its head.'
O'Brien and Lovett

The professional is no longer solely responsible for implementing the plan, nor can she carry all the blame if things don't work out. Professionals become people who can provide specific expertise and access to particular resources, rather than people who are expected to find all the solutions and put them into practice.

The professional role is to support the individual to work towards their desirable future by using their particular skill as required - whether this is designing a communication system, negotiating housing, or seeing if there is a way to improve the person's hearing.

An organising role

The main responsibility of this role is to support the person and find ways for them to participate as fully as possible. This might mean months of working with the person on their portfolio to help them discover and articulate what is important to them, or supporting the person to chair their own meeting, or simply organising coffee and cakes to make people feel more at ease.

This person may assist the person to choose who they want to take part in their plan, and help them issue invitations. They may need to find ways to actively encourage the participation of family and friends, including people from the past who have lost touch. Where someone is very isolated, their most important job may be to find an ordinary citizen willing to get to know the person and walk through the planning process alongside them.

A facilitating role

The role of the facilitator is crucial in person centred planning. They have two main tasks: to encourage the exchange of views and knowledge among the people involved in the planning process, and to ensure that the focus on the individual is never forgotten.

The dictionary definition of a facilitator is a person who makes a task easy. Brainstorming metaphors for the role of facilitator one group came up with a juggler, a baker, a catalyst, a guide through a maze, a conductor, a wizard drawing together ingredients for a spell, or a film editor. In all these roles bringing ingredients together to create something special is central.

Someone who takes on the role of facilitator needs to have an explicit commitment to the principles of person centred planning, and significant skills and experience. The style and method of facilitation will be different depending on the planning process used. It usually includes managing a meeting and may also include building up a shared picture of the situation through a number of one-to-one conversations and presenting this back to a group.

Some services have access to independent facilitators. As the facilitator does not bring in-depth knowledge of the individual or of their situation, it is easier for her to concentrate on listening to others.

Being independent is useful in situations of conflict because the facilitator will not be seen as belonging to either camp. On the other hand the person may not feel happy having someone they do not know well at the meeting, so the facilitator will usually make a point of going to see the person first and talking about the

process.
An independent facilitator can help to surface and resolve tensions within the group of people who are concerned about the person. She can make it safer for people to express and discuss deeply-held worries. An independent facilitator also has an important role in encouraging and motivating the group and helping people think positively.

The facilitator also has to pay careful attention to sequence. For example, Michael Smull advises people to think first about how someone wants to live, and only then to think about where. In building a picture of the person, it is essential to start with what they want and only then to look at 'what would it take?'.

The planning process travels continuously between a description of the present reality and a map of a more desirable future. The timing and order of these journeys is critical.

Whoever is facilitating the plan, Michael Smull suggests three 'nevers'

- Never plan with someone you do not like
- Never only plan once
- Never plan without a commitment to implement it

The role of the facilitator is always to listen hard, affirm and validate what is said and to ensure that the views of the person, their family and friends are heard.

The facilitator needs the skill of marginality described by Gerry Smale
"the worker's ability to operate effectively as a participant and as an observer in any circumstance, and to neither become a part of problem-perpetuating interactions, slip unintentionally into being a permanent part of "the solution", nor to remain impotently on the outside of the networks of people with whom they are involved."

The facilitator has to be 'constantly marginal', walking the line between detachment and involvement, between directing and reflecting.

The facilitator also needs skills in conceptualisation - the ability to make sense of information and see the patterns in it. Sometimes through a series of individual conversations the facilitator gathers all sorts of perspectives and snippets of information from different places and - like the Magic Eye pictures - lets a picture of what is important emerge into the foreground.

Process facilitation in person centred planning can include a whole range of tasks:

- Creating the space - getting the environment and tone right
- Holding the boundaries - managing groundrules, purpose, time
- Being in role - having an explicit and conscious role in the group
- Defending the process - giving it weight and momentum
- Eliciting - drawing out information, giving people a voice
- Validating - letting people know they have been heard, nurturing
- Mirroring - reflecting back what has been said, checking details
- Reframing - helping people to see the issue from a different angle
- Mapping - making connections, hearing themes
- Absorbing - allowing anger, pain and fear to be expressed in a safe way
- Holding the tension - allowing silence and feeling to come out
- Controlling the air space - managing the range of articulateness within the group

Graphic facilitation

Graphic facilitation may be familiar to many people as it has long been used as an aid in all kinds of meetings. It has several advantages:

- it encourages participation and is fun
- the proceedings of the meeting are recorded in a more memorable way - people are far more likely to remember ideas when images are allied with words
- everyone can see what is being said and agrees with the record as it goes up - the minutes are not typed up then disputed later
- the record serves as a reminder during the meeting of what was said earlier

- it helps the group stay focused
- previously unrecognised patterns and influences can be identified
- it encourages people to think creatively and in a different way
- position, colour, shape and arrows can be used to show connections between ideas

The process of graphic facilitation encourages people to think outside of their boxes, to come up with different pictures and different solutions.

A graphic record has a vibrancy lacking in a list of words. People who may be bored during the meeting are often engaged by the graphic.

WORKING ON INDIVIDUAL PANELS

why

To give participants an opportunity to experience being "in the hot seat". It also gives participants another opportunity to use graphics

how

Participants work in threes. Everyone takes a turn at being the focus person, the graphics facilitator and the process facilitator. As the focus person, people go through one panel from the Maps process - either the story panel or the dream panel (which might include some nightmares). The process facilitator draws out the information from the focus person, listening carefully but not intruding or analysing. The graphic facilitator records whatever is said. After 20 minutes, people swap roles.

In the large group we will discuss the process. How did it feel to be in each of the three roles?

When you were providing information:

- What did it feel like to give this information to a stranger?
- How much information did you feel comfortable about sharing?
- Did you keep a lot to yourself?
- Did the person listen intently enough to your story?
- Did they get it right or did they misinterpret some details?
- Did they miss things out?
- Did they recognise the most important bits of the story?
- Did the graphics help?

When you were trying to obtain information:

- What did it feel like to ask someone to tell you about their story or their dreams and nightmares?
- Did you find it easy to keep the person talking?

- What techniques helped?
- If you found this difficult, what did you find difficult?

When you were trying to graphic the information:

- Were you able to keep up?
- Do you feel you did a good job of recording the story?
- Were you able to feedback the story accurately to the person at the end?
- Did you have to make many alterations to the graphic?
- Did the graphics help?
- Were you proud of the graphic record when you finished?

As a service provider, did the exercise raise any issues with you about our expectations of people who use the service?

LOOKING AT THE POSSIBILITIES

why

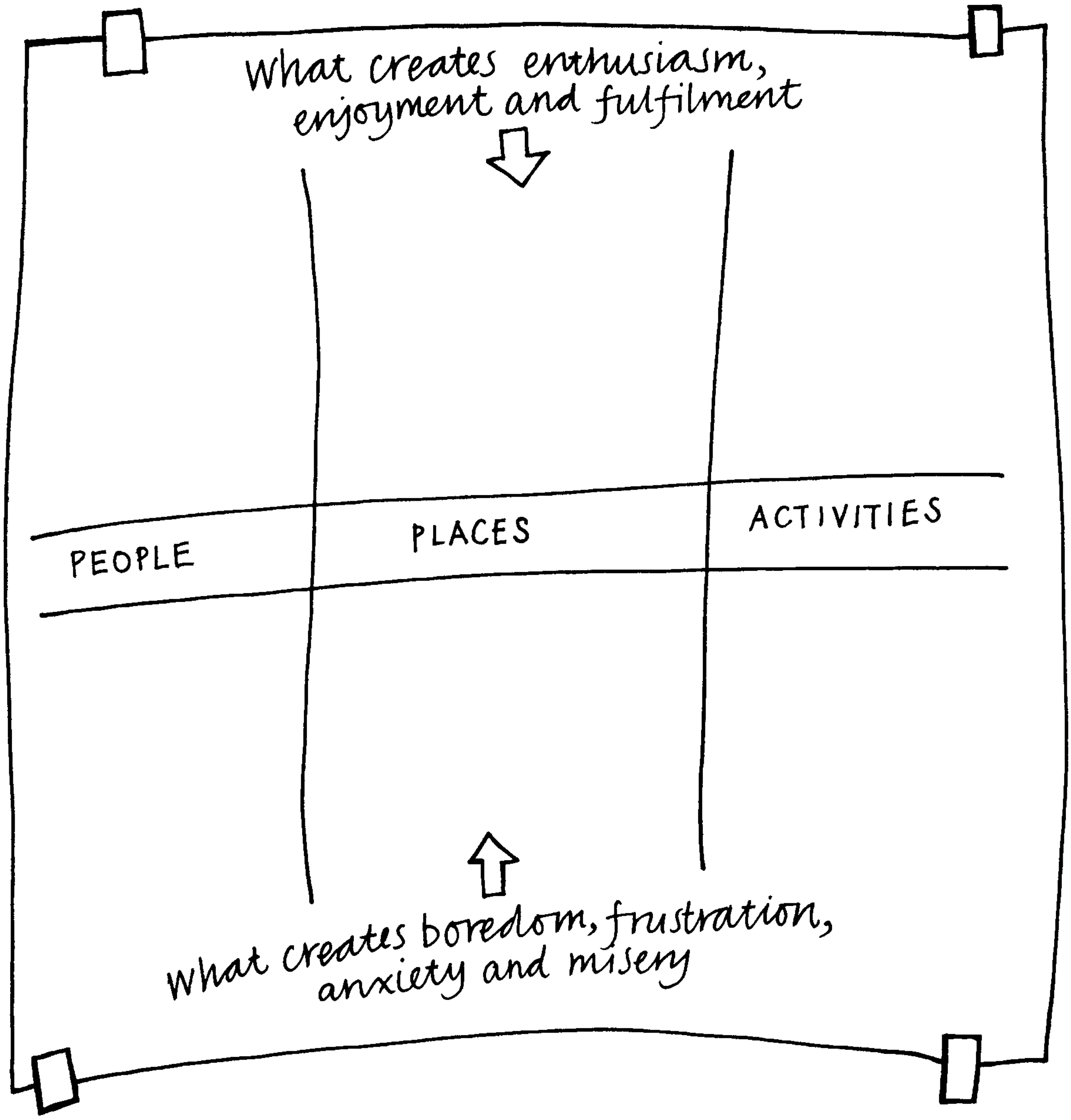
To practice creative techniques and find ways in which people's universal needs can be met.

how

The participants work in small teams of 5 or 6. At least one, preferably two, people are focus people and talk about someone who they currently support who has an empty life. One person coaches, one person graphics and the rest of the team listen for the first step of the exercise.

Step 1

The people talking about a person they support tells the rest of the team some of the person's gifts. They then tell them what people, places and activities create excitement, enthusiasm and fulfilment for them. They also tell them what people, places and activities they strongly dislike and create misery for them. The emphasis however should be on the positives.

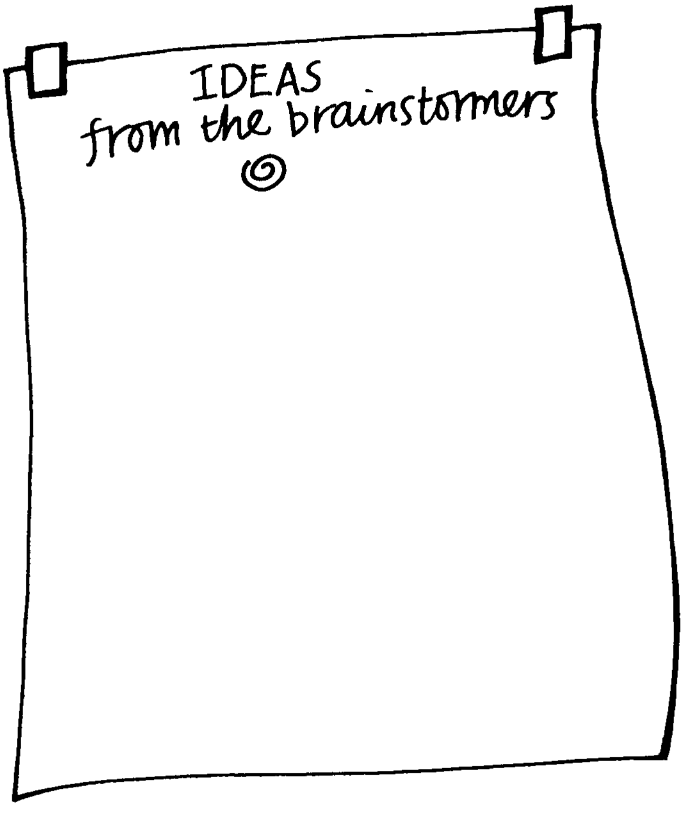


Step 2

The focus people swap groups. The graphic facilitator and the rest of the team tell the new focus people a bit about the person. They then brainstorm all the places activities and people that the supported person could meet and do.

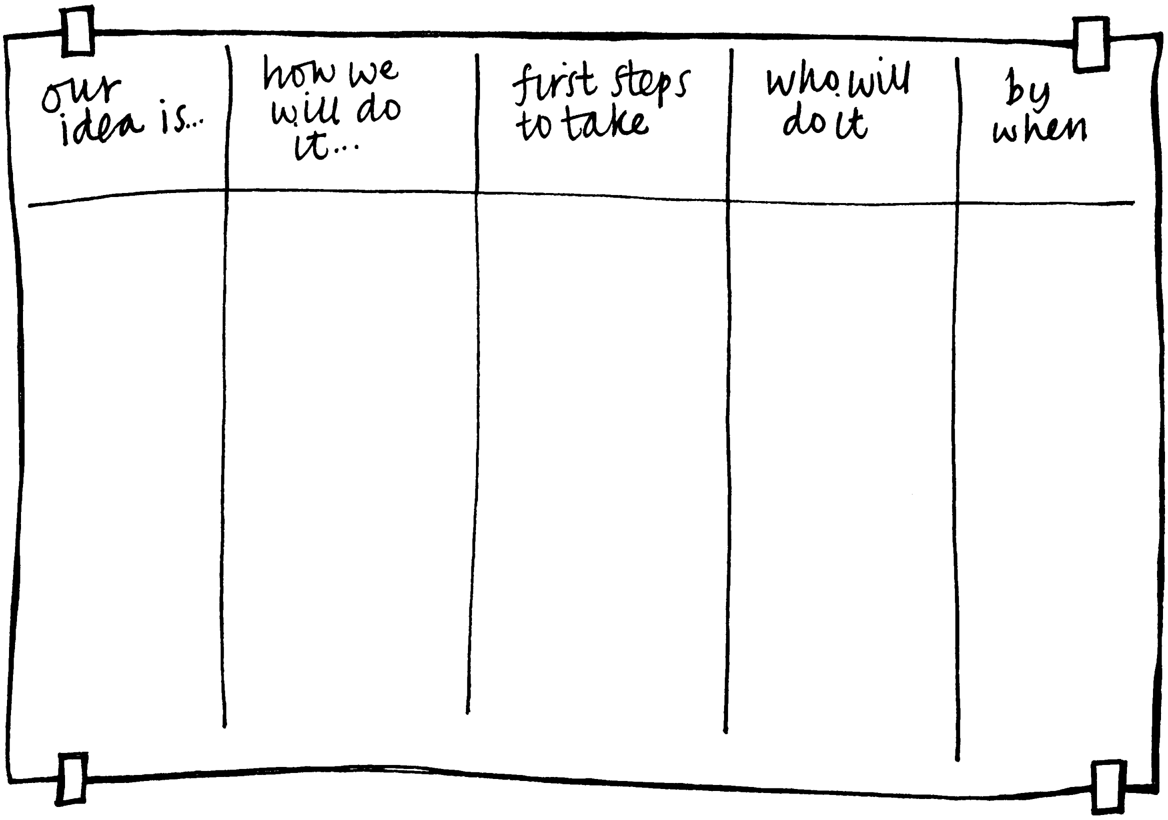
Step 3

The focus people swap back to their original groups. They look at the brainstorm and pick out the most positive and possible idea on the list, which must not be something which the supported person already does.



Step 4

The whole group then helps the focus person/ people to action plan. Using a what, how, who when table.



our idea is...	how we will do it...	first steps to take	who will do it	by when

EVALUATION FORM – END OF DAY 2

1. What do you think of the course?

2. Which part of the course did you find most useful?

3. What did you think the trainers did well?

4. What could they have done better?

5. Is there anything they could have done differently?

Thank you for your time in completing this form. SHS Trust

SPECIFIC FEEDBACK

1. What did you think of the 2 day format?

2. How do you think we could have improved the format?

3. What did you think of the trainers and they way they facilitated the sessions?

4. If you have any criticisms of the trainers, what are they?

5. Did you find the course folder helpful? If yes, in what way?

6. Any other comments?

Many thanks for your time in completing this evaluation. SHS Trust