Background materials ~ person centred planning

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Introduction

The information included in this pack is designed to accompany SHS work on the facilitation of person centred planning. It includes further explanations of the ideas and theories which inform the course content. It will help participants reflect on what they have learned and provide back up for the positive changes they plan in their life or the work they are doing with others.

Although designed as part of a training programme, it may be of use and interest to readers who had not had the opportunity to undergo an SHS training course.

This information is available in different formats. If you or someone you know would like any of the SHS materials in a different language or format please contact SHS Trust at the address shown at the beginning of this pack.

Leicester/04/05

SHS Trust and the work we do

At Scottish Human Services Trust (SHS) we believe that everyone has a right to the supports and services they need to enable them to participate fully in their communities.

At the core of our work is a commitment to the values of inclusion. We believe that communities are healthier, stronger and better when they learn to recognise and value diversity; that social exclusion is both damaging to individuals and detrimental to the community as a whole; and that becoming a more inclusive society requires changes in social policy, in the culture of human services, and in the way our communities and social institutions work. We also believe that people who are at risk of exclusion must be at the heart of the movement for change.

Some of the ways we work are:

- Developing leadership in the parent, family and service user movement across Scotland
- Training staff to work in a more person centred way
- Helping to establish new user-led organisations and networks
- Promoting patient involvement and consultation in health services
- Providing generic equality training
- Supporting independent advocacy
- Developing local joint strategies for improving services
- Hosting conferences and publishing books
- Undertaking research which focuses on the concerns of people who rely on services
- Working in partnership with organisations to change the way they look at things and become more responsive to the people they serve.

SHS was established in 1993. We work with local authorities, health boards, voluntary organisations, community groups and organisations of service users and carers throughout the UK, and with people in other parts of the world who share our aims and values.
Much of the material and our philosophy is indebted to the work undertaken over the last 25 years by our colleagues in the UK, North America and Europe - particularly Wolf Wolfensberger, John O'Brien, Kristjana Kristiansen, Marsha Forest, Jack Pearpoint, Judith Snow, Alan Tyne and Pete Ritchie.

The Trust does not receive any core funding from government. Income is generated entirely through grants and fees for specific projects.

The impact of power, status and kinship on quality of life

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
- the strength of their kinship network.

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. In Scotland, Nelson Mandela may have higher status than Jack McConnell, but less power.

A person'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. He has now been voted the greatest Britain, although many people hold highly critical views of him.

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 of time.

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 people who use services have low status and power

People who use services, 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 they are also seen as a member of a minority group, for example 'disabled people', 'old people' 'abandoned children', 'orphans', 'travellers', 'Asians', or 'the mentally ill.'

They have a particular social status as a group - and individuals from that group have to start with and work from that point.

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

So being a member of the group gives people a poor reputation to recover from. If society perceives an individual to be part of a group which has a devalued status, then that individual will inherit any social perceptions which surround that group of people.

Individual Status

People can achieve things as individuals that 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 a youth group, members of the board of directors, householders, employers, partners, parents, actors, writers, designers.

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.

Changing social perceptions

We tend to forget that the development of human services is relatively recent in historical terms. It is only really in the past 200 years that social policy has been concerned in any planned way with groups of people described as a “problem” or in need of some kind of help or intervention by local or national government. It is also the case that social policy has gone through many changes in this period and that services we may have imagined “always being that way” might in fact have altered greatly over the years. In the era of Community Care, it is perhaps surprising to realise that most of the hospital institutions built for people with learning difficulties grew most dramatically after World War II.

Wolf Wolfensberger points out that the service “models” developed and championed at any one time reflect the social perceptions of people that are prevalent at that time. He goes on to argue that most of our services today retain elements of models created in response to a range of different perceptions. We believe that the idea makes sense for any group at risk of exclusion. It is worth remembering that social policy has very often grouped people together whom we see in very different ways. A brief glimpse at medical journals from early last century might shock present day readers by their linking of disability, mental health, criminality, poverty and race.

People as an economic burden

People may be seen as primarily a drain on society, as people who do not contribute but simply require others to pay for and support them. The ‘colonies’ and ‘farm schools’ set up to provide for disabled people from 1870 onwards were organised to be as self-sufficient as possible, in order to reduce the costs to the public purse, and league tables were published to compare the performance of different institutions. Very large establishments were built in rural settings to achieve economies of scale. Many long stay hospitals in the UK had farms until recent years.

Continuing this tradition, people in adult training centres used to undertake jobs like packaging on a contract basis and, rather than get paid directly, would earn money for the local authority or the voluntary organisation running the centre. Many elderly people are now regarded as economic burdens for the rest of society and we are constantly warned that as a society we will not be able to sustain our ageing population. People immigrating in to the UK are sometimes accused of 'taking our jobs' or being 'benefit scroungers'. A recent survey has shown that this is particularly prevalent in respect of asylum seekers who have been described as 'parasites'. Those who have the misfortune to be unemployed have long been regarded in this light.

The ideas of cost and burden are also prevalent in the discussions around abortion of unborn babies who are suspected of 'defects' or 'abnormalities'.

People as child-like/eternal children

Tom Shakespeare, the Director of Outreach for the Policy, Ethics and Life Sciences Research Institute, has suggested that the fundamental social division is between adults and children. He comments that many other devalued groups have been seen as child-like.

Sometimes disabled people, particularly those with learning difficulties, are seen as children who never grow up. In fact, there are social clubs called the 'Peter Pan Club' based on exactly this view. Similarly, people with dementia are sometimes seen as returning to a childlike state.

Seeing and treating people as children is a theme which runs through many different services, and is often explicitly justified on the basis that people have a 'mental age' of 5 years, or 6 months, or whatever. This is given as an explanation for why people do not have a home of their own, or a job, or any money - and why they have not been consulted in crucial life decisions.

Services which treat people as children will seek to protect them from risk, from responsibility, from serious choices, from knowledge - to keep them in a state of innocence and also of powerlessness. Design, decor, activities and language all reinforce the message that 'these people are child-like' and 'we are the grown-ups'. Bedrooms are decorated with children's posters and the TV is switched on for the teletubbies. People are addressed as children - men and women in their 80's are referred to as boys and girls and asked to eat up their dinner. Older men and women, who are considered to be 'disorientated and confused' are asked to play team games with parachutes as a form of therapy.

Expressions of opinion by adults are simply discounted and not taken seriously. Staff assume a parent-like authority in relation to people of their own age and older, without even thinking about it. People are expected to ask permission and follow rules as if they were in primary school - while at the same time being told 'this is your home'.

Some villages and 'rural communities' for people with learning disabilities have a strong element of this approach - they wish to protect people and to create a make-believe world where they will be able to escape the dangers of the real world. However, some of these villages also miss out on much of the variety, fun and freedom of the real world.

People as sick, ill, diseased

People may be seen as sick or diseased when they are quite well, or their illness, medical labels or history may be seen as the most important thing to be known about them. Some of the consequences of this include:

- People being grouped by diagnosis, living alongside people with the same syndrome or label, in a service run by an organisation for people with that syndrome. It is not clear what benefits derive from sorting people into these groups, since the syndrome itself is not treatable or curable. Unlike TB, these syndromes are not contagious, and there are no benefits to other people from grouping people in this way.

- People's 'clinical needs' are the focus of intervention, and people's ordinary universal needs for housing, employment, friends etc. may be overlooked or seen as secondary. The people who are employed to provide day to day support in ordinary life matters may be nurses, medically qualified, or employed by the NHS.

- Medical and clinical perspectives and language are given overriding importance. Decisions about the risk attached to someone living in their own home are seen as medical matters. Support staff sometimes need to seek authorisation for supporting someone in ordinary activities from a more highly qualified medical professional. Normal activities such as riding, swimming or making things are redesignated as 'therapeutic', as if there is a sickness in people which these activities will cure.

- Information which is recorded or distributed about people often starts with medical information. The first thing that a new school finds out about a prospective pupil may be their medical diagnosis - something they've never heard of and which sounds worrying but tells them nothing useful.

- "Challenging behaviour" is seen as a side effect, not of neglect, abuse or boredom, but of the disability, or label - in medical terms, it is seen as a diagnosis rather than a symptom. It becomes a focus for clinical rather than environmental intervention.

- It is seen as acceptable and desirable to undertake research and observations on people in their everyday life. Some services use one way glass to enable them to observe and monitor people. Nurses may be located in observation stations.

Unfortunately, the sickness model does not always result in people getting good basic health care - in fact, many people living in hospitals, hostels and group homes have unmet primary health needs.

Often people in long stay hospitals have to be removed to general hospitals for medical treatment. They may not receive regular dental check ups or sight tests. Many older people in institutions have had their teeth removed, they share hearing aids and they don't have glasses. They may have far less information about the drugs they are compelled to take and their side effects than ordinary members of the public. They may have far less power to refuse medication and may often be sedated against their will.

This is nothing to do with the skills and qualities of people who have trained as nurses. This is about the model. A service model based on the perception of people as primarily sick is not focused on meeting their most important needs as people.

It is worth remembering that the long stay chronic care institutions were not mostly built as hospitals. Before the NHS was founded in 1947, they were called schools, asylums or colonies. They were included in the NHS almost as an afterthought. Only then were they renamed as hospitals and seen as places where people would be cared for by nurses and doctors rather than keepers, instructors, wardens or attendants.

A burden on charity, holy innocents or sinners

People may be seen primarily as objects of charity, "as gifts from God", or as people who have received divine punishment. Lynne Elwell, a trainer in this field of work, talks about the nuns regarding her deafness as a blessing but her left handedness as a sign of the devil.

In pre-industrial times, disabled people may have been supported in monasteries, by wealthy benefactors or through charitable donations from the parish. Many religious organisations, for example the Brothers of Charity and the Church of Scotland are major providers of care services. With the development of secular charitable and voluntary organisations, the image of people as objects of charity has been maintained as a way of raising money.

Organisations still use collecting cans, second hand shops, door-to-door collections, and summer fairs to encourage people to 'give to the handicapped' or whatever. Some organisations post bin bags to houses asking for second hand goods. Many large voluntary organisations use pity and fear as a way of making us put our hands in our pockets. One campaign in Christmas 1998 asked us to buy a Christmas decoration to 'hang on our tree' because the beneficiaries of the charity 'were hanging on' for our donation - presumably they weren't enjoying Christmas in the same way as 'us'.

Many people find this demeaning. It undermines their status as citizens - they do not have a right to decent services but should be grateful for handouts.

Some of the annual charity events in Britain are strongly criticised by organisations of disabled people and others for the imagery they perpetuate. Contrast this for example with the Big Issue where homeless people themselves do a disciplined job to earn some cash and produce a quality product. Comic Relief is another example of an organisation promoting positive imagery. Generally, this notion of people as objects of charity encourages organisations to be complacent and think of themselves as working out of the goodness of their heart. Instead they should think of themselves as privileged to provide a service to people, and as accountable to the people they serve.

People as in need of improvement

Sometimes it is assumed that people need to learn skills in order to gain acceptance in society. In other words they are not yet ready, but with enough help some of them may make the grade – and if they don't then there is good reason for them to be kept apart.

This way of thinking was the motivation behind the first residential schools for people with learning disabilities and/or physical impairment founded in the 1840s and 1850s in the UK and US. These were relatively small schools providing intensive training in trades such as printing, bookbinding, shoemaking, tailoring and brush-making. However, many students never 'graduated' to the point where they were economically self-sufficient, and many of these schools, founded with great optimism, gradually deteriorated into - or were replaced by - long-stay institutions.

A similar model has been used in 'adult training centres'. People may spend thirty years 'training' for something, but never getting there. Sadly, some of the trades which had a real economic relevance 150 years ago are still the focus of some of the activities in such centres, and have become nothing more than ways to fill the time. This idea of people as 'trainable' is double-edged. It encourages people to develop their skills and abilities – which is clearly a good thing. But at the same time, it puts people in the position of 'not yet ready to join in'. If people are seen mainly as deficient, in need of fixing, there is too much emphasis on their learning disability or impairment and not enough on them as a whole person. Also, many people will never learn to be 'independent'. As Judith Snow, an internationally recognised thinker and campaigner in the disability movement, comments:

> *"I am perfectly eligible to live in a chronic care institution. I have never had the full use of my body in all of my 44 years and the taxpayers of Canada would pay $150,000 a year for me to be hospitalised. But 5, or, even 40 years later I would still have very limited use of my body. People would allow me, even support me, to spend the rest of my life waiting to become a person who walks and moves my arms."*

People as a social menace

Another common social perception of people has been that they are a menace to the stability and prosperity of society. With this assumption the job of services becomes to keep them out of the social mainstream and prevent them from having children. This was done most aggressively in the early part of this century when there was an active policy of taking people away to segregated institutions.

It was commonly accepted that a wide range of 'mental deficiency' was passed on through a single recessive gene, and that this gene had to be eliminated through social engineering. Compulsory sterilisation was used. Although it was publicly rejected in both the US and UK as impractical as a mass policy, it was and still is used as a way to deal with particular individuals.

This attitude was taken to its logical extreme in Nazi Germany with the mass killings of selected groups of people during the 1930s. Sterilisation has only recently been changed in Canada.

In the midst of all this, it is worth noting that the Nazis at the Nuremberg War Trials cited the Alberta Eugenics Board in Canada as a source of inspiration for their policy of sterilisation. Many People First organisations in Canada are supporting people to sue their state over the fact that they were sterilised without either knowledge or consent.

The social menace model is perhaps strongest today in relation to people with mental illness despite the fact that the vast majority of people with mental health problems are in no way dangerous to others.

Despite the various Education Acts, disabled children still have to fight to get into the mainstream education system at age 5, and then have to keep fighting to stay in. Many teachers and parents still regard them as a menace or distraction to the 'ordinary' children. Despite the presumption of mainstream inclusion in the Standards in Scotland Schools Act 2000, children with labels of disability can still be excluded on the grounds of their assumed aptitude or ability, the perceived cost of their inclusion and their unfulfilled potential for interfering with the efficient education of other children. No other children have to pass such tests to attend their local primary school.

The social menace model reappears in the use of genetic testing and screening. Many people make the unconscious assumption that the world would be better off without disabled people. Therefore, they conclude, if we can find out that someone will be born with a disability we should organise an abortion as a matter of course.

A life not worth living, or less than human

Some people are seen as so disabled or impaired that their lives could not possibly be worth living. Older people with dementia may be described as ‘gone’. Nursing homes are sometimes referred to as “God’s waiting room”. People may be seen as less than human, so that it is assumed that their only needs are for food and shelter. The word ‘vegetable’ is sometimes used.

Sometimes this has effects on the standards of health care people receive. Judith Snow explains that she was told that “people like that don’t survive past 30” so that her ill health was seen as inevitable, and nobody realised that she was severely allergic to the food dyes in some of her vitamins.

People as commodities

The growth in the care sector, particularly over the last 10 years, and the integration of business language and ideology into the provision of care, has supported the view of people as commodities.

The following article by David Brindle in the Guardian newspaper on 2. September 1998 talks about older people being ‘bought and sold”.

> *“Old people are being bought and sold without any say or protection as nursing and other care homes change hands at on alarming rate, a campaign group is today warning.”*
>
> *... The alert comes from Counsel and Care, which specialises in advice and help for older people in care homes. It says that growing domination of the homes sector by bigger companies, and the accelerating withdrawal from it by local authorities, mean that home residents increasingly resemble a commodity being traded - often without knowing who ‘owns’ them. Some have experienced up to five different owners of their homes.*

The article goes on to say that there are now 16 companies each operating more than 1000 beds in nursing, residential or dual-registered homes. BUPA Care Homes is by far the biggest in the field, with almost 16,000 beds, but Ashbourne has more than 8,500 beds and Westminster Health Care almost 6,000. It states that there is “no direct voice for the users of the service - old people themselves and their relatives and carers.”

A new social perception - people as citizens at risk

All of our work at SHS is based on seeing people first and foremost as citizens - as adults and children first - who share common human needs, but who need more help than other people to get these needs met. For instance we believe that the sort of help that disabled people, or people with mental health problems need is not different in kind from the sort of help that everyone else needs from time to time in their life. What is different is the intensity of help, and the fact that some people may need help for most or all of their life.

We see everyone as having a contribution to make. We believe that society as a whole benefits from the presence and inclusion of all and that it would be a better place if the contributions of all were recognised and valued. Services based on this perception concentrate on helping people to be included; on increasing and maintaining their power and status, and building their networks of friendship and association.

The Consequences of Devaluation

The consequences of society having these negative perceptions about an individual are that, at the very least, they are looked down upon. In simple terms, people often get from society what society feels they deserve, and being 'devalued' means being treated less well. Wolfensberger points out that a consequence of devaluation is that "people get systematically rejected, not only by society as a whole but quite often even by their own family, neighbours, community, and even by the workers in services that are supposed to assist them".

Wolf Wolfensberger suggests that, as a consequence of rejection, an individual may express feelings of rejection by being violent or aggressive and this may result in them being assigned other labels such as 'challenging behaviour'. Other consequences of devaluation can be that:

- People are at risk of being made society's scapegoats. They and people who are seen to be 'like them' are blamed for multiple problems.
- People experience segregation. They find themselves spending their time in places away from the rest of society, along with other people who are seen to be like them.
- People lose control over their own lives. Other people gain power over them and make decisions for them.
- People may be moved from place to place and lack many personal possessions. Wolfensberger talks about 'discontinuity' to explain the way that some may lack the kind of personal environment that most of us build for ourselves using possessions, collected junk, carefully chosen clothes, and objects that are meaningful to us. It is useful to consider how many of us would allow another person to tidy our home for us, making decisions about what we should keep and what we should throw away.
- People experience discontinuity in their relationships. They may have to repeatedly say goodbye to those who are closest in their lives because these are the members of staff who provide day to day support. This is sometimes called serial bereavement to reflect the profound effect it can have. Older people often even have to give away treasured pets when they move into supported accommodation.

- People may have to accept what is available to them, and may be expected to be grateful. They may have a 'service-centred' life. Most of us can choose the country we live in, the city, the area, the type of house and the people we live with. Even if we can't afford expensive accommodation, we can still choose from a huge number of options. Compare this to the common experiences of people moving from large disability homes or leaving hospital accommodation after mental illness who may have their choice restricted to just one or two possibilities.
- People may be financially poor, with few valuable possessions.
- People can be denied participation in society and thus lack valuable social experience and support networks.
- People may feel they have a wasted life, spending lots of time waiting around, or getting ready for something to happen at some unspecified time in the future.
- People may be physically abused, and may die prematurely.

Working with the present - the impact of Russian dolls

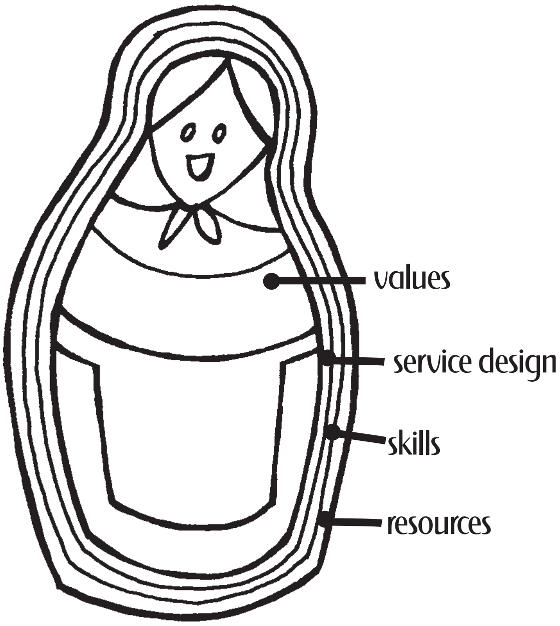
Despite the best efforts of staff most services tend not to address or meet people's most important needs.

The way we organise services tends to reinforce negative assumptions about people as a group. By providing separate facilities, by batching people together by group, and by organising strange activities and imagery around people we create a cultural apartheid in which people are seen as separate and unequal.

Someone's label - such as 'disabled', 'frail elder' or 'traveller' may be seen as the most interesting and important thing about them in other people's eyes. This obliterates other more important personal characteristics and qualities. People are assumed to have more in common with other people who are similarly labelled than with anyone else, even their own family.

Services typically face four different challenges in closing the gap between what people need and what they get. These are to do with: values and vision, service design, staff skills, and resources.

- Values and vision
- Service design
- Skills
- Resources



These factors are linked. The underpinning values shape the service design, and this shapes the skills we expect from staff. The skills of staff affect the range and type of resources available to the service. We use the diagram of the Russian Doll to illustrate this concept.

Organisations and services often say that all they need is more resources. However, it is clear that if the challenge is one of service design or of values and vision, just increasing staff resources will not prove to be a productive first step - it may be simply putting new wine into old bottles. Each type of challenge provides a constraint on what the service can achieve.

Understanding why things are the way they are

1. Thinking about values and vision

We have seen the central role of values in shaping the way we understand people's needs and the sorts of services we provide. It is difficult to get managers in a service to take time out to talk about values - about what they think people need, about what makes them go to work in the morning. Values are not something which can be simply written down in the mission statement and then left to look after themselves. Staff at all levels of the organisation need the chance to keep thinking about what they are trying to do, and why. This thinking works better if it can be done alongside the people who rely on the service.

Human services need to take as much care working on their values and vision as they take working on their budgets and their development plans. Otherwise, they will quickly go off course, and end up being very busy doing the wrong thing.

The values and vision must be clear, and they must be faithful to what people who use the service want and need. Otherwise, energy will be wasted and the service will not be focused on the right task. Every other decision will be flawed and may be counterproductive.

2. Thinking about service design

The service design must allow and enable the implementation of the values and vision. By design we mean the way the service is set up and managed: when, where and how people are able to use the service: the buildings that are used, the way people are grouped, the relationship which the service creates between staff and service user.

Many services were set up with a different set of values and vision and have inherited a design based on those different values. To make sense of their new vision they may need to make significant changes in design.

The explicit philosophy may have changed, but the models used are still the old ones. So we may talk about integration and inclusion but we still operate a

whole range of segregated services - special needs housing, sheltered workshops, special schools, horse riding for the disabled, nursing and residential homes, day centres for people with learning difficulties and club houses for people with mental ill health.. We are still using many of the buildings put up between 1850 and 1950 to keep people ‘out of sight and out of mind’.
The way we do things is influenced as much by unstated assumptions and custom and practice as by written policy.

Service practices, the ‘look and feel’ of the service, the design and location of the building, job titles and the way staff see their role, the messages the service sends out about what it is - all these often reflect very old-fashioned and sometimes unconscious assumptions about the people being served.
If you accept that some people are citizens at risk of social exclusion, the role of services is to support and strengthen the capacity of society to include them and to help them maintain and extend their positive social identity as valued members of their communities.

3. Thinking about staff skills

The staff skills must be up to the task. However clear the values and however beautiful the service design, a service cannot work well unless practitioners have the right skills. People who have done their previous job competently and conscientiously may feel defensive at the prospect of having to learn new skills, but without this a service may have all the right words but show no results. If the service has clear values and a clear vision, skilled and motivated staff can go a long way towards compensating for poor service design.

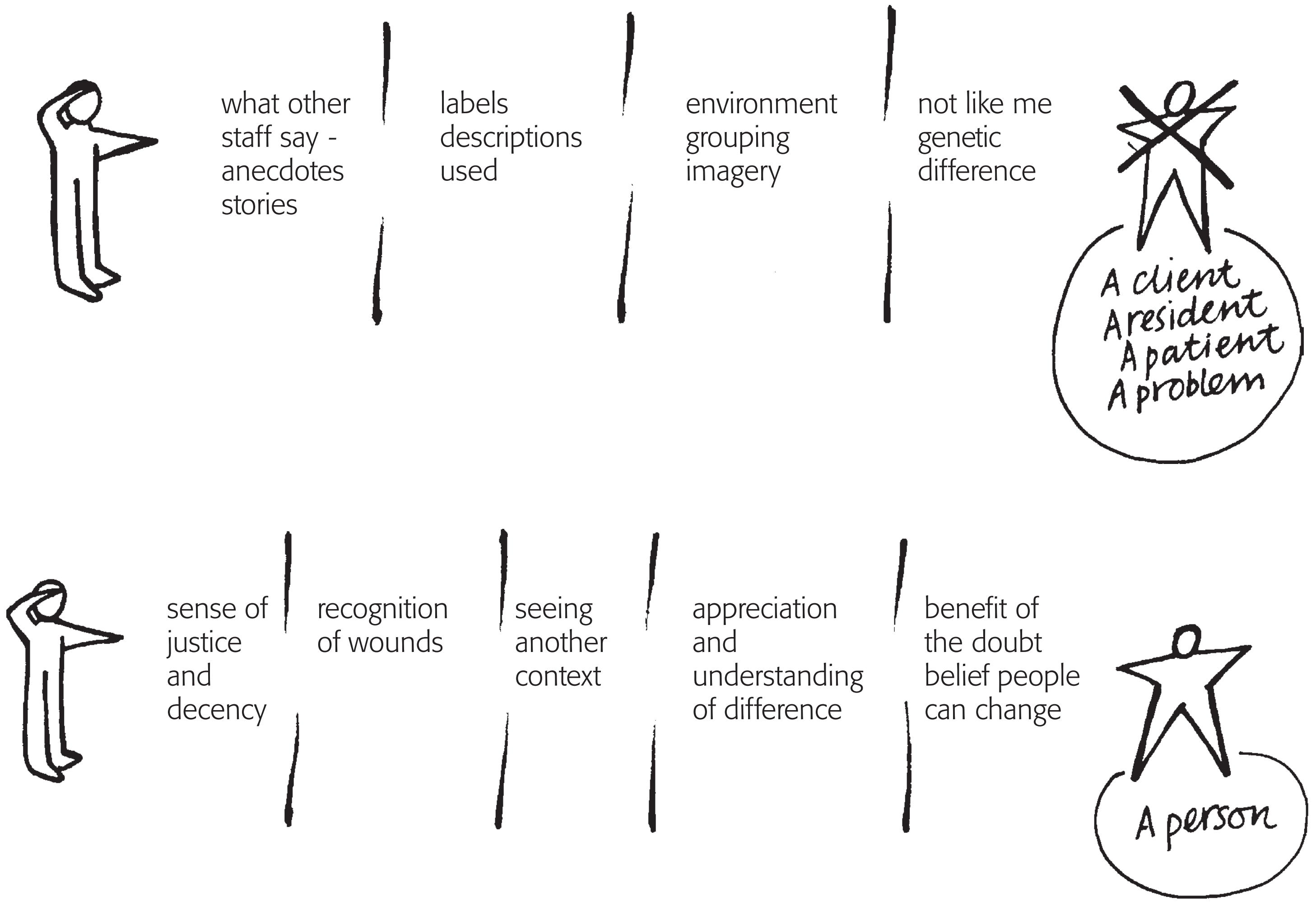
However, as a result of the way services are designed, staff become skilled in ‘doing for’ and even ‘thinking for’ people in the service. The language they use indicates very clearly where they believe the power lies in the relationship: they talk about “taking people to” places; of “allowing people “ to participate in activities. They become skilled at ‘organising’, ‘minding’ and ‘managing’. It is harder for them to learn ‘listening’ ‘standing back’ and ‘responding’.

Staff also become very comfortable inside ‘their’ building and less confident and comfortable ‘outside’. It is difficult for them to imagine functioning outwith the building and they begin to question the possibility of activity outside - ‘but what if it’s raining?’. Staff may not be skilful at introducing people they work with to people and places in the community, and may consciously or unconsciously mark people out as different and dependent.

4. Thinking about resources

Each of these three factors impose or remove a constraint on what is possible. Clearer vision, better design, higher skills increase the range of what can be achieved. The final constraint is the volume of resources - how many people, how much money can the service use. Everything else could be right and the service might be in a situation where progress can only be made if more paid staff are employed.

Most services would be happy to have an extra member of staff. But many services lack imagination in making use of the skills and resources of the people who use the service; or of their friends, families and contacts. Some services could also do more to make use of the skills and resources of their existing staff.


what other staff say - anecdotes stories
labels descriptions used
environment grouping imagery
not like me genetic difference
A client
A resident
A patient
A problem
sense of justice and decency
recognition of wounds
seeing another context
appreciation and understanding of difference
benefit of the doubt belief people can change
A person

Putting on the capacity lenses

One characteristic of most human services is their focus on peoples' deficits rather than their capacities. Older people are 'frail', 'housebound' or 'confused'. Children are 'attention seeking' or 'school refusers'. People with disabilities are 'wheelchair bound' or 'non verbal'. These 'reputations' often have their origins in genuine attempts to be helpful to people but in effect produce a view of individuals, which is distorted by its focus on the negative. So social workers are asked to undertake 'needs led assessments' in order to try and work out what services might help an individual or family but are not usually expected to ask what strengths and capacities they might have. Moreover, many of these descriptions or gategorisations of people can develop into reputations which might follow them around for most of their lives - an even greater risk when you have a file or report written about you at some time.

When thinking about reputations there are some important points to consider:

- 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 'pig-headed' 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'.
- 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.
- 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 seeing people through the lenses of:

- What other staff say, anecodotes, stories.
- Labels, descriptions.
- Environmental, grouping imagery.
- An assumption of fundamental difference.

To instead seeing people through the lenses of:

- A sense of justice and decency.
- A recognition of wounds.
- Seeing people in another context.
- An appreciation and understanding of difference.
- Giving the benefit of the doubt, the belief that people can change.

In effect a more person centred approach to working starts from these lenses. Although it is possible to see the real person through the distorted lenses of negative reputations and labels it is often almost impossible. To say that someone is 'autistic' or 'bipolar' or 'demented' actually says almost nothing about the real person behind the reputation.

People working in a person centred way have definitely stuck the capacity lenses on. This gives them a great opportunity to really get to know the person they are trying to help and what they have to offer. The rest of this section says more about some of the ideas and frameworks that might help keep the capacity lenses clear and focused and allow you to meet people with gifts, dreams, stories and contributions to make.

Working with gifts and capacity

In person centred working the accent is on what people's capacities and gifts are rather than their deficits. We have already described how people who use services very often already have plenty of information about them which focuses on what they can not do. Although, it may seem common sense to look for what is positive in a person it is not all that common in our culture. We are often quick to pick up on each others faults or the mistakes we have made and often it is frowned upon for people to be seen to "bang their own drum". To be successful in helping people at risk of exclusion plan, we need to change these habits. A person-centred approach offers some frameworks to help do this.

If you think of when you first meet someone it is unlikely that you would pick your own shortcomings to introduce yourself - "Hi! I'm an asthmatic middle aged man with myopia and a tendency to be grumpy if my routine is disrupted!" On the contrary, you might mention things such as your job, where you're from, what some of your interests are. Person centred planning takes a tremendous interest in this kind of information. How are individuals seen - as brothers, workers, sports fans, and friends? What kind of hobbies, interests and pastimes do they have? What things are they passionate about - as Tom Kohler says, "What gets them riled up?" What are their skills, interests and resources? Finding out these things begins to build a fuller picture of a person.

In person centred planning the expression "giftedness" is also used but it is important to realise that this is not meant in the conventional way. We do not mean someone who is a "gifted" pianist or painter (although some of the people we work with might be). Rather a gift is a "unique attribute" - something about you which creates a possible hook or connection with at least one other person. This therefore creates the possibility of a relationship and of greater community presence and involvement in the future. So someone might have a welcoming smile or an ability to be calm and quiet.

Discovering a person's gifts requires empathy, insight and the simple art of spending time with them. Sometimes friends, relatives and others, who know and like the person, might be better at seeing what your gifts really are and find it easier to say. Hearing others describe a person's gifts can be a positive and affirming experience for the person and their family.
Two leading thinkers on the subject are Judith Snow and John McKnight. Judith Snow describes giftedness as...

> *"...a common human trait, one that is fundamental to our capacity to be creatures of community. Gifts are whatever we are, whatever we do or whatever we have that allows us to create opportunities for ourselves and others to meaningfully interact and do things together - interactions that are meaningful between at least two people.*
>
> *...our presence is the fundamental gift that we bring to the human community. Presence is the fundamental of all other opportunities and interactions- of everything that is meaningful in our lives.*
>
> *Also fundamental to each person's presence is each person's difference. In fact presence is not possible without difference since even on a very simplistic level difference is essential to life (none of us would be here if the male and female difference did not exist). Meaning depends on difference as well, since if we were all the same there would be nothing to share or contribute to one another. Therefore, not sameness but presence and difference are fundamental to life and community...*
>
> *Each person has a variety of ordinary and extraordinary gifts. The people whom we call handicapped are people who are missing some typical or ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.*
>
> *In fact it is not just that walking is a gift and not walking is not a gift or that knowing how to put your clothes on right is a gift and not knowing is not a gift. Rather walking is a gift and not walking is a gift; knowing how to dress is a gift and not knowing how to dress is also a gift. Each creates the possibility of meaningful interaction."*

Gifts as described above are the basic tool of community. They are how we are able to interact with each other. When we seek to connect someone to community we are trying to find ways in which people can use their unique contribution so as to allow meaningful interaction.

No one is without gifts and it is our job to assist people to contribute those gifts in community. John McKnight writes, in "Building Communities from the Inside Out"

*"Does everyone have capacities?
There are some people who seem to be without any gifts or capacities. They may appear like an empty glass. And so they get called names - names like mentally retarded, ex convict, frail elderly, mentally ill, illiterate, and gang member. These are names for the emptiness some people see in other people. They are labels that focus attention on needs.*

One effect of these labels is that they keep many community people from seeing the gifts of people who have been labelled. The label often blinds us to the capacity of the people who are named. They appear to be useless. Therefore, these labelled people often get pushed to the edge of the community, or they are sometimes sent outside the community to an institution to be rehabilitated or receive services.

Nonetheless, every living person has some gift or capacity of value to others. A strong community is a place that recognizes those gifts and ensures that they are given. A weak community is a place where lots of people can't give their gifts and express their capacities.

In weak communities there are lots of people who have been pushed to the edge or exiled to institutions. Often, we say these people need help. They are needy. They have nothing to contribute. The label tells us so.

For example, She is a pregnant teenager. She needs counselling, therapy, residential services, special education." But also, "She is Mary Smith. She has a miraculously beautiful voice. We need her in the choir. She needs a record producer.

Her label, pregnant teenager, tells of emptiness and calls forth rejection, isolation and treatment. Her name, Mary Smith, tells of her gifts and evokes community and contributions.

Communities growing in power naturally or intentionally identify the capacities of all their members and ensure that they are contributed. However, the most powerful communities are those that can identify the gifts of those people at the margins and pull them into community life."

Person centred planning

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 planning with individuals we know in a person centred way.

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

- the focus is on the person and their 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 person and the people who love and care for the person are the primary authority
- the professionals are to be on tap and not on top - they are there to provide advice, knowledge, support and service - it is not their meeting
- the control is with the focus person and their advocates
- 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 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.

Roles and tasks in person centred planning

Process and graphic facilitation

Roles and responsibilities

At the outset, we think it would be helpful to outline some of the principles which underpin person centred planning.

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, with the obvious exception of the person themselves. 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 or partner or relative 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 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.

Facilitator independence can be very important. 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.

Sometimes the most important aspect of independence is the ability to ask new questions, and to receive new answers. If people are used to giving the answers expected, or are only asking for what they know is possible, better facilitation will be carried out by someone whose expectations are unknown, and who has no power to 'provide' anything material.

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.

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.

A list of facilitation tasks can include:

- 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.

The Facilitator Dance

Working effectively with a co-facilitator is a little like dancing with a partner. The sense of knowing where the other person is going to place their feet, the sense of togetherness, the rhythm, and the flow, are crucial to dancing well. Likewise in co-facilitating a plan each person must have that same sense of unity and trust and confidence in the ability, knowledge and skill of the other. Facilitators need to be able to depend on each other therefore when you are going to co-facilitate it is crucial that you spend time together before facilitating the plan - developing relationship and building trust. Beginning to do this when you are in the room facilitating is too late.

Co-facilitating with one partner is not the same as co-facilitating with another. Sometimes you'll find a partner that it just doesn't work with. However, when it goes right the experience will be very rewarding. You'll be in a partnership based on a huge amount of trust. You'll almost have a telepathic relationship, knowing just what your co-facilitator is thinking, when they need to be rescued, and when things are fine. When they interrupt or tell you what to do you can trust that it will be for a good reason, and nobody will notice anything out of the ordinary. While you are busy in the thick of it, they'll be able to notice things going wrong on the periphery, and will be able to let you know.

In the midst of facilitating a plan you and your partner need to work confidently and smoothly, demonstrating quiet control of what's going on, even when inside your brain and heart are working overtime.

Inevitably you'll step on each other's toes at some point but you don't have the luxury of stopping to work it out until the plan is over. Whatever happens between you, the people in the room must continue to see you working in complete co-operation with one another.

On the whole a process facilitator needs their graphic facilitator to:

- Stay in role, so that they hold control of the process and the graphic facilitator doesn't accidentally take it away.
- Listen intently.
- Pick up gentle hints, such as 'that sounds important, we better write it up' as direct instructions.
- Concentrate on recording, so that the graphic functions as a memory of the conversation, which will allow facilitators and participants to return to themes discussed earlier.
- Stand out of the way for sufficient time to allow sight of the whole graphic.
- Keep up.
- Have their pens at the point on the paper that is being discussed at the time.
- Be able to pick up when something important has been missed or misunderstood.
- Be prepared and able to provide a complete run through of all important details on the graphic at any point.

On the whole, a graphic facilitator needs their process facilitator to:

- Work at a speed that they can cope with, buying them time if possible, and recognising when they are missing important details.
- Issue gentle hints about things that they have missed or misunderstood.
- Watch and listen for gentle hints about things that have been missed or misunderstood.
- Concentrate on keeping the conversation alive, so that the participants don't start to relate only to what's being written down.
- Provide them with space to ask for clarification or to comment about things that they haven't been able to capture.
- Provide them with regular opportunities to provide a run through of recent work in order to allow them to check for accuracy/ appropriateness.

Using different tools

There are a number of different person centred planning tools which can enable us to plan for ourselves and with other people when changes have to be made in our lives.

In this pack we will touch on four planning frameworks:

- PATH, developed by Marsha Forest, John O'Brien and Jack Pearpoint
- MAP, developed by Mary A Falvey, Marsha Forest, Jack Pearpoint and Richard L Rosenberg
- Personal Futures Planning, developed by Beth Mount, Connie Lyle O'Brien and John O'Brien
- Essential Lifestyle Planning, developed by Susan Burke-Harrison and Michael Smull.

Many of the authors of these approaches to planning believe strongly that you should not use any of these tools unless you have experienced them for yourself - a principle which we think makes a lot of sense. Only then can you be trusted to use the process with the skill and humility it requires.

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. 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 allow the facilitator to speak to 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 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.

The Map process

Jack Pearpoint is based in Toronto and works worldwide as an advocate and campaigner for inclusion. Jack Pearpoint and Marsha Forest founded 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.

Here we describe the process from the point of view of a facilitator.

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. What is the map for - where is our desired destination.

The story

You are trying to get as much information as possible about the focus person and 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 script 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.

Dreams

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. We may need to use much of the information we gathered in the story to help us think about how to get things right. Some more ideas about dreams can be found in the section on Path.

The picture we draw here, whatever its content, should be energising and inspiring - it should engage the people in the room. Its 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.

Nightmares

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.

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.

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...

Gifts are the parts of oneself that it feels good to give. They are powerful clues about where and how the person might be included. Moving beyond more everyday statements like 'a good sense of humour' or 'friendly' to support a group or individual to think more deeply and positively about gifts takes practice and skill. Often someone's negative reputation can be reframed in positive terms at this time.

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.

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.

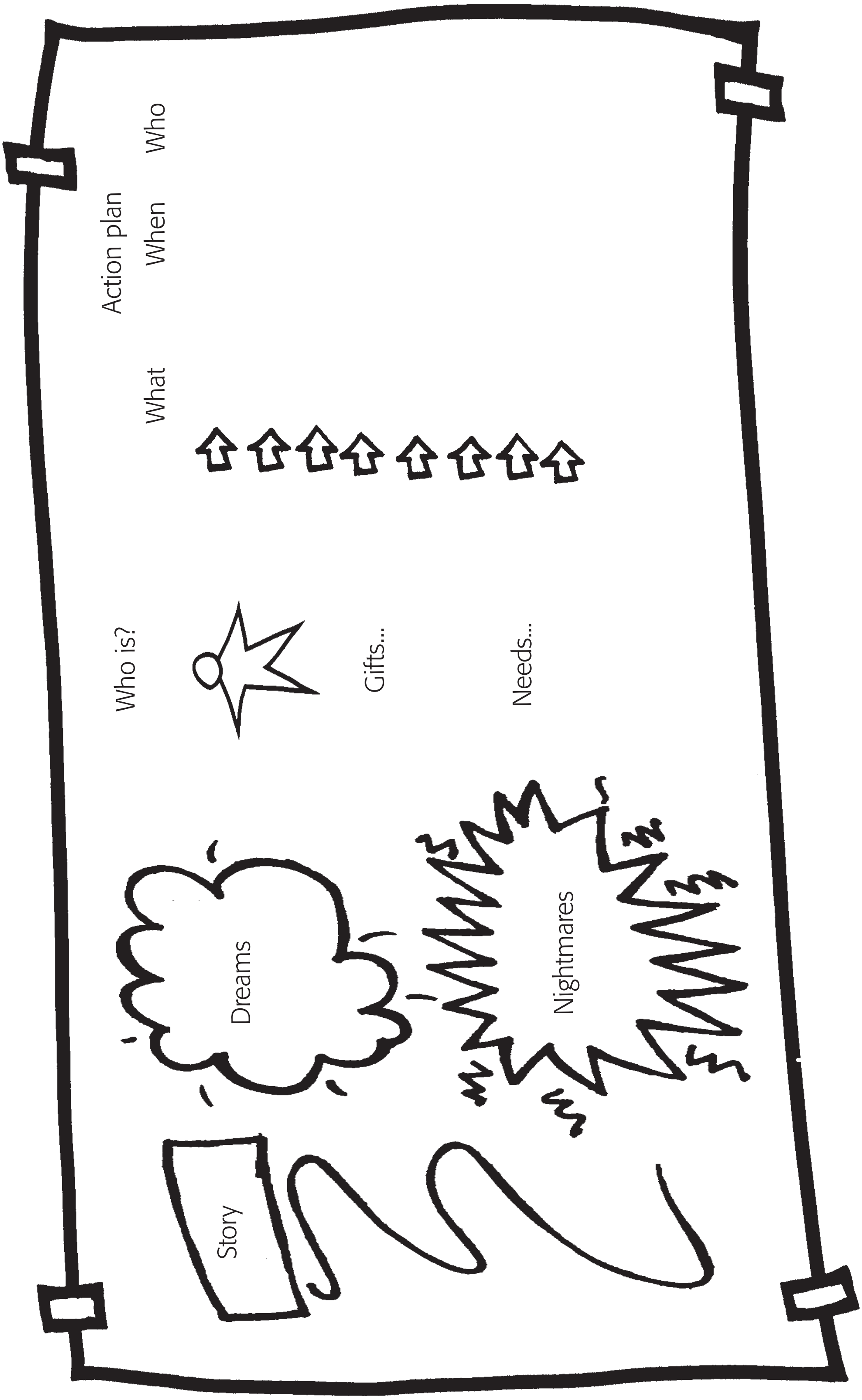
What does the person need now?

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?

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.

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.


Story
Dreams
Nightmares
Who is?
Gifts...
Needs...
Action plan
What
When
Who

Key steps

(see notes on pages 17 - 19 for full details)

Lots of work will precede a meeting so that the right people are in the room. As people arrive the facilitators must already be creating the safe and welcoming space and atmosphere in which planning will take place. For example the paper should be put on the wall confidently and efficiently.

The Map graphic doesn't require much preparation although faint markings of rough areas can help.

The sections of a Map can be completed in whatever order is most effective. Asking who is present and recording names can be useful as a beginning. Similarly asking 'what is a map' can get people talking. It may be useful to ask the focus person why they are doing this Map. In facilitating Map it is extremely important for the facilitator to keep track of time so that all sections, and particularly the action plan, receive sufficient attention.

Story. Ask the person (and their allies) to relate the person's story. This should provide enough detail and depth to engage people. It can sometimes help to provide an indication of the time available, and to ask for 'some significant stories from the past' rather than a life history. Drawing a yellow line in preparation, as a framework, can help.

Dreams. Ask about the future in whatever way allows the person to think 'out of the box', to identify images with enough imagination, richness and detail and power so that they can steer by this.

In person centred planning a facilitators role is never to help someone 'be realistic' in the sense of downgrading or limiting their hopes. Rather it is to create conditions that will allow their hopes, aspirations and dreams to flourish. This means creating a space that supports people to hear these and to be motivated by them.

Nightmares. Ask about what the person's life might look like if everything goes badly. Comparison with the dreams section creates tension and energy.

Who is? Ask the person and their allies 'who is (name)?' You are looking for positive descriptions of the person's identity, status, interests, passions and skills. It can help to ask 'what do people like about...' or 'tell me a favourite story' or ' when have you seen their face light up?'

Gifts. As part of the 'who is?' discussion, or separately, work out more about the person's gifts. See notes on page 18.

Needs. What is it that the person needs to be present in order to allow them to contribute their gifts and skills? What do the person's allies need to enable them to support this contribution?

Action plan. This is an extremely important section and sufficient time must be allowed to complete it. Use whatever facilitation skills are appropriate to draw up an action plan detailing 'who', 'what', 'when' ensuring that each contributor has committed to a first step.

The Path process

The Path process was developed by Marsha Forest, John O'Brien and Jack Pearpoint. 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. You may be familiar with the Framework for Accomplishment (the five service accomplishments) which John developed back in 1987.

The Path process uses some of the same elements as the Map process. 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.

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:

The dream

After you have welcomed everyone to the meeting and listed their names, you move straight to the Dreaming section of the Path. The first two sections of the Path focus on the vision of a desirable future for the focus person.

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. 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 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 ideas about avoiding a nightmare scenario creep 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.

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.

Now

We now have to take people out of the desirable future and bring them back to today.

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.

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.

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. The facilitators have to hold the tension in the room if there is any and deal with it.

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.

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 8.00 pm 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.

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.

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.

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

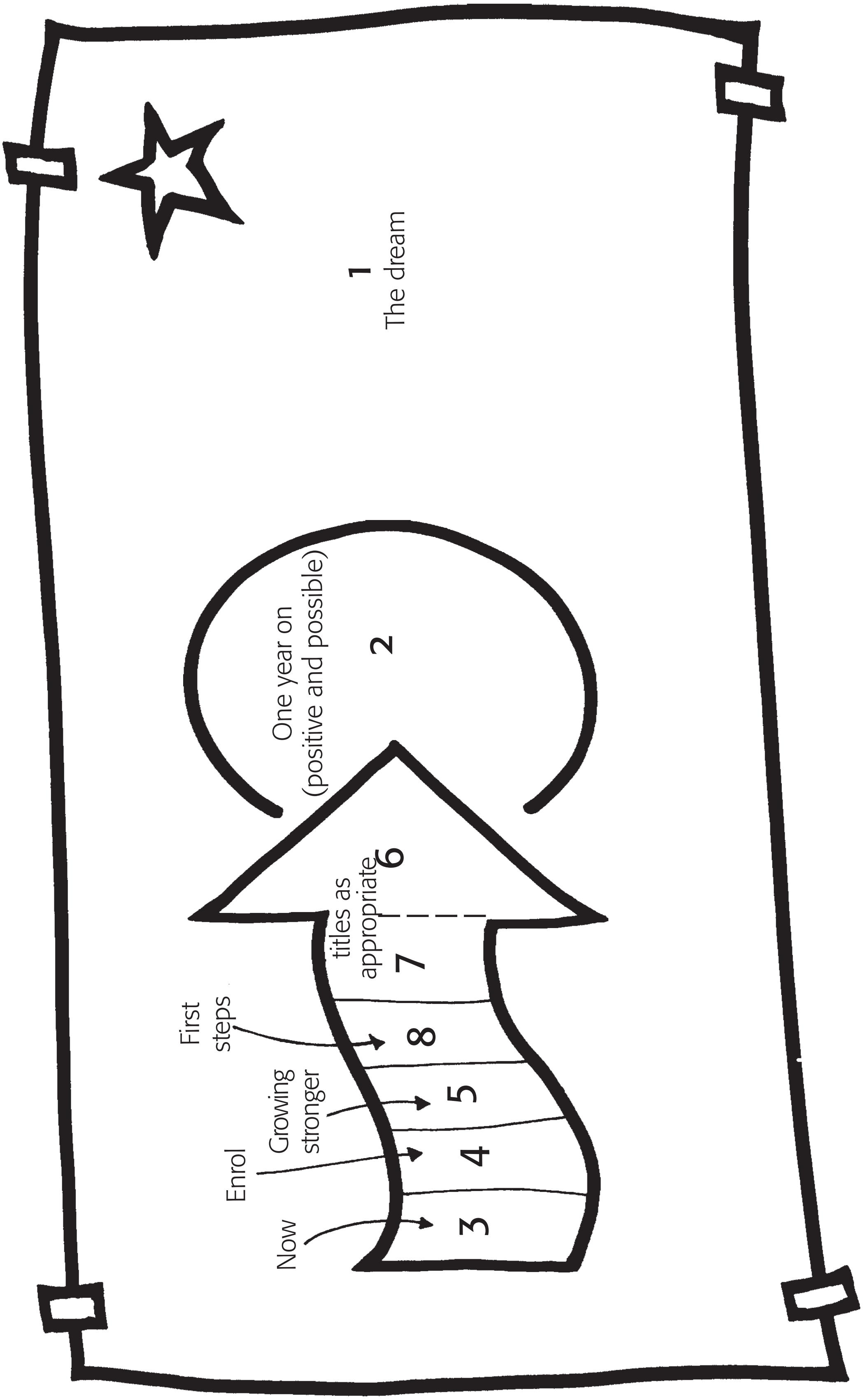
At the end of the Path, you have to agree when you will meet again and you have to agree who will be the keeper of the Path - who is going to keep the wallpaper. This is often the focus person, but they may want someone else to keep it for them. The ritual of rolling up the paper and presenting it to 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 can be rolled out again and reviewed at follow up sessions.

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.

And, very last words - 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!


1
The dream
One year on
(positive and possible)
2
titles as
appropriate
6
7
First
steps
8
Growing
stronger
5
Enrol
4
Now
3

Key steps

(see notes on pages 23 - 27 for full details)

Draw the graphic outline/introductions. Lots of work will precede a meeting so that the right people are in the room. As people arrive the facilitators must already be creating the safe and welcoming space and atmosphere in which planning will take place. For example the paper should be put on the wall confidently and efficiently.

When drawing the template for the graphic make sure that almost all of the right hand side of the paper is available for the dream/one year on sections while the arrow sits mostly in the left side. Leave out the titles and dividing lines until they are needed.

1. The dream. Ask about the future in whatever way allows the person to think ‘out of the box’, to identify images with enough imagination, richness and detail and power so that they can steer by this (hence the image of the north star).

In person centred planning a facilitators role is never to help someone ‘be realistic’ in the sense of downgrading or limiting their hopes. Rather it is to create conditions that will allow their hopes, aspirations and dreams to flourish. This means creating a space that supports people to hear these and to be motivated by them.

2. One year on. Invite people to imagine that they are one year on and describe what has taken place in the preceding twelve months (or longer if this feels more appropriate).

3. Now. Find out what life is like now. Path works best in situations where the ‘now’ isn’t a good place. The tension between what is described in this section and the first two sections (the dream and one year on) creates much of the motivation and energy which will drive the process forward.

4. Enrol. People agree to support the focus person in this effort. Ask them to write their own names on the paper.

5. Growing stronger. Support people to help them work out what they need to do to stay motivated, to make sure that important actions are completed or promises fulfilled.

6/7/8. Action planning. This is an extremely important section and sufficient time must be allowed. Use it as appropriate in order to action plan. It is important to end with the ‘first steps’ section. The arrow head/additional sections can be used to create images from half way there or sections for, say, 3 months and one month ahead.

End the meeting appropriately, perhaps with ‘last words’ from everyone.

Essential lifestyles planning

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.

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 made 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 require a lot of physical assistance, we may need to get very specific details about how 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.

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

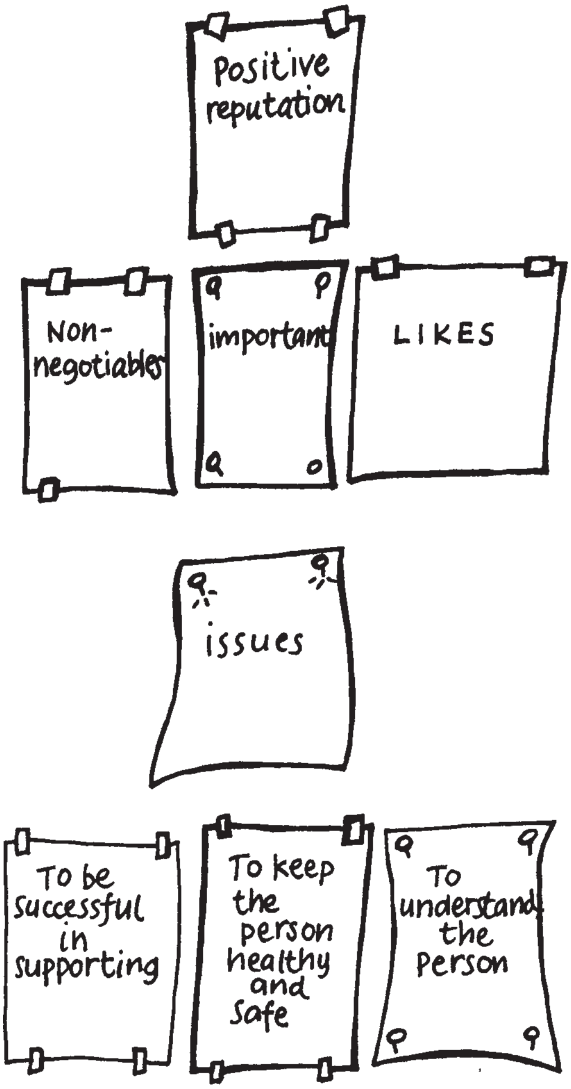
Phase 2

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 non-negotiables, 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 (non-negotiables, 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

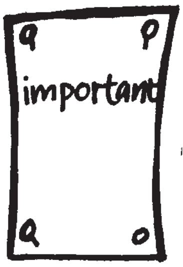
Our introduction to the plan is the person's positive reputation which may start off with the sentence "people who love and care for Mary say she is....." Like the "who is" panel in Map, this section should include positive and affectionate descriptions of the person, details about their age, identity 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". 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.

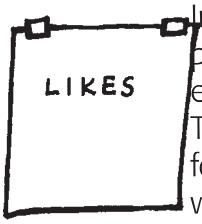
It is important to remember that essential lifestyles planning was designed specifically to assist service providers to support people the service found "challenging" and difficult to support. If there are issues around behaviour which contribute towards a negative reputation, we can deal with these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

Non negotiables, important, likes

The information is sorted out into three main categories: the non-negotiables (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 non-negotiables - 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 10.00 am...



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 programme 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 likes 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.

To be Successful in Supporting

This includes information about important rituals and routines in the person's life. It can detail the kind of support they require, 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.
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 on 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!'

To keep the person healthy and safe

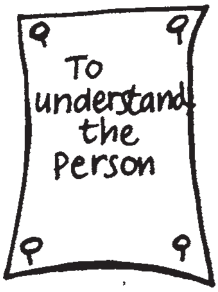
The inclusion or length of this section of the plan varies with the focus person. Sometimes you don't need this at all, sometimes this is very detailed and vitally important.

This section may contain details about:

- 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.
- If there are issues around behaviour, it is very important to describe the behaviour, 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 here 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.

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

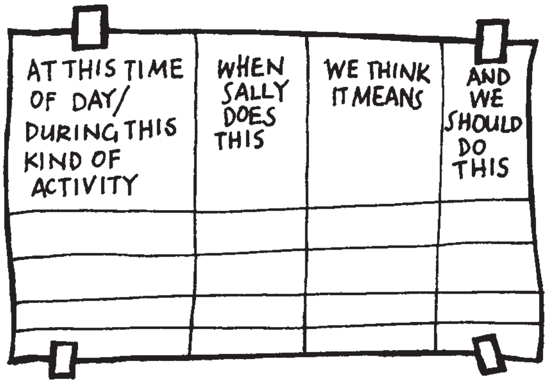


To understand the person

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.

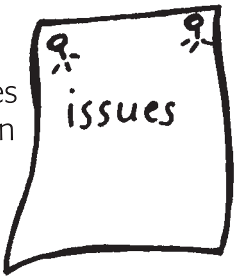
In essential lifestyle planning we can use communications sheets to try and build a better shared understanding of the ways in which a person communicates with us and how we can best communicate with them. For example if someone is both deaf and blind we may need to include a lot of technical information about symbols and signs we use to communicate with them. In addition to this, we need to details any clues we have about ways in which this person expresses their preferences and views to us.

Communication sheets can look like this:



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

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

The meeting - checking back the data and action planning

The focus person and the facilitator invite the people who have contributed to the plan to a meeting to review the plan and look at ways to put it into practice. The meeting generally has a number of stages:

Checking back the data

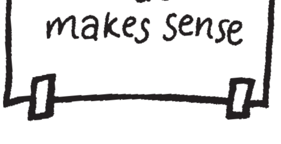
After welcoming people to the meeting and outlining the process, the facilitator should say who they have spoken to and then present the sections or panels prepared so far to the group. The facilitator may have written this information up on sheets of flip chart and have stuck them up on the way. The information in these sections of the plan should have been checked out with the focus person before this meeting to make sure they were happy with the content

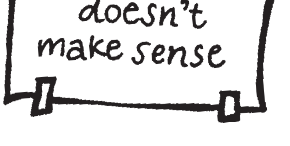
The information in the panels should be checked back with the focus person and their support group in detail - is there anything missing, did the facilitator misinterpret anything, does any of the information need to be amended or improved at this stage....

Any changes and corrections must now be made and agreed by the focus person and the group.

What makes sense, what doesn’t make sense
Up to this point in the process we have had data. This is really the start of the plan for change. The focus person and their support them then check out whether the things detailed in the plan are actually happening in the person’s life now.

To do this they have to work out what is making sense in the person’s life now and highlight the areas which do not make sense - we can write this up on two flip chart sheets





Action planning

The focus person and their support team 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:

- Issue.
- Situation now.
- What we can do.
- How we can do it.
- Who can do it and by when (choosing the best “hows” and “whats” we’ve come up with so far - if there is no-one who can do it, it won’t happen).

It is important to get people to work in pairs or team to brainstorm lots of “whats” before they think about any “hows”. Once they have loads of “whats” they can pick the ones they like best and brainstorm “hows” for each one. Once they have done this they can identify who can do it. Again you must be specific - names are required, not job titles and we should be using the people in the room and their personal networks to maximise the chance of success. The minute the “who” person is not in the room, the less likely it is that the “what” will happen.

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.

Ongoing Learning

As with other planning tools it is extremely important that an Essential Lifestyle Plan is not done once - for example when a person leaves an institution - but continually reviewed and amended as the person grows and develops their life. Michael Smull refers to this as ongoing learning and suggests a framework which asks the following questions:

- What have we learned?
- What have we tried?
- What are we pleased about?
- What are we concerned about?

Everyone is then asked to respond to each of these questions and the facilitators help the group to decide what makes sense and what doesn't in the way things are at present? Given all this information the meeting is asked:

- What do we still need to learn and what do we want to learn next?
- What do we want to maintain?
- What do we want to work on changing?

An Action Plan is then drawn up and the date for a future meeting is agreed.

A more detailed description of the Essential Lifestyle Planning process, along with many helpful ideas for reviewing progress and keeping the plan as a living and active framework is contained in "Essential Lifestyle Planning: a Handbook for Facilitators' written by Michael Smull and Helen Sanderson with Bill Allen (published by the North West Training and Development Team, Manchester 2001)

Person centred planning and groups

Introduction

One of the most powerful aspects of person centred planning is that it brings people together to support a person in their quest for a better life, or to make a positive change. In most cases this involves (at some stage or other) a meeting of the person seeking change and their allies and supporters. Two people will usually facilitate these meetings. One person will facilitate the process of the meeting and the other creates a vivid and contemporary record of the meeting - known in person centred planning as the graphic. Together, they are facilitating a group.

Groups can be scary, exhilarating, lonely, welcoming - no two are exactly the same. Below are a few ideas that might help you begin to make sense of what is going on when a group if formed.

The task and the emotional life of the group

One idea which has clear relevance in terms of person centred planning is the idea that a group works on two levels - there is a task and there is also a process. (In some literature, the process is referred to as the 'emotional life' of the group).

Or to put it another way, 'the task' refers to the need of the group to achieve its objectives, and 'the emotional life of the group' refers to the process which operates as the group goes about its business.

The 'task' aspect of being in a group is particularly obvious in a group which has come together to help a person plan for the future. Person centred planning tools include action plans, 'first steps' and clear arrangements for ensuring commitments are followed through. A person centred plan which does not include these tools will almost certainly fail in the task it is designed to fulfil.

Planning tools such as MAP and PATH pay considerable attention to the process of the meeting. For example, in drawing up a PATH there will be discussion of the ultimate 'Dream' goal and also of what the situation might realistically (and positively) be in a year's time, before looking at the present situation. This is a clear attempt to support the group and their facilitators to keep on track in coming up with some positive and concrete action steps.

However, although this helps, it is not strictly speaking about the emotional life of the group - it is more about ensuring that as far as possible, change will be an outcome. The emotional life of the group is more likely to exist rather like an undercurrent, which might flow at a different rate (or even in a different direction) to the surface flow of the meeting.

To ensure a positive outcome for the planning, it is important that the facilitators are aware of and attend to this process ‘undercurrent’. If this is done well, the group will work better together and be more effective. The group’s ability to undertake its task will be improved. Do the facilitators understand that individual anxieties might be due to the difficulty of the early stages of the process? That if someone is angry or sad, these feelings might be exaggerated, or muted, by the process of the group itself?

When the emotional life of the group is facilitated well the results can be startling. In his book, “Learning to Listen”, Herb Lovett describes an example of facilitation where he asked a group to share how they might have felt had they had the experiences of the child whose plan it was. This question really focused the feelings and intensity of the group. The result of making these emotions explicit was that the young person began to engage more closely (physically and emotionally) with the meeting as a whole.

As well as being a brilliant example of facilitating the meeting to be truly person centred, it also suggests that the process of what is going on the room is vital. It is not enough to simply follow the steps and ignore the process. The process or emotional life of the group will always be a factor to take into account in the facilitation of a meeting.

However, it is equally crucial to remember that the process is not therapy and that it is not the facilitator’s job to ‘dig deeper’ or to sort things out. This balance is a tough one to strike. The best kinds of meeting often feel a bit “therapeutic”- in the sense that participants might have been emotionally affected, and/or (in the case of those most involved) feel empowered by the experience.

To summarise - person centred planning attempts to strike a fine balance between task and process. When done well, this kind of respectful facilitation allows for creativity, energy, solidarity and empowerment, results in good plans and can lead to real changes for people.

When John O’Brien talks of person centred planning as an art, rather than a science, he is possibly describing this challenging balance. Having a clear understanding of the values which underpin person centred planning is crucial, but it is likely that respectful facilitation, with an understanding of group processes, will also be a big help.

Understanding the phases of the group

The person centred planning meeting is clearly a group; probably a group which is coming together for the first time (although in the case of the families and some of the professionals present this will not necessarily be the only time they have got together).

However, it will almost certainly be the first meeting with this kind of focus or approach and some people will be meeting for the first time. It will be important therefore to think about some of the issues associated with FORMING or BEGINNING the group. Having a welcoming environment, ensuring folk are comfortable and are introduced to each other are all vital. It will be important to set groundrules for the session (see below) and also to explain the process and remind people of the purpose of the meeting. Above all be aware people might be anxious and uncomfortable and that this will manifest itself in different ways, depending on the individual.

'Groundrules' are a familiar concept to professionals used to formal adult learning opportunities but it is unlikely that they will have been part of most peoples' experience of school. Jack Pearpoint uses a nice metaphor for groundrules: when you begin working on a new jigsaw you throw all the pieces on the floor; you need to find the corner pieces first, then the straight edges - this gives you the outline of the jigsaw and everything else falls within these edges. Jack describes this process as similar to that of setting groundrules: it helps the group to know what it's outer boundaries are and to have an idea of the areas it is legitimate to go during the meeting.
In person centred planning meetings some groundrules are clear - i.e., it is the person's meeting and we are focusing on developing a positive picture which helps us plan changes for the better. We also need to consider other apparently obvious things, e.g. timing of the day (including breaks), refreshments, listening and so on.

Clearly, much of the most productive work of the meeting will be done if these early stages can be negotiated and the group moves on to more of a NORMING/PERFORMING or MIDDLE/LATER stage. In order to be most productive from the person's point of view, this should coincide with the problem solving, brainstorming and action planning phases of the planning meeting - where the group needs to be at its most creative and collaborative.

Finally, the ending of the meeting is extremely important. There should be a clear outcome in terms of action points for the person and their family/supporters - in other words the task of the group is complete (or at least the first step is clear!)

It is often good to ask everyone present for a 'last word'. This closes the meeting in an obvious way and gives the opportunity for some early feedback to the facilitators. Where people have been affected powerfully by the process, facilitators should acknowledge this and allow for some discussion (most likely individually if requested) before leaving. People might also want a last cup of tea!

Of course, in some ways the group process of good person centred planning does not mark the end of a process, but the beginning. Good planning involves forming a supportive group around the person to value their contribution and dreams and beginning to plan for a future where these will be accepted and welcomed. A good planning meeting, therefore, creates firm foundations for the group developing around the person - as well as a sense of direction. It crucially models the beginnings of good teamwork - what Beth Mount calls the person's Intervisionary Team (as opposed to Interdisciplinary Team). As a consequence, some of the group stage issues might be a little more complicated than suggested above.

Some ideas about group facilitation

To establish a safe space at the start of a planning meeting

- Be confident and clear.
- Welcome people or support the focus person to do this.
- Be in complete control of the physical environment (knowing how to turn the heating off or open a window).
- Be prominent, standing at the centre of activity, not in a back room or sitting in a corner.

To silence unhelpful conversations taking place in the background

- Stand up, so that everyone knows you can see them.
- Stand or sit so that you don't have your back to anyone.
- Ask people to put off the conversation or whether they have something to add.

To support the focus person to talk about difficult things, discouraging interruption

- Sit down, close and in direct eye contact with them, talking more quietly so that it is clear that a personal, one to one, conversation is taking place.
- Be intently interested in what they say.
- Turn your back on the person you think might interrupt, put yourself between them and the focus person.

To encourage people to speak more loudly

- Stand further away from them.
- Stand on the far side of someone who is having difficulty hearing.

To explore whether someone can be brought on board with an idea

- Ask "what would it take for you to..."

To take the heat out of a situation where many are in disagreement

- Give each person an opportunity to speak, without interruption, for a set time.
- Do this in small groups, before asking each group to feed back to the whole group.
- Take a break.
- Find out what everyone agrees about.

To add energy to a group

- 'Turn up the temperature' by allowing conditions or discussion of things that aren't so comfortable.
- Support a discussion of things that irritate people.
- Support a discussion of a nightmare scenario.
- Support discussion of a dream.
- Let someone speak from their heart.
- Ask people what's worrying them.
- Take a break.
- During a break, ask someone in the know what's going on.

To support a group empathy about something sad or something exciting

- Behave in a sombre or animated fashion to mirror the emotion of what is being discussed.

To control how deeply a person engages with something unhappy

- Limit how far your emotions mirror theirs.
- Ask about something related, but less intense.
- Move the discussion on (appropriately and sensitively).

To encourage a person to speak

- Ask open questions.
- Ask about something they can easily talk about.
- Ask for a favourite story.
- Look intently interested.
- Say how interesting what they say is.
- Ask for a review of what has been written on the graphic.

To buy yourself time to think

- Ask for a review of the graphic.
- Suggest a brief break.
- Ask the graphic facilitator if they have any questions at this stage.

Personal development plan

What am I going to keep the same?

What am I going to change?

What challenges will I face in making these changes?

How am I going to get support to overcome these challenges?

Action plan for the next three months?

Evaluation form

Course title Dates

What do you think of this course?

Which part of the training so far did you find most useful?

What did you think the trainers did well?

What could they have done better?

Is there anything they could have done differently?

Thank you for your time in completing this form.