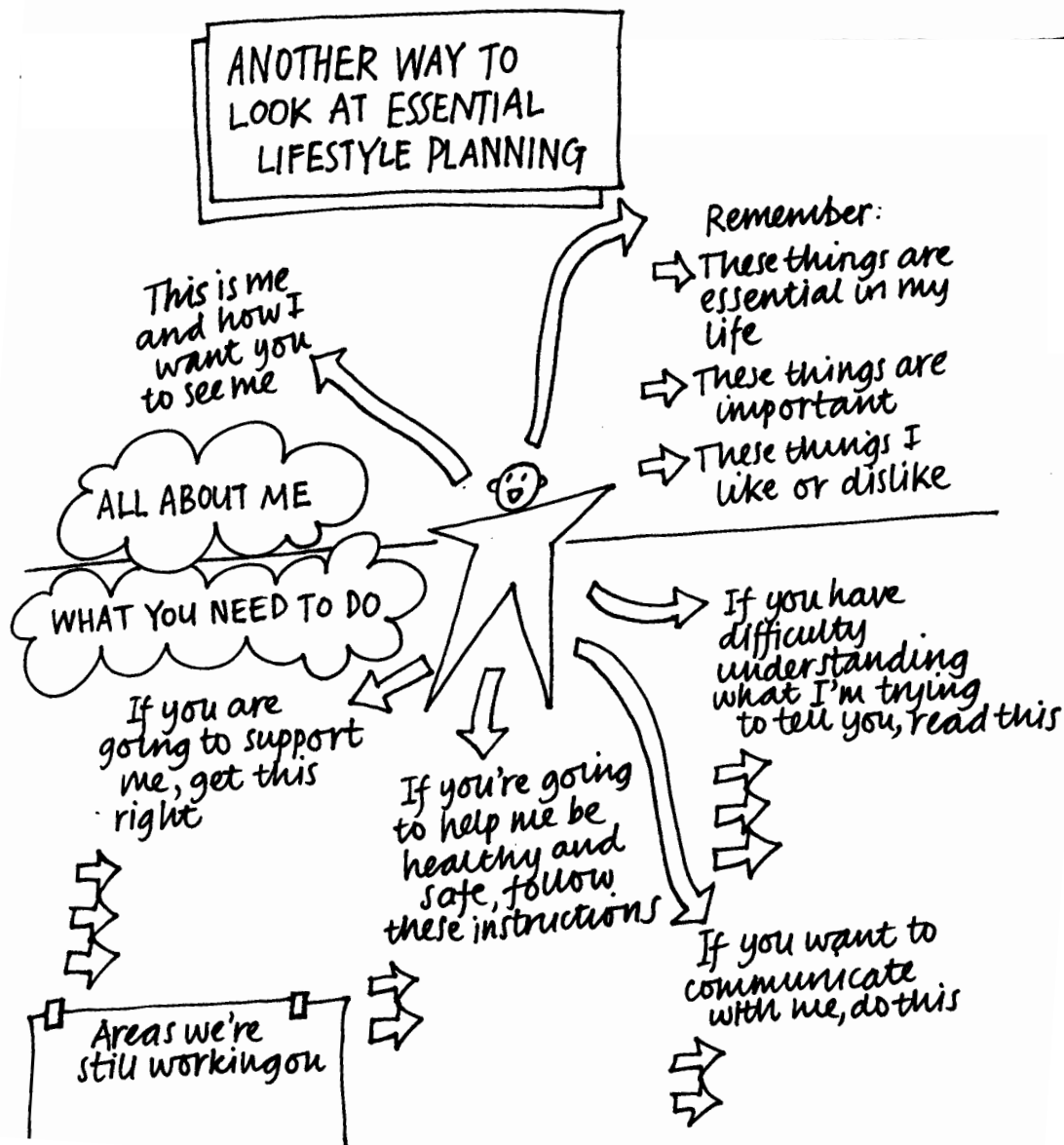


# ESSENTIAL LIFESTYLE PLANNING



# ESSENTIAL LIFESTYLES PLANNING

## AN OVERVIEW

### USING THE ESSENTIAL LIFESTYLE PLANNING PROCESS

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

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

Preparing an essential lifestyle plan requires a range of skills:

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

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

# PHASE 1

## UNDERTAKING INTERVIEWS AND GATHERING DATA

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

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

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

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

- How long have you known the person?
- How much time do you spend with the person?
- What do you like and admire about the person?
- Have you had a good time with the person recently? what did you do? what happened? what make it enjoyable...
- What are your favourite stories about the person?
- Have there been any bad days recently? what happened? what made them difficult days?
- How do you know the person is in a good mood or bad mood?
- What does the person like to do in the morning/ evening/ getting up/ going to bed.
- What rituals and routines are important to the person?
- Can you describe these ritual and routine in detail?
- What kind of things do you do that the person likes?

etc...

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

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

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

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

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

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

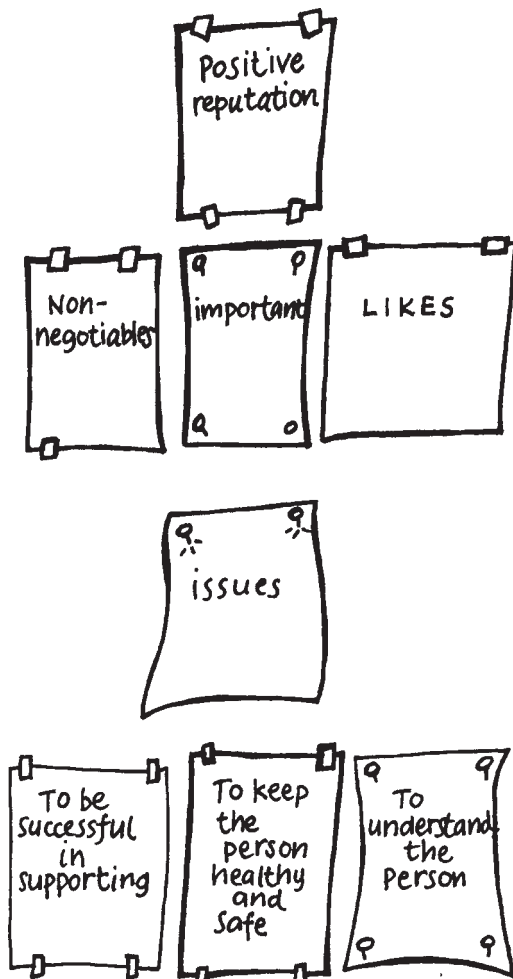
## PHASE 2

# CHECKING BACK, CLARIFYING, PRIORITISING AND SORTING DATA

Having completed your interviews, you now have to begin to sort out the data you have collected. This can often be like looking at a “magic eye” picture - you have lots and lots of dots and only by standing back and looking at the whole picture in a new way, can you begin to see the real picture coming into focus.

### THE SECTIONS OF THE PLAN - AN OVERVIEW

In essential lifestyle planning there are a number of different sections for the information and you have to begin to see the important patterns and crucial details. We will go through each of the sections or panels in detail, but here is an overview of the kind of sections you want to sort the information you have gathered into: It is crucial to remember in essential lifestyle planning that the essential, important and likes panels are written entirely from the person’s point of view. If the person likes smoking it must go down here. If there are health issues around smoking, this can be dealt with later in the “to keep the person healthy and safe” section - but we can not delete the fact that they like smoking because there are health issues.



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

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

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

## THE SECTIONS OF THE PLAN IN DETAIL

### POSITIVE REPUTATION

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

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

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

## ESSENTIALS, IMPORTANT, LIKES

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

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

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

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

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

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

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

# OVERVIEW OF THE SUPPORT PANELS

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

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

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

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

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

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

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

## TO BE SUCCESSFUL IN SUPPORTING

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



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

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

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

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

## PEOPLE WITH POWER AND CONTROL

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

## PEOPLE WITH LITTLE POWER OR CONTROL

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

It may be necessary to increase awareness of the methods and approaches which appear to be most successful with the person - this is vitally important when the

person does not use words to communicate and is at risk of being misunderstood or overlooked.

## DIFFERENT KINDS OF SUPPORT

It can be divided into different sections and it is important to remember that there are different 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. If the person is likely to respond negatively to certain situations or types of people, we need to give this support person information about how to avoid or manage these situations or encounters.

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

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

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

## TO KEEP THE PERSON HEALTHY AND SAFE

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

This section may contain details about :

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

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

## SPECIFIC HEALTH ISSUES OR MEDICAL CONDITIONS

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

### Medical treatment and specific conditions

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

### Aids and adaptations

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

We should also detail the use and frequency of use of any aids or adaptations which have been provided for the person - i.e. if someone has to have their arms in splints - what purpose do the splints serve, how long should they be worn, during which

activities is it most useful to wear them, when is it advisable to remove them and what damage is likely to occur if they are not used.

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

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

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

## GATHERING INFORMATION FOR THIS SECTION

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

Useful questions might be:

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

Again you are trying to have a conversation, not an interrogation. You are trying to have a structured conversation and you should follow up on things the person says,

not just follow the script. We all need the best information possible to prevent the person being at risk.

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

## COMMUNICATING WITH THE PERSON

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

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

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

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

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

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

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

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

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

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

We will go into more detail about recording and discussing communication issues on the course.

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

## UNRESOLVED ISSUES

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

## PHASE 3

# WHAT MAKES SENSE, WHAT DOESN'T MAKE SENSE AND ACTION PLANNING

### WAYS OF CHECKING BACK THE DATA

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

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

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

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

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

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

### HAVING A MEETING TO CHECK BACK THE DATA

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

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

will check all of the information back and reach agreement with the focus person about what is written down and how it is written down in public.

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

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

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

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

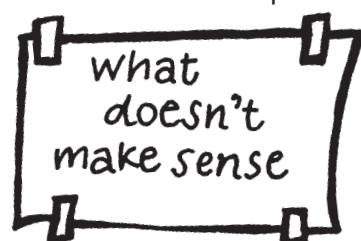
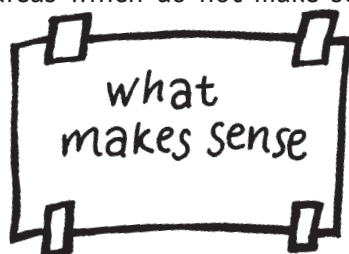
## WHAT MAKES SENSE, WHAT DOESN'T MAKE SENSE

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

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

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

At this meeting, present the key information the people attending the meeting need to help them work out what is making sense in the person's life now and highlight the areas which do not make sense - we can write this up on two flip chart sheets





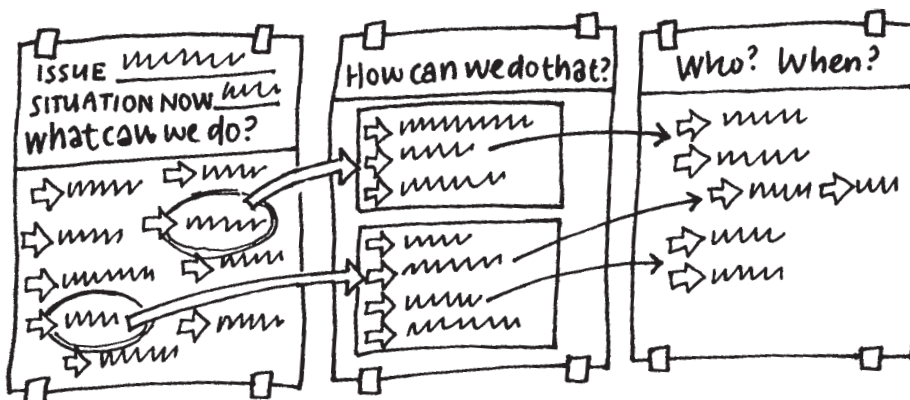
## ACTION PLANNING

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

- Safeguard the good things that are happening in the person's life now.
- Stop and change the bad things that are happening in the person's life now.
- Start exploring and doing new things which make sense to the focus person.

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

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



### What can we do

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

### How can we do it

Once we have a sheet full of ideas, the facilitator reads out all the ideas and the people in the meeting chose the best ones - which ones appeal to people there and sound like good bets. Taking each idea in turn, the facilitator asks the people at

the meeting to brainstorm ways of doing it - what could we do and how would we do it? The facilitator has to time manage this process and get as many ways as possible of achieving the desired outcome. Probably restricting it to 5 minutes per idea is useful. You need to help people in the room be energetic and creative - give them breaks when they are tired!

### Who can do and when can they do it

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

## CLOSING THE MEETING AND WORKING ON THE PLAN

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

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

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

# SOME SUPPORT NOTES TO ENABLE YOU TO PRACTICE ESSENTIAL LIFESTYLE PLANING ON THE COURSE

## PHASE 1 - UNDERTAKING INTERVIEWS AND GATHERING DATA

We will have asked people on the course to volunteer to act as focus people for the essential lifestyle plan. They will have nominated one or two other people on the course who know them to also be sources of information.

One facilitator will have 30 mins to interview the focus person. The other facilitator(s) will have 30 mins to interview the person's friend(s).

The purpose of the interview is to build up as rich a picture as possible of the person's preferences. The facilitators needs to be able to elicit stories and listen, both to what is said on the surface and to what this tells you about what is important to the person. Closed questions, which elicit yes/no responses, are to be avoided at the beginning of the information gathering process, but them might be useful later. The person being interviewed should be encouraged to talk as much as possible.

In order to do this, the facilitator interviewing the focus person has to ask open questions and encourage the facilitator to amplify. The other facilitators asks the friends similar kinds of questions about the person. The following questions might be a helpful starting point:

- Have you had a really good day at work/ at the centre/ in college recently? What happened? Tell me about it - what made it such a good day?
- If you could have your perfect day off, what would you do? How would you spend the morning? Where would it be, what would you be doing? What would make it special? How would you end it?
- What do you do when you get up in the morning? What's the most important thing which has to happen? What happens if this doesn't happen? How does that effect you for the rest of the day?
- Tell me about a bad day at work/ at the centre/ in college? What was it that made it a bad day?
- How do the people around you know when you are in a good mood or a bad mood?
- What helps you get out of a bad mood or puts you in a good mood?
- What's really important to you - what really winds you up?

These questions allow people to open up and provide us with lots of useful information. The task of the facilitator is to build up a rich picture - you are not to express your view of the person's preferences, or attempt to analyse the person. You want the person being interviewed to feel as if they are having a conversation with you and they should be enjoying talking about themselves.

However, whilst the tone is conversational, the process is not - you have to make sure you do not become involved in the conversation and use up the time to tell your own stories.

## PHASE 2 - CHECKING BACK, CLARIFYING, PRIORITISING AND SORTING DATA

At the end of the interviews, the two facilitators have 10-15 minutes to compare notes and have scribble their first draft of the first 4 panels about the person

- The person's positive reputation "People who like and care for Susan say..."
- The essentials - 'Susan must have...must not have...'
- The desirables - 'Susan should have...should not have.....'
- The likes - 'Susan likes...does not like...'

The focus person and their friends now come back into the room. The two trainee facilitators have to role play presenting back the data and checking it with the people in the room. There should be four blank sheets of flipchart paper on the wall and the facilitator does not write anything up until it has been agreed with the person.

If the teams have time, they can review the first four panels and make a start of the first support panel - "to successfully assist...."

All the way through the process the facilitators have to think about the language they use and be careful about tone and accuracy. They should be doing this as if the person they interviewed can no longer speak for themselves and may be supported by someone who doesn't know them. The information they write down has to be clear enough to enable a stranger to support this person well - always beware of ambiguities and generalisations.

In addition to sorting the information, they must try and quantify frequency and volume, i.e. 'Susan must see her mother once every two weeks' or 'John must go to a football match at least once a month'. It is not helpful to use generalisations - they are open to misinterpretation and tend to give us a caricatured version of the person rather than a rich and individualistic picture of the person. Be specific where ever possible.

