

Think before you plan

Michael W. Smull

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Be sure to think before you plan. Thinking about a few issues before you get started can help you achieve a better outcome, prevent problems, avoid unnecessary struggle, and save you from public embarrassment. Note that the plans being discussed here are not plans done in training (those issues are dealt with in the *criteria for a focus person*) but the ordinary, day to day efforts to understand how someone wants to live and what we are going to do about it. The overriding principle is that a plan is not an outcome, the life that the person wants is the outcome. The only acceptable reason to plan is to help someone move toward the life that they desire. In outline the issues to be understood before you plan are -

Make sure that -

you understand why this plan is being done and that the reason for doing the plan is acceptable; and

there is a commitment to act on what is learned.

Spend time with the person with who you are planning before you start the plan to:

get to know the person and her/his issues;

develop the ground rules for the planning; and

do any negotiation necessary to have a successful outcome

Look for opportunities -

to build relationships; and

help people be a more a part of their communities.

Learn if there are any issues and challenges in developing or implementing the plan and develop strategies to deal with them

In more detail -

1. Make sure that there is a commitment to act on what is learned. Remember that a plan is not an outcome. A plan is an organized way of learning what is important to someone and a description of what we will do to act on what have learned (including addressing any issues of health and safety).

2. More specifically, why this plan is being done with this person - is the purpose:

to help the person move to a new setting; or

to help them get more of what is important to them where they currently live; or

better understand how to help us support them in the life that they want while addressing issues such as a challenging behavior or a complex medical need; or

a combination of these things.

Once the purpose is understood ask what you need to learn and how it might best be learned. Remember essential lifestyle planning is only one way to learn. If the person has a clear goal that will take some time to achieve think about using PATH. If the person has a number of people who care deeply, who are not exclusively paid staff, and you have the skills and energy to mobilize these relationships, think about doing a personal futures plan. Keep in mind that you can do part or all of an essential lifestyle plan to support the development and/or implementation of another kind of plan.

3. Try to learn of the challenges/issues present in developing and implementing the plan before you begin. If this is a person whose parents or guardians have views of what is important to the person that are different (from the views of the person) try to determine how those differences can be addressed. It usually helps to set aside time to listen, to find common ground, before formal meetings. Always talk with the focus person about her/his options and support her/him in deciding how to proceed. Occasionally the best short term solution is to not to do a full plan but to help the person find the best short term compromise.

Do not forget that while someone may want something that their parents see as unsafe, he/she may also want to maintain a good relationship with his/her parents.

Do not forget that we all want mutually exclusive things (e.g. to be skinny and eat whatever we want or to be rich and work in human services), that part of your job is to learn what these mutually exclusive things are and to help the person find a balance that works for them.

Where what the person wants is not supported by those whose consent or assistance is needed for that person to get it, be careful. Do not engage in a process where hopes are raised, only to be crushed. (Be honest about what you can do.)

Remember that the best negotiation is one that no one notices. If you can learn about likely conflicts before that planning starts you can design a process where:

Everyone feels that they were listened to and that they participated in a respectful process.

Common ground is identified and nurtured (often starting with agreement that all of us have the same ultimate goals - for the person we are planning with to be happy and safe).

A dialogue about a balance that will work for the person (and the compromises that will work for others) is initiated and supported.

4. Do not forget the most important part - spending time with the person with who you are planning before you start the plan to:

get to know the person and her/his issues;

develop the ground rules for the planning; and

do any negotiation necessary to have a successful outcome

Develop the ground rules about who to talk with, what can and cannot be discussed, and how to keep the person informed. Where the ground rules that the person wants would interfere with them getting their life the ground rules are negotiated before the planning starts.

5. Look for opportunities to build relationships and help the person be connected to his/her community. Look for opportunities to:

to strengthen and extend current relationships, to build new relationships;

build partnerships among those who know and care about the person and with the community; and

help the person find situations where their gifts and contributions are appreciated and used.

Do not forget that an acceptable outcome from *thinking before you plan* is to decide not to plan. If the plan cannot be done respectfully, if there is no commitment to implement, do not plan. If the reason for planning is not acceptable do not plan. If planning is mandated, then the support and monitoring needed to:

insure respectful planning; and

have reasonable efforts to act on what was learned

also has to be mandated and provided.

Three Approaches to a Conversation

by Michael Smull

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There are three approaches to a conversation which can be useful in gathering information for an Essential Lifestyle Plan:

Linear

A linear approach is the easiest way to have a conversation without asking leading questions. If you are talking with the individual with whom you are planning you simply start with getting up and then walk through the day with the person. You ask what a "typical" morning is like and then ask if some are better than others and what is a good one like and what is a bad one like. You move through the day in pieces asking for what usually happens and then asking for good and bad versions of that part of the day. Try to get the person you are talking with to tell you stories that illustrate what they mean. Be prepared to adapt this approach to the circumstances and capacities of the person. One man could not tell us what a good or bad day was like but he could describe his last week, day by day, in great detail. Another man had not had any good days in some time but could tell us about good days from his past. When talking with someone who is involved during regular hours (e.g. 9 AM to 3 PM) simply start at the beginning of that time and walk through it asking questions about typical, good, and bad versions of each part of the day.

Branching

A branching approach starts in the same way, walking through time with the person, encouraging stories that illustrate the good day and the bad day. However, in a branching approach you look for opportunities for the person to tell related stories about other parts of a persons life. The result is a conversation that branches from one point in time and then meanders a bit until that line of conversation end. At that point you go back to where you where in time when the branch started. For example, if the branch started with breakfast and wandered off from there, at the end of that branch you would ask "and what happens after breakfast?"

Meandering

A meandering conversation is the most natural and also the most difficult. In a meandering conversation, instead of walking through time with someone, you start wherever your initial questions lead you and then shape the conversation so that you hear stories about is important to the individual's life across all of the areas that the person you are interviewing knows about. Having a meandering conversation requires that you keep the conversation moving and cover all the areas in the time that you have. The facilitator must be skilled and have a mental map of what she or he wants to learn, while always listening for the unexpected.

Increasing Your Opportunities for a Successful Conversation

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Introduction

As we move towards individualizing services and supports through person-centered planning, it becomes even more important to collect information directly from individuals and those who know him or her best. This adapted excerpt summarizes some of the issues faced by interviewers and includes some suggestions for increasing the chances of a successful conversation. This article was adapted and excerpted from **Are You Retarded? No, I'm Catholic: Qualitative Methods in the Study of People with Severe Handicaps** by Sari Knopp Biklen, Syracuse University and Charles R. Moseley, Syracuse University and Vermont Division of Mental Retardation. It was first published in the **Journal of The Association for Persons with Severe Handicaps, 1988, Vol.13, No. 3, 155-162.**

I. Six Common Concerns

Misunderstandings.

Here's an example:

Interviewer: How are supervisors different than counselors?

Paul: Oh, I like it.

Interviewer: How are they different?

Paul: Pretty good.

Interviewer: Are they the same?

Paul: Oh yeah.

Interviewer: They do the same jobs?

Paul: Yeah

Interviewer: Or, do they do different jobs?

Paul: Yeah.

Interviewer: What does the supervisor do?

Paul: Well, they have to clean up the stuff.

The interviewer was finally able to determine how the jobs differed by asking Pete to describe first his supervisor's job and then that of his counselor. Pete was not able to bring the supervisor and counselor together to compare them. One strategy used to overcome these difficulties, then, is to ask about people, things, and activities separately, rather than asking the individual to provide a comparison or analysis.

Some misunderstandings require repetition and honesty to overcome. During one conversation, an interviewer repeated his preference several times while developing rapport with Pat, who lives in a group home.

Pat: Doug, would you like a nice cold coke? Doug, a coke on ice?

Doug: Thanks, but you know, I'd rather have water if you have it.

Pat: Coke, Doug? Want a nice cold coke, Doug? A coke on ice?

Doug:(smiles) No thanks, but I'd love a cold glass of water.

Pat: No coke, Doug?

Doug: No thanks, but I'd love water.

Pat: Water it is, Doug.

The interviewer's honesty heightened their communication and revealed Pat's ability as a flexible and gracious hostess.

Taping interviews may help interviewers to better understand the individual's pronunciation. One interviewer found it easier to understand language when he listened to the tapes than when he was in the actual interview situation. Taping the interviews also enabled him to replay sections when desired.

Open-Ended Questions.

Most interviewers ask open-ended questions so that individuals can frame answers from their own perspectives. Sometimes, however, such questions may become more confusing than clarifying. When one interviewer asked questions such as "Tell me about your work" or "What do you think about what you are doing?", he received answers such as "It's okay," "All right," or sometimes no response at all other than a smile or a stare.

It's important to break requests for information into parts and ask separate questions about each. One interviewer, for example, broke down the original question "What did you do before

you worked here?" to "When did you start working here?" "What were you doing the day before you started here?" "Were you going to school, or were you in a workshop, or just at home?" This process may elicit richer responses and answers to other questions as well. You can obtain a response to questions involving more complex concepts if you can determine the right form to use.

In order to get past difficult spots and find this form, you can ask the individual questions which can be answered by "yes" or "no" or by giving a short answer. It is helpful to view this process as temporary rather than routine, however, because there are problems with it as well. For example, short answer questions may represent the concerns of the interviewer rather than those of the person being interviewed.

The Interview Environment.

Effective interviews need to occur in situations where the individual feels comfortable. Interviewers often talk about building "rapport" and interviewing people in settings where they feel most natural. For example, an individual living in a group home expressed great anxiety when she thought she would be interviewed in the group home office and requested that the living room be used.

The "Same Answer" Problem.

What do people mean when they use the same phrase over and over again in response to different questions? One interviewer found, for example, that one respondent frequently repeated "What I like to do is do all my work and get the job done, and that is what I like best." Perhaps the individual added this statement to many of his answers to reassure the interviewer that he was a good worker, or perhaps just to have something to say. As an interviewer you can use these repetitions as signals that respondents may not know the answer to your question (but will not say so), that you may not be asking questions that they find important, or that they may not understand the question.

Phrases may also be repeated because the individual is preoccupied by a particular concern or problem which is unsolved. In response to virtually any open-ended question, for example, one woman said something like "Oh, I don't want to work at the recycling company, I want to go out. Do you think they will let me? I don't think they will." She repeated this basic statement again and again. In this situation, the interviewer attempted to reflect the problem back to the individual and would ask "Well, what are you going to do about it?" or "What do you think you could have done in that situation?" Asking questions that encouraged respondents to think of other options seemed to help them concentrate on what they could do and moved the conversation along.

Pleasing the Interviewer.

All interviewers worry about the extent to which the individual says what the interviewer wants to hear. This concern can be especially apparent when the person being interviewed is not sure who

the interviewer is and may think that this is someone who has some kind of control over his or her services and supports. In these situations, people will not likely express what is really on their minds. It's important to clearly identify who you are and how you are connected to his or her life, services and supports.

Significant Others.

One strategy for working with people who do not use words or whose communication is extremely difficult is to interview important people in his or her life. There are both advantages and disadvantages to this approach. One advantage is clear. The friend, parent, or advocate frequently has spent considerable time with the individual and has a better understanding of the his or her language and methods of communication. In addition, these friends or family members often know specific dates or events that the individual may not remember.

This approach has clear drawbacks as well, the most serious being that the friend, advocate, or parent may act, not just as a translator, but as a filter as well. In fact, it is almost impossible not to get the perspective of the other person. The influence of that perspective on the conversation often depends on what stake this significant other has in the life of the individual. When there is a need to rely on others for information, it becomes important to have more than one source.

II. Use of Observation

Introduction.

Interviewers should seek opportunities to get unfiltered responses; so, observations play a key role in collecting information, especially when individuals do not use words or signs to communicate. The goal of observation is to discover the meaning that individuals make of their world.

Observe Over a Period of Time in Varied Settings.

Observation is a labor-intensive effort, but the effort can be used to sustain insights from interviews. Most of us will talk and act differently, depending on the environment in which we find ourselves. So, it's important to observe people in a number of different life experiences and over time.

Get to Know the Person.

One way to get to know individual in their natural environment is by spending time with them. You get to know their preferences, their habits, and their modes of interacting. Getting to know someone well allows you to see the person empathically.

Use Significant Others.

Significant others are as important in observing as they are in interviewing. Although there are some concerns in depending on advocates, friends, or parents to interpret meaning, there are benefits as well. Ideally, the interviewer would want to compare information collected about an individual's life with the person's perspective. If this is impossible to achieve, the interviewer can depend on others who know the person well to help. The best way to judge the importance of information from significant others is by the quality of the information that they give. Rich information, full of examples, given about a variety of situations over time is extremely useful.

Conclusion.

It is important for the interviewer who wants to learn about the world of another individual to supplement information received through discussion with observations in the places where they live and work. Interviewers enter natural environments to find out what meanings people make of their life situations, as well as to provide a framework in which to place these meanings and to help explain conflicting perspectives.

by

Michael W. Smull

Helen Sanderson, & Susan Burke Harrison

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Requests for copies should be made to: Michael W. Smull **Support Development Associates**,
3245 Harness Creek Road,
Annapolis, MD 21403.

(410) 626-2707 or (fax) 626-2708 or E-Mail: mwsnull@compuserve.com

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Reviewing essential lifestyle plans criteria for "best plans"

Michael W. Smull, Helen Sanderson, &

Susan Burke Harrison

The following is intended to assist trainers and others who are reviewing essential lifestyle plans to see if the plans meet the criteria for "good. or "best" plans. Please keep in mind that the criteria presented are for "best" plans and that this is an evolving standard. Plans that presented best practice a few years ago would be seen as unacceptable today. Like essential lifestyle plans, these criteria are a snapshot of a moving target. They will evolve as we continue to learn how to

plan with people and implement what we have learned. Those who read this are invited to contribute to the learning process. Please share what you have learned with any of the authors and we will use it in our on going revisions of the criteria.

When reviewing plans done with people that you do not know, remember that you cannot determine with certainty if the plan accurately reflects the person with whom it was done. Only the focus person and those who know the person can do this. A skillful evaluator can infer how well the plan represents the issues of the person but you can only evaluate with certainty how well the plan communicates. With this limitation in mind please use the following criteria to evaluate essential lifestyle plans.

Criteria for best plans - overview

Essential lifestyle plans provide the reader with a clear snapshot of how the person wants to live and what the reader needs to know or do to support the person.

Essential lifestyle plans (ELPs) communicate -

Who and what is important to the focus person -

in relationships with others and their interactions;

in things to do, things to have;

in rhythm or pace of life;

in positive rituals or routines.

What others need to know or do:

in helping the person to get what is important to them;

in having a life where issues of health or safety are addressed within the context of how the person wants to live.

ELPs communicate in plain, simple, but powerful language with a good balance between detail and brevity. Good plans are done "with" people not "for" people, they -

Separate what is important to the person from what is important to all of the others in the person's life (professionals, family, advocates).

Address issues that the people we are doing planning with (the "focus. person) see as sensitive (or private) in a way that respects their privacy while making certain that those who need to know have the needed information. (This is most often accomplished by having sections of plans that are only available to those who need the information while referencing the information in the appropriate section of the overall plan.)

Describe the admirable qualities of the person and demonstrate that those who know and care about the person contributed to the development of the plan.

Start with what is important to the person, while reflecting a positive balance between choice and risk.

Not only describe what has been learned but indicate what still needs to be learned.

Good Plans:

Are written with no jargon or "human service speak"

Use unambiguous language that the person (where possible), family, advocates, and those implementing the plan understand.

Are easy and inviting to read.

Balance detail and brevity, they have enough detail to understand what is meant and who the person is but not so much detail that the plan will not be read.

Good plans are reviewed with the focus person before they are widely shared and the focus person (or the person most likely to reflect the views of the focus person) has had a real opportunity to shape what is said and what is shared.

The best plans make you feel like you have met the person even if you have not.

They demonstrate a depth of insight coupled with a clarity of presentation that makes it likely that you would support the person well even in a new situation.

Detailed criteria by section/heading

Sections/headings that are always be present in an ELP are:

Who contributed to the plan

The positive reputation

What is important to the person (prioritized in 2 or 3 sections)

What do we need to know or do in order to support the person

What does and does not make sense in the life of the person

What we need to do to maintain those things that make sense

Action plan, changing those things that do not make sense what, who and when

Headings that are used as needed

Negative reputation (used with people without disability labels, collected but not used with people with disabilities)

How the person communicates

To help the person stay healthy

To help the person stay safe

Positive rituals/routines requiring physical assistance

Issues to be resolved/Questions to be answered

Concerns

Dreams

Things that we need to do (even if the person does not agree)

Any other elements that are needed to help the person get what is important to them and be safe, healthy, etc.

In more detail

Who contributed to the plan

The intent of this section is to inform the reader about who participated in the development of the plan, who facilitated the development of the plan, and the date of the plan. List names and then relationships. Relationships should show who is a family member, who is a friend and who is staff (including the support role of the staff member, e.g. - direct support, psychologist). Note that people can have more than one role, e.g. - people who are paid can also be listed as friends.

A reviewer who knows the person should be looking to see if the people who really know and care contributed to the development of the plan. A reviewer who does not know the person should look at this list and see if there is a mix of family, friends, and staff. If not, ask the person who developed the plan why not. An acceptable answer is that the person has no family and lives in circumstances where s/he has no friends. (Having no one in your life that cares about you requires that the reviewer look to see what is planned to change this. An empty life is not acceptable but care should be taken as, while no one's life should be empty, we all have different definitions of a full life. The need for relationships should be reflected in the plan as well as what people are do to help the focus person develop the relationships that s/he would like to have.) It is not acceptable to say that there was no time or it was not convenient to have family and/or friends contribute: people can contribute by phone; opportunities to talk individually can be scheduled; meetings are not the only way to gather information; and meeting can be held at times convenient for families and friends.

Positive reputation

The positive reputation should be a list of what people find admirable and what they like about the person. It sets a tone for the plan and helps people with disabilities to be seen as people and not a collection of deficits and problems.

The list should reflect what others have seen in the person and be said in terms that you would use for a friend or loved one. Examples-

for one person - lovable, humorous, affectionate, mischievous and fun, inquisitive; or

for another person - deeply religious, dedicated to family, magnetic personality, keeps her spirits up no matter what, great sense of humor, strong personality, incredibly patient

The list should not reflect:

"disability" accomplishments e.g. drinks from a cup, helps with dressing, accomplished 3 out of 5 goals; or

what the person likes or enjoys e.g. likes bowling, enjoys adventure movies (these should be reflected under what is important to the person).

If the list is very short the entire plan is open to question, as either the person does not have people who care in his/her life or the people who care were not asked. If the person is living with people who do not care about her/him then there should be something in the plan which says what is going to be done about it (e.g. the person will move). If the people who care have not been asked then the plan needs to be sent back for the inclusion of the information that those people have. The expectation of the reviewer should be that there will not only be a longer list under positive reputation but a richer description of what is important to the person and a fuller description of what we need to know or do to support the person. (Note that people who care about the focus person not only found on the formal team. All of the people who care about the focus person need to be identified and have the opportunity to contribute regardless of their role.)

What is important to the person

This section prioritizes and lists what is important to the person. It should reflect only what is important to the person, not what is important to any other people in the person's life. What is important to the person is divided by headings that prioritize how important things are. Most typically there are three levels of priority, although two are not uncommon. There are no "required" headings for each of the levels of priority. Any headings that make sense to the users are acceptable. Some that are currently being used are:

1st priority "non-negotiables", "things I must/must not have", "essentials"

2nd priority "strong preferences", "things I need to have/need to not have", "things that are important to me", "very important"

3rd priority "highly desireables", "things I enjoy or like/dislike", "enjoy/like or would like to try"

While the headings for what is important should be clear and unambiguous, the words used for the headings are not as important as careful learning and a powerful presentation. Developing and presenting what is important to the person should reflect

Careful learning that is rooted in listening to the person (their stories and their behavior) and in listening to those people who know the person and care about the person. "Learning includes spending time with the person, it does not include using forms, questionnaires, or asking a list of prepared questions. "

What is important to the person, not what is important to others, not what people think should be important to the person.

What has been learned about the person, not what people think they should know or are simply guessing about.

The plan should reflect who and what is important to the person:

in relationships with others and their interactions;

in things to do, things to have;

in rhythm or pace of life;

in positive rituals or routines.

After reading about what is important to the person you should know:

Who is important to the person, how important are they, and how the relationships) are maintained. Examples -

Must continue to live with my wife Andy.

I must talk to my sister on the phone whenever I want and see her every month or so.

I have to tell my mother and Bridgett when something good happens for me.

What is important to people in their interactions with others. Examples -

- Must be supported by people:

- I trust.

- who are not loud, aggressive or in my face.

- who are calm, not loud talking

- who listen to me. who won't give up.

Promises made must be kept

Living/working with people who support each other as they are and who encourage continuous growth

Any issues of health or safety that the person says are important. (Note issues of health or safety that the person does not say are important are still addressed, but they are addressed in later sections.) Examples

I must be supported in my diet: I can not consume more than 1000 calories a day and I must exercise because of my low metabolism.

Must have her Coumadin level checked every 3 4 weeks.

What the person wants to do or have. Examples -

Must have her easy chair to sit in whenever she is in the living room.

I have to watch my favorite TV shows X Files, Mantis, and Out of this World.

Have a job that: uses her gifts; where she feels she makes a difference in the lives of others; where co workers are kind and honest to each other; and pays enough to support her and her children.

Must always have Kleenex available!

Going out in the car (everyday).

Regarding Food:

no butter or margarine ever!

no mayonnaise (except a little bit in tuna or chicken salad)

eating most things "perfectly plain!"

no sauces or spreads

always have an onion in the refrigerator

loves eggs, cheese and crackers always have a loaf of bread and peanut butter in the house

Issues that relate to the rhythm or pace of life. Examples -

Must not be rushed, must do things at her own pace -

not to have to get up right after she sits down

to get ready and then move at her pace, to not have others try to make her move faster

Occasional weekends, couple of evenings/week unscheduled

Must stay busy - when not working, doing things with the children, being involved with their schools, being a part of my church

The parts of positive rituals or routines that are important to the person, that they want others to know about. Examples-

In the morning, get me up ONLY when I am ready.

When I come home from work I have to change into my sweats and Power Ranger tennis shoes.

In the morning do not talk to me until after coffee (and I start the conversation).

For people who require extensive physical assistance it is not unusual to have these routines detailed under their own headings (e.g., morning routine, arriving home routine, going to bed routine) with the information only available to those who actually provide, plan for, or oversee the support. There is always a reference to the existence of the routines in the "what is important to the person" section of the plan. Example -

The people who help me in the morning and the evening must follow my routines. They are written up exactly as I want them done. The only people who can have copies of my routines are the people who help me and the people that I agree need them. (If you need a copy, ask me.)

The most common errors in listing what is important to people are:

Assuming that if it is important to others in the person's life it must be important to the focus person. Among the worst examples was a plan that said that implementing a restrictive behavior program (that the person clearly hated) was a "non negotiable" for the person.

Describing what is important to the person in brief, telegraphic phrases that give an idea of what is important but are easily subject to misinterpretation by the reader. A common example is to have the single word "privacy" listed without saying more about what privacy means to the person. Since, in the absence of other information, people operate out of their own experiences and perceptions, privacy will be interpreted as meaning what it means to the reader. Unfortunately, what it means to the reader is likely to be different from what it means to the focus person. Plans need enough detail, enough examples, to guide the reader.

The basics should be assumed, unless there is a history of their being absent. A list of things that sound like a recitation of Maslow's hierarchy e.g. food, shelter, clothing should be avoided unless they have been absent in the person's life. Someone who has been hurt by an individual that they live with may want to say

that they must not live with people who hurt others. People who have never lived with such a person will take it as a given.

Negative reputation

Plans done by people on themselves or with their friends or family typically include a list of the negative things that are said about them. **Plans done with people who are receiving services from the disability system (or seeking to receive services from the disability system) should not have a negative reputation section.** This represents a change in what we have taught for the past several years. However, we have found that the negative reputation section of the plan is often a list that stigmatizes the focus person without helping those who support the focus person to know what to do.

The information that would be used in a negative reputation section should be collected and reviewed. For most facilitators, this is done by writing up a negative reputation section but not including it in the "published" version of the plan. Each item is then reviewed. If it represents a current issue that item is placed under a heading where what needs to be done to help the person (or others) to be safe and healthy is made explicitly clear, without unnecessarily stigmatizing the person. The headings that are used most often are: "to help the person stay safe"; and "concerns". Under these headings what the person does and our response can be made explicit. For example, a negative reputation section might say that someone "kicks and bites". If this is a current issue, a heading such as "concerns" could be used where there are explanations regarding: the circumstances under which the person will kick or bite; how to help the person avoid the need for the behavior; and what to do to keep everyone safe if it does occur. {This example is presented in more detail on pages 19 and 20.)

Comparing the negative reputations of people receiving services from the disability system with the negative reputations of people providing services makes the reason for this decision clear. There are clear differences in presentation, perception, and control. Where people do plans on themselves, with friends, or with loved ones, those contributing to the plan are more "positive" in the negative things that are said. The perception of the behavior is shaped by the valued role that the person occupies. The person writing the plan also has control over who is asked and what is reported. People with disabilities rarely have control over how they live, much less what is said. Too often the negative reputation is really a recitation of the focus person's non verbal critique of the services that they are receiving.

What do we need to know or do to support the person

(Also referred to as "In order to be successful")

This section of the plan describes what people other than the focus person need to know or do in order for the person to get what is important to her/him or for s/he to stay safe and healthy. This is a very broad heading which can cover a wide range of issues. Where there are important issues that need to be highlighted, where what we should know or do could be lost in a long list, those issues should be described under their own heading. (Examples can be found in the materials that follow.)

Everything that is important to the person should be considered to determine if there is something that those who support the person need to know or do. Where the focus person needs no assistance (and where our knowing about it is not a

example, Michael's plan notes that he must have strong coffee as he decides he needs it. There is no mention of providing strong coffee for Michael in the section for those who support him as he will make sure that he gets coffee with or without assistance.

Those who develop the plans should go through each of the items listed under what is important to the person and ask themselves if there is something that we need to know or do. Those who review the plans should be going from the headings about what is important to this heading asking the same question. Some examples -

The person for whom it was important that she not be rushed has in this section:

She must not be rushed, support her to move at her own pace.
Listen to her behavior, if you are rushing her -

- she will pull back,
- go in another direction,
- if really frustrated, she will slap her hand

For the person who has to watch his favorite TV shows it notes:

Respect Jon's desire to watch his favorite TV shows. If you must go out with Jon during a show he usually watches leave the house with him before the show starts (or wait until it is over).

Upon learning that Rhonda must be supported by people that she trusts, staff stated that:

- Rhonda should be involved and make choices in the selection of people who support her.

What does and does not make sense in the life of the person

Developing lists of what does and does not make sense in the life of the person is an important step in implementing plans. (Some people have difficulty in understanding what is meant by "makes sense. or "does not make sense". For those people an alternative explanation would be " what things that person finds important are present and what things are absent.") The challenge for the reviewer is that these are often only used to develop the action plan and are not included in the plan itself. People are reluctant to include a list of what does not make sense in a plan that will be reviewed by those who license and fund. If these lists were required to be part of the final plan, they might be distorted because of concerns about the consequences. Where those who review the plan are not trained in the process and/or not grounded in the values, making an extensive list of what is not working in someone's life may have an undesired consequence. Things that will take time to address may be given impossible correction deadlines. People may ask why an agency that is "doing so many things wrong" should be licensed or funded.

However, for many people, this is the aspect of the planning that bridges the gap between a theoretical list of what is important to a person and the actions that can be taken to help the person get what is important to them. These lists set the agenda for what should be changed and what needs to be preserved. These lists should always be done but need not be shared.

The list of what does make sense in the life of the person should include naming the people who truly care about the person, who help them get the things that do make sense in the life of the person. It should also include those things that might be lost in the process of helping the person change those things that do not make sense. For example, someone who is attending a facility based day program may need to leave that program for a community job in order to get the status and income that is important to her/him. At the same time s/he may have important friends at the day program. If s/he gets a community job without people paying attention to the importance of the friendships, s/he could lose the friends, become lonely and lose the job to get back to the friends.

The list of what does not make sense sets the agenda for change. In some instances it makes the need for immediate change starkly clear. One man was living with a roommate who had a behavior program for physically assaulting him. The professional language did not make it clear that he was living in a house where he was repeatedly stalked and attacked by someone that he could not get away from. By writing on the list of what did not make sense, "living with someone who lies in wait to hurt you" it was clear that change was needed and needed quickly. Usually the issues are less dramatic. One man was living with a family that loved him and who he loved in return but he had no friends outside of his home. One woman had people who supported her during the week who she trusted (who also honored her rituals and routines) while the people who supported her on the weekends were people she did not trust and who did not honor her rituals and routines. If someone has a severe mental illness and does not get adequate treatment, it should be on the list of what does not make sense.

What we need to do to maintain those things that make sense

The list of the things that do make sense in the person's life should be reviewed to see which items need to be monitored to make sure that they continue. One agency turned this into a simple check list that staff could review and managers could follow up on. It included items such as:

Make sure that "Bill" continues to talk to his Mom on the phone at least every other day.

Realize and respect "Bill's" dislike for coffee, orange juice, and oatmeal don't give it to him.

Make sure that you knock and get permission before going into "Bill's" room.

Action plan, changing those things that do not make sense what, who and when

The list of the things that do not make sense is usually further broken down into a list of things that can be changed now and a list of things that will require time, additional funding and/or some creative ideas. The list of things that can be done now becomes a 3 column list with the headings for each of the columns being: "what is going to be done"; "who is responsible for implementation"; and "by when". For things that will require time the following format is suggested:

Start with the "issue"

Describe the "situation now"

Generate a list of the "ideas" that people have to change the situation.

Review the list of ideas, identify those worthy of further effort and restate them in terms of what will be done.

Add 2 columns, "who is responsible for implementation", and "by when"

Examples of headings that are used as needed -

Essential Lifestyle Planning is an open, flexible process. As plans are developed, if there is information that does not seem to fit within the previous headings, use a new heading. Some of the headings that people have used are:

How the person communicates

To help the person stay healthy

To help the person stay safe

Positive rituals/routines requiring physical assistance

Issues to be resolved/Questions to be answered

Concerns

Dreams

Things that we need to do (even if the person does not agree)

Please keep in mind that these are only examples, any other headings that are needed to help the person get what is important to them and be safe, healthy, etc. should be used.

"As needed" headings in more detail

How the person communicates

For people who do not use words to talk, or who have difficulty in communicating with words, a section on how the person does communicate has been very helpful. People who develop plans have also found this section useful for people who do use words to talk but are difficult to understand and as a way of recording how we communicate with people who have difficulty in understanding what we say.

However, the mere absence of spoken communication is not necessarily an indication that this section is needed. For example there are many people who communicate quite well using sign language or an augmentative device such as a "liberator". This section is intended for people who have their own unique way of communicating. A reviewer should expect that this section will be used wherever people who have significant communication difficulties.

Its absence in these instances should be explained.

The heading "what is happening" describes the circumstances. The headings "and (person's name) does" describes what the person does in terms that are sufficiently clear that a reader who had not seen it would still recognize it. For people where it is something hard to describe (e.g. a facial expression), a picture or even a video recording may be preferred. The heading "we think it means" describes the meaning that people think is present. It is not uncommon for there to be more than 1 meaning for a single behavior. Where this is the case all of the meanings should be listed. The heading "and we should" describes what those who provide support are to do in response to what the person is saying with their behavior. The responses under this heading give a careful reviewer a great deal of insight into how the person is perceived and supported.

To help the person stay healthy

A separate section should be used wherever there is a desire to highlight important issues of health or where ever there are extensive health issues. The intent of this section is to inform those who provide support what they need to know or do to address issues of health. Medical terminology may be necessary to communicate precisely what is meant but it should be kept to a minimum. This section is not a substitute for medical or nursing records. This section is typically used to describe issues of physical health but it can also be used to describe mental health issues. Where issues of health are not extensive or do not warrant highlighting they can be described under "what we need to know or do".

For Ruth (in Grandma's plan) the following section appears:

On-going Medical Issues

- Ruth takes anti coagulant medication; her "pro time" must be checked every 3 4 weeks (or sooner if the doctor says); be extremely cautious if she cuts or bruises herself; call the doctor if she has a nose bleed

- She is very susceptible to pneumonia at the first signs of cough or cold (especially if she has a fever) she must see the doctor

- Her blood pressure must be monitored; with medicine it is well regulated, but it needs to be checked at least monthly

- Her medicine regime changes frequently... anyone supporting her must be up to date

For one man who has a bipolar disorder which is not entirely controlled by medication there is an extensive section which begins (in part) -

People supporting "Jim" must know that when he is becoming "manic", he will:

start gesturing/pantomiming (saluting, swimming, shooting, and/or exercising) without talking;

pantomime shooting "commies", helicopters, or whatever while standing on the front porch;

rearrange furniture and everything else;

not be able to focus on anything, be indecisive; and

start having conversations with people are not there and acts as if people who are his friends are actually Fidel Castro or Muhammad Ali.

The plan continues by instructing support staff to immediately notify the team leader who will contact "Jim's" psychiatrist. It instructs staff in how to interact with him by saying (in part)

Try to help "Jim" have a "regular" day but do not go out as much;

If "Jim" says something that is not true like "You're Fidel Castro", gently but confidently say "No, I'm (your name).

Back off! Let him know you are there for him but do not pester him. Say "If you need me I'll be in the (room you are going to)". You do not have to keep conversations going.

Let "Jim" know that you are coming to talk to him by approaching from the front and speaking to him before you are in his personal space (from 5 to 10 feet around him).

The plan goes on to describe what to do if he continues this "downward spiral" including how to support him if he is hospitalized.

Where the focus person has important health issues, that we need to know or do something about, the plan must address them. **Any plan that does not address significant issues of health is not acceptable.** One of the errors that facilitators make is to get so caught up in the positive aspects of the planning that they do not address issues of health, especially if they or the focus person are uncomfortable with the particular issues. The challenge is to look at health through the eyes of the person as well as through the perceptions of the disability system and find a balance that works for both. Where there are issues of health that are sensitive and/or very personal there needs to be a judgment about who needs to know the information and with what detail. A good plan may let the reader know that there is a section on health care that is only available to people who need to know the information. Where the person is sensitive about an issue that needs to be widely known, such as a seizure disorder not fully controlled by medication, those developing the plan need to figure out with the person the most respectful way of sharing the information. (Those evaluating plans need to be able to review all sections, including those seen as private or sensitive, but should do so with knowledge and the permission of the person, where ever possible.)

Please keep in mind that vital issues of health (or safety) may not be important to the person. Where this is the case they should not be noted under the headings for what is important to the person but must be accounted for either under this heading or under the heading "what we need to know or do to support the person."

To help the person stay safe

A separate section should be used wherever there is a desire to highlight important issues of safety or where ever there are extensive safety issues. The intent of this section is to inform those who provide support what they need to know or do to help the person stay safe. Where

issues of safety are not extensive or do not need highlighting they can be described under "what we need to know or do".

For one man issues of safety included:

His food must be cut into pea size pieces to keep from aspirating/choking on his food.

When he is taking a bath someone must be with him or nearby and checking on him every minute or so to keep him from drowning. He cannot get his head back above water if he slides down in the tub.

Issues to be resolved/Questions to be answered

Where people cannot agree on something or where the information is not available, the issue is listed here. This heading is used during meetings to "park" issues on which discussion is not leading to resolution. At the end of the meeting these issues are revisited and where resolution is achieved they are moved to other sections. Where they remain unresolved or unanswered they are listed in the plan. A wide variety of questions or issues may be listed. The examples that follow are intended to illustrate the range of issues that may be found.

Can the teacher who reportedly liked "Dan" when he was in school 5 years ago be found?

There is information in "Bill's" past that he has hit and kicked people, is this still an issue?

We know that it is important for "Jane" to be involved in selecting her staff, how can we make that happen?

"Susan" has been taking high doses of psychotropic medications for the past 11 years, can the dosage be safely reduced?

Concerns

Issues that need to be addressed that relate to keeping others safe can be described here. It is important that they not be presented simply as labels but as descriptions of the issue and how others need to address it. This section can be used to address a wide range of issues raised by people do things such as injuring others, engaging in unlawful behavior, and destroying property. This section of the plan should identify what the person does, how you can help the person to avoid doing it, and what you should do if it happens.

Example -

When "Steve" gets angry he may strike out at people or break things. He is a strong person and can hurt people. He has kicked, punched, bitten, and pulled people down by their hair. He has thrown things and broken radios, furniture, and walls. While we have not learned how to prevent every episode, we have learned that:

Steve is most likely to get angry when he is confused or frustrated

The people who support Steve must understand what he is saying with his gestures and his sign language;

Only 1 person at a time should tell Steve what needs to be done and/or give explanations;

When talking with Steve, give him time to think before you expect him to reply; and

When asking Steve to do something, give simple, clear directions and give him time to complete them.

Steve needs to be appreciated for the things that he does, let him know by thanking him when he helps and by praising work that he does well.

Steve does not like to be told no. If Steve is doing something he should not be doing and/or should be doing something else, just let him know what he should be doing.

Steve needs things to look forward to and does not have a good sense of time. Remind him of things that are going to happen soon (within the next week or 2) that you know that he will really enjoy. Use a calendar to help him understand when they will happen.

If anything that Steve is looking forward is going to be canceled or to needs to be rescheduled, make sure that Steve understands why it will not happen and that he has something else to look forward to.

If Steve gets angry anyway -

Give him space! Back off, support him to be in a room by himself, encourage him to go to his own room or get everyone else out of the room he is in.

Once he has space, give him time to calm down on his own, without comments or suggestions (2 5 minutes is usually sufficient).

If he continues to strike out at other people or if you are worried that he will hurt himself, get help. Once or twice a year physical restraint has been needed to keep other people safe. Keep in mind that this usually means that you did not think things through. Anytime you have to resort to restraining Steve look back at what happened and determine if anything could have been done to avoid his being angry and/or to avoid his being restrained.

Steve forgets his anger quickly, be ready to smile and forget as quickly as he does.

Steve has learned that being angry gets him out of places that he does not want to be. Anyone that is going to support Steve needs to know how to help him deal with his anger and needs to be prepared to "ride out" some anger as Steve tests them.

Dreams a picture of what I want in the future

Essential lifestyle plans are a snapshot of how someone wants to live now. Dreams of a desired future that is further away than tomorrow may not be elicited or recorded unless an effort is made. Where people have dreams of how they would like to live the dreams must be recorded and efforts made to work toward helping people get them. The question for those developing ELPs is whether it is better to describe the vision of a desired future under the headings that describe what is important, under a heading that says "dreams a picture of what I want in the future", or to use another planning format. Facilitators and reviewers need to consider whether or not using a another planning format such as personal futures planning or PATH would yield a better picture of a desired future and/or do a better job of mobilizing the resources needed to get the desired future. Facilitators and reviewers need to remember that the goal is to help the person get the life that they want, not to develop beautiful plans. Facilitators should use what works. A plan that combines elements of an essential lifestyle plan and a personal futures plan (or PATH) is preferable if it works better to get the person a desired life.

While dreams must be acknowledged and efforts made to support them, those developing plans should remember that most people's first dream is to have a life that reflects what is important to them. Most people want and need some control over their lives (and some life experiences) before they have their own dream of a future that is more distant than tomorrow. For these people the section on what is important to them describes their immediate dream. Building a vision of a better and more distant future for these individuals can be safely and powerfully done only if they have a number of people in their lives who truly know and care about them and a skilled facilitator. For example, skilled facilitators of personal futures plans mobilize the people who are already present into a circle of support and build a vision of a better future using the collective knowledge and energy of the circle. The dangers arise when either the circle of committed, knowledgeable people is absent or where there is a less skilled facilitator. With either of these conditions absent it is easy to have a quest for dreams to turn into a guided fantasy. Those who do careful planning guard against this, those who do not often have their own dreams turning up in the plans of others.

Things that we think are important and need to know or do (even if the person does not agree)

This section has been used to make it clear that there are things that we need to insure even when the focus person does not agree. This heading has been particularly helpful for staff who are still learning to separate what is important to the person from what is important to them. Where it is used it may replace the "what we need to know or do" heading. Some examples follow -

"Bill" must take his medications, as prescribed, to maintain good health.

"Bill" must use his safety belt when he is using his wheelchair, shower chair, or commode chair.

Remember that "bill" lives to please staff. He will often agree/go along with staff ideas even when he does not agree. Double check with him when he agrees with something that seems to be in conflict with what is important to him.

Other issues in developing and reviewing plans

Looking beneath the surface

Good plans describe what is important to someone, best plans look beneath the surface and identify the underlying themes. If you review what is important to a person you can see how items can be grouped to communicate more powerfully. As items are grouped they should be considered to see if they begin to identify a theme for the person. By "theme, we are not referring to a "cookie cutter. arrangement of items around the areas of importance listed on page 1, themes should reflect and organize what is important to the person. This may be an abstract idea such as the need for control or something very concrete such as issues around food. The best plans not only describe the present but also allow you to predict what someone may like and how to support someone in a new situation. They do this because they have identified the core values for people that will transcend where they live, that will run through the person's life.

The importance of helping people have opportunities

Good plans describe what is important to a person now and what we need to know or do to help the person get what is important to them. Best plans suggest what opportunities the person might like to have, what the person might like to try. In developing plans you should ask: What opportunities should be present so that the person can continue, to grow and continue to discover what they like (and do not like)? Where it is clear that the person would like to try new things it is easy to add them to the part of the plan that talks about what is important to the person (e.g. things I would like to try). Where people have had limited life' experiences, this can be more challenging. They might not know what they would like to try. In these instances what we think they might like should be listed under the section of the plan that describes what we need to know or do. In either instance simply listing them is not sufficient. What is going to be done to give the person the opportunity to try them must also be described.

Helping people learn, the role of teaching

In doing essential lifestyle plans the focus is on what people want and how to help them get it. This means that teaching a skill simply because it was the next skill in a developmental hierarchy is no longer warranted. People should be learning what they want to learn. We should look for the skills that will help people get what is

important to them (making sure that they are really needed within the environments that they would be used) and then see if the focus person is willing to learn the skill. If not, we should find another way to support the person. This kind of learning is often implicit in the plan as people learn by doing (with support). However, it is acceptable, and often preferable, to explicitly list and describe what we are going to help people learn. This increases accountability and also makes it easier for a reviewer to assess whether the learning proposed has occurred. Where what people are going to learn is explicit it can be listed under its own heading.

The use of graphics

Anything that makes a plan more accessible to the focus person or that makes a plan communicate more powerfully should be encouraged. One of the limitations of essential lifestyle

planning is that it is often difficult for people who do not read to understand their own plan. Computer graphics and/or hand drawn pictures can help the focus person understand the plan and should be used where ever they provide that assistance. However, graphics that are added simply because the facilitator has access to a graphics program should be discouraged. The goal is have a document that communicates. powerfully. Graphics that are merely decorative detract from the communicative power, graphics that help people understand what the words mean increase the communicative power.

Whose voice to use

One of the abuses of person centered planning that can be found with distressing frequency is to change traditional plans from third person to first person and call the result a person centered plan. These plans then have statements that are both silly and offensive, such as "If I become angry I may need 4 point restraint." In developing essential lifestyle plans things that are important to the person may be stated in first or third person. Statements about things that are important to those who support the person should only be stated in third person.

The plan is a means not an end

Those developing and reviewing plans need to remember that the plan is a tool, it is a way to help people get the lives that they want. Reviewers of plans should take an interest in what is being done with the plans that they review. Planning creates expectations among all participants.

Planning without real implementation breaks an implicit promise made to the participants.

Planning without implementation hurts the focus person and damages any trust that the person had in those who participated.

Planning without implementation increases cynicism about person centered planning and person centered services among all of those associated with the focus person.

Planning without implementation hurts the organizations that support the focus person. It contributes to a culture of mistrust and disempowerment.

The intent of this document is to help reviewers determine whether or not plans meet criteria as "good" or "best. plans. There is an assumption that good outcomes for the people that we plan with are more likely if we have good plans. However, experience has shown that good planning can occur without any implementation. The authors would like to ask that everyone involved remember that, any effort that helps people with disabilities have the lives that they desire is acceptable, while good plans that are not implemented are unacceptable.