

Families Planning Together: Starting Work on an Essential Lifestyle Plan

This manual belongs to:

_____ 's family.

It contains confidential information.

Please do not read it without their permission.

4th Edition
Developed by
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A Note

This manual may only be reproduced by those who are working on the development of a plan for a family member. Those who wish to reproduce it for other purposes should seek permission from the ELP Learning Community.

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Adapted from
Your Personal Passport
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Listen to Me!
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Reviewing Essential Lifestyle plans: Criteria for Best Plans
by Michael W. Smull, Helen Sanderson, & Susan Burke Harrison

Planning for Yourself
by Michael Smull and Bill Allen
with support from Michigan Department of Community Health

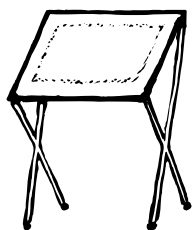


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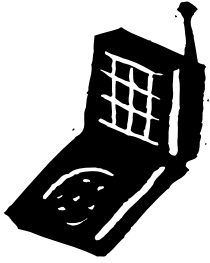
Appendix 1 - Families Planning Together: Sample Plans

Using Paul's Plan to Show How Information You Have Gathered is Organized into a Plan

Other Sample Plans

Note: This manual should be used while looking at sample plans. You can find some sample plans at <www.elpnet.net>. When you get to that website, click on **Plans**. Or, you can click on **Families Planning Together** to find a downloadable version of this manual.

Appendix 2 - A Checklist for Developing a Plan



A Message to Families

This workbook has been created to help you develop an essential lifestyle plan with your family member. You should have a copy of one or more example plans with the manual and you should have someone trained in developing Essential Lifestyle Plans working with you.

Example plans can be found on the web at www.elpnet.net. If you need help in developing your plan, try subscribing to the ELP Families list serve (see instructions below). If you need additional help, such as downloading a sample plan or you need someone to work with, contact us (call, fax, drop a note, or send an e-mail). We will send you a plan or try to connect you with someone who can help.

If you are using this workbook to help you design services for your family member, it may be helpful to think about this as an ongoing process. It has four basic parts that change as you learn more about how to successfully support your family member:

1. Discovering and describing what is important to your family member in everyday life and what other people need to know or do so that they get what is important to them while staying healthy and safe (developing a plan).
2. Using what is learned to explore how the plan could be implemented - to explore the world of possibilities and to decide what are the best options. (Making sure you get to look beyond what is available locally.)
3. To be able to make the options you select happen where you live.
4. Learning what works and what doesn't work from the things that you try.

This manual will help you with part 1. It is not designed to help with the next 3 parts. However, thinking about the other 3 parts of the process while you develop a plan is a good idea. We have found that it's important to finish the plan (part 1) before you start figuring out what the supports and/or services should look like (parts 2-4).

If you need more help than is locally available, or if you just want a chance to learn about other families' experiences, sign up for the ELP families list serve by:

1. Using your e-mail application program, create a new message;
2. In the *send to* space, type - **listproc@lists.cc.utexas.edu**
3. In the body of the message, type -
subscribe elpfamilies Yourfirstname Yourlastname
(example: subscribe elpfamilies Bill Allen)

4. You will receive an e-mail with instructions about how to use the listserv (e.g., receive digests, unsubscribe) and at the very end of the message, you will find a welcome note from Shelley Dumas (our fearless listserv leader) and Michael. You will find that message on the following page.

If you need help at any point in the process, feel free to ask. There are some exercises that we have developed that may help with figuring out what is possible (that we can send you) and there are other people who can help. You can use the list serve to ask for help as well. Keep in mind that many of the service systems out there are not very responsive to families or individuals. Your efforts to describe the services and supports that make sense for your family member will create some of the pressure needed to change the system.

Tips on using the manual

The manual is long because we want people to be able to use it with a minimum of help. One way to manage it is to:

- Put the entire workbook in a 3-ring binder and add a sample plan or two at the end.
- Pull out the checklist - Appendix 2.
- Read the introductions to each section all at once and before writing down any of your answers. This will give you an idea of how the whole process works.
- Don't feel like you have to do any part of the manual perfectly or completely. Do just enough to get a decent start (a "first" plan) and then add to it as you have time.
- Read through the example plans. Look for parts of plans that will help you with issues that you are facing and help you understand how the plan you're working on might look.
- Some parts of developing a plan may be hard or confusing, if you are not sure what to do, ask for help.
- Put a large envelope or folder in the front pocket of the binder. As you complete the individual pages in the *Information Gathering* section, check them off on the checklist and place the completed page in the envelope or folder.

This is the fourth edition of this manual. We will revise it again and would appreciate your help. Please send us feedback. Use the list serve, send us e-mails, fax, or phone us. Don't forget to tell us how it helped as well as how we can improve it.

Michael Smull, Mary Lou Bourne, and Bill Allen



Welcome to the ELP (Essential Lifestyle Planning) Families List Serve

The purpose of this list serve is to support you in developing and implementing essential lifestyle plans with (or for) your family member. If you have a question, a concern, or a comment you can post it here by sending a message to the list serve. Those on the list serve are free to give answers, suggestions, or advice. This is a place for you to get support, but it is also a place where you are welcome to give support.

Please keep in mind that this is an "unmoderated" list serve which means that anyone who is a member of the list serve can say anything they want. We do reserve the right to remove anyone from the list serve who is using it for another purpose but we do not expect that to happen. Some people who are trainers in essential lifestyle planning are also on the list serve and may be able to help with some of your questions.

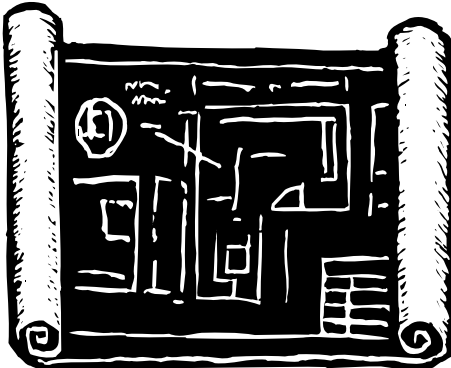
As you use the list serve there are a few things to remember -

- When you press "reply" to a message you are sending that message to everyone. (If you want your reply to only go to one person you need to enter the e-mail address of that person on a "new" message.)
- The advice, answers, and support are coming from people who are not being paid to help and what they are able to offer depends on the time that they have.
- This is a place for you to get support but please do not hesitate to offer support. Sometimes the best answers, advice, or support come from people who have had similar experiences.

We hope that this list serve gives you a place to get some of your questions answered and to have a dialogue with others who have similar issues. We also hope to be able to do more to support people over time. We will keep you informed of our progress.

Shelley Dumas and Michael Smull

P.S. If you haven't been there already, check out the material at the website <www.elpnet.net> - some of your questions may be answered by what has been posted there.



Introduction

Why use this workbook? Why write a plan with your family member? Some of the reasons why families have developed plans include:

- To help with the development of IEPs;
- To help with transition from school to work;
- To describe what parents have learned about how to help their son or daughter get what is important to them, while staying healthy and safe, as a safeguard, in case something were to happen to them;
- To help with determining what services and supports make sense and then to use the plan to ask service providers how they would deliver those services; and
- To assist in teaching others what it takes to successfully support their family member.

Think about this as a process that has 4 simple stages:

- 1. Think about what you want to learn**
- 2. Gather the information**
- 3. Develop a first plan**
- 4. Recording on-going learning and using what has been learned**

Keep in mind that you do not have to develop a “perfect” plan. You are just developing a first plan. The first plan that you develop with your family member should describe:

- What you have learned about -
 - What is important to the person, and
 - What others need to know or do to support the person

Families Planning Together: Starting Work on an Essential Lifestyle Plan

- It should be better than what you had before
- It should do no harm, in the sense of -
 - It will help to maintain and enhance existing relationships,
 - It respectfully addresses all important issues of health or safety; and
- It reflects a commitment -
 - To act on what has been learned and
 - To continue to learn.

The purpose of a written plan is to record what we have learned and describe what we are going to do with that learning. A first plan should be seen as a framework for on-going learning -

- Encouragement to write on the plan should be provided
- The plan should have built in space where the learning will be recorded
- What is written on the plan is incorporated into the plan often enough for those writing on the plan to feel that their learning is recognized and valued.
- Planning for action is based on what has been learned or needs to be learned

If you want other people to write on the plan then you need to make it “easy” to do. You not only need to make it “easy” by building in space for writing but by also leaving some “easy” learning for others to do. If you collect everything every body knows and put it in your first plan there will be nothing left to write until the person tries something new or changes their preferences. Don’t try to learn everything everybody else knows. Learn enough to create a framework in which other people can write what they know.

An exception to this “rule” occurs when you (and perhaps 1 or 2 others) are the only people who know how to support your son or daughter. Then you are going to try to write down everything important that you have learned as a safeguard. But even here you do not have to write it all down at once. Write down enough to give you a good start and create your own frame for learning and add as you remember and notice things about what is important to the person and what others need to know or do.



Stage 1

**Think About
What You Want
to Learn**

Stage 1

**Think About
What You Want
to Learn**

Think about what you want to learn

In developing essential lifestyle plans you are striving to answer 2 questions:

1. What is required for my son or daughter to be happy? and
2. Within the context of being happy, how can he or she stay healthy and safe?

These are simple questions but they have complex answers. Some of what makes us happy is dangerous or unhealthy. However, if we do not have much of what is important to us in everyday life (one definition of happiness) then we are more likely to do things that are not safe or are unhealthy. What you are trying to discover and write down is the balance needed between being happy and being safe. The balance is different for each of us, including your family member. It's important to remember that these things change over time.

Please spend a few minutes answering the questions on the following page before you start working on a plan.

What do you want the plan to accomplish?

How can the person with whom you are planning- best participate in the development of the plan?

How to make sure that the process feels respectful to the person with whom you are planning?

Who else needs to participate/agree for the plan to be implemented?

Who knows what it takes for your family member to be happy?

Who understands the issues of health or safety (if any) that your family member has?

Learning who to talk to

The easiest way to learn who to talk to is to do a simple *relationship map*⁴ with the person. On the following page, you will find one (developed by Louisa Hext and Leah Holden⁵). to complete with your family member.

You will notice that the circle is divided into four parts:

- *Family* - people who are related to the person
- *Home and supports* - paid or unpaid people, who are not family, who provide support at home or in the community
- *Friends* - people that the person sees as friends (who are not listed under home or in the community)
- *Work/School* - paid or unpaid people who provide support wherever the person spends his or her days

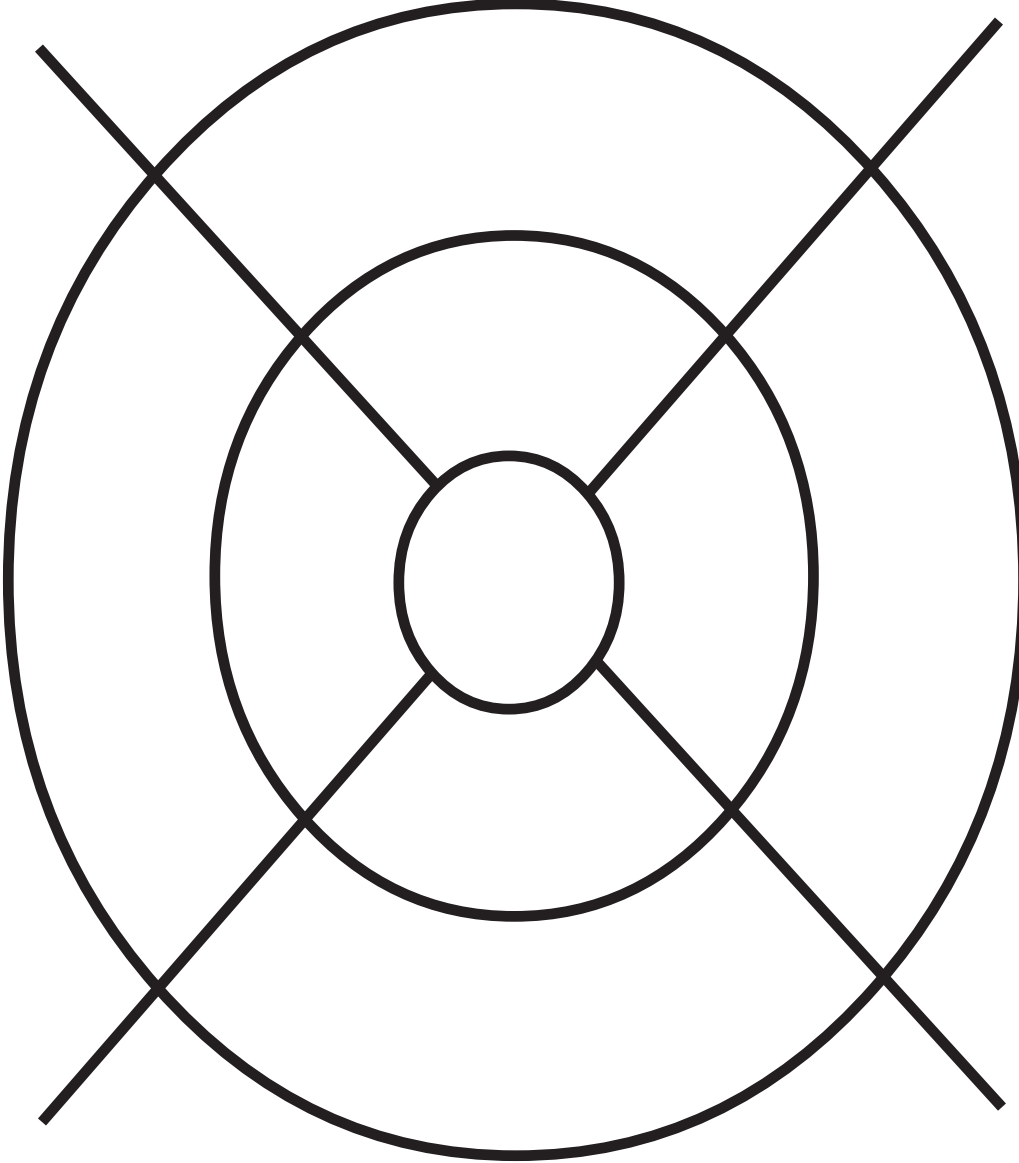
At the center of the circle, write the person's name. In the next circle write the names of those people closest to the person. Remember that these may or may not include those who spend the most time with the person, they are the people that the person feels closest to (those whom the person loves; good friends). Put those people who the person feels somewhat less close to in the next circle (friends, people the person cares about). On the outside put those people who are acquaintances, or relatives that the person does not feel close to. Paid staff may be in any of these circles. Ask how the person feels about them.

Please note that although some people have multiple roles (e.g. they are friends and are paid to provide support) they should only be listed once. The purpose of the map is to have a quick way of looking at relationships and to help you with who you should talk to (who should contribute to the plan).

⁴ For information about a more complete relationship map and other *maps* see [All my life is a circle](#) by Falvey, Forest, Pearpoint, and Rosenberg, published by Inclusion Press. They have a web site where information about their publications can be obtained (www.inclusion.com). Also look for publications by John O'Brien, Connie Lyle O'Brien, and Beth Mount.

⁵ From *It's My Life* facilitator's guide (1996).

Family



**Home
and
Other Paid
Supports**

**Work/
Day Services/
School**

Friends and Non-paid Relationships

Things to figure out

Many families have found that keeping a “running list” of any questions that come to mind (while you are developing the plan) is very helpful. Using the next page (Things to Figure Out) is one way to keep track. Some of the most common ways for people to use this list are -

- As a reminder list (e.g. Don't forget to ask ...)
- As a place to write down things that you don't understand, where you need more information
- As a place to note things that you are struggling with, where you may have written something but you are not satisfied

As you remember or as you figure things out, just cross them off this list (or delete them if you are using a computer)

Pull this list from this part of the manual and use it through out your efforts to gather information and develop a plan. Then put in the plan right after the “how to keep ... healthy and safe” section.

Things to Figure Out

What are the things that you are still trying to “figure out?” What are the things about your family member or the supports that he or she gets that you don’t understand or where you need more information? What are the things that are getting in your way?

New Things We Need to Figure Out



**Stage 2
Part One**

**Gathering
Information:
Learning From
Your Family Member**

Stage 2 Part One

Gathering Information: Learning From Your Family Member

Learning from Your Family Member

The person that you're planning is the most important person to listen to. Most professional plans have been done "for" the person. You are striving to plan "with" the person. The following material (from *Listen to Me*) will help you have a conversation that will begin to tell you what is important to the person without asking questions with built-in answers or questions which lead the person. If the person does not use words to talk, you still need to spend time with them so that you have some ideas about how they would answer these questions. After you have given each section some thought, go to the communication chart. Then continue your information gathering with "*learning from those who know the person.*"





What are some great things about you?

What are some great things about you? What do you like about who you are? What are some things you're good at? Proud of? What are things that people say when they compliment you?

What do people thank you for? This is sometimes hard for people to answer, so you might want to start by asking a friend or relative. If these questions are hard to answer, it's okay to skip them and go to the next page

Great Things About You

Look at what is written above. Consider what should be written in the plan under **Introduction: Great things about this person on page 81**. If you aren't sure, look at a sample plan for the kind of things that other people have listed.

What things do you like to do?

To help you get started on your lists, ask yourself and people who know you: What things do you like to do? Where you live? Where you spend time during the day? For fun? Around town? On vacation? At home? At school? At work? At day program?



Your List of Favorite Things

Look at what is written here. Things that are important to the person go on their plan under - **What is important to . . .** on page 83.

What things do you dislike?

What are things that bug you? Where you live? Where you spend time during the day? For fun? Around town? On vacation? At home? At school? At work? At day program?



**Your List of Things
You Don't Like**

Look at what is written here and think about how important it is to have these things **absent** from the person's life. If it is important that something listed be absent, put it under **What is important to . . .** on page 83.

Your Week Day

What would a great week day look like for you? What do you do when you first get up on a great week day? What do you eat for breakfast, lunch, and dinner on a great week day? How would you spend your time and with whom on a great day? What happens at night? What would be your worst week day? What kinds of things would make you mad, sad, or frustrated during your worst week day? If you feel that you don't have any "bad" days think about all of the good and bad moments you have had over the past several years. Write a list of the good moments under "great week day" and a list of the bad moments under "bad week day."



A Great Week Day Would Be



A Bad Week Day Would Be

Look at what is written here. Are there things that are important to the person noted here? List them under the **What is important to . . .** section (page 83). Look to see if there are parts of good days or bad days that depend on what other people do. Write it in the section of the plan with the heading **What other people need to know or do** (page 87).

Your Weekend

What would a great weekend look like for you? What do you do when you first get up on a great weekend? What do you eat for breakfast, lunch and dinner on a great weekend? How would you spend your time and with whom on a great weekend day? What happens at night? What would be your worst weekend? What kinds of things would make you mad, sad, or frustrated during your worst weekend? If you feel that you don't have any "bad" weekend days think about all of the good and bad moments you have had over the past several years. Write a list of the good moments under "great weekend day" and a list of the bad moments under "bad weekend day."



A Great Weekend Would Be



A Bad Weekend Would Be

Look at what is written here. Are there things that are important to the person noted here? List them under the **What is important to . . .** section (page 83). Look to see if there are parts of good days or bad days that depend on what other people do. Write it in the section of the plan with that heading **What other people need to know or do** (page 87).

What Kinds of People Support You Best?

To do this, first take a look at your People Map on page 16.

- Who is closest to you in your “people map”?
- Who helps you have good days?
- Who do you enjoy spending time with?

Take a look at who these people are and write the “personality” characteristics that they have in common. The list of characteristics goes in your plan under the heading **Characteristics of people who support you best.**

Look at the map again.

- Is there anyone that you dislike, that you try to avoid?
- Is there anyone who can make you have a bad day just by being around you?

Take a look at who these people are. Are there “personality” characteristics that these people have in common? These are the characteristics that need to be absent when you are looking at who should help you. Write what you learned under the heading in your plan called **Characteristics of people who support you best** (page 85 of *Your First Plan*).

Are there people who have different jobs/roles (for example, teachers, support coordinators) who help you have fun?



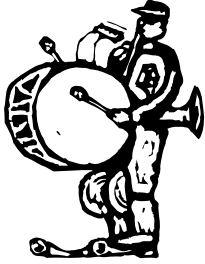
Stage 2

Part Two

Gathering Information: Learning From Those Who Know the Person

Stage 2 Part Two

Gathering Information: Learning From Those Who Know the Person



Some Thoughts About Talking to People Who Know and Care

Introduction

Before you begin to have conversations with people who know and care about your son or daughter, you should have some ideas about what you need to learn. For example, you want to learn:

Who and what is important to your son or daughter -

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.

Who to talk to first

Many of you do not have time to talk to everyone and no one talk to everyone at once. Look at your "people" or relationship map" and ask yourself -

"Who knows what is important to my family member?"

"Who else knows what is important for my family member?"

Among those people, who should you ask for information to get a good first plan? A first plan just needs to have enough information to tell people the basics about what they need to know and creates a framework for more learning. Make a list of those people in the 'map' on page 16 and then answer each of the following questions for each person.

For each person:

- **What are they likely to know?** Do they spend enough time with the person to know what a good day or a bad day is like? Do they know about the entire day or just part of the day? Do they know about what holidays or birthdays are like? Are they people who have known him or her for a while but he or she really don't spend a lot of time with them?

- **What information gathering pages should you use with them?** Read through all of the information pages before you decide which ones to use. Ask everyone to fill out the first 2, “individual interview form” and “unlimited power questions” and then look at which ones would make the most sense to get from which people:
 - Individual interview form
 - Unlimited power questions
 - Some great things?
 - What things do you know that I like?
 - What things do you know that I dislike?
 - A week day
 - A week end
 - Positive rituals?
 - How I communicate?
- **Think about how to get the information from the person. What way would be the most effective and time efficient? Should you:**
 - Give the person blank sheets and ask the person to write down their answers to the questions?
 - Interview the person?
 - If an interview -
 - One at a time?
 - Small group?
 - On the phone?
 - Information gathering party (where people would write answers on flip chart paper on the wall, with conversation)?

Summarize what you learned about who to talk to using this form

<p>Name</p>	<p>How to get the information -- a conversation, ask individuals to write down the answers, a group discussion, a party or gathering</p>	<p>What does this person know? Which information gathering pages to use: Page</p> <p>Individual interview form Unlimited power questions What are some great things about me? What things do you know that I like? What things do you know that I dislike? A week day A week end Positive rituals? Staying Healthy and Safe? How I communicate?</p>

Listening to others

Each person you talk to will have important contributions to make and most will become important participants in your son or daughter's plan, if you remember to:

Listen with respect to what each person has to say, and the concerns that they have about your son or daughter's future;

Keep them informed and solicit their participation throughout the planning process; and,

Where there are disagreements or challenges, enlist their participation in problem solving.

As you talk with people you need to help them articulate their concerns as specifically as possible. The more general the concern the more difficult it is to address. For example, if someone tells you that they think that your son or daughter is vulnerable and they are worried about safety, try to find out as much as you can about what this means.

Remember, this is a conversation and not an interview

While you should think about what you want to learn you must be prepared to learn things that you did not anticipate. If you just have an interview (by asking a set of prepared questions) you will learn only what you expected to learn. If you have a conversation (and listen carefully) you will learn things that are important and that no-one suggested in advance. In each conversation you want to avoid:

Questions that are close ended. Questions whose answer is yes or no (e.g. Does my daughter seem easy to get along with?) and questions whose answer is one or the other (e.g., Do you see my son living in a house or an apartment?).

Questions that have a built in answer (e.g. Would my son benefit from having more opportunities to make friends?). Keep in mind that some of the built in answers are a bit more subtle, they come with a head nod, a change of inflection, etc.

Questions where people who are eager to please simply look to you for the answer.

A few questions like these are nearly unavoidable in the course of a conversation but there are at least three ways to avoid having the whole conversation revolve around these kinds of questions. These 3 ways of having conversations are: linear, branching, and meandering.

Linear

A linear approach is the easiest way to have a conversation without asking

leading questions. For example, When my son is at school, what does he like to do first? And, next, what does he like to do? Try to get the person you are talking with to tell you stories that illustrate what they mean about your son or daughter.



Branching

A branching approach starts in the same way, walking through time and 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 your son or daughter's life. The result is a conversation that branches from one point in time and then meanders a bit until that line of conversation ends. At that point you go back to where you were in time when the branch started. For example, if the branch started with break time on the job and wandered off from there, at the end of that branch you would ask "and what happens after break time?"

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 what is important to your son or daughter's life. Having a meandering conversation requires that you keep the conversation moving and cover all the areas in the time that you have. You must have a mental map of what you want to learn, while always listening for the unexpected.

Who to listen to versus who to talk to

Take a look at the questions on the next pages⁷. They will give you an idea of who to listen to ("talking to people who know and care an individual interview") and what to ask (unlimited power, best/worst days and positive rituals). The questions about how long you have known the person and how much time is spent with the person tells you if the individual you are interviewing has spent enough time to know the person. The questions about "like, admire" and "fun" tell you if the individual you are interviewing has a personal connection with the person. If the individual you are interviewing does not have a personal connection with the person then they do not have the kind of information that you are looking for about what is important to the person. Those individuals who spend no real time with the person do not have the kind of information that you are looking for. However those who spent significant time with the person in the past and had a personal connection may have important information to add.

⁷ Use common sense as you ask the questions. Don't ask questions when you already know the answers. Where people can't "walk" through time, think of other ways to get the same information.

As you decide which individuals to, listen to you need to decide what to ask them.

- Those who spend some time with the person but not enough to be able to tell you about best days or worst days (or at least parts of them) should be asked the “unlimited power” questions. Check to see if they know the answers to one or more of the positive rituals questions.
- Those who spend consistent time with the person should be asked the unlimited power questions and then “walk” through the time that they spend with him or her using the best/worst day format. Check to see if they know the answers to one or more of the positive rituals questions.

We have provided three copies of the conversation guides for you. Please don't be limited by these copies, feel free to make extra copies, use e-mail, or handwrite your own if you need them.

Talking to People Who Know and Care: An Individual Interview



Name of the Person Interviewed:

What is the relationship to my son or daughter?

How long have you known my son or daughter?

How much time do you typically spend with my son or daughter?

What do you like the most about my son or daughter?

What do you admire the most about my son or daughter?

When was the last time you had fun together, what did you do?

Other Notes:

Look at what is written here. Should some of this information be included under the section called **Introduction: Great things about this person?** on page 81. Does the information give you ideas about what to include under **What is Important to . . .?** for page 83.

Unlimited Power Questions

If you were given unlimited power, authority and money and you were asked to help my family member have a great day and/or a great week-

What would you do?

What would the day/week be like?

To help us learn what people shouldn't do and what should be absent from the person's life, what would make my family member have a really awful day/week? What would happen?

What would the day /week be like?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Two Minute Drill

Imagine that you are supporting my family member and you have an emergency that means you suddenly have to leave. The person who will “fill in” has arrived and you have two minutes to give advice, suggestions, or tips about supporting my family member. What would you say?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Talking to People Who Know and Care: An Individual Interview



Name of the Person Interviewed:

What is the relationship to my son or daughter?

How long have you known my son or daughter?

How much time do you typically spend with my son or daughter?

What do you like the most about my son or daughter?

What do you admire the most about my son or daughter?

When was the last time you had fun together, what did you do?

Other Notes:

Look at what is written here. Should some of this information be included under the section called **Introduction: Great things about this person?** on page 83. Does the information give you ideas about what to include under **What is Important to . . .?** for page 87.

Unlimited Power Questions

If you were given unlimited power, authority and money and you were asked to help my family member have a great day and/or a great week-

What would you do?

What would the day/week be like?

To help us learn what people shouldn't do and what should be absent from the person's life, what would make my family member have a really awful day/week? What would happen?

What would the day /week be like?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Two Minute Drill

Imagine that you are supporting my family member and you have an emergency that means you suddenly have to leave. The person who will “fill in” has arrived and you have two minutes to give advice, suggestions, or tips about supporting my family member. What would you say?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Talking to People Who Know and Care: An Individual Interview



Name of the Person Interviewed:

What is the relationship to my son or daughter?

How long have you known my son or daughter?

How much time do you typically spend with my son or daughter?

What do you like the most about my son or daughter?

What do you admire the most about my son or daughter?

When was the last time you had fun together, what did you do?

Other Notes:

Look at what is written here. Should some of this information be included under the section called **Introduction: Great things about this person?** on page 83. Does the information give you ideas about what to include under **What is Important to . . .?** for page 87.

Unlimited Power Questions

If you were given unlimited power, authority and money and you were asked to help my family member have a great day and/or a great week-

What would you do?

What would the day/week be like?

To help us learn what people shouldn't do and what should be absent from the person's life, what would make my family member have a really awful day/week? What would happen?

What would the day /week be like?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Two Minute Drill

Imagine that you are supporting my family member and you have an emergency that means you suddenly have to leave. The person who will “fill in” has arrived and you have two minutes to give advice, suggestions, or tips about supporting my family member. What would you say?

Look at what is written here. Is there information that should be included under the section called **Important to . . .?** or **What Others Need to Know and Do to Support . . .?**

Gathering More Information About Your Son's or Daughter's Lifestyle



What are some great things about this person?

What are some great things about your son or daughter? What do people like about him or her? What do other people like or admire about your son or daughter? What are some things he or she is good at? proud of? What are some nice things that people say about this individual? These are important things to think about when you are figuring out the kinds of supports and services your son or daughter might need. Ask these questions of people that have demonstrated they really care about your family member.

Great Things About This Person

Look at what is written above. Consider what should be written in the plan under **Great Things About This Person** on **page 81**. If you aren't sure, look at a sample plan for the kind of things that other people have listed.

What things do you know that he or she likes to do?

To help you get started, you might ask your son or daughter and the people who know him or her best:

What things does he or she like to do? at home? at work? at program? at college? for fun? around town? on vacation? What kind of music does he or she like? What kind of movies? What kind of food? How about hobbies?



Things You Know That He or She Likes to Do

Look at what was written here. Things that are important to the person go on the plan under - **What is important to . . .** (page 83).

What things do you know that he or she dislikes?

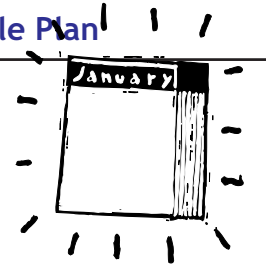
What are things that you know bug this person? Where he or she lives? Where he or she spends time during the day? For fun? Around town? On vacation? At home? At school?



**Things You Know
That He or She Doesn't Like**

Look at what was written here and think about how important it is to have these things **absent** from this person's life. If it is important that something you have listed be absent, put that under **What is important to . . .** (page 83).

The week day



What does your son or daughter's Monday through Friday morning look like right now? What does he or she do when first getting up? Eat for breakfast? Leave for work? Next, what would be his or her best Monday through Friday morning? If it could be anything, what would it be? Finally, what would be the worst Monday through Friday morning? What kinds of things make him or her mad, sad, frustrated in the morning? What kinds of things bug him or her when first getting up?

What does the day look like, Monday through Friday, right now? What happens when first getting to work or program? What kinds of work or activities occur now? Next, what would be the best Monday through Friday day? If anything, what would it be? What kinds of activities make him or her happy? With whom would he or she do these things? Finally, what would be the worst Monday through Friday day? What kinds of things make this individual mad, sad, or frustrated during the day? What places (or people) would he or she like to stay away from?

What does night time, Monday through Friday, look like right now? What happens when first getting home? What's for dinner? What kinds of activities? Next, what would be a best Monday through Friday night? If anything, what would it be? What kinds of activities make this person happy? With whom would he or she do these things? Finally, what would be the worst Monday through Friday night? What kinds of things make him or her mad, sad, or frustrated during the evening?

Do not do all of a typical day, then a good day, then a bad day. Take 'horizontal' slices of time - what is a typical, good, bad, morning like.

Your Notes:

What did you find out?➔



Best Week Day Would Be

When first get up



Week Day Right Now

When first get up



Worst Week Day Would Be

When first get up



Best Week Day Would Be

During the day



Week Day Right Now

During the day



Worst Week Day Would Be

During the day



Best Week Day Would Be

At night



Week Day Right Now

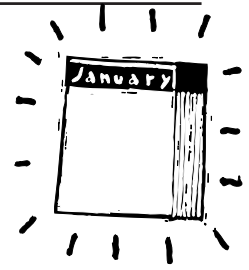
At night



Worst Week Day Would Be

At night

The weekend



What does Saturday and Sunday morning look like right now? What happens when he or she first gets up? What time is it? What does he or she eat for breakfast? Next, what would be the best Saturday and Sunday morning? If anything, what would it be? Finally, what would be the worst Saturday and Sunday morning? What kinds of things make him or her mad, sad, or frustrated in the morning?

What does Saturday and Sunday look like right now? What kinds of activities occur now? Next, what would be the best Saturday and Sunday? If anything, what would it be? What kinds of activities make this individual happy? With whom would he or she do these things? Finally, what would be the worst Saturday and Sunday? What kinds of things make this person mad, sad, or frustrated during the day? What places (or people) would he or she like to stay away from?

What does Saturday and Sunday night look like for him or her right now? What's for dinner? What kinds of activities? Next, what would be the best Saturday and Sunday night? If anything, what would it be? What kinds of activities make him or her happy? With whom would he or she do these things? Finally, what would be the worst Saturday and Sunday night? What kinds of things make this person mad, sad, or frustrated during the evening?

Again, remember not to take a whole, typical Saturday or Sunday. Take pieces of time and ask for the typical, best and worst version of it.

Your Notes:

What did you find out?➔



Best Weekend Would Be

When first get up



Weekend Right Now

When first get up



Worst Weekend Would Be

When first get up



Best Weekend Would Be

During the day



Weekend Right Now

During the day



Worst Weekend Would Be

During the day



Best Weekend Would Be

At night



Weekend Right Now

At night



Worst Weekend Would Be

At night

Additional information (if needed): positive rituals survey

Positive rituals ease us through our days and help us mark special occasions. For each of the following questions, include as much detail as you can. Do not be trapped by the space provided, use extra sheets of paper. Remember that the more physical assistance someone needs and the less they are able to talk about their support needs, the more detail is needed for the positive rituals and routines. Positive rituals that detail intimate personal care can be part of someone's "private" plan that you only show certain people.

1. List some of your son and daughter's daily rituals. Pay particular attention to the beginning of the day and the end of the day rituals. Each of us have specific activities that we do every morning including whether we brush our teeth before bathing, during our shower, before we leave the bathroom, or after breakfast, that comprise our morning rituals.

List morning (getting up) rituals -

List nighttime (going to bed) rituals -

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- 2. List some of your son or daughter's rituals of transition - What does he or she do everyday when arriving at work, school or training? When arriving home from work, school or training? What helps him or her ease into the next activity?

List arriving at work, school or training rituals -

List arriving at home rituals -

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3. List some of your son or daughter's weekly rituals -

List Sunday rituals (if there are a couple of different ways, list them all)-

List any regular weekly rituals (friends that are always visited, TV shows always watched) -

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4. List some of your son or daughter's rituals of celebration and comfort -
Indicate how he/she likes to celebrate when something good happens.-

Indicate how he/she comforts him or herself when something unpleasant happens.
How does he/she make him or herself feel better?

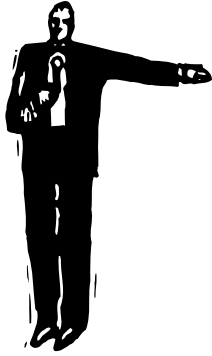
5. List some holiday rituals -

What has to happen for the person to feel like his or her birthday is being celebrated?

What foods have to be on the table at which holidays?

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What does he or she have to do during some holidays (e.g., go look at the Christmas lights, lighting the menorah for Chanukah)?



Listen to Me Communicate

This part of the manual is designed to support people who do not use words to talk, or who have difficulty in communicating with words. This section is also 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.

The heading **what is happening** describes the circumstances that seem to affect what the person does. For example, it could be the place, the people around, or the activity that affect someone's behavior. The heading **(person's name) does** describes what the person does in terms that are clear to a reader who has not seen it and 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 one 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.

The following pages have some examples to help you get started.

What is happening	KD _____ does this	We think it means	And we should
KD approaches a man	<ul style="list-style-type: none"> Leans her body into his Appears to try to kiss his face 	She would like to have a relationship	<ul style="list-style-type: none"> Freak out (Mom) Encourage her to shake his hand Look for ways for her to develop a relationship
When music with singing is playing on radio or TV	KD squinches her face and makes humming noises	I'm singing	Sing with her Tell her you enjoyed her song



It's easiest to start with what the person does, then move on to what we think it means and then outward to what is happening and we should.

What is happening	<u>Katherine</u> does this	We think it means	And we should
KD is eating	<p>Turns her head to the side</p> <p>Hands you her spoon</p> <p>Makes "The Mouth"</p>	<p>Wants no more food</p> <p>Feed me</p> <p>I need to burp</p>	<p>Put the food away</p> <p>and we do</p> <p>Wait until she has burped or belched before she eats more</p>

What is happening	_____ does this	We think it means	And we should

What is happening

_____ does this

We think it means

And we should



Stage 3

Developing a First Plan

Stage 3

Developing a First Plan

Using what you have learned to write a first draft

Keep in mind that you do not have to develop a “perfect” plan. You are just developing a first plan. The first plan that you develop with your family member should describe:

- What you have learned about -
 - What is important to the person, and
 - What others need to know or do to support the person
- It should be better than what you had before
- It should do no harm, in the sense of -
 - It will help to maintain and enhance existing relationships,
 - It respectfully addresses all important issues of health or safety; and
- It reflects a commitment -
 - To act on what has been learned and
 - To continue to learn.

The purpose of a written plan is to record what we have learned and describe what we are going to do with that learning. A first plan should be seen as a framework for on-going learning.

Look at everything that you have learned as the source material you need to write up the plan. Pull out the folder with all of your gathered information. Use the checklist found in Appendix 2. Begin with the questions about Stage 1 and Stage 2. If you have at least 4-6 boxes checked, you are ready to write your first draft. Go through everything that has been written. Use a highlighter (or whatever works for you) and highlight those things that will go in the various sections of the plan.

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Decide whether you are going to use the computer template for writing essential lifestyle plans or the paper version in this workbook. If you use the template you can ignore the paper version.

Whether or not you are using the template or the paper version, work on one section at a time. Using the checklist found in Appendix 2 (Developing A First Plan), work your way through all of the information gathered.

The sequence that we suggest for completing the information follows. However, if you think of something that goes in a section different from the one you are writing, go ahead and write that down in the section where it goes in before you forget. Also, as you are writing you will think of other things you need to learn, people you need to talk with, and things you want to figure out. Use your "**things to figure out**" list as a running list. Finally remember that this is a first draft. Don't worry too much about whether or not you have it in the correct section or if you have said it the right way. Just get it written and then worry about how it looks in the next draft.



Getting started with writing your first plan

- **The initial plan date is today.**
- **If you like, you can finish this cover page after you've finished the other parts of the plan.**
- **Purpose of the plan**
Look at what you wrote in the think before you plan section and describe the purpose of the plan here
- **People who helped with this plan?**
Who was already interviewed or is going to be interviewed for this version of the plan. Note their names.
- **Who do we still need to talk to?**
Who will be interviewed for future versions of the plan? If you have some people in mind, write their names here.

_____’s Plan	
--------------	--

<u>Date of the 1st plan</u>	
<u>Dates the plan was changed</u>	

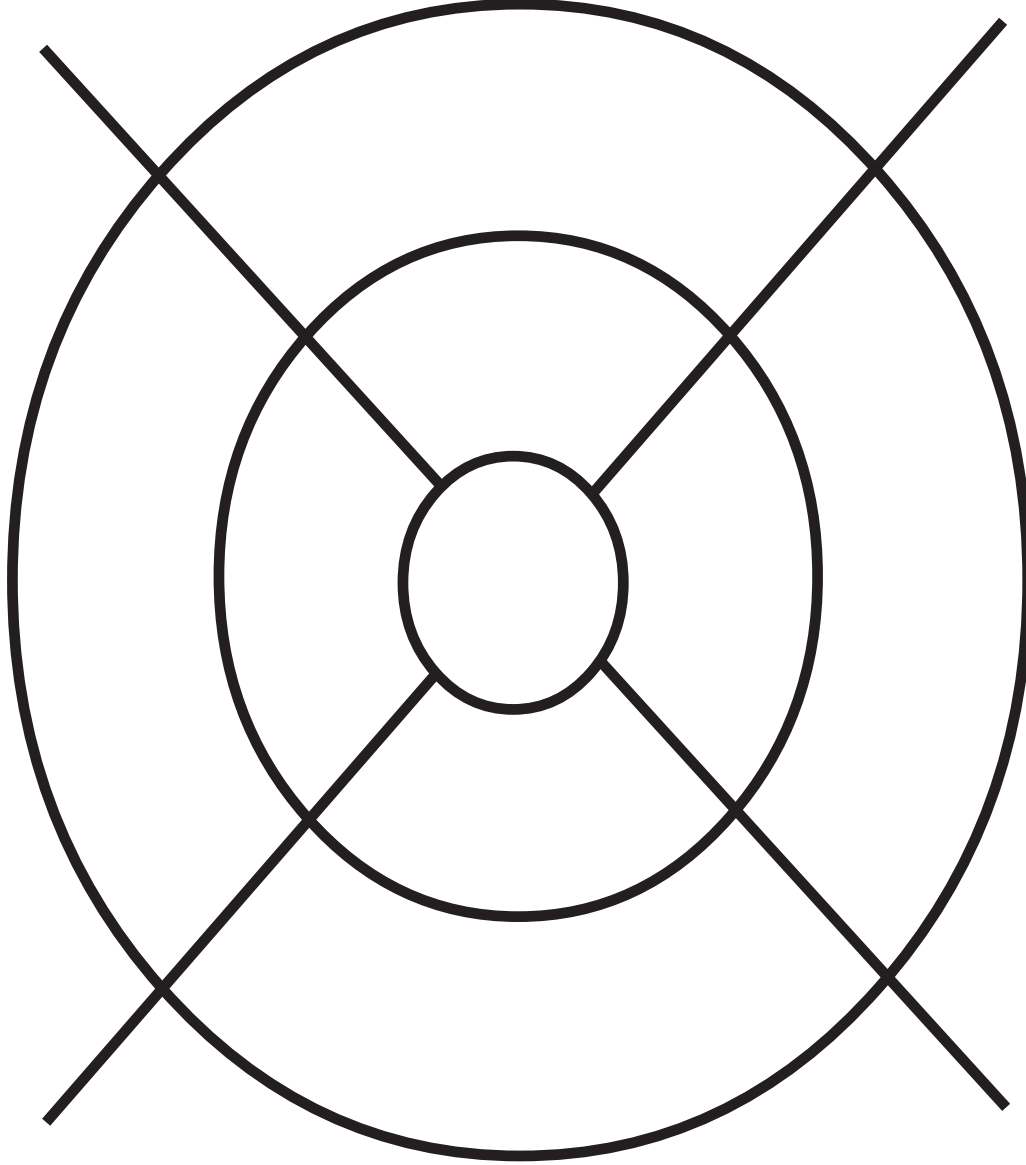
<u>What do you hope that this plan will help you accomplish?</u>
--

<u>Who helped you with this plan?</u>	<u>(Who gave you information?)</u>
•	•
•	•
•	•
•	•

<u>Who do you still need to talk to?</u>	<u>(Are there others who can help you get more information?)</u>
•	•
•	•
•	•
•	•

Take the people map that you did (page 16)
and put it here in your plan

Family



**Home
and
Other Paid
Supports**

**Work/
Day Services/
School**

Friends and Non-paid Relationships

Building the Introduction - Great things about this person.

Look at the answers to the questions regarding:

- What do you Like the most and Admire the most (pages 37, 40 and 43) and
- Great things about the person (pages 23 and 48.)

Keep in mind, this section introduces your family member to new people in his or her life. It should list things we might like or admire about anyone of roughly the same age. It should not include words that we only say about people with disabilities. It should not include faint praise. To test if information belongs here, ask yourself “would I use these words to introduce a friend or a neighbor?”

Looking at the information you’ve gathered, record the answers here, using one or two word phrases, or descriptive language. If you have a lot of information, group it into similar thoughts, separated by several spaces.

As you write other sections of the plan, keep looking for things to add here.

Introduction - Great Things About This Person

What do people like and admire about this person? What are the good things they say about him or her? How would he or she like to be introduced?

--

<p>New Things We Have Learned</p>
--

Building the “What is Important to ...” Section

This section should include what your family member considers important in

- Relationships
- Things to do
- Places to spend time
- Rhythm or pace of life
- Rituals or routines

When developing this section, keep in mind it is your family member's perspectives on what is important TO him or her, not what others think SHOULD be important to him or her. There is a place for that information later in the plan. Here, you want others who provide support to gain an understanding of what really matters to your family member.

Look at the person's relationship map. Ask yourself who is important to the person. Where there are natural groups of people, list them. (For example, Family, then list their names, or Friends at School, then name them.) You do not have to list everyone, just those that you would want other people to know about.

Look at the answers to:

- Favorite things - **pages 24 and 49**
- What you don't like - **pages 25 and 50**
- Good and bad Days - **pages 26-27, 51-58**
- Positive rituals - **pages 59-64**

Ask yourself, what do these sections tell you about what is important to your family member. Record it here. Don't forget to put what needs to be absent from the person's life (what they dislike) as well as recording what they like. If there is a natural group of information, such as “things to do with friends” record it that way, and separate the information from other information with a space or blank line.

Look at the answers to the Unlimited power questions on **pages 38, 41 and 44**. Ask what the answers tell you about what or who should be present or absent from the person's life. What does this tell you about what is important to him or her? Look for agreement among the people that you interviewed. Where there is agreement, you can feel comfortable that the information is probably an accurate reflection of the person's life.

Finally, ask yourself if there are other people you need to talk with in order to complete this. What is the easiest and best way to get the information? Write yourself a note or record it on **page 33**.

What is important to this Person

What do you want other people to know about the things that are important to your family member? Who are the people that are most important to him or her? What do they do with them? What are the things that this person has to do (and things he or she needs to have) to be happy?

New Things We Have Learned

Building the "Characteristics of People who Support this Person Best" Section

Look at the characteristics you recorded on page 28. If the list is general characteristics, record them here.

Consider if different roles in your family member's life require different characteristics. If so, be sure this is clear. For example, someone may have these distinctions

Personal Care Assistant

- Gentle
- Kind
- Respects my privacy

Tutor

- Firm
- Sets clear limits with kindness
- Focused
- Consistent

What are the characteristics of people who support this person best?

If you were going to pick a new person to work with your family member (e.g. case manager, staff in a home) what would you look for? What do the people that he or she likes to work with have in common? Have there been people that he or she couldn't work with? What do they have in common?

New Things We Have Learned

Building the “What Other People Need to Know or Do to Support . . .” Section

Go back through what you have noted about what is important to the person, and ask yourself “What does my family member need other people to know about this? AND, What does my family member need other people to DO to make sure this is present in his or her life?”

Look again at the rituals and routines information on **pages 24-26, 49-50 and 51-58** and the Positive Rituals - **pages 59-64**. If the person requires a lot of assistance to get things done and can’t tell people how they prefer it to happen, record those details here. If things like the order, or a particular brand really matter, record it here. This is also where you can record what the person dislikes, and how others can help him or her to cope with situations where the least favorite thing must occur anyway. (For Katherine, she doesn’t like brushing her hair, but there are ways to help her cope while it happens.)

This is where what is important FOR the person can be recorded. As parents or family members, this is where you get to record the things you feel are important for your son or daughter.

Sometimes what others need to *KNOW* is not enough. Make sure you also ask, “What do others need to *DO*” to make sure this happens? For example, it is not enough to know that Karrie gets upset if small children are running near her. People must know what they should *DO* to make sure she isn’t in this situation, or what to do if she suddenly is near small running children.

While none of us live in an ideal world, most of us can successfully stay away from things we greatly dislike. People with disabilities often lack the control over their day to day life to assure this for themselves. Therefore, be sure to include what others need to *do* to prevent unpleasant things from happening, or what they should do to make sure that those things your family member becomes greatly distressed over happen as few times as possible (or not at all if possible).

**What Others Need to Know
or Do to Support the Person**

If the person is going to have the things that are important to him or her, what do people need to know? What do they need to do? How does the person need to be supported at home, at work, or out in the community?

--

New Things We Have Learned

Building the “What Others Need to Know or Do to Help this Person Stay Healthy and Safe” Section

Ask yourself if there are health and/or safety issues that you want to make sure other people pay attention to. If so, list them, being careful to respectfully describe what people need to KNOW, and then specifically what they need to DO to keep your family member healthy and safe.

Go back and look at the answers to the last question on **pages 38, 42 and 45**. (The two minute question). See if there are any issues of health or safety that someone else has pointed out that you may have forgotten.

This section should include things that should not be overlooked such as:

- o Allergies
- o Conditions or illness for which your family member takes medications regularly
- o Concerns related to what or how the person eats or drinks
- o Where, when or under what circumstances it is okay for the person to be on his or her own (if at all)
- o If there are specific directions to follow in an emergency, or someone to contact in a crisis, list them

Any other issues of safety or health that you feel are important should be listed here.

Finally, ask yourself if there are other people you need to talk with in order to complete this. What is the easiest and best way to get the information? Write yourself a note or record it on page 33.

**What Other People Need to Know
or Do to Help This Person Stay
Healthy and Safe**

Does this person have medical conditions or mental health issues that other people should know about? Are there times when he or she needs help in managing medical or mental health?

--

<p>New Things We Have Learned</p>
--



Stage 4

Ongoing Learning

Stage 4

Ongoing Learning

On-going learning and using what has been learned

Continuing the learning and recording what you learn -

Who else needs to contribute? What is the best and easiest way to get their contribution?

Some of the ways listed below may work. Remember that you can use just one of them or combine them -

- Continue to interview people
- Send some of the information gathering pages from the manual
- Send parts of the draft plan for them to write on
- Have an information gathering party

How are you going to record the on-going learning?

People change and our understanding of them deepens over time. You need to have easy ways to record this learning or it will be lost. Think about who will be doing the learning and what way(s) of recording it will be easiest for them. To figure out the best way to sustain the learning, ask the people who helped you learn how to do this, one of the authors of this guide, or post it on the families *list serv*.

Using the plan (acting on what was learned)

The purpose of developing a plan is to help the person move toward the life that they want while addressing any issues of health or safety. For people who are not getting paid services this process can be very informal. For people who receive paid services the process of planning and review often have federal and state requirements. While essential lifestyle plans can and are being written to meet these requirements, some changes and additions are usually required. Every agency also has its own planning format and develops and updates the plans through a formal meeting process.

However, regardless of the process, any gathering of people who are looking at the future should seek to answer the following questions. Since the last time we got together -

What have we learned?

What have we tried?

What else might we try?

What else do we need to learn?

What do we need to do next?

This is another area where you may need help - please ask us and we will do our best to connect you with someone who can assist you.

**Families Planning Together:
Starting Work on an
Essential Lifestyle Plan**

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