

**HELPER'S GUIDE TO
"THOUGHTS ABOUT
MY LIFE"**

The type of support suggested in this guide are primarily derived from materials used to develop Essential Lifestyle Plans, especially “Developing First Plans”, “Listen to Me”, “Reviewing Criteria for First Plans” by Michael Smull. Other materials referenced include “Read My Lips, It’s My Choice” by Bill Allen, “Capacity Works” by Beth Mount and the Whole Life Planning guide developed by the Institute for Community Inclusion at Children’s Hospital in Boston, Massachusetts.

This particular guide to the “Thoughts About My Life” workbook was developed by Karen Manning, Robin Reale with consultation by Michael Smull and Liz Obermeyer. The Metro Region of the Massachusetts Department of Mental Retardation supported preparation of this guide. The opinions expressed in the workbook are those of the authors and do not necessarily represent those of the Massachusetts Department of Mental Retardation.

INTRODUCTION

This guide has been prepared for those who are interested in helping self advocates and others to use the “Thoughts About My Life” workbook. Helping a person to use “Thoughts About My Life” is a great opportunity to get to know a person better. It is a way to learn about what is really important to a person, how he or she wants life to be and some changes (s)he hopes will come about.

A variety of outcomes may occur while you are involved in helping a person to use the “Thoughts About My Life” workbook. One likely outcome is that you will learn enough about the person to support him in a way that makes sense. Another possible outcome is that you will know more about how to help the person speak up about the type of support he wants and needs. The information the person shares through the workbook will also be invaluable if the person chooses to use it to develop a plan for his life like an Essential Lifestyle Plan.

The first thing to figure out before helping a person to use “Thoughts About My Life” is whether the person is really interested in using the workbook. Once the person has shown her interest in using it, you must learn how much and what kind of help the person wants and needs. It is intended that each person use “Thoughts About My Life” in any way that makes sense to her. We see at least three possible functions the workbook may have for self-advocates and others. Many people will use it in one of these three different ways.

- A. To write about things in their life that are important to them.
- B. To get better at reading and writing.
- C. To have fun writing and reading their own stories.

Some people may even want to use it for all three purposes. How the person chooses to use the book is purely up to the person.

A). Those Helping a Person Describe What is Important to Him or Her

The questions in the workbook are organized in a way to help people think and write about things they like. They are also organized in a way to help people think and write about things they don't like. That is one way for people to describe what is important to them. Other questions in the workbook are organized in a way to help people to think and write about things in their life they want to stay the same as well as things that they wish would change. Our hope is people may be more inclined to speak to others who can help them plan and get closer to the kind of life they want.

While "coaching" a person to write about what is important in his life it is important to help him think and write what is truly on his mind without hesitation. Some things may take some time for a person to think about and describe. At other times, it may be hard for a person to think about things that remind him of painful experiences. In any event, the workbook is lengthy and will require some time at different intervals for people to work through. For these reasons, the guidelines on the following pages are intended to help coaches keep the person's individual preferences and needs in mind.

General Guidelines

- Help the person to write in the workbook at his own pace.
- Never rush the person to be finished with the workbook or any one section of the workbook in any time frame.
- Rephrase any of the questions in a way that makes more sense to the person if he is having a hard time understanding the content of a question.
- Never tell a person what to write. It is possible to tell a person how to spell a word or words.
- Have a conversation with the person to help him think about an answer to a question. Be sure not to tell the person what you think he should write as an answer.
- Never lead the person to write his or her story in a way that makes you or others feel more comfortable or less threatened.
- Give examples of ways you or others might write in a section to help a person think about what to write.
- Encourage the person to write about things he feels comfortable writing about.
- Be prepared to help a person work through or get help with emotional distress that may not have been anticipated.
- Remember to acknowledge that the person never has to write about anything he doesn't want to.
- Remember that a person never has to share his story with anyone that he doesn't want to share it with. Help him protect any information he writes down in a way that keeps it private.

Proposed Step By Step Guidelines

Note: The steps by step guidelines are not intended to be restrictive. They are intended to be a helpful tool for those who want specific instructions in how to coach a person to use the “Thoughts About My Life Booklet”. Those who know a person well and care about her may know other ways to help that make more sense to the person. It always makes sense to help in ways that are unique to the person.

1. Help the person to locate the Table of Contents. Be sure that the person understands that she can begin wherever she wants to and feels most comfortable.
2. Explain to the person that she can make up her own rules when writing in the book. This may include:
 - a. Skipping any sections or question she wants.
 - b. Starting and stopping anywhere she wants.
 - c. Using pictures, drawings, newsclippings, mementos or anything else that helps the person represent things, people, places, events that are important to him or her.
3. Help the person locate the chapter she wants to start. Remember the general guidelines and help only as much as the person wants and needs your help.
 - a. People In My Life
 - Question 1: Help the person name all people she lives with if she has a hard time remembering or identifying them.
 - Question 2 and 3: If necessary, ask the question for each of the people the person lives with.
 - Question 4: Help the person name all the people who help her at her house or apartment.

- Question 5 and 6: If necessary, ask the question for each of the people who help the person at her house or apartment.
- Question 7: Help the person name all of the people who help her at work or the day program if she has a hard time remembering or identifying them.
- Question 8 and 9: If necessary, ask the question for each of the people who help the person at work or the day program.
- Questions 10 through 13: Be careful not to lead the person to identify people that you think she should identify. On the other hand, you can help the person to remember people that make sense to identify if the person has a hard time thinking of people (e.g. Who's the person you go shopping with? Is that someone you have fun with? --- Or --- Who comes to visit you on your birthday? Is that someone you want to see more often?)

b. My Work Day

You may substitute the name of the person's day habilitation program for all of the questions that ask about work.

- Questions 1 through 3: If necessary, rephrase any of these questions in a way that helps the person understand them better.
- Questions 4, 6, and 8: For a person who doesn't tell time, you may identify the typical time that these things happen. Or a person may be comfortable describing an activity that happens before (e.g. after I finish my breakfast).

- Question 5, 7 and 9: If necessary, help the person to imagine the part of the day described. You can help the person tell all about that part of the day by asking more questions (e.g. And then? Where do you like to be? Who do you like to be with?).
- Questions 10 through 13: If you know the person's routine or schedule well, you may ask more specific questions to remind the person of things he does each week night. Or use a calendar, date book, written schedule, picture schedule or any other tool that the person typically uses to help him follow a routine or schedule. If you absolutely know of something that is important to the person that he is leaving out, you may suggest it to him. If he doesn't agree with your suggestion, leave it out.
- Question 14: If necessary, help the person to imagine a good day at work. Ask specific questions that might help the person to think deeply about how he wants to answer the question. (E.g. Who is there? What are you doing? And then what do you do? How do you feel?)
- Question 15: If necessary, help the person to imagine a bad day at work. Ask specific questions that might help the person think deeply about how he wants to answer the question. (E.g. Who is there? What are you doing? And then what do you do? How do you feel?) Keep in mind that this may be a hard question to answer. A person who has bad experiences at work may have trouble coping with the bad feelings he may remember.
- Question 16: This question may or may not be hard for the person to answer. Thinking about and describing a dream job may take some time. It is ok if the person wants to come back to this question after thinking about it a little more.

It is also important to remember that some people have had very little experience with different jobs. The person may need help exploring different options before he could begin to come up with a reliable answer.

One way to help the person explore with questions is to ask about other jobs the person has had. Ask specifically what he liked about the other jobs and what he didn't like about the other jobs. Helping the person to come to a better understanding about what he liked and didn't like about other jobs may help the person identify different types of work he may want to try.

It may also be necessary for the person to do some things with you or someone else he trusts to explore alternatives to the work or situation he has now. Looking through books and magazines, visiting different people at work, trying out different types of work in many ways without making a firm commitment may help the person to learn more about the different options available to him.

c. My Day Off

- Question 1: For a person who doesn't tell time and that you see when she gets up on her day off, you may identify the typical time she typically gets up. Or the person may not have a specific time to get up on a day off and may want to say "when I feel like it" or something like that. Or a person may describe a pleasant or unpleasant situation that happens that causes her to get out of bed on her day off.
- Questions 2, 3, 4, 5, 6, and 7: If necessary, help the person to imagine the part of the day described. You can help the person tell all about that part of the day by asking more questions (e.g. And then? Where do you like to be? Who do you like to be with?). If you know

the person and her routine really well you may make suggestions (e.g. What about...?)

- Question 8: If necessary, help the person to imagine a great day off. Ask specific questions that might help the person to think deeply about how she wants to answer the question. (E.g. Who is there? What are you doing? And then what do you do? How do you feel?)
- Question 9: If necessary, help the person to imagine a bad day off. Ask specific questions that might help the person think deeply about how she wants to answer the question. (E.g. Who is there? What are you doing? And then what do you do? How do you feel?) Keep in mind that this may be a hard question to answer. A person who has bad experiences on her days off may have trouble coping with the bad feelings she may remember.

d. Special Days

- Question 1: If necessary, help the person to imagine his birthday and all of the things that could or should happen to make it feel like his birthday. Ask specific questions to help the person think deeply about how to answer this question (e.g. Who will be there? What will you do? What will you eat? Where will you be?)
- Question 2 and 4: If necessary, help the person to identify all the holidays and traditions that are important to him. Use a calendar, pictures, photo albums, mementos, cards or anything that might help the person to identify and list his favorite holidays.
- Questions 3 and 5: If necessary, help the person to imagine each specific holiday and tradition that he identified in questions 2 and 4. Ask the person specific questions to help the person think deeply about how to answer these questions (e.g. Who will be there? What

will you eat? Where will you be? What will it smell like? What are some things you will need to bring or have when you're there? How will you dress?) Use a calendar, pictures, photo albums, momentos, cards or anything that might help the person to imagine and describe his favorite holidays and traditions.

- Question 6: The person may or may not have an answer to this question. The person may write whatever makes sense to him here. You could provide examples of days that are special only to you or to other people you know (e.g. your son's birthday, your daughter's wedding day, your anniversary, etc.)
- Question 7: If necessary, help the person to imagine each of the special days he identified in Question 6. Again, ask the person specific questions to help the him think deeply about how to answer these questions (e.g. Who will be there? What will you eat? Where will you be? What will it smell like? What are some things you will need to bring or have when you're there? How will you dress?) Use pictures, photo albums, momentos, cards or anything that might help the person to imagine and describe his unique special days.

e. Where I Live

- Question 1: If necessary, help the person to be specific about the place that she lives (e.g. what town, address, the size of the place, nice or not so nice, on a busy or quiet street, big or small, yard or no yard, etc.).
- Question 2: If necessary, ask the question in a way that helps her understand and answer it better.
- Question 3: If necessary, help the person imagine being in her favorite room (e.g. Where is it?, What does it smell like?, What will you see in your favorite room? What do you do when you're there?).

- Question 4: If necessary, help the person to think about and describe all of the things she likes to do at home. Ask specific questions that help the person to identify those things that she likes to do (e.g. What do you like to do at your house/apartment to relax? ...to have fun? ...to calm down? ...to go to sleep? ... to feel good?, etc.)
- Question 5: If necessary, help the person to be specific by asking more questions (e.g. Do you have enough room for you and your things? Do you like the way it looks? Do you like the furniture? Is there a place for you to be outside when you want to be?)
- Question 6: If necessary, help the person to be specific by asking more questions. Remind the person of anything she said she wasn't happy with when answering Question 5. Help her to describe how she would like some of those things to be different (e.g. You said that you didn't have enough room for all of your things. How would you like to change that to make sure you have enough room for your things?)
- Question 7: This question may or may not be hard for the person to answer. Thinking about and describing a dream home may take some time. It is ok if the person wants to come back to this question after thinking about it a little more.

It is also important to remember that some people have had very little experience with the idea of a place they would truly call home. The person may need help exploring different options before he could begin to come up with a reliable answer.

One way to help the person explore with questions is to ask about other places the person has lived. Ask specifically what he liked about other places she's lived and what she didn't like about other places she lived.

Helping the person to come to a better understanding about what the person liked and didn't like about places that she's lived may help the person describe the type of home she wishes for.

It may also be necessary for the person to do some things with you or someone else she trusts to explore alternatives to the living situation she has now. Looking through books and magazines, visiting and spending time with different people at their homes, going to look at different possibilities without making a firm commitment may help the person to learn more about the different options available to her.

f. My Kind of Fun

- Questions 1, 2, 3, and 4: Help the person to be as specific as possible when answering these questions. Use pictures, photo albums, momentos, souvenirs or anything that might help the person to imagine and describe how he likes to have fun.
- Question 5: Keep in mind that the person's experiences may be limited. If so, the person may not know of many places to go and things to do that are available to him. Use photographs, magazines, travel brochures, newspapers, event calendars, etc. as a preliminary way to help the person explore different options. Also, ask the person about things he did that he doesn't do anymore. Help the person talk about what he liked about the things he used to do and what he didn't like about things he used to do. Having this discussion may help the person to identify characteristics of "things to do" that he might like to explore more fully.

You or someone else the person likes to spend time with may need to help the person explore these things further by trying out new things to do. Typical ways you and I might try new things is to find someone else

who is interested in trying the new idea or someone who already likes doing the new thing the person wants to try.

g. Things I Can Do

Note: Anything goes in this section. This includes things the person does both with and without assistance. Things the person does without assistance are not considered greater than things the person does with assistance.

- Questions 1 through 6: If necessary, help the person to think of and describe as many things as she can. Find other ways to ask the questions that help the person to understand them better.
- Question 7: This question may or may not be hard for the person to answer. Many people have had limited experiences and may not know of the many things she could try. Also, many people have been convinced that they can't and will never be able to do certain things. Help the person to really brainstorm reminding her that anything goes. Use pictures, magazines, videos, brochures, photographs, newspapers, advertisements, etc. to help think beyond what is currently familiar.

h. How I Want Help

- Question 1: This question may or may not be hard for the person to answer. If necessary, help the person to think of the people who help him. Then ask the person to tell about who helps him in the best way. Ask what he likes about them. (Some possible answers may be "gentle", "funny", "patient", "likes to do things I like to do", etc.)
- Question 2: If necessary, help the person think of things he needs others to help with. You might try helping the person to walk through his day or through

different scenarios to help him think of things he wants and/or needs help with.

- Question 3: This may or may not be a hard question for the person to answer. Try talking about the things he identified as things he wants and/or needs help with. Ask the person if there are ways people help him with specific things that make him feel uncomfortable. (E.g. A person who needs help with a bath may say that it feels uncomfortable when people use a rough facecloth. A person who needs help eating may say it feels uncomfortable when people put something that looks like a bib on him.) Or if think you know of a way others have helped the person that made him uncomfortable you could give that example and ask if that is true.
- Question 4: If necessary, try following the same approach that is outlined above for Question 3 only focusing on the type of support that helps the person feel comfortable.

i. My Dreams

- **Question 1: Anything goes with this question. The person may want to write about major things that she would like to change. Or there could be little things that are really getting in the person's way.**
- Question 2: This question may or may not be hard for the person to answer. Many people have had limited experiences and may not have considered the possibility of having a dream. Also, many people have been convinced that some things they hope for are unrealistic and unattainable. Be sure to tell the person that anything that comes to mind can be written here. Help the person to really brainstorm. Use pictures, magazines, videos, brochures, photographs,

newspapers, advertisements, etc. to help think beyond what is currently familiar to her.

**B. Those Helping a Person Use the Workbook
To Practice Reading and Writing**

**C. Those Helping a Person To Just Have Fun Writing
and Reading His or Her Own Stories**