

# Supported Living Services Your SLS Training Tool Box



## Part Four: Tools and Applications

Connections for Information and Resources  
on Community Living (CIRCL)

April, 2001



# Supported Living Services Training Tool Box

## General Information for SLS Staff

Developed for

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### Introduction

This section of the Training Toolbox includes practical tools to help you do the work of supported living and to help you implement the principles of supported living services. These tools were gathered from supported living service agencies all over the state. These tools are intended only as examples and should be modified and individualized so they are useful to the individual who is receiving services. For example if the individual can not read you may want to use pictures instead of written words.

CIRCL, Connections for Information and Resources on Community Living, is building a library or database of useful tools that can be shared among people doing this work. We hope that you will send any tools that you develop to CIRCL, 4171 Starkes Grade Road, Placerville, CA 95667 it would also be nice if you would share them with others who are on CIRCL's supported living list serve (computer e-mail list). For information on how to participate on the list serve you can go to [www.allenshea.com/CIRCL/CIRCL.html](http://www.allenshea.com/CIRCL/CIRCL.html) (remember to bookmark the website) and scroll to the bottom of the page.



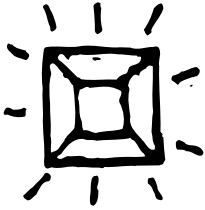


# **Section 1.**

## **A Home of One's Own**







## Finding the Ideal Neighborhood

(from Towards Maximum Independence, San Diego, CA)

This list can be used to help you think about the neighborhood you would like to live in. Choosing a home of your own is about choosing the neighborhood you live in and choosing your own home or apartment in that neighborhood. You will want to drive around and see a lot of neighborhoods before you choose the one you want to live in.

**1. Would you like to live in the same area you live in now?**

**2. Do you have any family or friends that you would like to live near? Where do they live?**

**3. What are your favorite places to go?**

**4. When you go out in the community how do you get around? Will you need to be near a bus stop or near a center of town so you can use public transportation?**

**5. Will your family, friends or the supported living agency be driving you to any of the places you like to go? What areas or neighborhoods are they coming from?**



**6. What is your weekly schedule for going out?** For example do you go to a job everyday, or to a day program? Do you go to church or attend any other community groups or organizations? Where do you like to go and where do you need to go in the community?

**7. Places I Go:**

**How I Will Get There:**

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**8. Are there new places you want to go in the community?**

**9. Do you have any favorite places that you go to now like grocery stores, banks, parks, or recreational centers?**

**10. Would you like to live in a quiet neighborhood (for example with retired people and not much traffic) or a louder busy neighborhood with children.**



**11. Would you be happiest and safest living with neighbors close by or would it be better if you lived on a large lot away from neighbors.**

**12. What areas have you lived in before? What did you like about any of these neighborhoods? What didn't you like?**

**13. What are some other things you might want to consider when you choose a neighborhood?**

**14. Is housing affordable in the areas you would like to live? If the rent is high, do you want to consider having one or more housemates?**

**15. Does the neighborhood seem safe? If you take a bus would you feel comfortable waiting at the bus stop?**

**16. Have you talked to any of the neighbors? Are they friendly?**



## House or Apartment Checklist

(from Towards Maximum Independence, San Diego, CA)

**Here is a way to look at a house or apartment where you might want to live. It will help you decide what is good about the place and what could be better. The best way to use this checklist is as follows:**

1. Make sure you get a chance to view the house or apartment and the immediate neighborhood.
2. If you need assistance with the checklist, ask you Community Support Coordinator or someone else you feel comfortable with.
3. Write notes about what you find out about the place in the box provided.
4. Think about all of these things before you decide if you want to live in the house or apartment or not.
5. You may be looking at several different places - use this checklist to decide which house or apartment is best for you.

**1. The place is close to stores, banks, places to eat and other resources I will need.**

**2. The place is clean inside and outside.**



**3. The place is in an area of my choice.**

**4. The place is near and easily accessible to bus routes.**

**5. The neighborhood feels safe and I'm comfortable when I leave the house or apartment.**

**6. The rooms in the house or apartment are spacious and wheelchair accessible, if needed.**

**7. The place is in good repair.**



**8. I can afford the deposit required by the landlord.**

**9. The rental agreement is a: \_\_\_\_ month to month \_\_\_\_ lease  
and I am comfortable with this arrangement.**

**10. I have read over the rental agreement or had someone assist me to  
understand it.**

**11. The stove is gas or electric and it works well.**

**12. There is a refrigerator that works well.**



**13. There is a dishwasher that works well.**

**14. The heater/air conditioner works well.**

**15. A credit check is required:    \_\_\_ Refundable    \_\_\_ Non-refundable**

**16. The neighbors are friendly and supportive.**

**17. IHSS referral has been made.**



**18. If others will live there, they have agreed upon "house rules."**

**19. I am comfortable with the level of privacy I will have there.**

**20. The place is wheel chair accessible with ramps and enough space to get through gates.**





# House or Apartment Availability Checklist

(adapted from Towards Maximum Independence)

House or Apt?	Address	Contact Person	Phone #	#Bedrms	#Bath	W/C Access	Pool	Deposit	Rent	Avail.	Extras	Subsidy?

Used during the home hunting process. If several individuals are looking for a place together, this can help them reach a consensus



## Accessible House or Apartment Checklist\*

(from Towards Maximum Independence, San Diego, CA)



Apartment Name: \_\_\_\_\_ Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Manager: \_\_\_\_\_ Date: \_\_\_\_\_

1. What type of apartment do you have available?  
 Studio     1 Bedroom     2 Bedroom
2. What is the rent? \$\_\_\_\_\_ Studio    \$\_\_\_\_\_ 1 Bedroom    \$\_\_\_\_\_ 2 Bedroom
3. Is the apartment on the ground floor? **YES**    **NO**  
     If no, is there an elevator?       
     Is there a step at the apartment entrance?
4. Is there a laundry room?       
     Are there steps?
5. Are the entrances into the apartment at least \_\_\_\_\_ inches wide?  
     (Put width needed to accommodate your wheelchair)
6. Is there a bathtub with/without (circle one) shower? **YES**    **NO**  
     Is there a shower stall?
7. Is there room in the kitchen for a small dining table?
8. Do you have off street parking?
9. Is the stove next to the kitchen sink or connected by counter space?       
     Is the stove: \_\_\_ electric    \_\_\_ gas  
     Is the refrigerator self-defrost?
10. Do you have a wheelchair accessible apartment?

**IF YES, PLEASE CONTINUE. IF NO, YOU MAY STOP HERE.**

*\*This can be used when looking for accessible apartments or houses.*



## Part Four: Tools and Applications

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- |  | <b>YES</b>               | <b>NO</b>                |
|--|--------------------------|--------------------------|
| 11. Are there disabled parking spaces near the apartment?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Are there grab bars around the toilet?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Has the kitchen sink been lowered?   | <input type="checkbox"/> | <input type="checkbox"/> |
| Has the kitchen counter space been lowered?  | <input type="checkbox"/> | <input type="checkbox"/> |
| Has the stove top been lowered?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Are the hanging rods in the clothes closet lowered?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Is there an emergency call system in the bedroom?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Is there space enough under the kitchen sink for a sitting person to comfortably put his legs? | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Do doors have ___ round or ___ straight door handles?  |                          |                          |
| 18. Is the carpeting ___ shag, ___ short nap, ___ indoor/outdoor?                                  |                          |                          |
| 19. Is there a ___ tub or a ___ roll-in (no step) shower?  |                          |                          |
| 20. Is there an incline on the approach to the apartment?  | <input type="checkbox"/> | <input type="checkbox"/> |



# Things You May Need for Living on Your Own

(Adapted from CHOICES, Arcadia, CA)



## KITCHEN

\_\_\_

**DISHES**



\_\_\_

**SILVERWARE**



\_\_\_

**GLASSES**



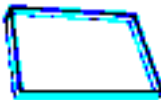
\_\_\_

**FRY PANS**



\_\_\_

**BAKING PANS**



\_\_\_

**POTS**



\_\_\_

**CONTAINERS**



\_\_\_

**BOWLS**



\_\_\_

**COOKING SPOON**



\_\_\_

**SPATULA**



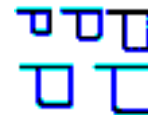
\_\_\_

**PEELER**



\_\_\_

**MEASURING CUPS**



\_\_\_

**MEASURING SPOONS**



\_\_\_

**SPATULA**



\_\_\_

**COLANDER**



\_\_\_

**PITCHER**



\_\_\_

**GRATER**



\_\_\_

**WHISK**





**KITCHEN**





## FURNISHINGS

\_\_\_ **BED**



\_\_\_ **DRESSER**



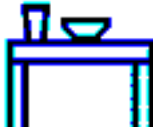
\_\_\_ **COUCH**



\_\_\_ **SMALL TABLES**



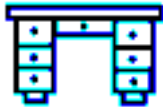
\_\_\_ **DINING TABLE**



\_\_\_ **CHAIRS**



\_\_\_ **DESK**



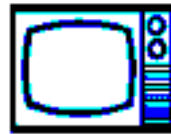
\_\_\_ **RUG**



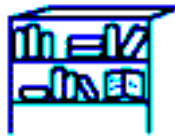
\_\_\_ **CURTAINS**



\_\_\_ **TV**



\_\_\_ **BOOKCASE**



\_\_\_ **STEREO**



\_\_\_ **LAMP**



\_\_\_ **FAN**





### BATHROOM



### BEDROOM





### MISCELLANEOUS

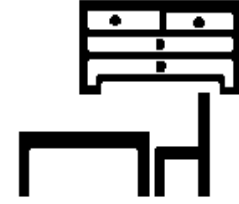






# Inventory Checklist\*

(from Towards Maximum Independence, San Diego, CA)



1. It is suggested that you complete the “condition on arrival” section prior to moving in and give it to your apartment manager for verification. **Please Note:** Some apartment managers may have their own form they use. If so, use their preferred form.
2. Have the apartment manager verify the condition as reported.
3. Sign the form and give it to the manager within two (2) days; any discrepancies should be resolved at that time. You could be held responsible for all discrepancies not listed after two days from your move-in date.
4. Keep a copy of this for your records and use the copy for a checklist when you move out.

Apartment \_\_\_\_\_ No. \_\_\_\_\_ Tenant \_\_\_\_\_

Living and Dining Rooms

Item	Quantity	Condition On Arrival	Condition On Departure
Carpets			
T.V. Adapter			
Walls/Ceilings			
Windows (Drapes, Screens, Tracks)			
Closets			
Miscellaneous			

\* *This form is completed within the first 2 days of the move-in. It is used to check the apartment's condition when a deposit for the apartment is required. A copy is made for the apt mgr and the original is maintained by participant in notebook kept in the apartment.*



	<b>Item</b>	<b>Quantity</b>	<b><i>Condition On Arrival</i></b>	<b><i>Condition On Departure</i></b>
<b>Bedrooms</b>	Carpets			
	Walls/Ceilings			
	Closet			
	Windows (Drapes, Screens, Tracks)			
	Doors			
	Miscellaneous			
	<b>Bathrooms</b>	Floor Coverings		
	Walls/Ceilings			
	Shower & Tub			
	Toilet			
	Plumbing Fixtures			
	Medicine Cabinet (Including Mirror)			
	Sink			
	Windows (Drapes, Screens, Tracks)			
	Doors			
	Light Fixtures			
	Miscellaneous			



## Part Four: Tools and Applications

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<b>Item</b>	<b>Quantity</b>	<b><i>Condition On Arrival</i></b>	<b><i>Condition On Departure</i></b>
Carpet			
Walls/Ceilings			
Closets			
Light Fixtures			
Heating System			
Cupboards			
Floor Coverings			
Walls/Ceilings			
Counter Tops			
Stove (oven, hood, pan, filter, etc.)			
Refrigerator (drip pan, ice trays)			
Sink/Garbage Disp			
Dishwasher			
Windows (drapes, screens, tracks)			
Doors (knobs, locks)			
Light Fixtures			
Miscellaneous			
Patio (Porch, Deck)			
Yard			
Carport/Garage			
Other			



## Decorating Your Home



Now that you are moving to your own home you have a chance to decorate any way you want. Here is a list of things you might want to think about as you make your decorating decisions. You can write your answers in the boxes.

You may want to ask someone to help you think about each of these questions and help you understand all of the options you have. You may want to look at decorating magazines or go to furniture stores to think about what you want in your home. You may want to think about places you like to go and things that make you happy.

**1. What are your favorite colors? What colors do you not like?**

**2. What are your hobbies or special interests?** For example, some people love football and decorate with a sports theme or some people love country music and decorate with a country theme.

**3. Do you collect anything? How do you want to display these things or will they be stored?**

**4. Do you have items that are important to you that you want to use or have out?**



**5. Will you have any pets or house plants?**

**6. If you already have some pieces of furniture that you plan to use – what colors are they?**

Keep in mind every room can be decorated with different colors and with a different theme if you want.

**I want to use the following ideas/themes and colors:**

**In my living room:**

**In my bathroom:**

**In my bedroom:**

**In my kitchen:**



# Monthly Budget Worksheet

(Adapted from CHOICES, Arcadia, CA)



**Telephone Bill**

\_\_\_\_\_



**Rent**

\_\_\_\_\_



**Haircut**

\_\_\_\_\_



**Gas & Electric Bill**

\_\_\_\_\_



**Groceries**

\_\_\_\_\_



**Laundry**

\_\_\_\_\_



**Dial-A-Ride or Bus**

\_\_\_\_\_



**Fun**

\_\_\_\_\_



**Out to Dinner**

\_\_\_\_\_



**Savings**

\_\_\_\_\_



**Vacation/Holiday Savings**

\_\_\_\_\_



**Other**

\_\_\_\_\_

**TOTAL**

\_\_\_\_\_



## **Section 2.**

# **Tools and Applications for Supporting Choice and Self-Direction**







## **Tools to Support Decision-Making**





### **Considerations for Increasing Staff Support in the Face of Risky Decisions**

If someone is making decisions which are putting him/her at risk, the following considerations should be addressed at an *at risk* meeting to determine whether more staff support/intrusiveness is justified.

- A. *What is the person's history of decision making?*
  - previous experience or practice in exercising autonomy and rights
  - ability to learn from the natural consequences of poor decision making
  
- B. *What are the possible long and short term consequences associated with poor decision making? (What is the worst that could happen?)*
  - death
  - illness, injury
  - involvement with law
  - financial difficulties
  - exploitation
  - isolation, rejection by others
  - substandard living conditions
  - lack of enriching experiences
  
- C. *What are the possible long and short term consequences of increased direction and control by staff or system?*
  - decreased confidence or self esteem
  - likelihood of increased dependence on staff
  - improvement in person's quality of life
  - possibility of person refusing to work with Options. If this is likely, the following issues should be reviewed:
    1. Under current circumstances, how is the person benefiting from Options involvement?
    2. What would be the impact of Options terminating services if the client refuses our increased involvement?
    3. Does the client require protective measures to be taken, i. e. guardianship, protective placement, other?
  
- D. *What are the trade offs of continuing the current situation?*
  
- E. *Existence of safeguards to protect person's rights?*
  - Is the person sufficiently assertive to advocate for his/her rights?
  - Is there the presence of an advocate, friend, or guardian to represent the person's interests? If not, should Options locate such a person?
  
- F. *Should more control and direction be provided? If yes, list proposed support.*

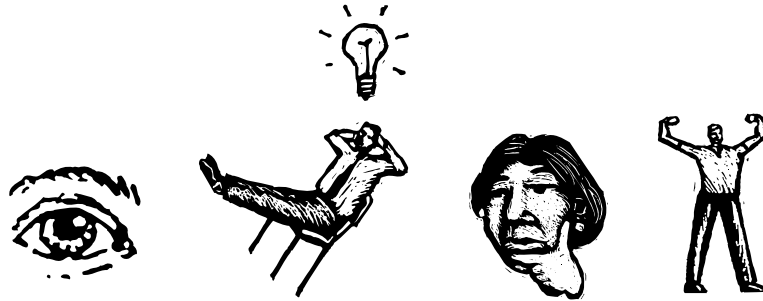
(Originally adapted from OPTIONS, Madison, WI; reprinted from *Patterns of Supported Living*, Department of Developmental Services, 1993)



## **Considerations for Increasing Staff Support in the Face of Risky Decisions**

If someone is making decisions which are putting him/her at risk, the following considerations should be addressed at an *at risk* meeting to determine whether more staff support/intrusiveness is justified.

- A. What is the person's history of decision making?*
  
  
  
  
  
  
- B. What are the possible long and short term consequences associated with poor decision making?*
  
  
  
  
  
  
  
  
- C. What are the possible long and short term consequences of increased direction and control by staff or system?*
  
  
  
  
  
  
  
  
- D. What are the trade-offs of continuing the current situation?*
  
  
  
  
  
  
  
  
- E. Existence of safeguards to protect person's rights?*
  
  
  
  
  
  
  
  
- F. Should more control and direction be provided? If yes, list proposed support.*



**Excerpts from  
A Guide to Training in Decision-Making  
for People with Developmental Disabilities**

**Horrigan Cole Enterprises**

**Originally Printed, June 1996  
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**For more information on this guide, contact  
SherryBeamer@compuserve.com**



## Basic Steps in See Think OK Go (STOG)

Step 1: "See"



The first step is "What do I see"? or "What is the choice or problem?"

Step 2: "Think"



List all the possibilities or solutions to the choice or problem.

Step 3: "O.K.?"



Go back to the list of ideas and decide which solution or choice you like best.

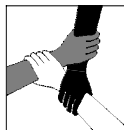
Explore all parts of the possible solution or choice by thinking about four symbols and answering some questions that go along with these elements. The four elements are:



HEAD



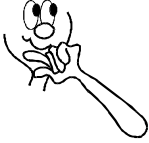
HEART



HANDS



FUTURE



### HEAD

The head stands for the sensible part of the choice. To decide if a choice is right for you, ask yourself the following questions:

- ≤ Can I afford this choice?
- ≤ Will this choice help me get other things I need and want?
- ≤ Is this the best choice for me?
- ≤ How will this affect me in the future?
- ≤ How will I feel about this choice tomorrow?



### HEART

The heart stands for how you feel about your choice. The following questions will help you learn how you feel:

- ≤ What do I think about this choice today?
- ≤ Do I feel happy? Why?
- ≤ Do I feel afraid? Why?

Sometimes a person feels one way about a decision, but after some thought changes his or her mind. It's okay to change your mind about a decision if it's truly what you want. Make sure the decision is based on what is best for YOU. Your decision should not be based on what someone else has "talked you into." Your first reaction to a decision is usually the right choice.



### HANDS

Hands represent how a choice will affect other people. Ask yourself:

- ≤ Whom will my decision affect?
- ≤ How will my decision affect others?
- ≤ Will anyone try to stop me from making this decision? Why?
- ≤ Is there someone I should ask for advice?
- ≤ What are my responsibilities (legal)?
- ≤ Is it safe?



### FUTURE

Future talks about if and how your decision will affect the rest of your life. Hopefully you have a dream for your life. Your choices and decisions should help you to live your dream.

<Assist the group in reviewing each choice or solution by using the pictures on the following page : “Head, Heart, Hands, Future.” Then, ask the group to discuss which choice or decision seems the best. This will be their choice or solution.>



### Step 4: “Go!”

The last step is to try out your choice or solution. This is an important step because many people do not actually do what they say they will. When you are finished, ask yourself if the choice or solution worked. If not, you can use the S.T.O.G. again to find another choice or solution. Use S.T.O.G. for making decisions in your self-advocacy group, or for personal decisions in your life.





S.T.O.G.  
A Good Way to Make Decisions



What do I see? (What is the choice or problem?)



Think about and list the possibilities or solutions.

1.				
2.				
3.				

**Then think about:**

- Head - Is this the best choice for me?
- Heart - How do I feel about this choice?
- Hands - Who will be affected by this choice?
- Future - How will this affect my life and/or dreams?



Make a decision



Go for it! How did it work?



SAMPLE

S.T.O.G.  
A Good Way to Make Decisions



See

What do I see? (What is the choice or problem?)

**I want to find a boyfriend.**



Think

Think about and list the possibilities or solutions.

1. **Try to find someone through the telefriend program.**



Yes



The regional center telefriend program is safe



n/a



I want to leave the group home to live with a boyfriend

2. **Go to a party or dance given by a group I know.**



No



It's safer to go to a party given by people you know



n/a



3. **Meet somebody at work.**



OK



n/a



I work

Then think about:



Head - Is this the best choice for me?



Heart - How do I feel about this choice?



Hands - Who will be affected by this choice?



Future - How will this affect my life and/or dreams?



O.K.?

Make a decision

**I will try the Regional Center telefriend program.**



Go!

Go for it! How did it work?

**I called the Regional Center. I am waiting for the information.**



SAMPLE

S.T.O.G.

A Good Way to Make Decisions



See

What do I see? (What is the choice or problem?) **Some decisions (like planning meals or choosing foods at the market) take a long time to make. When I'm under pressure I get nervous and I can't make a decision.**



Think

Think about and list the possibilities or solutions.

1. **Tell, in a polite way, the person who is putting pressure on me to make a decision, to give me some more time.**



Yes - I need more time



I may get verbally frustrated



•Others may have to wait  
•My mom may get upset



I want to think faster to make decisions on my own

2. **Make a choice and don't worry if it's completely right.**



3. **Plan or get information before I need to make a decision, or find someone to discuss it with, so I know what I need to do.**



Then think about:



Head - Is this the best choice for me?



Heart - How do I feel about this choice?



Hands - Who will be affected by this choice?



Future - How will this affect my life and/or dreams?



O.K.?

**Make a decision** Tell, in a polite way, the person who is putting pressure on me to make a decision, to give me some more time.



Go!

Go for it! How did it work?

**I don't have the courage yet to say "give me more time."**



# Helping Staff Support Choice

by Michael W. Smull

As more and more people with significant disabilities are moving from group homes to supported living the challenges in supporting them in their choices increase. The staff involved with these individuals are often told to simultaneously support choice, build community relationships (and acceptance) and assure health and safety. Staff blessed with common sense understand how to achieve this balance instinctively. However, many other staff members solve the perceived dilemma by only hearing the first or the last part of the message. They either support choice regardless of consequences or overly restrict people in the name of health or safety. The middle part of the message, building community, gets lost in the struggle between choice and concerns over health and safety. What staff (and managers) often miss is that this is a balance, a balance that needs to be defined with each person supported.

In searching for ways to help people understand how to achieve a balance in supporting people I came across Charles Handy's "doughnut" principle (see figure 1). As adapted for use in supporting people with developmental disabilities, it suggests that there are three areas of responsibility that we can define with each person we support. At the center of the doughnut are the core responsibilities, those things that we expect staff to do without fail. These "core responsibilities" are typically a mix of issues of health or safety and those things that are most

important to the person supported. The ring just outside of the core represents those areas where we expect staff to use judgment and creativity. They may continue to include issues of health and safety but they are in areas where staff are expected to try new ideas and not be punished if the ideas do not work. Outside of the doughnut are those areas that are not our responsibility, that are none of our business.

The boundary between core responsibilities and areas where people are to use judgment should be sharp and clear. If this conceptual framework is to be helpful, sufficient time must be taken with staff to be certain that each person understands what responsibilities are within

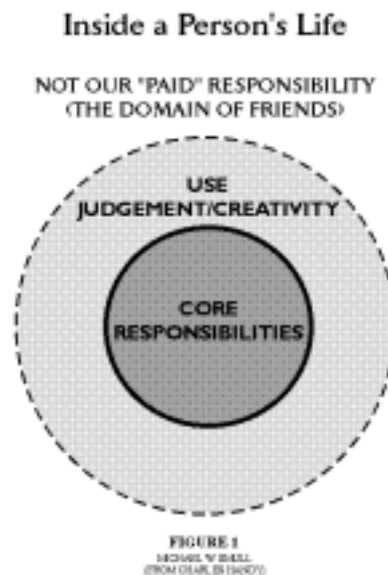




FIGURE 2

career as a speaker and consultant. Jon also has Prader-Willi syndrome and much of his support revolves around helping him maintain the independent life that he loves while staying within his very limited diet. Some examples of the 3 areas of staff responsibility inside Jon's life are shown in figure 2.

Elizabeth is a woman who one friend described as a busy lady who wants to be busier. People who met her during her recent presentations to the Presidents Committee on Mental Retardation and at TASH in New Orleans have commented on her charm and wit. Those who have taken the time to talk with her have realized how much we have to learn from what Elizabeth has to say. As this is being written, she is living with her family but this will change as soon as she can recruit a qualified paid roommate. Because

the core and which are in the area requiring judgment. On the other side, the boundary between what is and is not our business, is deliberately kept "fuzzy". For example, what someone wears might be "none of our business" on a day to day basis but should fall into the area of "use judgment and creativity" when something inappropriate is being worn for a job interview.

The content of each area within and outside of the doughnut varies widely from person to person. Two people who illustrate how this works are Jon and Elizabeth. Jon lives in his own apartment in Benicia, California. Jon is a man with a great imagination who is also an eloquent presenter. He has found that traditional disability system employment programs (workshops, enclaves, and work crews) do not work for him and is trying to build a

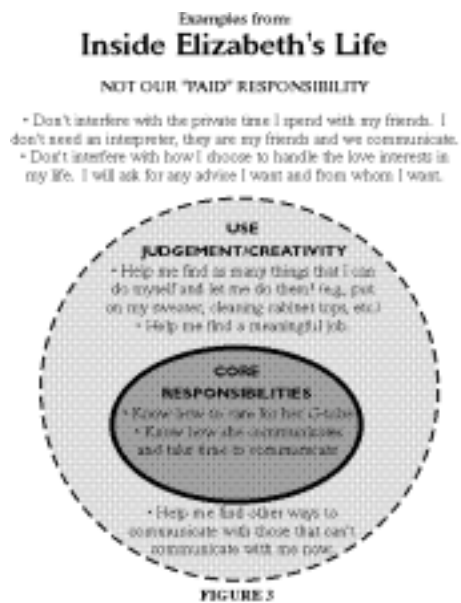


FIGURE 3



Elizabeth communicates by pointing slowly to words it is easy to not listen to how she wants to be assisted and Elizabeth needs a great deal of personal assistance. She relies on others for most of her personal care and eats using a G-tube. On the other hand she gets around quite well in her power chair and doesn't need anyone with her when she is off visiting during a conference. It will be critical for Elizabeth's life that staff understand their three areas of responsibility, some examples of which are shown in figure 3.

In the not too distant past we were quite comfortable in deciding where people with disabilities should live, who they should live with and how they should spend their time. Now we are trying to help people direct their own lives. We plan with people rather than for them and struggle to

support the choices of each person. When we are careful and successful we help each person find the balance in their lives. A balance that reflects what people want, the resources available to them, and any issues of health or safety. Not surprisingly one of the lessons that we are learning is that we need to help staff find the same balance in the support they provide. This adaptation of Handy's "doughnut principle" provides a structure to help staff find that balance with each person they support.

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## Revisiting Choice, Parts 1 and 2

by Michael W. Smull



Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system. For some people choice means that how they want to live has been discovered and carefully supported. For others choice is an excuse or the basis of a bizarre rationalization. Perhaps because choice is the word de jour, it has been used to argue that congregate facilities are needed in order to ensure residential "choice". An even more egregious example is justifying the use of pain to control behavior to allow "choice among a full range of treatment options". (The same argument could be made to retain "bleeding" as a treatment option for the flu.) Other abuses are more subtle. When you look behind the rhetoric of agencies which say "we offer and teach choice", you find places that ask people what they want to wear but not who they want to live with. What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.

### **Preferences, opportunities, and control**

Choice, as it is being used in current disability discussions, appears to have 3 related concepts embedded in it - preferences, opportunities and control. Preferences include not only what someone likes but also their desires and dreams. Preferences includes: who people

want to spend time with; what to do during that time; and where to spend their time.

Opportunities are the available array of: people to spend time with; things to do during that time; and places to spend that time. Opportunities should also include being able to spend time by yourself. Preferences reflect what people want while opportunities reflect what is available.

Control is the authority to make use of an opportunity to satisfy a preference.

### **Looking at preferences, desires and dreams**

Any effort to support choice should start with discovering what is important to the people who are being supported. What do people want in their relationships with others? How do people want to spend their time? What do people want to do (and not do)? What kinds of environments in general and what specific places do people want to spend time in or avoid? Do people have dreams about how they would like to live and do they have nightmares about what they are afraid will happen to them?

While answers to these questions are sought (with varying degrees of emphasis) in all of the formal processes for person centered planning, careful efforts are required. Many people lack the life experiences necessary to know what they





like and dislike. Will something that sounds desirable to a person feel that way when it is experienced? Some people want to try things or live in ways that put their safety or health (or both) at risk. Many people need to have a life of their own before they can have a dream of their own. As people try things (and as they age) their preferences change. In a system that offers real choice, people continuously have opportunities and are continuously supported in expressing their preferences. Supporting choice requires that there be recognition that everyone has preferences and desires regardless of the severity of disability.

Supporting choice also requires that we recognize that what we need to know is taught by the people that we support. Some of what my colleagues and I have learned about preferences from the people that we have listened to follows.

### **We have taught learned helplessness, now we need to teach trust**

Many people have experienced systematic ignoring of their preferences. This is an unintended consequence of current "individual" planning and professional practice within the disability system. We cope with the poverty of opportunities for the people we support by suppressing their preferences for what is absent. "Learned helplessness" has been taught and many of those we support have learned this lesson well. For these people, what needs to be taught is that we can be trusted. Trust is "taught" by having those with control listen to all expressions of preference and, where possible (and sensible), to help people get what they want. "Teaching choice" is a poor label. Those who teach must remember that they are not "offering

choices" but soliciting preferences and then demonstrating that staff can be trusted to honor the preference expressed. Staff must learn to acknowledge the preferences that people are expressing with their behavior while not asking what people want until there is a commitment to honor their requests.

### **Shouting (with behavior) has been the only way to be heard**

Most of us have had the experience of raising our voices in the belief that it will increase understanding. We shout so that we will be heard. A number of people with disabilities have learned to "shout" with their behavior because it is the only way that they are heard. If you do not like your current job, complaining about it does not produce change. Acting in unacceptable ways does produce change. Complaining about who you live with is unlikely to get you a new roommate, but aggression often works. "Shouting" gets our attention, but rarely gets people what they really want. We need to listen for the preference that is underneath the shouting. Once real preferences are understood (and acted on), the need for "shouting" with behavior is eliminated (although the person may always be someone who has a loud "voice").

### **Most of what people want is modest**

What people want is usually modest. When critics say that we cannot afford choice they have typically confused what is important to people with what might be nice to have. There is also a difference between learning what is important to people and taking someone on a guided fantasy. Careful planning discovers preferences such as: having a say in who





helps me; having privacy in the bathroom; being asked not ordered; going for a walk when I want; and (for one person who uses a wheelchair) to be able control the direction in which I face.

### **A few people's desires are not modest**

While the vast majority of people have modest desires, there are a few people who sincerely want frequent trips to the tropics, a car continuously at their disposal and support staff who take on the role of servants. They may see these as essential to a reasonable quality of life. They are "virtual yuppies", without the income needed to support their desired lifestyle. They are also unusual, as careful planning identifies very few people with these expensive tastes. Where rational decisions are being made about allocation of resources, these people are disappointed with the outcome.

### **Some people have reasonable requests that are difficult to afford**

The fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. However, we do have an obligation to respond to sincere requests as we can. For example, there are many people who would like to try living by themselves. The cost of support (in staff and housing) presents a real challenge to those attempting to create a system of support. The demand for living alone is somewhat reduced when there is more careful listening. For example, some people really do not want to live alone but simply do not want to live with other people who have disability labels. Other people have always had to share lives (e.g. it is Tuesday so we all go bowling) and have not learned

that you can also live with someone where you only share space.

After these situations have been clarified there are still many people who simply want to have the experience of living by themselves. Where people have been able to live by themselves for a year or two, many would like to have a roommate for company (but not to share lives with). Some people, however, find that living alone is the only way they wish to live. The support costs for most of these people decline dramatically as behaviors change, skills are learned and connections to the community are built. However, the cost of support for some people remains high. From the perspective of a system, a small percentage of people can always be supported in relatively expensive lives. The challenge is to not have that percent exceed the resources available.

### **What people don't want is as important as what they do want**

In learning people's preferences, it is important to discover what they dislike. Simple lists are not adequate. We must go beyond a statement that George likes barbecues and dislikes broccoli. We have a significant degree of control over who we spend time with and what we do. We use that control to avoid people and activities that we strongly dislike. People with disabilities have not had that control. In the absence of being able to "vote with your feet" we need to insure that those things that people hate or strongly dislike are absent.

### **Choice making is not a solitary activity**

Figuring out what we want is usually not a solitary activity. To tell people that



yesterday we made the choices and that today they are in charge is to ignore that few of us make significant choices without discussion. Before we make major decisions, such as changing jobs or changing partners, we have typically discussed the "pros and cons" at some length. We seek advice, support and people who just listen. We strive to determine what is right for us. We frequently get conflicting advice and pick the advice that agrees with what we want. We reserve the right to make "bad" choices after we have heard the "good" advice. People with disabilities need the same opportunities.

### **What people ask for may not be what they want**

People will ask for those things that they know about. One woman who was being assisted in leaving an institution said that she wanted to move to a "group home". One man said that he wanted to live alone. The woman who said that she wanted to live in a group home spoke very little English. She knew that she wanted to leave the institution and the only place away from the institution that she knew of was a "group home". The man who said he wanted to live by himself thought that the only choices that existed were to live by himself or with other people with disabilities. The woman is living happily in supported living and the man is living in a house that he wanted where he rents rooms to 5 people who have no formal disability labels.

When people express a desire for a job (or anything else) where their disability or circumstances preclude obtaining what is asked for, we need to listen to what lies beneath the surface. One man said he wanted to be a pilot. After a lot of

discussion we discovered that while he did want to be a pilot he also just loved airplanes. We could not help him become a pilot, but we could help him get a job at an airport. Some years ago I worked with another man who said that he wanted to have a job just like his father's. His father is a well known research scientist with the federal government who determined what projects got funded. Many conversations later we found that the characteristics that mattered to him were that he be treated with the same respect that his father received and that he wear a tie to work. We helped him find a job where he wore a tie and ran a large copying machine at a facility that did scientific research. If you were a scientist who wanted your latest journal article copied you went to his copy center. If you just filled out the form your article would get copied in turn, if you treated him with "respect" he would do your copying while you waited.

### **Sometimes what people want is not possible**

A woman I met in the Midwest, Susie, wants to live with her mother. It is so important to her that she sees it as the only acceptable place for her to live. Unfortunately this is not possible. Susie had lived with her mother for several decades and her mother had been the person who provided care and support. After a sudden loss of capacity, Susie left her home and entered a hospital and then a nursing home. The supports necessary to support Susie in her mother's house are available and affordable. However, Susie's mother would not agree to her return regardless of the supports that could be provided. This is not to disparage Susie's mother. She continues to be deeply caring and



intimately involved in Susie's support, but she is "burnt out" as a caregiver. In these circumstances our obligation is to acknowledge and honor the positions of both Susie and her mother. Honoring her mother's position requires that we not use guilt or otherwise coerce her to support Susie's return to her home. It requires that we support her in developing her new relationship with her daughter. Honoring Susie's position requires that we acknowledge what is important to her and help her get on with her life. We have to avoid the temptation to deny the presence of a preference that cannot be realized. We also have to help Susie deal with a very real loss and to help her begin to develop new relationships. She needs support in her changing relationship with her mother and in developing new relationships.

### **Helping people be safe and happy requires thought and effort**

One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the "pursuit of happiness" and then seek to reduce or avoid risk within that context. What is not acceptable is to simply say it was his choice, that is why I stood by while he hurt himself. Helping people be happy and safe requires thought and creativity. The following stories give some examples of the efforts needed.

A story that I enjoy telling (and writing about) is that of a man who wants to go for walks whenever he wants and who also thinks that, when he crosses a street, traffic

should stop for him. The initial thinking was that he needed one to one staffing across all waking hours. The cost of the staffing necessary for a couple of walks each day was an expense that was disproportionate to the result. On the other hand, not being able to go for walks on his schedule significantly reduced the quality of his life. Further discussion lead us to realize that this man would be happy to live in a rural setting. He moved to a house on a five acre Christmas tree farm where he goes for walks whenever he wants without having to cross a street.

One man that we did planning with liked to use "found objects" in his art projects. The challenge was that he would "find" objects in stores and leave without paying for them. He understood the concept of money but was remarkably uninterested in it. The people who supported him could have said that it was his "choice" and let him be arrested. Instead they would go to stores with him, with his money in their pocket. (He would give his money away if it was in his pocket.) As they left each store the support staff would ask if he had "found" something in that store and, if yes, the staff would pay for it.

We got a phone call several years ago from a service provider asking for help with someone who was severely injuring himself. This man is now described as a tall, charming, ladies man who does not use words to talk. At the time, his brother said that he looked like a hockey goalie with the helmet and all of the padding that he wore to keep from injuring himself. There were people who said that he needed a "more restrictive" setting and there were people who said that pain



should be used to control his behavior. The service provider could have argued that an institution would be the "safe place" for him to be. Instead we were asked to help the provider "listen" to what this man was asking for. After listening to what he was saying with his behavior and after listening to what those who loved him knew, we found that there was no single answer. However, there were a host of simple things that we could do. There were many ways in which we were not listening to how he wanted to live. Some examples include that he: needs to close all doors (except for his bedroom door at night) and to line up all shoes; must be able to make and eat his own snacks when he wants them (including raw onions with salt); must not be ignored (even if it is planned); and he must always have a non-glossy magazine to hold onto. His life is not perfect and he still gets upset occasionally. On these infrequent occasions he still needs people who keep him from hurting himself. However, because we have been listening carefully to what he is asking for, he is living in his community. He lives (and goes to concerts with his brother) without pads, splints or a helmet.

### **Choice requires opportunities and sharing control**

A preference is something that people want. Unless they have already experienced it, they will not know whether or not they like it or not. Many people with disabilities have never had the life experiences necessary to determine how they really want to live. Honoring choice for these people requires opportunities and taking advantage of the opportunities may require encouragement. As people begin to find that their choices are honored they

want control over those choices. Honoring choice requires that control is shared. This is the subject of part 2 of revisiting choice.

### **Revisiting choice - part 2**

Choice, as we are using it, is a simple word that contains 3 concepts - preferences opportunities and control. Learning people's preferences is a complex and on-going activity. What people want (and the values that underlie their desires) provide a picture of how people want to live. This was the subject of part 1 of "revisiting choice". However, learning how people want to live is only the beginning. It is the necessary foundation but just the foundation. In order to get the life that you want and to maintain it, you need opportunities and control.

For people with disabilities, the absence of control and opportunities is a devastating combination. Flooding people with opportunities or simply handing over control can be equally devastating. Everyone needs opportunities and everyone needs control but they need them on their own terms. People who have never had opportunities need to sample life in their own way. Some people need to dive in. They do not want and cannot tolerate transitions. Others are most comfortable with first putting a toe in. They want lengthy and careful transitions. Both need the control necessary to change their minds. Some people have been demanding control over significant aspects of their lives and we have seen them as having challenging behaviors. Some have given up hope and we see them as withdrawn or even as compliant. However, regardless of the severity of disability,



people want control over parts of their lives.

### **Providing opportunities, sharing control**

Having control is how we maintain a balance in our own lives. Each of us needs control sufficient to keep (or secure) what we value in our lives and to reject (or leave) situations that we cannot stand. One definition of emotional health is that we recognize what a balance is and that we recognize opportunities that enable us to maintain or enhance that balance. That is, we are able to use opportunities to get more of what we value or less of what we dislike. Control is what allows us to try new things and discard them when they do not fit. Control is what we require when we find our lives out of balance and we look for the opportunities that will bring a positive balance. The situations we find the most frustrating are those where we lack control and/or where the opportunities that we need are absent.

Control is a complex concept. Having control means that we have to make decisions and all of us create a set of positive rituals or routines that allow us to get through much of our day without treating each situation as if it were new. Most of us do not want absolute control. We may joke that if we were in charge of the world we could fix things, but most of us want (and welcome) limits to the areas where we have to make decisions. We conform to large sets of societal rules without much thought and only remark on those few areas where we disagree. Those of us who live with others find that we have to share control. Each of us has our own rules that we insist that our partner honor and our partners expect the same of us. Where expectations regarding behavior

are not met, or are mutually exclusive, conflict arises. The outcome of a resolved conflict is a mutual agreement on the behaviors expected. Our vision of the best outcome is that our partners will see the error of their ways and the wisdom of our words. A more rational outcome is that each of us will better understand the other and make the compromise that works for the relationship. In reciprocal relationships control is shared.

If we apply what works for everyone to people with disabilities, then we should be helping people with disabilities to have sufficient control to maintain a balance in their lives and to create their own rituals and routines. We should help them develop relationships (both paid and unpaid) where control is shared. A brief description of what the disability system should be doing is: to discover how people want to live; provide them with the opportunities necessary to get the lives they want; and help them have the control needed to maintain it. Many of the challenges in doing this arise from the disabling environments in which people have lived. We have created these environments with a binary view of control. Either I have control or you have control. The idea that control can and should be shared seems to be an alien concept.

### **Control, opportunities and preferences as developmental triplets**

Parents support the development of their children by asking the child to choose from alternatives and then honoring the choice the child makes. As children grow in capacity and experience, the span of control gets broader. Children may move from what they will wear, to when they





will go to bed, to how they spend most of their waking hours. They move from nearly constant supervision to doing what they want within defined (and often disputed) boundaries. Parents transfer control slowly. All parents worry about whether their children are "ready". When a child breaks a rule about the boundaries of behavior, the child loses control for a time (smaller children may go to their rooms, older children may be "grounded"). Parents share control with their children while they are transferring it. Typical children go through phases where they rely on their parents control for most things, go through a period where they both want and do not want parental control (teenagers can simultaneously tell their parents that they are ruining their lives while wanting limits to push against), and end up, as adults, with control regardless of their parents' desires.

For people with disabilities the analogy with the developmental process that children pass through is both helpful and dangerous. It is helpful in that it provides some guidance as to where someone is and how we might help them move forward in a safe and rational way. The analogy breaks down as the inevitability of autonomy for typical children is not present for people with disabilities. It is dangerous in that we are talking of supporting adults who may have already been trapped by developmental concepts such as mental age.

### **Control and capacity**

How much control we have and what we have control over should be a function of desire and capacity. However, our stereotypes of people with severe cognitive impairments cause us to overlook the

capacities that are present. I have met a number of people who do not use words to talk but who are good at training staff in listening to their behaviors with regard to what they want. They demonstrate a much greater capacity for (and interest in) controlling their lives than they are given credit for. At the same time, we need to recognize that positive control is learned and control should be coupled with a knowledge of consequences.

We need to ask, what are people asking for and how can we help them get it without putting them at unnecessary risk. It can be as simple as supporting Rhonda, who uses a wheel chair, in being where she wants to be. Any sunny warm day she will want to go outside and enjoy the sun. Unfortunately, she is also very allergic to pollen and needs to be told, on days with a high pollen count, that she would not enjoy the consequences of going outside.

### **Timing and opportunities**

Timing is important in how people respond to opportunities. We tell our friends that we are not ready or that we will do it when we are ready. Opportunities have a developmental sequence. People need to be offered what they are ready to try. What people are ready for and when they will be ready requires judgment. Given the uneven, but generally impoverished, life experiences that people have had, they need to be encouraged to try new things. They may need to have an opportunity presented again and again. Judgment is required to determine where encouragement stops and coercion starts. At the same time a lack of experience coupled with uneven deficits in skills and capacities makes people more vulnerable. Opportunities can lead to



injury and judgment is again required. There is little growth that comes without risk. People need to be able to fail and to feel hurt. Supporting people in having opportunities so that we will know what they will want tomorrow is as important as it is to learn what people want now.

What opportunities we provide, hold back, encourage people to find, or protect people from, depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.

### **Looking for control**

Most of us seek, and to a large degree achieve, the amount and kind of control that we want over major aspects of our lives. Control is part of what gives us the predictability that we value. One of the more devastating feelings that people report is being out of control or experiencing a loss of control. When we have less control than we desire, increased emphasis is placed on the control that remains. For people with disabilities who live in very controlled settings, control is sought where ever it can be found. Some of the behaviors that we want to change around food, aggression, self-injury and sexuality are a reflection of a lack of desired control over other aspects of life. When people gain positive control over

their lives, the behaviors that have caused us concern may diminish and with some people vanish.

### **The difference between sharing control and giving control**

Control is not a fixed quantity. It ebbs and flows in our relationships and it can ebb and flow with the people we support. An agency in North Carolina that is supporting people with severe and persistent mental illnesses as well as cognitive impairments sees control as moving toward the person supported whenever possible but also returning to staff when the person supported has an acute episode. Someone with a severe seizure disorder may be able to do some things when the seizures are under control and should not have the same opportunities when the seizures are not under control.

### **Rethinking choice**

Our recent history is filled with stories of people whose lives were totally controlled and who now live in happy interdependence. People who were seen as not competent to select what to wear are now living in their own homes. We are also hearing of the people who have been injured when some one used choice as an excuse to not think. We need to recognize that the people we support are the experts on what they want, while we are their partners in helping them get it. We need to have relationships where we share control and continuously support people in gaining as much control as is possible. Many people, especially those with severe disabilities, are only asking for modest control. They want to be able to: control the pace of life (to not be rushed); to be listened to (to only got to bed when they



are sleepy); and to have a say in who their staff are (to only be supported by people that they trust).

In our relationships, we should help people grow and remember that there is a dignity to risk. At the same time, there is no dignity in serious injury. We need to see the key to growth as starting with

understanding what people want today and then helping people find opportunities so that they will know what they want tomorrow. We need to recognize that everyone wants and needs control over some aspects of their lives. Our jobs include supporting people in gaining that control.

1995

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## **Tools to Help People Hire Their Own Staff**





# Some Tips on Hiring a Personal Assistant

(adapted from **Becoming Independent**, Santa Rosa, CA)

### **About Your Lifestyle**

Before considering hiring someone to work for you in your home or looking for a roommate it is helpful to assess what kind of person you want to be with by first looking at your own personal lifestyle preferences. Once you have an idea of the kind of lifestyle you prefer you will be able to decide what kind of person will fit into your lifestyle. Ask yourself the following questions:

#### **Personal habits, etc.**

1. Do I smoke?
2. Do I drink alcohol?
3. Do I take drugs or smoke pot?
4. Do I like to sleep late in the morning or get up early?
5. What time do I usually go to bed at night?
6. Do I go out to visit friends or participate in activities?
7. Will I want to entertain friends and family at my home?
8. Am I ok with my roommate having overnight guests?
9. What do I like to do for entertainment?
10. Do I like to watch TV? What are my favorite shows?
11. Do I like to listen to music? What kind? What volume?
12. Do I like a quiet atmosphere?
13. Describe my personality?
14. Do I consider myself easygoing?
15. How do I react if I have to change my plans at the last minute?
16. Is there a spiritual aspect to my life which is important?



### **Food and eating arrangements**

1. What kind of foods do I usually eat?
2. Do I like to cook?
3. Where do I shop for groceries?
4. Do I eat at regular times or when I feel like it?
5. How do I feel about eating with my Personal Assistant?
6. Do I have kitchen appliances and/or dishes, pots and pans?

### **Housekeeping**

1. What do I do around my home for cleaning and laundry?
2. Do I like things very neat or am I not particular?
3. Would I like a definite cleaning schedule or a casual arrangement?

### **Personal Care**

1. How often do I bathe and/or shower?
2. What are my basic grooming habits? How long does it take?
3. Do I need any help from a Personal Assistant with my personal care?



### Job Description

Now that you have clearly defined your needs and examined your lifestyle preferences, you are ready to make a formal job description. This job description will be a major tool with your face-to-face interview in the hiring process. You may want to ask for assistance in this process from your supported living agency.

#### **Benefits of Job Descriptions**

- Gives you an opportunity to define your lifestyle, strengths and limitations.
- It can be used as a guideline for more in depth questions in the interview process.
- It will give a prospective employee an idea of what the position requires.
- After an individual has been hired, it can serve as a checklist of duties of the position.
- You, the employer, can use it as an evaluation tool for your Personal Assistants.
- It can be used if there are disagreements regarding the job responsibilities.
- This job description can help to keep the relationship open.



## Developing a Personalized Job Description

1. State the title of the job you are describing:
  
2. Describe the schedule of the job including days and hours of work:
  
3. Describe the areas that you need assistance with:
  - Personal care needs:
  
  - Grooming needs:
  
  - Bathroom needs:
  
  - Lifting/Transferring needs:
  
  - Meals:
  
  - Housekeeping:
  
  - Mobility/Transportation:
  
  - Medication:
  
  - Communication:
  
4. Describe what kind of training you will provide for this job:
  
5. Describe the Supported Living Agency's policies and/or record keeping duties:
  
6. Describe the wage, pay schedule, benefits and other compensations.



## How to Write a Personal Employment Ad

Writing an ad to find someone to hire as your personal assistant or companion is a real skill that will help you get started on hiring the right person to work for you. Here are some suggestions for writing an effective ad.

### Step 1: Cost of the Ad

Figure out how you will get funding for an ad if you decide to advertise in a newspaper. Some supported living agencies may be willing to pay this nominal fee to assist their consumers in this step of the hiring process. If there will be no costs for your form of advertising, you may want to gather the materials (e.g., marking pens, typewriter, or colored paper for flyers) you may need to begin this project.

### Step 2: Research

Read the classified ads in the newspaper or other sources for attendants, caregivers, aides, etc. This can give you an idea of how to or how not to write your own ads. See which ads seem attractive to you and develop an ad with some of those ideas in mind.

### Step 3: Writing

Start with the bare essentials (See Precautions):

1. Title or name of position available
2. Job prerequisites (e.g., needs car, non-smoker, prior experience)
3. Pay and schedule
4. Where to contact for more information, e.g., a phone number

#### Precautions

When writing your personal employment ad there are some **precautions** to take as this information is going to the general public and not to people you already know and trust. Some general guidelines:

1. Do not give your full name in the ad
2. Do not give your street address
3. For newspaper ads, do not mention if you are a male or a female

### Step 4: Finish

Now you can have fun and make some additional descriptive statements that may make the ad more attractive to someone interested in the job. For example:

1. Energetic, young woman .....
2. Active man in his thirties looking for .....
3. College student with disability needs help with...
4. Very social woman with physical disability needs....



### Phone Interview Questions

- What is your name and how do you spell it?
- What is your address and phone number?
- How did you hear about the job?
- What experience do you have that relates to my job?
- Do you have any experience doing personal care with intimate contact?
- Why are you currently looking for a job?
- What do you use for transportation?
- Do you have car insurance?
- Are you willing to drive for me?
- Do you smoke or use alcohol?
- Do you have any physical limitations that may affect your ability to do my job?
- Can you lift up to \_\_\_\_ pounds?
- What hours and days of the week are you available to work?
- Would you consider a Live-In position?
- Would you consider Relief or On-Call work?
- How much money do you expect to be paid?
- Would you like me to send you a job description and application?
- After I receive your application could you come meet me for an interview?
- Do you have any questions about me or the job that I have available?





### Tips for Interviewing

**Conducting a good interview is a true skill. A “good” interview is one that results in both parties being heard and understood by each other. Here are some tips.**

- Arrange for privacy.
- Limit physical barriers (such as desks or extra furniture) to ease conversation and make applicant comfortable.
- Introduce yourself and anyone else involved with the interview.
- Describe the job.
- Preview the interview process.
- Explain you will be taking notes.
- Tell the applicant when they will hear from you again.
- Ask each applicant the same questions for ease in comparing answers.
- Use prepared situational questions like....

Can you tell me an interaction you had with a disabled person that was positive/negative?

Describe a time you were overwhelmed and how you resolved it.

What makes you want to be a paid roommate?

In terms of time, what kind of commitment to such a position (to me) are you willing to make?

What other interests or activities are you involved in which would affect the amount of time or support you will be able to provide to me?

What will you expect from me as a roommate?



## **Hiring People to Provide Personal Support Services**

(Towards Maximum Independence, San Diego, CA; reprinted from  
Getting to Know You: Planning for Services in Supported Living, CIRCL, 1999)



## ADVERTISING FOR AN ATTENDANT

Be creative and imaginative as you can in selecting where and how to advertise. Ask others who have done this what has worked for them. This is a very individual thing and will depend on your specific needs and the resources in your community.

### Places to Advertise

- Local newspaper, weekly advertiser, etc.
- Financial Aid Office (i.e., community colleges, etc.)
- Bulletin Boards (i.e., apartments, grocery stores, libraries, etc.)
- Word of mouth
- Social Service Agencies/Church Newsletter

### Sample Ads

Full-time personal care attendant needed for female with a disability. Assist with personal care, grocery shopping, housekeeping, etc. Minimum wage, hours vary. Ideal for student. Call \_\_\_\_\_.

Part-time personal care attendant needed for male. Eight to twelve noon weekdays, \$\_\_\_\_ per hour. Call \_\_\_\_\_.

## TELEPHONE SCREENING

- 1) It is important when talking on the phone to be friendly and pleasant.\*
- 2) Give a brief description of what the job is, the pay and the hours.
- 3) Ask if this is the type of position the person is looking for or interested in.
- 4) If the person is not interested, thank them for their inquiry and hang up.
- 5) If the person is interested, set up a time to meet and conduct a formal, personal interview. Be sure and get the person's name and phone number in case you need to reschedule. For safety reasons, it is highly suggested you have someone you trust present at the formal interview, perhaps a parent, friend, casemanager, etc.

\* Suggestion: Limit information about yourself over the phone - maybe have it written down so that you can share it during the personal interview.



## Attendant Application

### Part A -

Name: \_\_\_\_\_

Phone No#.: Home \_\_\_\_\_/Work \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Contact incase of an emergency: \_\_\_\_\_

Emergency Phone No.# \_\_\_\_\_

### Part B -

1. Are you looking for a Come-in \_\_\_\_\_ or Live-in \_\_\_\_\_ position?
2. Dates available for hire: \_\_\_\_\_
3. Are you looking for a Permanent \_\_\_\_\_ or Temporary \_\_\_\_\_ position?
4. What hours and days are you available to work? \_\_\_\_\_
5. Do you have another job? \_\_\_\_\_/Are you a student? \_\_\_\_\_
6. What is your schedule? \_\_\_\_\_ How flexible can you be?

\_\_\_\_\_

7. Are you willing to do emergency attendant work? \_\_\_\_\_

### Part C -

1. What is your means of transportation? \_\_\_\_\_
2. Do you have a valid California driver's license? \_\_\_\_\_
3. Are you willing to run errands? \_\_\_\_\_
4. Are you willing to drive me to the doctors? \_\_\_\_\_



**Part D -**

1. How did you hear about this job? \_\_\_\_\_
2. Who referred you? \_\_\_\_\_
3. Are there any jobs that you would not want to do? (ex: driving, asst. doctors appts. or any other jobs included on the job description, etc.)

**Work Record**

**Part E -**

List most recent employer first:

1. Employer: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

What type of work: \_\_\_\_\_  
 Dates of Employment: From: \_\_\_\_\_ / To: \_\_\_\_\_  
 Reason for leaving: \_\_\_\_\_

2. Employer: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

What type of work: \_\_\_\_\_  
 Dates of Employment: From: \_\_\_\_\_ / To: \_\_\_\_\_  
 Reason for leaving: \_\_\_\_\_

May I contact current employer?



### **Applicant Profile - Continued**

#### Skills:

CPR

First Aid

OT/PT Training

#### Comments:

#### **Personal:**

Pet(s)

Children

Smokes

Willing to assist with personal care/IHSS

#### Comments:

#### **Reason For Desiring Roommate/Neighbor Position: (If applicable)**

#### **On File:**

Fingerprints

DMV Printout

Professional References

Personal References



## Important Things To Know About Me

Name: \_\_\_\_\_

(This is information that you will want to share with an attendant or roommate that you're thinking of hiring. Do not share anything you do not wish to share. Consider ways people can be most helpful yet respectful of your rights and privacy.)

- A. Routines (Consider daily needs related to getting up in the AM, preparing for work, personal care, mealtimes, etc.)

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- B. Complex/Medical Needs (Think about specific assistance you will require with such things as medication, equipment, lifting, transferring, etc.)

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C. Interests, Hobbies, Preferences (What do you like to do? Where do you like to go? Favorite foods. Pet Peeves. Allergies, etc.)

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B. Other (Consider any other important things someone might need to know about you.)

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This allows a person to share valuable information about themselves in a way which suits them as opposed to sending them off to read "collateral". It gives the prospective or new roommate/neighbor or support worker an idea of what is/will be expected of them.





## What Services You Need and When You Need Them

SERVICES	WHEN	OTHER INFORMATION
<p><b>Domestic Services:</b></p> <p><b>Related Services:</b></p> <ul style="list-style-type: none"> <li>• Prepare meals</li> <li>• Meal clean-up</li> <li>• Laundry</li> <li>• Shopping for food</li> <li>• Other shopping errands</li> </ul> <p><b>Non-Medical Personal Services:</b></p> <ul style="list-style-type: none"> <li>• Respiration Assistance</li> <li>• Bowel, bladder care</li> <li>• Eating</li> <li>• Routine bed baths</li> <li>• Dressing</li> <li>• Menstrual Care</li> <li>• Ambulation</li> <li>• Move in/out of bed</li> <li>• Bathe, oral hygiene/grooming</li> <li>• Rub skin, repositioning, help on/off seats, in/out vehicle</li> <li>• Care/assistance with prosthesis</li> </ul> <p><b>Transportation Services:</b></p> <ul style="list-style-type: none"> <li>• Medical Appointment</li> <li>• To alternate resources</li> </ul> <p><b>Protective Supervision:</b></p> <p><b>Teaching Demonstration:</b></p> <p><b>Paramedical Services:</b></p> <p><b>Total Monthly Hours:</b></p> <p><b>Basic Schedule:</b></p>		



## HIRING

Now it is time to make a decision.

1. Call the person you have chosen to tell her/him the good news. Also, be prepared to give a start date.
2. Call the other applicants saying you have hired someone else for the job. Then ask if for some chance the position reopens if you could call them back.

- OR -

Ask them if they are willing to work relief when necessary.

## TRAINING

It is best to have a former attendant assist with training if possible, or someone who knows what you need and how to do it.

1. Explain your disability and challenges.
2. Explain any technical words that you use.
3. Be sure to emphasize anything relating to safety or emergencies.
4. When giving instructions involving a procedure - include each step and why it's important that it be done a certain way.
5. Don't take for granted they know what you meant; ask for feedback.
6. Be patient - your new attendant will probably not get everything right the first time.

HINTS:

It may be helpful to have technical words, procedures, etc., written out or taped on a cassette.



## COMMUNICATING WITH YOUR ATTENDANT OR HOW TO BE A "GOOD BOSS"

**Note:** Throughout this guide you will find a strong emphasis on communication. Learning good communication skills and using those skills are the keys to working effectively with an attendant.

### **Good Work Environment**

It is a fact that attendant work is usually not well paid and offers few, if any, fringe benefits. Therefore, those who take this kind of job often do it because it has other rewards, such as personal satisfaction or a chance to work closely with other people. That makes the work environment a most important factor in keeping your attendant.

Good employers create a work environment that will bring out the best an attendant has to offer. You will want your attendant to have good morale, be happy and satisfied with his/her work and therefore, be a productive employee. Good communication between you and your attendant can help do this.

To create that good work environment:

1. Reward attendants for the work they are doing. Besides paying them, it is important to praise them frequently as well. Everyone wants to feel appreciated, needed and important.

For example, your attendant has transferred you very smoothly from your bed to your wheelchair. You might say, "That was a really smooth transfer. You do it very well and I feel very safe." You have communicated your appreciation in a very concrete way and your attendant will know that he/she has performed this task well.

2. When you must criticize something your attendant has or has not done, it is important to be open and honest and to criticize the action, not the person. For example, your attendant has returned an hour later than planned. He/she did not call to explain and you are angry. You might say, "You said you would be home an hour ago. I feel frustrated and angry when people are late. In the future, I would appreciate it if you would call me and let me know you'll be late." Don't say, "You stupid idiot--you're always late! I don't know what I'm going to do with you." This will only make your attendant defensive and angry and you won't resolve anything.



3. Don't let small irritations build up until an angry explosion occurs. Anger vented in these explosions often is expressed in a hurtful and destructive way. If you feel irritated about something that is happening, talk about it as soon as possible. This may happen daily, especially if you have just begun to work together.
4. Respect your attendants. They are human beings and should be treated accordingly. Use the Golden Rule and treat your employee as you would like to be treated. Be honest, fair, kind, respectful and patient.
5. Attendants have their own lives too. Especially with people who live-in, it is important to be sure to respect their privacy, leave them alone during their time off and realize that unexpected events sometimes disrupt schedule. Although your attendant has responsibilities to you, you should not attempt to control his/her life. Flexibility and compromise are important qualities for both of you.
6. Ask your attendant how he/she feels about their work and about you as an employer. Set a regular time to share feelings about your relationship. And then, both of you be open to making changes in the routine, in attitude or in anything else that can correct a problem. After all, you are not in a nursing home where routines are set--this is your home where changes can and should be made.
7. When things just don't work out even after repeated attempts, it is time to terminate the agreement. There are good and poor ways to do this as well.

Do state your reasons clearly without attacking him/her personally.

Do give a period of notice, usually two weeks. This allows time for him/her to find a new job and/or place to live and you to find a replacement.

Do not withhold payment of wages even if you are not satisfied with his/her work. Just give notice and terminate the agreement.

To summarize, you as the employer, have the opportunity to provide a positive work environment for your attendant. This in turn helps him/her to be happy, productive and motivated to work for you. Good communication between the two of you is the key to this interdependent relationship. An attendant who is happy in his/her work will stay with you longer and do a better job, which will benefit both of you. If you are interested in learning more about communication skills, check with your local social service organization, colleges, universities or technical schools for classes in assertiveness, conflict management or basic communication skills.



## GIVING PRAISE

1. Always be sincere. Don't say something you don't really mean.
2. Give compliments often.

### TWO STEPS FOR GIVING COMPLIMENTS

Step 1: Describe the situation or event which you liked.

Step 2: Tell what your feeling was when it happened.

or

Say that you appreciated it

or

Say "Thank you"

## GIVING CRITICISM

1. Give the criticism as soon as possible after the situation that you dislike occurs.
2. Criticize only one incident at a time.
3. Do not bring up things from the past. Stick to the present.
4. Criticize the person's actions; not the person.
5. Keep the criticism brief and to the point.

USE CRITICISM AS A TOOL FOR SHARING INFORMATION WITH YOUR ATTENDANT THAT WILL HELP HE/SHE TO WORK WITH YOU MORE EFFECTIVELY. THREE STEPS FOR GIVING CRITICISM:

STEP 1: Describe the situation or event that you disliked.

STEP 2: Tell what your feeling was when it happened.

STEP 3: State what would make it better next time. Give a suggestion.

WORK TOGETHER TOWARDS A SOLUTION.





# **Section 3.**

# **Tools and Applications for Relationships**







## Some Tips on Organizing and Nurturing a Circle of Support

1. Interview the focus person (and family and friends) and get names, addresses and the telephone numbers of people to invite (for example, parents, siblings, other family, friends, neighbors, teachers or therapists, pastor, physician, etc.). Note: If the purpose of developing a circle of support is clear (for example, helping the person decide where to live and with whom), be sure to invite people who can make a difference.
2. Set a convenient time and place for the initial meeting. This should be the focus person's home or other comfortable, non-agency place. Suggest that the focus person (or family) prepare or bring cookies, cheese & wine or whatever.
3. Send a letter inviting people to come to an initial meeting. The person with a disability may wish to follow-up by telephone.
4. Typical ground rules are (1) to ask people to come to the first and at least one follow-up meeting; (2) no one should feel obligated to offer support (advice, information, personal assistance, etc.); and (3) keep it light and have fun.
5. A facilitator should be recruited in advance. He or she should have an easel, flip-chart, marking pens and be good at writing things down and keeping the conversation moving along. **Note:** If possible, someone other than a parent should do this so that it is a community (rather than an exclusively family) affair.
6. After introductions, you can agree on additional ground rules, which might include:
  - Take turns
  - Listen to one another and probe only to clarify
  - Be respectful of each other's ideas and information
  - Keep all information [at least private information] in the room
  - If you say you will do something, follow through
  - Support one another.
7. Go through a set of questions that will provide information and direction for the future. Ask the focus person first, then family, then friends. Note what people say. Move to the next question. Summarize the consensus and wrap-up the meeting with the three or four bottom-line questions (for example, what kinds of support do you need to get there).



8. Set date and time for follow-up meeting (say, in 4 weeks). Write up what was learned, the vision of what is wanted, the steps to get there and what people offered to do. Send out these notes, perhaps with a second letter.

### Some lessons learned

The following factors are often critical or very important in maintaining a personal team, constructively involved in supporting the person:

**Communication.** One person agrees to write up the results of get-togethers and to send out notices of upcoming get-togethers.

**Listening.** Trying to respond to what the person wants and building consensus. Teams which listen carefully to the focus person and each other, who respect each person's views and who base offers of assistance on what the person wants or on what the group perceives as in the person's best interests do best.

**Facilitation.** Someone may need to facilitate meetings by keeping track of time, identifying issues and offers of assistance and seeing that each person has an opportunity to contribute.

**Having fun.** Teams whose members enjoy each other and have fun together, often stay together longer and are eager to continue to be involved with the focus person within the context of a circle of support. Having fun can help maintain a group, but sometimes people need to share their anger, despair and outrage. Not all circle meetings are light.

**There is no single, best way.** One needs to be adaptable and responsive to the needs and desires of the focus person. One person may not like or do well with large, formal get-togethers. If so, try strictly social meetings. One person may wish to keep friends at some distance from one another; let this person direct the group. One person may want a full-blown personal futures plan; another may have a more limited need (like additional recreation). The circle and its processes should reflect these differences.



# Why Friends Are Important?

(Adapted with permission from Direct Support Professional Training Curriculum, Year 1)

## Introduction

We all take friendship for granted. We might miss our friends if they are gone for a while, but most of the time we don't really think about the fact that we **have** friends. We have started to see the importance of people with developmental disability labels having connections with ordinary people. So many of the people in the lives of the people we support are paid to be there. While those may be satisfying relationships, there still is the element of paid friendships that is very different from most of our lives.

Friends don't care what's in the person's IPP objectives. They like the person "just because." There is no program for starting a friendship. There are no data to maintain.

Friends can offer people a way to practice what we teach in our programs. Have you ever had to do something difficult – like give a speech or register a complaint – and you practiced first with a friend?

Friendships have an energy that can't be otherwise created. When two people do things together, more can be accomplished than if they had each tried on their own.

Friends accept us as we are. Our friends are used to some of our unusual behaviors or mannerisms, and don't try to change them. The people we support need someone who also accepts unusual behavior as "just a part of the person they like."

We can't write programs for making friends. We can, though, help to set up ways in which friendships can happen. People can join activities that they enjoy and meet people in the course of the activity. People can "hang out" at places where other people get to know them. Think about some ways that you can help people make connections.

## As Relationships Grow

Studies show that the reason friendships grow is because people live close to each other and are able to see each other on a regular basis. Supported living support staff may have to assist people in starting relationships and be available to encourage their continuation. We might have to provide transportation so people can spend time away from our homes, assist in planning activities and assist with training on social skills that are needed to continue relationships.

Some of the skills that friendship requires have never been taught to people with developmental disabilities. People need to know things like how to listen to another person. We know that listening is a very difficult skill requiring practice. All people have a very tough time listening. Yet, listening to someone is the best way to learn more about them.



A friend needs to be able to communicate well enough to get their message across to another person. A person needs to know either what words or what gestures to use to assure that the person to whom they are speaking will understand what they are trying to say.

Friends are thoughtful and do thoughtful things for each other. Are there ways that people you support either need to learn to think about what might please another person or think about ways they can let another person know they care?

These are some of the skills that are important to starting and keeping friendships. Perhaps you can think of others as well.

## Natural Supports

*Natural supports* are something often talked about when working with people with developmental disabilities. For so long there have been very few natural supports in the lives of people with disabilities, particularly adults. In the case of children, the only natural support has been family members.

*Natural supports* are services and supports, freely available, from family members, friends, co-workers and associations of one kind or another (e.g., churches; clubs; community service organizations). Natural supports are for all people and not specifically for people with disabilities.

*Natural supports* make you feel part of something, give you friends, are your most important relationships, help you and make you feel good.

There are many ways that *natural supports* can assist individuals in leisure and recreation activities including: helping make friends, being a “buddy”, helping make accommodations, “smoothing the way” if there are problems, leading to more independence and “just feeling good.”

There are a few questions that come to mind:

### **Is the natural support needed by the person?**

Many times a person with a disability doesn’t really need any help once he or she becomes familiar with a situation or the natural support may develop without assistance.

### **Is the natural support available to the person?**

Although the most common natural support is the family, sometimes family just isn’t available. Parents may be too ill to be supportive...or, in some cases, there may be no family at all.

### **Does the natural support meet the person’s needs?**

Sometimes people prefer someone other than family to provide assistance. For instance, an adult with personal care needs may prefer a paid attendant to help with toileting instead of a friend or family member.





## Sex is Natural\*

People with developmental disabilities have heard for years that sex is not meant to be pleasurable, and people who want sex are bad and will take advantage. Many people have been told that harmless pleasure, like masturbation, is bad as well.

Studies show that teaching people about sex makes it less likely that they will be sexually abused. Hingsburger outlines what needs to be taught so that people can protect themselves from sexual assault.

1. **Vocabulary** – Body parts need names, and people need to know what purpose the body part serves. People need to be taught accurate terms.
2. **Pleasure** – People need to know that they have parts on their body that give a lot of pleasure. This is a good thing.
3. **Context** – People need to know that giving and getting sexual pleasure belongs in the context of a loving relationship. They need to know that both people agree to provide and get pleasure.
4. **Responsibility** – People need basic information about pregnancy, and safe sex behavior. Pregnancy is a choice people may make, but they must be informed.

5. **Facts** – People need to have information about sexually transmitted diseases and how to protect against their spread. Hingsburger recommends teaching from the point of view of love, and not fear of death, particularly about HIV. Rather than tell people that not using a condom could lead to death, he has found a more effective way to teach safe sex: If you really love and care for someone, you want to keep them healthy. [**Note** : It's important to remember that condoms, even when properly used, do have a relatively high failure rate and do not guarantee protection from contracting HIV and other serious sexually transmitted diseases.]

**Note:** It's important to remember that most individuals have very strong beliefs about sex. These beliefs may originate from religious, cultural, familial, and/or experiential sources. However, whatever the personal beliefs of the people we're supporting may be, our job is not to try and change their beliefs but rather to ensure they have accurate information.

(Adapted from Hingsburger, Dave, *Just Say Know: Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities*, Diverse City Press, Eastman, Quebec, 1995.)



## How Much Do You Really Know About Sex?\*

Mark a T if you believe the sentence to be true.

Mark a F if you believe the sentence is false or a myth.

- \_\_\_\_\_ 1. People with developmental disabilities do not know and cannot learn the basics of sex.
- \_\_\_\_\_ 2. Most people get information about sex from their parents.
- \_\_\_\_\_ 3. People with developmental disabilities will always have babies that are developmentally disabled.
- \_\_\_\_\_ 4. Masturbation makes people go blind or become crazy.
- \_\_\_\_\_ 5. People with developmental disabilities cannot control their sexual drives.
- \_\_\_\_\_ 6. People with developmental disabilities are not capable of having good relationships or marriages.
- \_\_\_\_\_ 7. People with Down Syndrome cannot make babies.
- \_\_\_\_\_ 8. A person will be homosexual as an adult if they acted sexually with a person of the same sex when they were a child.
- \_\_\_\_\_ 9. A woman can get pregnant during her menstrual period.
- \_\_\_\_\_ 10. A woman must have an orgasm to get pregnant.
- \_\_\_\_\_ 11. People who have developmental disabilities do not masturbate as much as other people.

\* Adapted from material from *Committee on Sexuality* training program.



## Part Four: Tools and Applications

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- \_\_\_\_\_ 12. People with developmental disabilities do not want sex.
- \_\_\_\_\_ 13. Alcohol can make a person better at sex.
- \_\_\_\_\_ 14. You can contract or get HIV or AIDS from someone if they cough on you, hug you, or shake hands with you.
- \_\_\_\_\_ 15. Using a condom can be effective in stopping the spread of sexually transmitted diseases, but they are not foolproof.
- \_\_\_\_\_ 16. The clitoris is the main place on a woman's body that helps her reach orgasm or get sexual pleasure.
- \_\_\_\_\_ 17. Sex education can teach people to be safe from sexual abuse.
- \_\_\_\_\_ 18. Women who are sterilized (so that they cannot get pregnant) will not have a menstrual period.



## How Much Do You Really Know About Sex?

- 1. People with developmental disabilities do not know and cannot learn the basics of sex. (F)**

Many people with developmental disabilities don't have enough knowledge of intercourse, pregnancy, menstruation, sexually transmitted diseases and other parts of their sexual lives. There is some misinformation and ignorance among people without disability labels as well.

- 2. Most people get information about sex from their parents. (F)**

People with developmental disabilities report peers and personal experience is how they learned about sex. Many people report that their parents never discussed sex with them. For those that did discuss sexual behavior, it tends to be out of fear that someone will take advantage of their child.

- 3. People with developmental disabilities will always have babies that are developmentally disabled. (F)**

Less than 10% of the known causes of developmental disabilities are genetic and those occur in the total population.

- 4. Masturbation makes people go blind or become crazy. (F)**

Masturbation is a harmless source of sexual pleasure that helps relieve sexual tension and helps people learn about their own bodies. Masters and Johnson, in an early study, report that 90% of men and 60% of women masturbate at some time. It is not physically harmful and doesn't harm your mind. It is only harmful if the person feels guilty about it.

- 5. People with developmental disabilities cannot control their sexual drives. (F)**

It is not true that all people with developmental disabilities show poor self-control. There are people who need emotional and social support to learn how to best interact in certain situations.

- 6. People with developmental disabilities are not capable of having good relationships or marriages. (F)**

Many people with developmental disabilities are successfully dating and marrying. Some people may need additional supports if they become parents.





**7. People with Down Syndrome cannot make babies. (F)**

Women with Down Syndrome have become pregnant and have had children. Men with Down Syndrome are almost always unable to produce children. Their sperm is known to not move quickly enough in the woman's body.

**8. A person will be homosexual as an adult if they acted sexually with a person of the same sex when they were a child. (F)**

Same-sex experiences are common during the growing up years. According to an early Kinsey study, 60% of men and 33% of women had some kind of homosexual sex play before they were 15 years old. This does not lead to becoming homosexual.

**9. A woman can get pregnant during her menstrual period. (T)**

A woman could have a short cycle, so she would ovulate on the 7<sup>th</sup> day of her menstrual cycle. Sperm can live in the fallopian tube for up to 5 days. So the woman could get pregnant between day 3 and day 7 of her cycle.

**10. A woman must have an orgasm to get pregnant. (F)**

This is false AND a woman could get pregnant even if the MAN doesn't have an orgasm. There are thousands of sperm in what's called the preseminal fluid that comes out of the penis before orgasm. Any time sperm enter the vagina (even on a finger) there is a possibility of pregnancy. So, "playing around" has the risk of pregnancy.

**11. People who have developmental disabilities do not masturbate as much as other people. (T)**

There is less masturbation among people with developmental disability than other groups of people. They may be noticed more because they are less able to find privacy, but they do not masturbate more.

**12. People with developmental disabilities do not want sex. (F)**

Sexual drive is not related to disability. Sex drive is present, although some conditions and how severe the disability is may affect it.



**13. Alcohol can make a person better at sex. (F)**

Alcohol may make people THINK they are better at sex or may make a person less able to say no to sex. In men, alcohol may make it more difficult to become erect or to have an orgasm. However, alcohol can lower the inhibitions of someone who does not want to have sex.

**14. You can contract or get HIV or AIDS from someone if they cough on you, hug you, or shake hands with you. (F)**

HIV is spread through semen, vaginal fluid, blood or breast milk according to the Center for Disease Control.

**15. Using a condom can be effective in stopping the spread of sexually transmitted diseases but they are not foolproof.. (T)**

The best protection against sexually transmitted diseases is abstinence. Condoms are not foolproof. The only way to be absolutely protected is to not have sex.

**16. The clitoris is the main place on a woman's body that helps her reach orgasm or get sexual pleasure. (T)**

The clitoris is much more sensitive than the vagina, which has few nerve endings. The clitoris has the same amount of sensitive tissue as the penis.

**17. Sex education can teach people to be safe from sexual abuse. (T)**

Sex education can teach people about body parts and how those parts work, about how to meet people that they might want to get to know and to report when someone touches them in a way they don't like.

**18. Women who are sterilized (so that they cannot get pregnant) will not have a menstrual period. (F)**

Tubal ligation, a surgery, doesn't effect a woman's periods. The only way that periods stop is if the uterus and/or ovaries are removed. This is called a hysterectomy. A hysterectomy cannot be done to sterilize someone.



# **Section 4.**

# **Tools and Applications for Community Membership**



**Activity Checklist:**  
**My Own Leisure/Recreation Style**  
(from Year 1 Direct Support Professional Training Resource Guide, 1999)

**I prefer activities where I am:**

**Alone**

**With a couple of friends**

**In a big group**

**When I have free time, I: (circle as many as you wish)**

**Watch TV**

**Go to the health club**

**Read a book**

**Work on a hobby**

**Go out to dinner**

**Travel**

**Go on a walk**

**Listen to music**

**Take a class**

**Make something**

**Hang out with friends**

**Camp**

**Take a nap**

**Play on a team**

**Go shopping**

**Hike**

**Go to a concert**

**Play**

**Think**

**Watch sports**

**Play with pets**

\_\_\_\_\_  
**(other)**

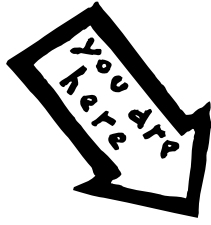
\_\_\_\_\_  
**(other)**

\_\_\_\_\_  
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\_\_\_\_\_  
**(other)**

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**(other)**

\_\_\_\_\_  
**(other)**



# Excerpts from A Guide to Developing Community Connections

Compiled by  
Patsy Davies and Claudia Bolton  
October, 1996





# An Associational Map

Prepared by John McKnight

Northwestern University

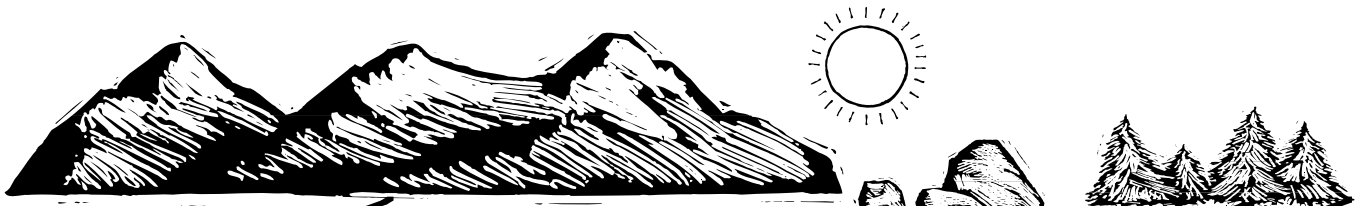
Center for Urban Affairs and Policy Research

*Associational life is rich in all of our communities. Learning about where the community networks are is useful information to have on hand. This is a guide to help you learn about the possible associations in your community. Use this list to think about the various organizations people belong to. You can identify groups in your area in a number of ways - talking to others, looking in the phone book, reading area and neighborhood newspapers, surveying churches and existing groups, checking with the Chamber of Commerce, etc. Make your own listing and use it as a resource as you think about connecting specific people.*

Associations (examples)	Your Area
<b>Artistic Organizations</b> choral, theatrical, writing	
<b>Business Organizations</b> Chamber of Commerce, business associations	
<b>Charitable Groups &amp; Drives</b> Red Cross, Cancer Society, United Way	
<b>Church Groups</b> service, prayer, men's, women's, youth, seniors	
<b>Civic Events</b> July 4th, art fair, festivals, Halloween	
<b>Collectors Groups</b> stamp collectors, flower dryers, antiques	
<b>Community Support Groups</b> Friends of the Library, nursing home, hospital	
<b>Elderly Groups</b> Senior Citizens	
<b>Ethnic Associations</b> Sons of Norway, Black Heritage Club, Hibernians	
<b>Health &amp; Fitness Groups</b> bicycling, jogging, exercise	
<b>Interest Clubs</b> poodle owners, antique car owners	



Associations (examples)	Your Area
<b>Local Government</b> town, fire department, emergency units	
<b>Local Media</b> radio, newspaper, local access cable TV	
<b>Men's Groups</b> cultural, political, social, educational, vocational	
<b>Mutual Support (Self Help) Group</b> Alcoholics Anonymous, LaLeche League	
<b>Neighborhood &amp; Block Groups</b> crime watch, beautification, Christmas decorations	
<b>Outdoor Groups</b> garden clubs, conservation clubs	
<b>Political Organizations</b> Democrats, Republicans, caucuses	
<b>School Groups</b> printing club, PTA, child care	
<b>Service Clubs</b> Zonta, Kiwanis, Rotary, AAUW	
<b>Social Cause Groups</b> peace, rights, advocacy, service	
<b>Sports Leagues</b> bowling, swimming, baseball, fishing, volleyball	
<b>Study Groups</b> literary clubs, bible study groups	
<b>Veterans Groups</b> American Legion, Veterans of Foreign War	
<b>Women's Groups</b> cultural, political, social, educational, vocational	
<b>Youth Groups</b> 4H, Future Farmers, Scouts, YMCA	



In addition to formal and informal associations, learning about the places in your community is an important exercise. The following map was developed by Allen, Shea & Associates as a way for you to explore the various places in your own community. It is helpful to do this exercise with someone else who lives in your community (two heads can be better than one!). Consider the various places, setting, activities and gathering places that are part of your community.



Where do people go on the weekends?



Where do people gather?



What do people go for fun?  
Where do they go?

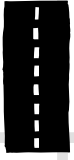


What clubs do people join?



**TAKE A WALK AROUND YOUR**





What are the major streets for shopping, services, entertainment?



What are the public places (library, community center) that people go?



Where is the center of the community? What's there?



What are favorite places to shop?

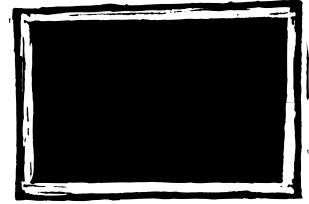


What is unique to your community?

# COMMUNITY, WHAT DO YOU SEE?



# These Are The Opportunities In My Community



**Brainstorming Places That Enhance Community Contributions.** *Be creative and develop a wide variety of opportunities. Consider all of the possible sites, settings and roles in which people can contribute.*

<i>Summarize the interests, gifts, qualities and identities you hope to develop.</i>	<i>List the community opportunities, settings, associations, networks and places where people come together with similar interests, talents and values.</i>

Adapted from *Capacity Works: Finding Windows for Change Using Personal Futures Planning*, Mount, 1995



## Five Action Steps for Getting Started

*Identify several ideas that seem most appealing and then outline five specific strategies for getting started. Remember to include who you will contact, when and any additional information you may need to get started.*



# Community Groups, Organizations and Places



**Thinking** about how to connect a person to a place requires: knowing the person well; knowing the place; thinking about the supports everyone involved will require; providing support in the most effective, flexible manner; and thinking, rethinking and evaluating your approaches.

***The next exercise was adapted from one developed by Kathryn Kemery McClain as a way to think through the characteristics and rituals of a particular place or organization. It is designed to assist you to explore the various possibilities for involvement in a particular activity or place. It is important to know about the setting, the demands and the opportunities it may place on the person. This activity helps us remember the progression of activity one would go through in order to participate. The next step for you after this exercise is to consider the supports a specific person will need during each stage of interaction.***

## **THE STAGES OF INTERACTION.**

**Arrival:** List things related to how other people arrive at the group or place.

**Entry:** List things related to how people actually get into the building or location. Do people have to walk up steps, knock, open the door?

**Getting started:** List anything that happens from the point that you get into the building until the activity actually starts. This could include things like finding a seat, knowing to be quiet when the meeting begins, greeting other people, introducing yourself, etc. Sometimes the atmosphere is very informal while other situations have more formality. Are there unwritten ground rules?

**Participation:** List anything that occurs during the main portion of the situation or meeting. This varies greatly. Look for the unwritten rules, types of interaction and types of conversation as well as the “things” that are required. For example, you would want to go to a coffee house with money.

**Finishing up:** How can you tell the activity is winding down? Are there specific things that occur? Again, remember the unwritten rules.

**Exit:** List whatever is required to leave the building. Pay attention to whether people talk with one another on the way out, whether folks go out for coffee after the activity, etc.

**Departure:** List how people leave.

**CHARACTERISTICS.** A running description of anything relevant that occurs at that particular stage. This can include things like how people are dressed, seating arrangements or anything else that seems relevant given the setting and the person you will be supporting.

**EXPECTATIONS AND DEMANDS.** Includes anything that the setting demands during a particular stage. It could be a response such as shaking hands or saying good-bye, an ability or skill, etc.

**DESCRIBE THE PEOPLE WHO ARE PART OF THE SOCIAL SETTING.** This can include a variety of things such as age, sex, “type” of person or anything that strikes you as relevant or defining about the group.



Name of Group or Place: \_\_\_\_\_

Location: \_\_\_\_\_

Community Places		
<i>Stages of Interaction</i>	<i>Characteristics</i>	<i>Expectations and Demands</i>
Arrival		
Entry		
Getting started		
Participation		
Finishing up		
Exit		
Departure		

Describe the people who are part of this place or group:

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# **Section 5.**

# **Tools and Applications for**

# **Flexible, Tailored**

# **Services and Supports**







## **SUPPORTING PEOPLE WITH CHALLENGING BEHAVIORS**

**(by LaShawn Wells and Krista Loomis, Consultants, CIRCL)**

### Introduction

There may be times when the person you are supporting communicates through behaviors that are dangerous or could be perceived as dangerous to their well-being, others well-being or the environment. The following information describes what types of challenging behavior could occur, why it may occur, how to try and prevent it from occurring and how to respond if it does occur.

It is important to remember that the responsibility of a support staff is to support the person to be safe, make choices and live a quality lifestyle in the community. This responsibility as it pertains to a person who is exhibiting challenging behavior is to: (1) support the person to not have the need to exhibit those behaviors; (2) respond in a manner that is respectful and non-judgmental; and (3) not attempt to control or “fix” the person. Each supported living agency should have specific guidelines on how to respond to challenging situations but the main focus should always be supporting the person in a respectful manner to be safe.

The following information attempts to give broad guidelines on challenging behaviors, why they occur and how to respond. Almost all human behavior is complicated and occurs for a multitude of reasons and there is never a simple explanation or reason why challenging behaviors may occur. Very often, it is almost impossible to know exactly why challenging behaviors occur so it is important to never try to classify or label the person by their behavior. By having a better understanding of challenging behaviors, a support staff will be able to respond in a manner that is safe and supportive.

Each agency should provide training to staff on their guidelines, policies and procedures on how to support people with challenging behaviors. It is also the agency’s responsibility to provide the staff with information on the individuals that they are supporting so that they are able to know how to support the person. This information could include the person’s ISP (Individual Service Plan), an ELP (Essential Lifestyle Plan) and their support plan as well as talking to the individual’s family, friends, staff and others who know and care. The staff’s responsibilities are to learn as much as they can about the person, uphold



supported living philosophies as well as the agencies and honor the rights of the person they are supporting.

The questions that many people face is how can they receive support in SLS if they are someone who manifests their actions through challenging behavior. The very idea that someone can be supported within the philosophy of SLS and yet that person exhibits challenging behaviors is an oxymoron. The concepts of “choice”, “dignity” and “support” collide with ideas like “control” and “restricted movement”. Two key concepts to remember.

### **Control versus Support**

A staff person who restricts a persons right to move about freely or who controls the person in any way whatsoever is not only denying that person their civil right to move about freely, they are also not acting in accordance with the principles of SLS. Control over the person takes place when the person who is receiving support is not allowed to go through the process of choice that is fundamental to everyone. Support is the process of working with the person to find out what he or she likes and supporting them in the choices that they make. This does not mean supporting them to hurt themselves or to break the law. Support means having a responsibility to them as a human being, not as a disabled person. Support may mean supporting people through bad decisions. If a person chooses to be overweight like many Americans, they should be supported to know the risk involved, yet they should not be controlled to go on a diet. It is important for the individual to feel that the people who support him or her are assisting them to be in control. At times, the individual may need the staff to be in control, but not be controlling, there is a difference. This may help to relax the individual, making them feel at ease especially when they are out of control.

### **Informed Choice**

Many would argue that because individuals may not understand the consequences of their choices, their choices should be limited. What needs to be stressed is that as support staff for people with disabilities, it is our role to help people understand the consequences of their choices but not to limit their choices. For many people disabled or non-disabled, understanding the consequences of making poor choices requires personal experience with the consequences of those choices. Also, understanding the consequences of one's choices doesn't always affect one's choice. Most people who smoke know and understand the dangers of smoking but still choose to do so.



## Information on Challenging Behaviors

For years the field has used the word “behavior” to describe actions that are not considered “normal” or “appropriate” ways of acting. A different way of looking at challenging behaviors is to see them not as behaviors but as coping mechanisms for very valid feelings, conditions or situations. The way a person responds to a situation or copes with a situation may not be the most socially appropriate but it is often what has worked best for the person, given their history, or it is the quickest, most direct way to deal with the emotions and feelings they are experiencing. So rather than looking at the actions described below as challenging behaviors, look at them as coping mechanisms or strategies for dealing with difficult emotions and situations. Trying to come up with a list for the challenging situations that may occur is difficult. The following list is not exhaustive and sometimes some of the actions or situations, which are listed here as challenging are very real and appropriate responses to situations or other people’s behavior.

<b>Physical aggression</b>	<b>Self-injurious behavior</b>
<b>Property destruction</b>	<b>Verbal threats</b>
<b>Screaming</b>	<b>Throwing things</b>
<b>Nudity in community</b>	<b>Unsafe sexual behavior</b>
<b>Stealing</b>	<b>False accusations and reports</b>
<b>Unsafe behavior with strangers</b>	<b>Ingesting hazardous materials</b>
<b>Refusal to follow good health practices</b>	<b>Sexual intimidation</b>
<b>Fire starting</b>	<b>Alcoholism and drug abuse</b>
<b>Refusing to take medications</b>	<b>Refusing to eat, or overeating</b>
<b>Disappearing without notice</b>	<b>Suicide attempts</b>

Here are 4 general categories for explaining why challenging behaviors may occur. The 4 categories were taken from PART-R (by Paul A. Smith, Ph.D., 1993) training material. Some of the information included has been added by the authors.

- 1. Fear** – Person may feel under attack or think that something is going to be taken away. Person may feel threatened, out of control and vulnerable or that there is a need to escape, defend against or eliminate a perceived threat. This response/behavior could be a result of the person having a personal history as being a victim of



abuse. The person who is feeling fearful may become aggressive either physically or verbally, become destructive to their environment or become aggressive to themselves.

### **Signals to watch for:**

- Posture could be tense and the person could look like they are prepared to defend, hide or run away
- Person could have a fearful expression, wide-eyed, pupils could be dilated
- Breathing could be rapid, shallow and irregular
- May be unable to speak or gasping

### **How to respond:**

- Posture should be relaxed and open; hands in full view
- Gestures should be slow and palms up
- Should be positioned slightly off to the side of the person and far enough away to make it clear that they are not under threat of attack
- Voice tone should be soft but firm, reassuring and confident
- Speech content should be logical, encouraging calmness, use the rule of 5 (Sentences consisting of 5 words or less)
- Eye contact only if the person seeks it otherwise don't force it on them
- Physical contact only if the person gives permission and should be light with slow movements

- 2. Anger/Frustration** – Person feels angry/frustrated and not in control of their environment or situation, as in fear may feel out of control, threatened and vulnerable, behavior is an attempt to gain control of situation by attacking the source of their anger/frustration. The person may have a history of low tolerance for frustration and impulsiveness. The person who is feeling angry/frustrated may become aggressive either physically or verbally, become destructive to their environment, or become aggressive to themselves.



### **Signals to watch for:**

- Posture is tense and ready to attack
- Skin color may be splotchy with tones of purple and red
- Facial expression may be tense, focused and angry
- Voice quality may be menacing, aggressive and loud
- Breathing could be loud, deep, long and heavy

### **How to respond:**

- Posture should be self-confident and commanding
- Gestures should be firm and commanding, palms out or down
- Position should be directly in front just outside striking range
- Voice quality should be quiet, firm and commanding in tones low enough to make the frustrated person strain to hear
- Speech content should be repetitive and confident and commands should be without threat
- Eye contact should be direct

- 3. Manipulation** – Person is trying to control the environment. Person may lose control of themselves in order to manipulate others in an indirect attempt to obtain or avoid something in exchange for not losing control. A person may make a calm but unreasonable request and when the request is not met they may threaten to lose control i.e. yelling, threatening behavior or aggression. It can be especially effective when out in public. Remember: Beneath every manipulative demand there is a legitimate request.

### **How to recognize: (May be difficult)**

- Person keeps increasing their demands with their voice tone becoming more and more strident or demanding. Tone of voice may become more aggressive and the person may begin to make threats.



### **How to respond:**

- Posture should be closed and relaxed
- Gestures should be relaxed and causal
- Position should close but far enough away to show noninvolvement
- Voice quality should be detached, mechanical and slightly bored
- Speech should be quiet and repetitive
- Eye contact should be avoided, look at the person's chin or shoulders

- 4. Intimidation** – Similar to manipulation but the person threatens physical injury. A calculated attempt to get something in exchange for freedom from the threat of injury.

### **How to recognize:**

- The person's voice and posture may be menacing. They may use threatening words and gestures or may crowd or stand too close. They may have a history of physical assault.

### **How to respond:**

- Posture should be poised and ready to react or move quickly, but not giving the impression of fear
- Gestures should be few
- Position should be of the greatest defense advantage, not allowing exit to be blocked or keeping something (furniture) between you and the person
- Voice quality should be matter-of-fact, monotone and emotionless
- Speech content should be clear and direct, repeated as often as needed, threats avoided, unrealistic consequences are not offered
- Eye contact should be used sparingly to emphasize a statement



There are other factors to consider in trying to understand why someone is exhibiting challenging behaviors. This is a broad list and there are many reasons aside from the ones listed below. Things to consider:

- **History of the person** - Did the person previously live in a large institutional setting or a group setting where their choices were not honored and they had little input about their day to day life? Is there a history of being abused or mistreated (post traumatic stress syndrome may be factor)?
- **Difficulty with communication** – Is the person able to communicate their wants, needs and feelings in a way that is understood? If they do not use speech to communicate, is there a system in place to help them communicate?
- **Health issues** – Does the person suffer from PMS, allergies, chronic pain or other medical problems? Are there problems with their medications or side effects from their medications? Is the person having difficulty sleeping? Are there mental health issues or is the person facing aging issues of dementia? Has there been a recent change in health or medications? Could the person be suffering from depression (can be somewhat prevalent in people with disabilities)
- **Support issues** – Has there been a change in support staff? Has staffing been inconsistent with many changes? Has there been a change in routine outside the person's control?
- **Relationship issues** – Are there problems with family members, friends, significant others, roommates, co-workers, neighbors or support staff? Is there a loss of an important person from the person's life?
- **Environmental issues** – Is the temperature too hot, too cold, too dry or too wet for the person? Has there been a sudden change in weather? Is it a hard time of year for the person (e.g., change of seasons, holidays, anniversary of a painful event)?



### Preventing the Need for Using Challenging Behaviors

The best way to try and support someone who has challenging behaviors is to learn all that you can about the person and develop a relationship with that person. If you really know and have a relationship with the person you are supporting, you will have a greater ability to help the person in a difficult situation. The better you know what situations, conditions, or problems can upset the person or make them angry, the better you can be prepared to help the person you are supporting deal with it, possibly without them feeling the need to engage in actions that might result in injury or further problems.

You can also possibly help the person avoid situations that upset them (for example, if crowds are bothersome you would try to help the person avoid crowded areas). If the upsetting situation cannot be avoided, you can at least warn the person that the event is coming up and that you will be there to support them (for example, if the person is afraid of the doctor but needs to go, you can help prepare them). There will be times that even with the best of preparation, challenging behaviors will occur. The better you know the person the better you are able to assist them.

Learning about the person can happen in several ways. First, from the person themselves through watching and observing them. Second, from others who know the person. When developing a relationship with the person you are supporting, it is important to do it at a speed that is comfortable and relaxed. In all relationships it takes time to get to know someone. It is also important to not judge or label the person by their actions. You must also respect the person's right to be different and understand that they might respond in ways that don't seem to make sense. By learning about and observing the person you will also learn what helps the person feel more relaxed during stressful situations. By honoring the person and their choices you will be showing that you respect the person. As you develop this honest and caring relationship with the person, you will also be building trust, which is the key factor in supporting someone.





## Responding to Challenging Behaviors

Once you get to know someone you will be aware of what situations can possibly cause the person to become upset or engage in challenging behaviors. In more technical terms the situations that can cause challenging behaviors are called antecedent conditions and the warning signs (person wringing their hands, crying, becoming tense) are called antecedent behaviors. It is important to look at antecedents on a personal level as it relates to the individual you are supporting. In other words “knowing” the person you are supporting so well that as a result you have a good idea of every possible antecedent condition that may affect the person you are supporting. You also must remember to not see the “behavior” as something that is negative or take it personally. Some ways to respond to challenging behaviors can be found on the following page.



### Tips for Responding

- See the “how to respond” section in the description section for tips on how to respond.
- Once you know the person, you will know when to back off, when to leave and when to get assistance or have someone else take over.
- Remember the rule of five – when someone is upset, use sentences of five words or less with words of five letters or less. Keep it simple.
- Try not to overreact. Sometimes you have to act rather than react.
- Your goal is to keep everyone safe. You may have to ask others leave the area if the person is becoming agitated.
- Remember that when the person is upset or agitated that it is usually not the time to try and lecture on consequences. You have to know the person well enough to know when they can hear what you have to say and when they can't.
- Knowing the person well will help you be able to read the person and their moods or state of mind so that you can adequately judge if the crisis is over.
- Dealing with challenging behaviors out in public can be very difficult. If someone has a history of this, ask for ideas from others on how to handle the situation.
- Good communication with the person you are supporting is one of the most important aspects of assisting them through challenging times.
- Be knowledgeable of the agency's policies.
- Remember to do your best to stay calm in crisis situations.
- There is a difference between breaking a dish and breaking a window, don't overreact.
- You may have to let go of a routine or plans when the person is having a hard day.
- There are very few things that are so important that it is worth risking someone getting hurt over it.



## Support Staff and Agency Responsibilities

- There should always be a section in a person's support plan outlining how to respond if the person has a history of challenging behavior.
- Anytime the person you support engages in behavior that you believe could result in injury to themselves or others, you must report it to your supervisor who then may have to report it to the person's case manager, the regional center, or the person's physician. It is important to be very detailed, especially if the incident results in injury or property damage.
- It is not uncommon when beginning to work with people with disabilities to feel fear or anxiety. What is important, is to realize when the fear and anxiety is not lessening and is affecting your ability to provide good services.
- As a support staff, you have to develop a relationship based on trust and respect. The person needs to know that you will be there through good days and bad.
- When out in public you must remember that if something happens that involves a community member, you must be professional. You may have to explain your role (remembering the person you support has the right to confidentiality) and you may have the police become involved.



## In Summary

In conclusion, there are four final points that need to be made.

- 1. Commitment** – Anyone who chooses to work with people with disabilities needs to be committed to providing good services in a respectful manner. Being committed to the person being supported means more than showing up and doing your job. It requires developing a caring relationship that is based on mutual respect and trust. Without this, it is very difficult to provide support in a manner that is beneficial to the person.
- 2. Rights of the people served** – The fundamental rights of people with disabilities should be guaranteed in the same manner as people who do not have disabilities. Those rights should be advocated for people with disabilities in a proactive way to insure that people who can not speak or defend those rights for themselves will have them.
- 3. Rights of staff** – At no time are the rights of staff put aside because of the rights of the people who are being served. In order for staff to be able to look at the people they are serving as equals, their rights or safety should never be in jeopardy because of the people they are serving.
- 4. Responsibility of the agency** – Lastly, it is important for each agency to know and realize that they are ultimately entrusted and responsible to the individuals being served. To do that the agency must provide staff with the philosophies, guidelines, information and training to be responsible, respectful, caring support staff.



## Supporting Individuals with Children: Family Support Services

(by Sharon Fallis, CIRCL consultant, June 2000)

The need to provide support to parents with developmental disabilities and their children is becoming more and more common within our communities. However, most staff who work with disabled adults often feel their expertise is inadequate when it comes to the *specialized* support which families require. Although there is definitely much more to know when it comes to wrap-around services for an entire family vs. an individual, Family Support Services (FSS) can be considered an extension of supported living services.

The most effective methods for providing family support services include offering services which take place in a family's *own* home and community. Parent Support groups help to reinforce skill building, socialization, role-modeling and advocacy. However, group instruction should be in conjunction with individual family support services to be most effective. There are several roles which a Family Support Services Facilitator (staff of the supported living agency) would need to manage when working with a family:

### **Mentor Parent**

FSS Facilitators provide role modeling and guidance for building effective parenting skills. The facilitator will often spend *chunks* of time with a family and offer hands-on learning while in the family's home. It is important that the facilitator has experience with teaching parents, and is comfortable modeling nurturing and consistent parenting skills. It is equally important to understand that *modeling* parent behaviors should not be confused with the *actual* parenting of the children. Helping to build on the relationship between the parent and the child should be the main objective - model a skill or behavior and then refer to the parent for example and follow through.

### **Parenting Educator**

Each appointment with a family should be carefully considered for the "teachable opportunities." Whether the appointment is focusing on money management, cooking, a visit to the pediatrician or the park, teaching parenting skills should be overlaid in each activity and recognized as an essential objective for each family visit. There are curriculum-based models available for teaching parenting skills and there are individual family plans which can be created to reflect the specific needs of a family. Which ever way your organization chooses to teach parenting, there are key elements which should be considered in each family support services plan: parent-child bonding; child development; the importance of play (Lekotek philosophy); child management and positive discipline; health and wellness; nutrition and meal planning; personal/home/community safety; family communication; stress/anger management; child abuse prevention; drug and alcohol abuse prevention; and family social/recreational time - just to name a few.



Redesigning or modifying parenting materials to meet the learning needs of an individual parent is strongly recommended. Collection of available training materials is a great way to start. The following companies offer free materials and information on such topics as nutrition, breast feeding, bathing, etc.: Mead Johnson (800•422•2902), Gerber (800•828•9119), Carnation (800•782•7766), Wyethlabs (800•99989384), Ross Productions (800•227•5767), Mount Vernon Foods (800•932•5525), Beechnut Foods (800•523•6633), Proctor and Gamble (800•285•6064), Kimberly Clark (800•544•1847). Other companies which offer parenting education materials through their catalogs include: ChildBirth Graphics and Health Edco @ WRS Group, Inc., Waco, Texas 76702-1207; Health Education Services, P.O. Box 7126, Albany, New York, 12224; Channing L. Bete Company (800•628•7733); March of Dimes, 1275 Mamaroneck Avenue, White Plains, New York 10605. Remember that OB/Gyns, pediatricians, Head Start, WIC and the health departments are other avenues for obtaining instructional information.

### Resource Developer

Because there have not been a lot of materials and resources developed specifically for families headed by parents with cognitive challenges, it is important to *gather, keep and share* materials and resources as you find them. A facilitator who is most effective is sure to have their own resources library bursting at the seams of their desk or trunk! It's extremely helpful to cultivate working relationships with staff from other agencies: regional centers; Area Boards; family resource centers; early intervention programs; Protection and Advocacy; Public Health, etc. The Community Services Directory for your area is extremely valuable, as is, knowing the healthcare providers within your area who work well with special needs parents and their children.

### Family Advocate

It is important to embrace the role of "advocate" when working with parents who have a disability. There are many biases and stereotypes that people have when it comes to raising children. The parents we offer support services to are mostly impoverished, often isolated and are often devalued by their own families, neighbors, and communities. Making a commitment to a family to provide support services certainly would be lacking if you were unable to also offer yourself as a competent advocate. Advocacy efforts need to be coordinated with the parents, support staff and professionals working with the family, and natural supports - such as family and friends. Introducing parents to support groups, self-advocacy groups, People First chapters, etc. gives them every opportunity to *learn* how to be a strong advocate for themselves and their children. Establishing ways for a parent to understand more about self-confidence, self-esteem, and community inclusion will go a long way to benefit the entire family. Advocacy on behalf of a family should be a unified effort between the parent, facilitator and other supportive people.



### Family Networker

A facilitator who provides family support services does not have to be an expert on every topic related to parenting. However, they should be good at *finding* the experts. Developing an assortment of people and organizations to reference for specialized assistance for a family is valuable. By working with others on behalf of a family, a couple of things can happen: First, the focus of supporting a family is no longer on the one FSS facilitator, but instead on a group of professionals - all having various expertise. Second, the family becomes involved with others within the community which can translate into ongoing working relationships. Another important role of the FSS facilitator is that of “The Hub.” Keeping track of all the *players* involved with the family helps to insure effective, consistent service provision. Collecting information on the family’s medical providers, social services, school information, family and friends, family routines and schedules, and preferences and styles allows a facilitator to be better informed and prepared for how best to support the family. Get into the habit of NEVER throwing anything away! Collecting pertinent information about the family will allow for an easier time when cultivating natural/generic supports; preparing “Family Futures Plans;” and passing updated information on to new or transitioning staff.

### FSS Facilitator Training Requirements

In addition to an organization’s routine training requirements for supported living staff, family support facilitators should also be trained and competent in the following areas:

- basic parenting skills
- child-proofing and household safety
- child development/parent-child bonding
- community access for families
- child abuse prevention and reporting requirements
- infant/child/adult CPR and first-aide
- communicable diseases and bloodborne pathogens

FSS facilitator skills and knowledge base can be greatly enhanced by participating with various organizations, conferences and workshops which promote family issues.

Networking with generic agencies helps to provide community awareness to the needs of parents with developmental disabilities. Networking with other agencies who also provide family support services helps to create collaborative situations which benefit all families being served.

Finally, working with parents and families can be complicated. Providing this type of support is not for everyone or every agency. Facilitators should extensively consider their own biases, stereotypes and value systems prior to making such a commitment.



## Family Support Services Resources

- American Red Cross** Parenting: Your Child From Birth To Three  
Parenting: Your Child From One To Six  
Parenting: For Special Needs Parents  
First Aid Fast  
The American National Red Cross (Check Your Local Listings); 1998.
- Baladerian, Nora J.** SURVIVOR: For People with Disabilities - Sexual Assault Series. Mental Health Consultants in Culver City (310-391-2420); 1985.
- Booth, Tim and Wendy** Parenting Under Pressure: Mothers & Fathers With Learning Difficulties. Open University Press - Bristol, PA; 1994.
- Dinkmeyer, Don** The Parent's Handbook: Systematic Training For Effective Parenting. American Guidance Service - Circle Pines, Minn; 1982.
- Feustel, Joyce** At Greater Risk: Legal Issues In Sexual Abuse Of Adults With Developmental Disabilities. Wisconsin Council on Developmental Disabilities (608-266-7826); 1992.
- Franz, John P.** Facing The Challenge: The Children's Code. Wisconsin Council on Developmental Disabilities (608-266-7826); 1990.
- Heighway, Susan** Helping Parents Parent: A Practice Guide For Supporting Families. Wisconsin Council on Developmental Disabilities (608-266-7826); 1992.
- Jones, Deb** Let's Prevent Abuse: Prevention Handbook for Early Childhood Professionals. PACER Center (612-827-2966); 1990.
- Jones, Deb** Risky Situations: Vulnerable Children. PACER Center (612-827-2966); 1993.
- Mandeville, Howard** Building The Foundation: Public Policy Issues in Supported Parenting. Wisconsin Council on Developmental Disabilities (608-266-7826); 1992.





- Mount, Beth** Person-Centered Planning - Using Personal Futures Planning Graphic Futures, Inc. in New York (212-362-9492); 1992.
- Rodgers, Judith** Mother To Be: Pregnancy/Birth For Women With Disabilities Demos Press (Through The Looking Glass 800-644-2666); 1991.
- Parentmaking: Handbook For Teaching Parent Classes. The Banster Press - Menlo Park, Ca; 1983.
- Snodgrass, Polly** How Much Is Too Much? - Providing Effective Family Support. Wisconsin Council on Developmental Disabilities (608-266-7826); 1993.
- Snodgrass, Polly** What's Wrong With You? - Helping Parents With Cognitive Limitations. Wisconsin Council on Developmental Disabilities (608-266-7826); 1993.
- State of California** Child Abuse Prevention Handbook. Office of Child Abuse Prevention (916-657-2030); 1993.
- Sweet, Mark** Discovering The Parent's Language Of Learning. Wisconsin Council on Developmental Disabilities (608-266-7826); 1990.
- Taylor, Steven J.** The Variety of Community Experience: Studies of Family/Community Life. Paul H. Brooks Publishing Company - Baltimore, MD; 1995.
- Through The Looking Glass** Adaptive Parenting Equipment Book. Through The Looking Glass (800-644-2666); 1995.
- Traustaclottir, Rannveig** Women With Disabilities: Issues, Resources, and Connections. The Center On Human Policy, Syracuse University; 1997.
- Webster, Susan Kidd** Preserving The Bond: A collection of family stories. Wisconsin Council on Developmental Disabilities (608-266-7826); 1993.
- Whitman, Barbara Y.** When A Parent IS Mentally Retarded. Paul H. Brooks Publishing Company - Baltimore, MD; 1990.





**Section 6.**  
**Person-Centered Planning**  
**Tools to Help Learn**  
**What is Important**  
**to the Person**





# Getting There From Here!

Excerpts from  
Tips on the Person-Centered  
Planning Process

**Originally Developed for**

Harbor Regional Center  
21231 Hawthorne Blvd.  
Torrance, CA 90503  
(310) 540-1711  
11/92



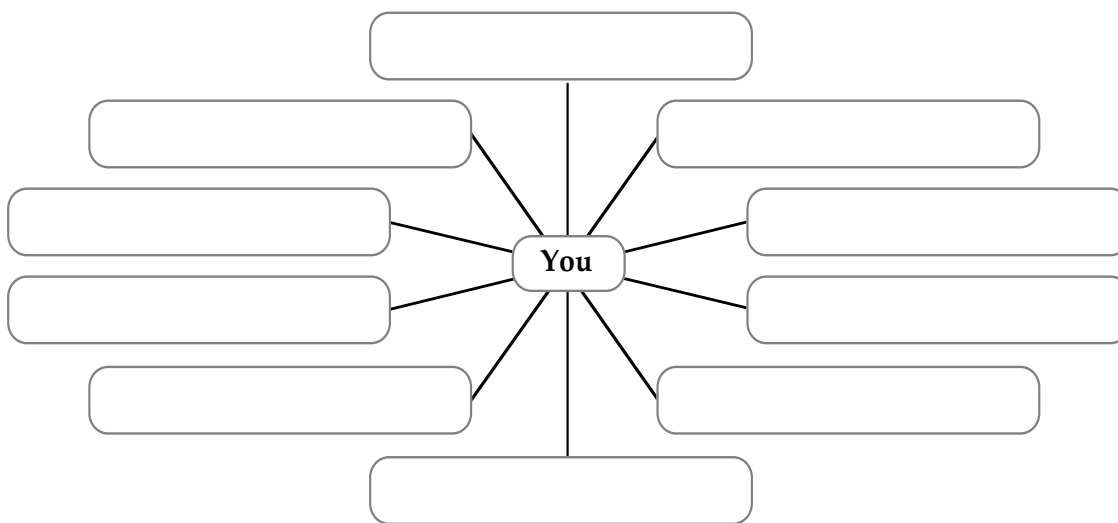
# How to Get There From Here!

## Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (3) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary*. However, we think that you'll find it useful as well as fun!

1 Who is this about?

2 Who's on your team? Who helps or supports you? Who are your friends?  
Who do you turn to for help when you need it?



3 What are some *great things* about you?

Adapted from *Personal Futures Planning* (Mounts) for R.C.E.B. & H.R.C by Allen, Shea & Associates; revised 4/92.



*How to Get There From Here!*  
*Things About You*

4 What things do you like to do? around town? at home? for fun?

5 What new things would you like to do? around town? at home? for fun?

6 What makes you happy?

7 What makes you mad or sad or frustrated?



## How to Get There From Here! About Work

8 If you're not working right now, what do you do during the day?

9 If you're interested in working, what jobs have you had?

If you're not interested in working, please turn to the page called *Things About How You Live and Would Like to Live*. If you're already working, please go to question #12.

10 If you're interested in working, what kinds of jobs interest you?

11 Do you need support in getting a job?

Are you looking for your first job?      \_\_\_ yes \_\_\_ no

Does it take you a long time to learn a job?      \_\_\_ yes \_\_\_ no

Do you get social security benefits?      \_\_\_ yes \_\_\_ no

Do you need support in things like using money or getting to work? \_\_\_ yes \_\_\_ no

If you answered **yes** to any of these questions, you could probably use some support in getting and keeping a job.

12

### Already Working, How's Your Job?

	Yes	No
Is it the kind of job you like?	___	___
Are the hours and days okay?	___	___
Do you get the support you need?	___	___
Does the pay cover your bills?	___	___
Do you get benefits?	___	___
How do you get along with people at work?      ___ great      ___ okay      ___ not very well		

When you think about your job (check the one that shows how you feel most of the time)

- \_\_\_ Are you glad you got it
- \_\_\_ It's okay that you got it
- \_\_\_ You're sorry that you got it





*How to Get There From Here!*  
**Things About How You Live and Would Like to Live**

13 How do you live now?

Alone?

With a roommate?

With your parents?

With other relatives?

In a group home?

Other? \_\_\_\_\_

14 What do you see as the *best things* about where you live right now?

15 What do you see as the *biggest challenges* of where you live right now?

16 What kinds of support do you need where you live right now?

17 Are you living where you want to live and with whom you want to live?

If you're living where you want to live for now, please go to question #19.

18 All things possible, where would you like to live and with whom?



*How to Get There From Here!*  
*Looking Ahead*

19 What are your dreams and hopes for the future?

20 What scares you the most about your future?



*How to Get There From Here!*  
*Looking Ahead*

21 What do you see yourself doing in 3-5 years?

22 What support would you need to get there?

23 Who can help you with that support? How?

24 Who worked on this plan?



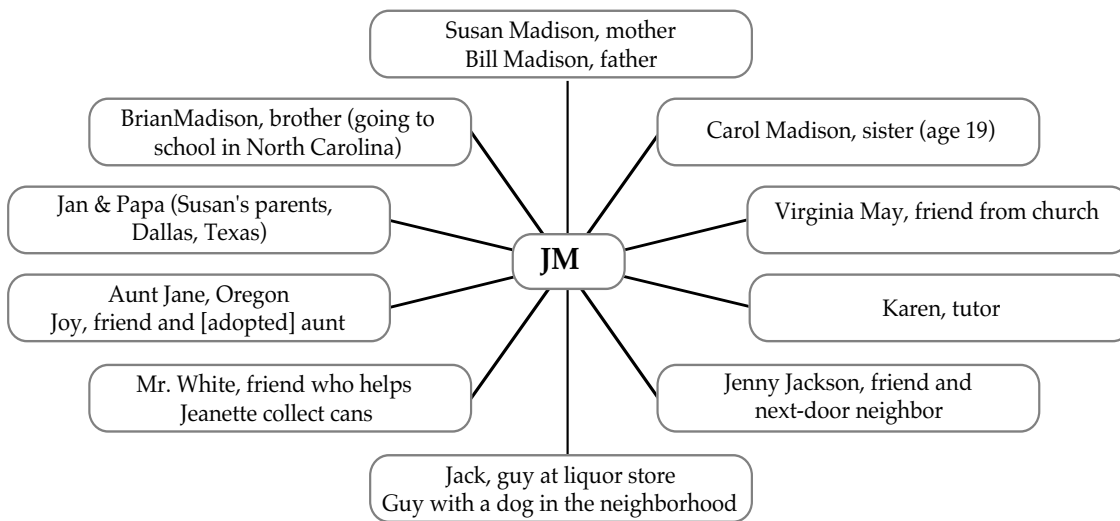
SAMPLE

# How to Get There From Here!

## Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (3) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary*. However, we think that you'll find it useful as well as fun!

1 **Whose plan is this?** Jeanette Arnopole, age 22



3 **What are some great things about you?** Jeanette mentioned things she does, but not characteristics of her personality. Others, including parents, shared the following observations:

- |   |  |
|---|--|
| Out-going   | Honest   |
| Almost always happy   | Dependable -- If Rebecca says she will do something, she will follow through |
| Plans ahead/like to schedule things                                   | Brave (taken airplane trips on own; learned buses)                           |
| Hard worker   | Plans activities   |
| Very independent  | Talks things through 'til comfortable  |
| Concern for others/animals  | Thoughtful (e.g., gifts, cards for friends)                                  |
| Makes people feel comfortable   |  |
| Good with John, a neighbor's child<br>(e.g., organized East Egg Hunt) |  |

Adapted from *Personal Futures Planning* (Mounts) for R.C.E.B. & H.R.C by Allen, Shea & Associates; revised 4/92.



*How to Get There From Here!*  
**Things About You**

**4 What things do you like to do? around town? at home? for fun?**

*Jeanette said:*

Crush cans to make money (and later it was learned that this relaxes neck muscles and relieves tension)  
Going for walk with dog in neighborhood

*Others said:*

Going out to eat  
Talking with people  
Talking with pets, and taking care of them  
(Sister mentioned chasing bird in the bathroom, and getting it back in its cage.)

Making pizza and other items  
Games, such as Parcheeze , Hearts, Jenga  
Planning parties and giving them  
Holidays (decorating, shopping, etc.)  
Using coupons and shopping for groceries

**5 What new things would you like to do? around town? at home? for fun?**

*Jeanette said:*

A job, such as handing out coupons at a store

*Others said:*

Learn how to type/use computer  
Doing crafts with sister  
Helping at Humane Society as volunteer (This is in the works, currently.)

**6 What makes you happy?**

*Jeanette said:*

Parties  
Listening to music

*Others said:*

See old friends, etc.  
Going out to eat  
Jan, Papa, Brian coming to visit  
Walking to store on own  
Planning trips, parties, etc.

**7 What makes you mad or sad or frustrated?**

*Jeanette said:* Sometimes angry with sister

Dad telling her to be quiet, if he's watching TV

*Others said:* Sometimes loses cool

Brother and sister doing things that she cannot do

Seeing a dog in neighborhood chained and not being petted

The family dog (Toby) died

When treated like a child

If people say she is 'little'

If things are not ready on time; if people are late

If change in unanticipated, or not scheduled, or not announced

If she doesn't understand directions

If she really wants to do something, and it is interrupted



## How to Get There From Here! About Work

### 8 If you're not working right now, what do you do during the day?

*Jeanette said:*

Crushing cans (about \$8 per week)

*Others said:*

Takes up offerings at church

Folds bulletins for Luthern Church (Pastor lives up the street)

### 9 If you're interested in working, what jobs have you had?

*Jeanette said:* See #8, above.

*Others said:* See #8, above. Red Cross (volunteer couple of hours per week: rolling pennys; tidying paper; labels; ink stamps); Humane Society (volunteer couple hours per week: feeding; grooming; etc.); Convalescent Hospital (quit; couldn't understand what was wanted; staff not helping enough); Eden Express in San Pedro (dishes, ironing, folding napkins, etc.); JTPA/ROP job at Vet's Hospital (swept, napkins, towels, aprons, etc.; didn't like yard work); Work experience job (addressing at Special Services); Dollar Saver (delivering papers; stuffing envelopes); and, Pet Store (volunteer work: too confusing; too many different types of birds and of bird seed that needed to be matched, etc.)

### 10 If you're interested in working, what kinds of jobs interest you?

*Jeanette said:*

Animal care (feeding, watering, grooming, cleaning cages)

*Others said:*

In general, Jeanette likes working around people and animals, and her mother feels that Jeanette is best if there are breaks interspersed with more focused work.

Being a greeter at a party

Restaurant work is probably out (doesn't like it)

Messenger (e.g., delivering mail between offices in a complex)

### 11 Do you need support in getting a job?

Are you looking for your first job?  yes

Does it take you a long time to learn a job?  yes

Do you get social security benefits?  yes

Do you need support in things like using money or getting to work?  no

*Others said:* Making change is sometimes difficult Jeanette did well rolling pennies and didn't need close supervision. There was a discussion about whether supervisors/co-workers provide accurate, candid feedback as to their experience with Jeanette as a worker/volunteer. Julie, at ARC-Long Beach, is said to see a need for a lot of supervision. Others, including Jeanette's tutor, don't see it this way. Perhaps different supervisors report different things to family and Julie.

12

### Already Working, How's Your Job?

	Yes	No
Is it the kind of job you like?	___	___
Are the hours and days okay?	___	___
Do you get the support you need?	___	___
Does the pay cover your bills?	___	___
Do you get benefits?	___	___
How do you get along with people at work?	___ great	___ okay
		___ not very well

When you think about your job (check the one that shows how you feel most of the time)

\_\_\_ Are you glad you got it

\_\_\_ It's okay that you got it

\_\_\_ You're sorry that you got it



*How to Get There From Here!*  
**Things About How You Live and Would Like to Live**

**13** How do you live now?

Alone?

With a roommate?

With your parents? ★

With other relatives?

In a group home?

Other? \_\_\_\_\_

**14** What do you see as the *best things* about where you live right now?

*Jeanette said:*  
Having a tutor to do things with

**15** What do you see as the *biggest challenges* of where you live right now?

*Jeanette said:*  
Cleaning up the house (shares vacuuming, dusting, and other responsibilities with sister)

**16** What kinds of support do you need where you live right now?

*Others said:*  
Jeanette is fine at home, without anyone around for substantial periods of time, and can keep herself appropriately occupied.  
If away for a few days, mother suggests having friend over, and would not be comfortable with either daughter being home alone.

**17** Are you living where you want to live and with whom you want to live?

*Jeanette said:*  
Would like to live somewhere else, with a roommate  
Doesn't know who or how  
Would like to live with one or two other people

If you're living where you want to live for now, please go to question #19.

**18** All things possible, where would you like to live and with whom?

*Jeanette said:*  
A place that is 'affordable'  
Jeanette has friend Lee Ann, who stayed over and was 'bossy' and 'nosey'

*Others said:*  
Close to friends/family



*How to Get There From Here!*  
*Looking Ahead*

19 What are your dreams and hopes for the future?

*Jeanette said:* Not sure

20 What scares you the most about your future?

*Jeanette said:*  
She can take her own meds (oral, 2x per day)

*Others said:*  
Sister fears that if Jeanette is not more independent, she could come live with her but would likely be disgruntled  
Jeanette may fear loss of health/function (e.g., some possible progressive hearing loss; etc.)  
Jeanette is probably fearful of not having enough money for food, etc., if she moves away from home





*How to Get There From Here!*  
**Looking Ahead**

**21 What do you see yourself doing in 3-5 years?**

*Jeanette said:*  
Getting a job  
Leaving home

*Others said:*  
These are the two things Jeanette talks about often

**22 What support would you need to get there?**

*Jeanette said:*  
Need help from Julie at ARC-Alameda County in finding and learning a job  
Regarding living on own, I need help cooking (e.g., using the oven; etc.) and how would I shop for groceries? Jeanette can shop for groceries, but would need getting groceries home. There was discussion of getting a cart, and living near a grocery store where there are curb cuts.

*Others said:*  
Is there any way to get information and work with others to help find and develop a job for Jeanette?  
Others asked Jeanette if she would need help (training/assistance) in changing sheets, getting oriented to use of public transit, getting to the doctor's office for appointments, going to places not on bus routes, doing own laundry, keeping her place clean? In many of these areas, she may need prompts or assistance.

**23 Who can help you with that support? How?**

Carol will look into getting Jeanette a cart to haul groceries from the store.  
Susan and Karen can help by asking supervisors: "What can Jeanette work on to improve her work performance?" and asking people to be candid.  
Family/friends will see about putting marks on oven dial, so that Jeanette can use oven properly.  
Susan would like information on conservatorship.  
Carolyn is seeking information/support on special needs trust, and has had person from Los Angeles (Estate Planning for the Disabled) out to talk about it.  
John Shea was asked, and agreed to share results of meeting with Julie at ARC-Long Beach, because (a) there may be ways to collaborate, and (b) some of the ideas/information shared might be useful to Julie.  
Looking at alternative living arrangements was identified as a likely area of interest.

**24 Who worked on this plan?**

Susan Arnopole, mother; Carol Arnopole, sister (age 19); Virginia May, friend from church; Joy, friend and [adopted] aunt; Jenny Jackson, friend and next-door neighbor; and, Karen, tutor



# An Overview of Essential Lifestyle Planning

**Our quality of life everyday is determined by the presence or absence of things that are important to us - our choices, our rituals.**

**M. Smull, 1996**



## **An Overview of Essential Lifestyle Planning**

Adapted from an article by  
Michael Smull and Susan Burke Harrison

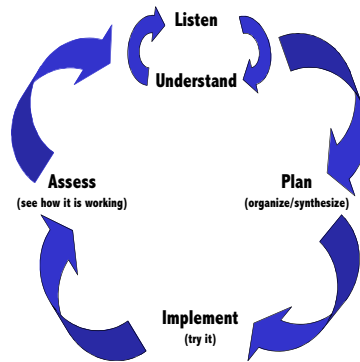
**Essential lifestyle planning is a guided process for learning how someone wants to live and for developing a plan to help make it happens. It's also:**

- **a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow;**
- **a way of organizing and communicating what is important to an individual in “user friendly”, plain language;**
- **a flexible process that can be used in combination with other person centered planning techniques; and,**
- **a way of making sure that the person is heard, regardless of the severity of his or her disability.**

**Essential lifestyle plans are developed through a process of asking and listening. The best essential lifestyle plans reflect the balances between competing desires, needs, choice and safety.**



### The Learning Wheel



**Developing plans that really reflect how people want to live requires:**

- the perspectives of those who know and care about the person;
- their stories about good days and bad; and,
- what they like and admire about the person.

**Good plans reflect the perceptions of the focus person and those who know and care about him or her. Learning how people want to live is just the beginning, the foundation. Helping people have their own lives requires changing:**

- how we think;
- how we are organized; and
- how we act.



**Each of us want lives where we:**

*are supported by & contribute to our communities*



(with apologies to Abraham Maslow)

**For more information, contact:**

Michael Smull  
Support Development Associates  
3245 Harness Creek Road  
Annapolis, Maryland 21403  
(410) 626-2707 • FAX 626-2708  
e-mail <mwsnull@compuserve.com>

Or, check out the M. Smull and Friends website at  
<[www.allenshea.com/friends.html](http://www.allenshea.com/friends.html)>



# Positive Rituals and Quality of Life

by Michael W. Smull

## Rituals ease us through our day

Every morning when you arrive at work, you head for that first cup of coffee. Only after the cup is in your hand and you have chatted about the prior evening's events with your co-workers do you feel that you are really at work and ready to start. If there is an urgent phone call before you have that first cup of coffee in your hand, you grumble to yourself because you are not really in the office until you have your coffee. When you arrive home from work you do not feel like you are home until you have changed out of your "work clothes." Both of these are examples of the daily rituals that we employ to help us cope with transitions.

We give our daily rituals and habits scant conscious attention as they ease us through our days. Perhaps it is the absence of conscious attention that has led us to neglect the role of ritual in the quality of life of people with disabilities. However, rituals are as much a part of quality of life for people with disabilities as they are for everyone else. Families know this. They have looked for substitutes for acquisition of the driver's license, realizing that this is the American secular rite of passage to adult life. They worked to make confirmation, bar mitzvah, and graduation ceremonies accessible to their sons and daughters. It is time for those of us who support people with disabilities to consciously consider the role of ritual and to insure the presence of positive rituals.

## Daily rituals

Rituals begin every day with our morning routines. Each of us has a pattern of waking up and getting ready to face the day. These daily rituals are comforting. An example is bathing. Each of us has a pattern in how we wash our bodies. Is your face washed first or last? For those people who need assistance in bathing and cannot speak for themselves, the pattern of bathing may change with every change in staff. Yet when one mother in Ontario, Canada requested that her daughter's face be washed last, this was seen as an example of her being overly involved and controlling.

"John" (who was learning how to do "essential lifestyle planning") was sharing the person centered plan done on himself. He noted that he gets up slowly in the morning and does not want bright lights, loud music, or perky people around him until he has had his first cup of coffee. He described his fiancé as one of those perky morning people who bounce out of bed ready to go at full speed. Their accommodation is that she leaves the bedroom and is perky elsewhere. Because they respect and love each other, their incompatible morning rituals are accomplished without intruding on each other. Supporting the daily coping rituals of people with disabilities begins with paying attention to the personalities of those we support. Many direct care staff can tell you how they already do this, but the absence of sanction from professionals means that



rituals that are supported today may be seen as non-compliant behavior tomorrow.

### **Maintaining and building rituals**

In Rituals for our times, Imber-Black and Roberts describe the importance and nature of rituals for all of us. They note that: "Daily rituals define the boundary between the family and the outside world." They include all of the important minutia of our lives at home. Common rituals around food include: the times at which we eat, what food is served on special occasions; where does each person sit at the table; and do we watch TV while we eat. These reflect our current preferences and our histories. Every time new people come into a home we need to remember that they bring their preferences and history with them. In houses owned or rented by the service provider, the rituals are often those of the service provider and change as staff turn over. Where people have spent decades in institutions they may not have any rituals that work in small settings. People with disabilities and staff who come from families rich in positive rituals can help to create new rituals in the homes in which they live. However, systematic efforts to discover, build and sustain these rituals is required.

Our efforts need to begin with these daily rituals. We have found that some of the people referred to us because of "non-compliant" or aggressive behavior simply have daily rituals that were not recognized. Our obsessions implementing program plans and continuous training have resulted in our ignoring, suppressing and trying to replace rituals that are positive, individual adaptations to the rhythms of daily life. Once the issues are seen in this context, staff were able to accommodate the

positive rituals of the individual within program schedule requirements and offer training as it made sense

Beyond the daily rituals there are others that also deserve our attention. The topography that Imber-Black and Roberts use divides rituals into those that express "relating, changing, healing, believing and celebrating (p. 56)." To consider the significance of these, we need only look to the importance of Sundays in our own patterns of rituals. For some of us, Sundays are days of spiritual renewal and relating to those who share our faith. For others of us, Sunday is the day when you not only sleep late you pad around in sleeping garb well into the afternoon. During football season, Sundays are the day when family and friends gather to yell at the television set. The Sunday rituals of each home should be the rituals of the people who live there and not be subjected to the vagaries of changing staff.

### **Rituals of comfort**

We also need to remember that some rituals are rituals of comfort. We have sets of behaviors that we use to help us feel better when the "slings and arrows of outrageous fortune" strike us. After a bad day at work, we will go home and say to our partner "I do not want to do the chores planned for this evening. I had a really bad day at work. Let's go out for dinner or the movies instead." We say it even when it was our behavior that resulted in the bad day at work. If you are someone with a disability who goes to a day program, it is not unknown to have your day program counselor call your residential counselor and say: "he was really bad at his day program, do not let him have any privileges at home tonight."



We need to ask ourselves why there is a saying among self-advocates that says "Never tell them what you like because they will make you earn it. Never tell them what you dislike because they will do it to you when you are bad."

### Rituals and relationship

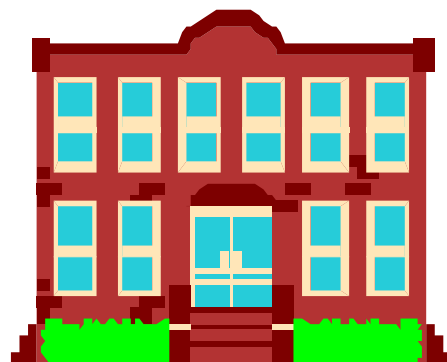
As we look at supporting people in their communities we need to remember that much of the richness of "community" comes from the relationships that we have and the rituals that celebrate and build those relationships. Despite its central function, the role of ritual is rarely discussed. In our rapidly changing, mobile and fragmented society, positive rituals deserve attention for all of us regardless of the presence of disabilities. For people who need substantial support to get through life, developing positive rituals should be a priority. For many people with disabilities, these rituals will need to be developed with the assistance of the staff and then supported by the staff. Once established, however, they should change at a pace dictated by the individual, not by the rate

at which new staff arrive. The rituals must be rooted in who each individual is as well as each person's current circumstances. Properly used, rituals will help people through major life changes as well as daily existence. In the support plans of the future more space should be spent on how to support people in their positive rituals and less on how to program every waking moment of their lives.

April, 1993

Imber-Black, E. & Roberts, J. (1992). *Rituals for our times: celebrating, healing, and changing our lives and our relationships*. New York: Harper Collins.

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# Getting to Know You:

Planning for Services in Supported Living

Compiled for  
Connections for Information and Resources  
on Community Living (CIRCL)

by

Claudia Bolton (**NorthStar Services**) and  
Bill Allen (**Allen, Shea & Associates**)

1999



# Getting to Know You:

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4171 Starkes Grade Road  
Placerville, CA 91006  
**(530) 644-6653**

by

Claudia Bolton (NorthStar Services) and  
Bill Allen (Allen, Shea & Associates)

1999

This workbook may be copied with permission from CIRCL. However, since much of the material is adapted from Essential Lifestyle Planning, we would recommend training in that process. For more information about Essential Lifestyle and Person-Centered Planning, contact Claudia Bolton at (530) 644-6653 or Bill Allen at (707) 258-1326.

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## Introduction

This workbook for getting to know someone was developed from two methods of person centered planning, the *Personal Profile* and *Essential Lifestyle Planning*. We want to acknowledge the creative work of John O'Brien, Connie Lyle O'Brien and Beth Mount for the Personal Profile (Framework for Accomplishment Workshop) and Michael Smull for the Essential Lifestyle Planning process.

We also want to recognize USARC/PACE (Solano County) and Bill Allen (Allen, Shea & Associates) for developing training materials that support people who use the Essential Lifestyle Planning process. Their helpful instructions are included in this workbook.

This workbook was compiled with the assistance of several supported living providers in the Regional Center of the East Bay area of California. Becoming Independent from Santa Rosa allowed us to revise their Community Supported Living Curriculum Guide, and Personal Assistance Needs Assessment. We thank them for their thorough work.

The integration of these two methods of person centered planning can assist supported living agencies to begin to know and understand a person referred for services. Getting to know someone is an ongoing process of uncovering who they are and what is important to them. Much as an onion has layers that can be peeled back one at a time, we all have complex layers of information to be unfolded throughout our relationships with one another.

We hope this framework for getting to know someone helps you as you begin this journey. The best way to get started is to complete the workbook on yourself. We also recommend that you receive training in Personal Futures Planning (e.g., PATH and MAPS) and Essential Lifestyle Planning.



## Some Things to Think About as You Gather Information

### **Some Hints for Effective Conversations**

Here are some ideas for starting and holding a successful conversation (adapted from *Interviewing Adults . . .* by Mary F. Hayden, University of Minnesota):

- pick a place where everyone is comfortable;
- make sure everyone knows each other and why they are there;
- start with something to break the ice;
- use body posture and facial expressions to encourage conversation;
- show acceptance of whatever is said;
- try to keep the interview experience positive;
- when someone gets off the topic, try to redirect or suggest talking about it later;
- allow up to 30 seconds with no response before asking someone the question again or moving to someone else;
- respect someone's right to choose not to answer a question;
- if someone becomes uncomfortable or upset, offer to end the interview and try again later; and,
- end the interview with a positive summary of what was discussed.



## **Three Approaches to a Conversation**

### **by Michael Smull**

There are many ways to go about holding a successful conversation. The following are descriptions of three techniques. You will probably find yourself using all three in the course of a conversation:

#### **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 what 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.

### **Remember that a Plan is a Promise**

When you spend time asking a person what is important to them, who is in their life, and their hopes and dreams for the future, you are asking them to trust you with this information and you are building a relationship with them. Do not ask a person to divulge themselves to you unless you are willing to give power to what they tell you. Put another way, you must be willing to make a commitment to help them get what is important in their daily life and to move toward their desired future. If you and your agency decide that you can not provide services to the person, then make a commitment to sharing the information you learn with the people who will stand up for the person to help them get what they need and want.

### **Getting to Know You - Information Gathering Process**

Get as much information as you can from the focus person. What the person wants for themselves and how they want to live is the most important information. Second is what others want for the person. You will most likely want to interview others about the person. Ask the person who is important to them, who knows and cares about them. The first two exercises in the workbook will help you identify these people. You will need to ask permission to interview them and you will want to ask the focus person if they would like to be present when you interview others about them. When you record the information, distinguish the information the person tells you from information others give you.

If the person does not communicate with words, you will want to interview the people who know, like and care about the person. Everyone communicates. People who do not use words to talk usually communicate with their behavior. The Listen To Me Communicate section of this workbook will be especially helpful for clarifying how and what the person is communicating and what we can do to support the person.

Your interviews with the person should occur in a place that is comfortable for the focus person. This may be their home, their day program, at school, in a coffee shop, park or in your office. The person should decide where they are most comfortable.

# Getting To Know The Person: Planning for Services in Supported Living - Assessment Process

## Part One: Information Gathering:

People in Your Life  
Your Relationships and Groups You Are A Part Of  
Great Things About You  
Your Experiences and History  
Best and Worst Day Exercises  
Positive Rituals Survey  
Your Experience Making Choices  
Information About Your Health  
Your Hopes and Dreams for the Future

## Part Two: Individual Assessment Options

### ← Listen to Me Communicate

(When the person uses behavior to communicate or when the person doesn't communicate in typical ways)

### ← Daily Living Skills Assessment

(When the person wants to learn to do things by themselves or with little assistance)

### ← Personal Assistance Assessment

(When the person needs physical assistance, close support or significant assistance to complete activities of daily living)

### ← Pattern of Support - Weekly Schedule

(For people who need assistance to complete their daily rituals and other activities of daily living)

## Part Three: Summing It All Up:

What is Important to Me

1. Non Negotiables
2. Strong Preferences
3. Highly Desirables

Things I Want to Learn To Do

Things You Need to Know or Do to Help Me Get What is Important to Me

Things You Need to Know or Do to Help Me Stay Healthy and Safe

Notes, Comments, Recommendations and Things that are Unresolved



Getting to Know You:  
Planning for Services in Supported Living

# Part One: Information Gathering

This workbook belongs to:

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Connections for Information and Resources  
on Community Living (CIRCL)



**Getting to Know You:**  
Planning for Services in Supported Living

**Part One:**  
**Information Gathering**

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**Getting to Know You** will help your team from the supported living agency figure out the services and supports that will work best for you. Learning more about how you want to live *now*, will save everyone a lot of time later.

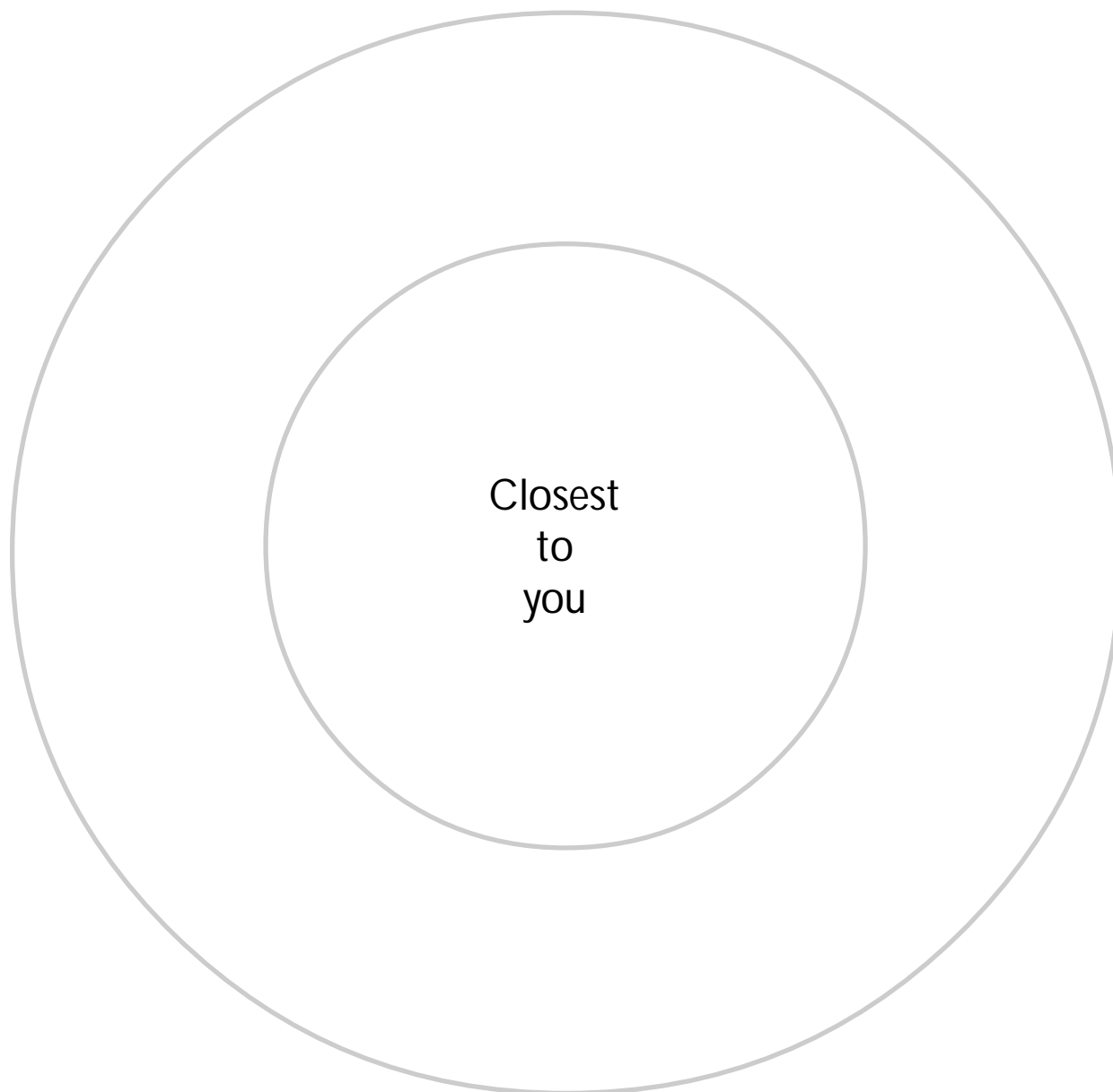


## The People in Your Life?

Who are the people you are close to? people in your family? people at work or school? neighbors and friends? Who are the people you do things with? talk to? turn to for help?

Who do you spend the most time with? Who are the people who know you best? Who are the people who are most important to you? These are people who might be able to support you in your plans for the future.

Think about who they are and write their names in these circles. Write down when you see them and your relationship to them. Some people write the names of people who are closest to them in the middle, but you can do it any way you want.





# Your Relationships and Groups that You Are A Part Of?\*

Another way to look at the people we know is to think about the role they play in our lives. To think about their relationship and commitment to us.

**Who are the Anchors in your life? These are people who you have known for a while. They are not new friends.**

Who loves you? Who is concerned about you and gives you advice or support? Who protects you or sticks up for you? Who protects you? Who has helped you get what you wanted in the past?

**Who are your Allies?**

Who spends time with you and does things with you? Who knows what you like and what you need to be happy? Who introduces you to other people? Who helps you? Who do you like to spend time with? Who supports your goals for the future?

**What Assistance do you get?**

Is there any one who gets paid to provide services or support to you? Do you pay anyone to do things for you? Like instructors, job coaches, personal assistants, counselors, doctors, dentists, gardeners or hair dressers.

**What Associations are you a part of?**

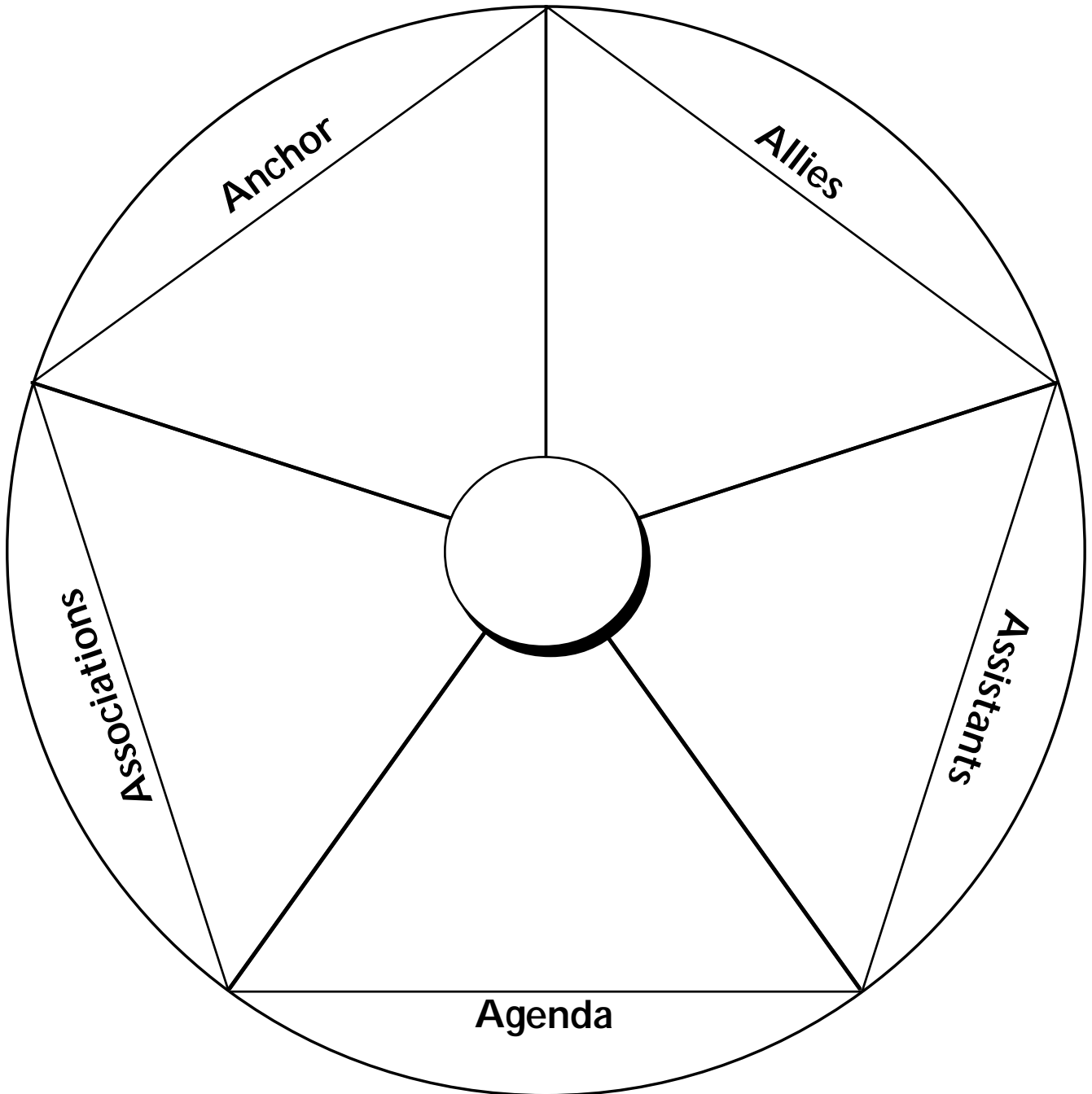
What groups, clubs and organizations do you belong to? Do you get together with other people to share common interests?

**What Political agendas are you a part of?**

Are you active in advocating for change? Do you participate in any self-advocacy groups or councils? Are you on any Boards or committees?

\* From *Members of Each Other* by John O'Brien, Connie Lyle O'Brien, Inclusion Press, 1996.







## What are some great things about you?

What are some great things about you? What do you like about you? What are some things you're good at? proud of? What are some nice things that people say about 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.

These are important things to think about when you are figuring out the kinds of services and supports you need and want.

**(Note to Facilitator:** This is not a place to discuss or list “disability” accomplishments, e.g., is able to read, can cook three meals, accomplished IPP goals.)

Great Things About You



## **Your Experiences and History**

What important things have happened in your life?

Where have you lived, worked, gone to school?

Describe the best times of your life.

Are there people who were important to you whom you no longer see?

Are there things you used to do that you'd like to do again?

## **Notes About Your Life**

# Notes About Your Life



## **Your Lifestyle - Best and Worst Day Exercises and Positive Rituals Survey**

The next two sections, Your Lifestyle - Best and Worst Day Exercises and Positive Rituals Survey, will help you identify what is important to the person right now and what we need to know and do to support the person. These exercises come from the Essential Lifestyle Planning process. These exercises will help you get information about:

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;

What others need to know and do -  
to help the person to get what is important to them;  
to help the person stay healthy and safe within the context of how the person wants to live.

How much you need to learn about each of these areas varies with the person. Some examples -

We all have positive rituals and routines. However, the more physical assistance the person needs to accomplish them the more detail you need to learn. You need to explore how much help is needed or wanted and the importance (to the individual) of things like the order in which they get help, how the help is given and how they communicate this.

For many individuals with challenging behaviors there are (or have been) people involved in their lives whose behaviors and/or attitudes result in fewer instances, less severe instances or even an absence of the challenging behavior. You need to learn what it is about these people that had this positive result. This will begin to tell you what is important to these individuals in how they are treated and who needs to be present (or absent) in their lives.

Where the people you are planning with have health issues, especially complex health issues what others need to know and what they need to do to help the person stay healthy has to be learned and described.



# Your Lifestyle

## Best week day

*Imagine the best of week days. Close your eyes, lean back and visualize what it would be like.*

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

Would you be at work, in a program or at school?

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening?

Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?



**Best week day**



## **Worst week day**

Imagine the worst of week days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

Would you be at work, in a program or at school?

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that you really dislike?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would worsen the evening?

Would you be with someone?

Would you end this worst of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

**Worst week day**



## Best vacation day

Imagine the best of vacation days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening? Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

**Best vacation day**



## **Worst vacation day**

Imagine the worst of vacation days. Close your eyes, lean back and visualize what it would be like.

Where would you be?

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

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Would you be with someone?

Would you end this worst of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

**Worst vacation day**



## The best of Saturdays

Imagine the best of Saturdays. Close your eyes, lean back and visualize what it would be like.

What time and how would you wake up?

Would you be by yourself or would someone be with you?  
What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that would improve your day?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would improve the evening?  
Would you be with someone?

Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?



## **The best of Saturdays**



## The worst of Saturdays

Imagine the worst of Saturdays (if you are on shift work imagine any great day off). Close your eyes, lean back and visualize what it would be like.

What time and how would you wake up?

Would you be by yourself or would someone be with you?

What would your morning ritual be like?

What would you do between breakfast and lunch? Who would you do it with? (Being by yourself is acceptable, just unusual.)

What would you have for lunch? Where would you eat?

How would you spend your afternoon and who would you spend it with?

It is now early evening. Are there any afternoon/evening rituals that you really dislike?

What would you have for dinner, where, with who?

How would you spend the evening?

When would you go to bed? What night time rituals would worsen the evening?  
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Would you end this best of days with special dreams? What would they be like?

Are there other things that would be present? For example, is there music that you would be listening to? What would the weather be like?

## **The worst of Saturdays**



## 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.)

1. List some of this individual's daily coping 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 that comprise our morning rituals, including whether we brush our teeth before bathing, during our shower, before we leave the bathroom or after breakfast.

**List morning (getting up) rituals -**

**List nighttime (going to bed) rituals -**

2. List some of this individual'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?

**List arriving at work rituals -**

**List arriving at home rituals -**

3. List some of this individual's weekly rituals -

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

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



4. List some of this individual's rituals of celebration and comfort -

**Indicate how he/she likes to celebrate when something good happens.-**

**Indicate how this individual 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 in order for it to be his or her birthday?**

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

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



## Your Experience Making Choices\*

Let's talk about decisions you make for yourself, decisions other people help you make, and decisions made by other people in the following areas of choice.

Note to recorder: In the assessment area of "What I Need to Know and Do to Support the Person" record any areas of life in which the person will need support to make decisions.

**Daily routines** - Which decisions do you make about your daily routine (such as what to wear, what and when to eat, when to go to bed, etc)

**Scheduling decisions** - Which decisions do you make about your schedule for doing things like going out, choosing activities and choosing who you go with?

**Do you decide how to use your money?** Does anyone help you now? If so, how do they help you?

**Big Decisions** - Did you decide on the job you have or the program you go to? Do you decide when to visit friends and who you visit? Did you decide where to live and who you live with?

\* Adapted from *Person Profile*, Frameworks for Accomplishment, John O'Brien and Connie Lyle O'Brien, and Beth Mount.



## Getting to Know You: Planning for Services in Supported Living

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Think about:	Own choices	Choice made by person with support	Choice made by others
Daily activities			
Routine Scheduling			
Money matters			
Major Choices: Where to live Who to live with Where to work			



# Information About Your Health

Check here if all health care needs are handled independently

Or by: \_\_\_\_\_

**Physicians:**

Name: \_\_\_\_\_ Type: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

Name: \_\_\_\_\_ Type: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

Name: \_\_\_\_\_ Type: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

**Dentists:**

Name: \_\_\_\_\_ Type: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

Name: \_\_\_\_\_ Type: \_\_\_\_\_ Phone #: \_\_\_\_\_

Address: \_\_\_\_\_

**Ongoing Medication Required:**

Name: \_\_\_\_\_ Dosage/Frequency: \_\_\_\_\_

Purpose: \_\_\_\_\_ Used: \_\_\_\_\_ to \_\_\_\_\_

Name: \_\_\_\_\_ Dosage/Frequency: \_\_\_\_\_

Purpose: \_\_\_\_\_ Used: \_\_\_\_\_ to \_\_\_\_\_

Name: \_\_\_\_\_ Dosage/Frequency: \_\_\_\_\_

Purpose: \_\_\_\_\_ Used: \_\_\_\_\_ to \_\_\_\_\_

**Check Box if Health Assistance Needed To:**

Make/keep doctor or dentist appointments

Get prescriptions refilled

Purchase medications

Monitor specific health care need

Take medications as prescribed

Monitor general health care needs

## More About Your Health

When did you last go to a doctor?

Do you visit the doctor a lot?

When you go see a doctor, what kinds of health problems do you have?

Do you have health problems that are with you all the time? What are they?

Do you have seizures?

If yes,

When did you last have a seizure?

How often do you have seizures?

How long do your seizures usually last?

What do you do when you have a seizure?

## Other Information About Your Health



## Hopes and Dreams for the Future

Collect images and ideas about how the person would like to live. Use the person's own words as much as possible. Encourage the person and his/her family and friends to dream about a desirable future. Don't let barriers stop the dreaming. Ask the person:

What do you look forward to in your future?

How do the people who care about you describe a desirable future?

What would you like to have? Do? Be?

Where would you like to live?

Is there anyone you would like to live with?

Your Hopes and Dreams for the Future are ...



## Getting to Know You

Planning for Services in Supported Living



Getting to Know You:  
Planning for Services in Supported Living

# Part Two: Individual Assessment Options

This workbook belongs to:

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Connections for Information and Resources  
on Community Living (CIRCL)



**Getting to Know You:**  
Planning for Services in Supported Living

**Part Two:**  
**Individual Assessment Option**

compiled for

Connections for Information and Resources  
on Community Living (CIRCL)  
4171 Starkes Grade Road  
Placerville, CA 91006  
**(530) 644-6653**

by

Claudia Bolton ( **NorthStar Services**) and  
Bill Allen (**Allen, Shea & Associates**)

1999





These **Individual Assessment Options** are available to help gather additional and more specific information as needed.



## Important Facts

Name: \_\_\_\_\_

Birthdate: \_\_\_\_\_ Social Security Number: \_\_\_\_\_

UCI #: \_\_\_\_\_ Medi-Cal #: \_\_\_\_\_

### Address

Phone Home: \_\_\_\_\_ Phone Work: \_\_\_\_\_

Landlord: \_\_\_\_\_ Landlord Phone: \_\_\_\_\_

#### *New Address*

Phone Home: \_\_\_\_\_ Phone Work: \_\_\_\_\_

Landlord: \_\_\_\_\_ Landlord Phone: \_\_\_\_\_

#### *New Address*

Phone Home: \_\_\_\_\_ Phone Work: \_\_\_\_\_

Landlord: \_\_\_\_\_ Landlord Phone: \_\_\_\_\_

### Directions to Home

### Income Sources

Income Total: \_\_\_\_\_

*New Income Total:* \_\_\_\_\_

*New Income Total:* \_\_\_\_\_

Soc Security Payee? \_\_\_\_\_

Conservator? \_\_\_\_\_

## Getting to Know You: Planning for Services in Supported Living

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Case Manager: \_\_\_\_\_

*New Case Manager:* \_\_\_\_\_

*New Case Manager:* \_\_\_\_\_

### **People Information (attendant, neighbor, friend, family member, etc.)**

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_

*Name:* \_\_\_\_\_ *Relationship:* \_\_\_\_\_

*Address:* \_\_\_\_\_ *Phone:* \_\_\_\_\_



### **Work, School or Program Information**

Work, School or Program Name: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Contact Person: \_\_\_\_\_

*New Work, School or Program Name:* \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Contact Person: \_\_\_\_\_

### **Emergency Assistance System Description**

#### **Person to notify in case of an emergency**

Name: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Work Phone: \_\_\_\_\_

### **Important Emergency or Health Information**

Community Support Facilitator Name: \_\_\_\_\_

Phone Number: \_\_\_\_\_

*New Community Support Facilitator Name:* \_\_\_\_\_

Phone Number: \_\_\_\_\_

IHSS Case Manager: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Hours of IHSS: \_\_\_\_\_ *New Hours of IHSS:* \_\_\_\_\_ *New Hours of IHSS:* \_\_\_\_\_

Adaptive Equipment Resource:

**Other Notes**



# Daily Living Skills Assessment

(Adapted from Harmony Home SLS)

\_\_\_\_\_  
Name of Person

\_\_\_\_\_  
Date

## 1. BUDGETING, BANKING AND

### PAYING BILLS

	Yes	No	Update	Comments
Counts money	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows spending priorities	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses ATM card	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Reads amount/due date on bills	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Addresses/stamps bills	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cashes check	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Writes checks	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses money orders	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Fills out deposit slip	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Fills out check register	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Balances check book	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Follows budget plan	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

## 2. SHOPPING

Makes a list	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Locates items in store	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Reads prices	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Compares prices	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Pays for purchase	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses coupons	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Asks for assistance	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

## 3. SSI/SSA

Knows Social Security number	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows what SSI/SSA is	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Carries ID card	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows how much each month	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Reports wages to Social Security	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

## Getting to Know You: Planning for Services in Supported Living

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<b>4. TRANSPORTATION</b>	<b>Yes</b>	<b>No</b>	<b>Update</b>	<b>Comments</b>
Has a bus card	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses Dial-A-Ride	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses other transportation	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>5. EATING OUT</b>				
Chooses restaurants	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Orders meals	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Pays for meals	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Eats properly	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Requires assistance to eat				
<b>6. TIME</b>				
Tells time	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Sets a clock	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Sets an alarm	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Reads/Uses calendar	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows current date	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Makes appointments	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>7. USING PHONE + PAY PHONE</b>				
Knows own phone number	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Dials numbers	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Calls people	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Talks on phone	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses phone list of important numbers	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows emergency procedure	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses directory assistance	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses phone directory	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses operator	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____



**8. SUPPORT SYSTEMS**

**Yes**

**No**

**Update**

**Comments**

Knows who to ask for help

---

---

Utilizes family/friends

---

---

Utilizes work/school/prof

---

---

Attends support group

---

---

**9. HOUSEHOLD**

**EMERGENCIES/SECURITY**

Knows who to contact

in an emergency

---

---

Knows what to do in

an emergency

---

---

Knows what to do in

case of a house fire

---

---

Knows how to use

fire extinguisher

---

---

Knows what to do in earthquake

---

---

Responds on how to handle

prank/obscene phone calls

---

---

Responds to unwanted visitors

---

---

Home/apartment security

---

---

**10. COMMUNITY SAFETY**

Knows what to do if lost

---

---

Knows what to do if purse/

wallet lost

---

---

Knows response if mugging or

other crime occurs

---

---

Mugging prevention

---

---

Knows what to do in response

to a con artist

---

---



## Getting to Know You: Planning for Services in Supported Living

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<b>11. STREET SAFETY</b>	<b>Yes</b>	<b>No</b>	<b>Update</b>	<b>Comments</b>
Follows vehicle laws/safety	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Follows street safety	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>12. KITCHEN/DINING</b>				
<b>ROOM CLEANING</b>				
Sweeps floor	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Mops floor	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Washes dishes/pots & pans	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Puts dishes away	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wipes counters	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wipes stove top	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wipes spills	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cleans sink	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Does on regular basis	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>13. BATHROOM CLEANING/ UPKEEP</b>				
Cleans tub/shower	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cleans sink	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cleans toilet	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cleans mirror	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Unclogs sink/toilet	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Stops overflowing toilet	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Does on a regular basis	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Washes rug/towels	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses correct cleansers	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____



<b>14. CLOTHING/LINEN</b>	<b>Yes</b>	<b>No</b>	<b>Update</b>	<b>Comments</b>
Dresses/Undresses	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wears appropriate to weather	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wears appropriate to occasion	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Clothes that fit	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wears clothes that are neat/clean	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Washes clothes/linens	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Sorts dirty clothes/linens	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Stores clean clothes	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Changes linens	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>15. BODY CARE</b>				
Showers/bathes	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Washes hands	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Trims fingernails	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Trims toenails	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Shaves	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses deodorant	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses feminine hygiene	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>16. HAIR CARE</b>				
Brushes/combs	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Shampoos hair	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cuts/trims hair	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cuts/trims mustache/beard	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
<b>17. TEETH CARE</b>				
Brushes/flosses teeth	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

**18. EMERGENCY**

**MEDICAL CARE**

	<b>Yes</b>	<b>No</b>	<b>Update</b>	<b>Comments</b>
Gets emergency help when needed	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Carries Medi-Cal card/insurance	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Name of doctor	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cares for minor injuries	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Cares for oneself when sick	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Obtains medication as needed	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows doses of prescription meds	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows over-counter, common meds	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Takes medication daily	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Wears Medic Alert tag	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows dangers of substance abuse	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Avoids substance abuse	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

**19. SEXUAL HEALTH AND SAFETY**

Knows information/sexual health	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows information on pregnancy and birthing	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses birth control	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows laws on sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

**20. SOCIAL RELATIONSHIPS**

Communicates effectively with others	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Develops/maintains friendships	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Develops personal/social skills				
Inappropriate interaction with strangers	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____



**21.ESSENTIAL COOKING**

**UTENSILS/APPLIANCES**

	<b>Yes</b>	<b>No</b>	<b>Update</b>	<b>Comments</b>
Uses stove	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses oven	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses microwave	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses toaster oven	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses knife and cutting board	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Uses timer	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

**22.MEAL**

**PREPARATION/PLANNING**

Plans meals	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Follows simple instructions	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Performs basic cooking skills	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Performs basic food preparation	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Disposes of grease	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Washes hands	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Stores food and leftovers	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Thaws meat	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Recognizes spoiled food	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

**23.SELF-ADVOCACY**

Communicates for self	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Is tactful when expressing self	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Is aware of their rights	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Attends people first	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____
Knows protocol when lodging complaints	<input type="checkbox"/>	<input type="checkbox"/>	_____	_____

TRACE  
**Personal Assistance  
NEEDS ASSESSMENT\***

**CONTENTS**

- 1.0 LIFTING AND TRANSFERRING**
- 2.0 BATHROOM**
- 3.0 GROOMING**
- 4.0 MEALS**
- 5.0 COMMUNICATION**
- 6.0 TRANSPORTATION AND MOBILITY**
- 7.0 EMERGENCY PROCEDURES**
- 8.0 MEDICATIONS**
- 9.0 HOUSEHOLD RESPONSIBILITIES**
- 10.0 PERSONAL NEEDS**
- 11.0 INTERPERSONAL RELATIONSHIPS**

\* Adapted with permission from *Becoming Independent*. Revisions were made with the assistance of Anita Cotton, Occupational Therapist, Regional Center of the Easy Bay.

**Note to Facilitators:** A number of these questions are both personal and intrusive. For that reason, please be respectful and ask only those questions you must ask in order to help someone get support the way they want it.



## 1.0 LIFTING AND TRANSFERRING

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |   | Y                        | or | N                        |
|------|---|--------------------------|----|--------------------------|
| 1.1  | Do you need to be lifted and or transferred as part of your care.<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.2  | Do you use or need any special adaptive equipment to transfer.<br>Explain:    | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.3  | How do you like to be lifted and transferred?<br>Explain:                     | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.4  | Are you able to instruct an assistant how to lift/transfer you?               | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.5  | Do you have use of your arms and/or legs?<br>Explain:                         | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.6  | Do you grab, pull, or resist when transferring?<br>Explain:                   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.7  | Are you able to control grabbing, pulling and resisting?                      | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.8  | Can you sit or stand by yourself?<br>Explain:                                 | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.9  | Should any precautions be used when being lifted or transferred?              | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.10 | How do you get into bed?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |

(CHECK APPROPRIATE BOX—YES OR NO)

- |   | Y                        | or | N                        |
|---|--------------------------|----|--------------------------|
| 1.11 When in bed, what position are you most comfortable in?      | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 1.12 How do you lift and/or transfer onto the toilet?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |

## 2.0 BATHROOM

### 2.0 Universal Infection Control Procedures

- |  |                          |  |                          |
|--|--------------------------|--|--------------------------|
| 2.1 Do you know the basic universal precautions?                               | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.2 Do you know how to prevent the spreading of germs?<br>Explain:             | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.3 Do you wash your hands on a regular basis?                                 | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.4 Do you require intimate personal care from an assistant?<br>Explain:       | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.5 Do you have or need supplies for personal care such as gloves?<br>Explain: | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.6 How are those supplies paid for?<br>Explain:                               | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 2.7 How do you communicate the need to use the bathroom?<br>Explain:           | <input type="checkbox"/> |  | <input type="checkbox"/> |



## 2.0 BATHROOM

(CHECK APPROPRIATE BOX—YES OR NO)

2.8 Describe what assistance you require when you use the bathroom?    
Describe:

2.9 What supplies, if any, do you use for bowel and bladder care?    
Explain:

2.10 Do you use or need any adaptive equipment to use the bathroom?    
Explain:

2.11 Do you have a schedule for when you generally use the bathroom?    
Explain:

2.12 Do you take any medications to help with bowel/bladder routines?    
Explain:

2.13 Are you able to use a public bathroom?    
Explain:

## 3.0 GROOMING

3.1 Are you able to test water temperature accurately?

3.2 Can you bathe independently?    
Explain:



## Getting to Know You: Planning for Services in Supported Living

---

(CHECK APPROPRIATE BOX—YES OR NO)

		Y	or	N
3.3	Do you use adaptive equipment such as lifts, belts or commodes? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
3.4	Do you need help entering or exiting tub? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
3.5	Do you have a bathing schedule? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
3.6	Do you use special hair care products? Explain	<input type="checkbox"/>		<input type="checkbox"/>
3.7	What safety precautions are needed when using electric appliances in the bathroom? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
3.8	Do you need help combing or brushing your hair?	<input type="checkbox"/>		<input type="checkbox"/>
3.9	Do you cut your own nails?	<input type="checkbox"/>		<input type="checkbox"/>
3.10	Can you give your personal assistant instructions on how to do cut your nails?	<input type="checkbox"/>		<input type="checkbox"/>
3.11	Do you have a podiatrist? If yes, list: <u>Name</u> <u>Phone</u> <u>Duties</u>	<input type="checkbox"/>		<input type="checkbox"/>
3.12	Do you have problems with your feet? Explain:	<input type="checkbox"/>		<input type="checkbox"/>



### 3.0 GROOMING

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |  | Y                        | or | N                        |
|------|--|--------------------------|----|--------------------------|
| 3.13 | Do you have orthodic devices?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.14 | Do you shave independently?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.15 | Do you have any allergies to shaving cremes or lotions?<br>Explain:                                    | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.16 | Do you brush your teeth independently?<br>Explain:   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.17 | Do you wear dentures?  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3 18 | Do you swallow or clench your teeth involuntarily?<br>Explain:   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.19 | Do you have a habit of biting hard when something is in your mouth?                                    | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.20 | Do you ever choke? What would cause you to choke?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 3.21 | Have you ever had sores on your bottom or body that come from your bed or your wheelchair?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |

### 3.0 GROOMING

(CHECK APPROPRIATE BOX—YES OR NO)

Y or N

3.22 Do you take medications or have a condition, such as diabetes, that might delay the healing process?  
Explain:

3.23 Are there ways that you feel more comfortable?  
Explain:

3.24 Are there times when your muscles feel looser than other times?  
Explain:

3.25 Do you need help to get dressed?  
Explain:

### 4.0 MEALS

4.1 Do you prefer to eat or avoid any particular foods?  
Explain:

4.2 Do you have a doctor's order in place for a modified diet or eating techniques?  
Explain:

4.3 Do you have any food allergies?  
Explain:



## 4.0 MEALS

(CHECK APPROPRIATE BOX—YES OR NO)

- |     |  | Y                        | or | N                        |
|-----|--|--------------------------|----|--------------------------|
| 4.4 | Are you able to help with meal preparations?<br>Explain:                       | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 4.5 | Can you eat independently?   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 4.6 | Do you have any difficulty swallowing or chewing?<br>Explain:                  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 4.7 | Are there ways you like to be seated when you eat?<br>Explain:                 | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 4.8 | Are there special set-ups or utensils that help you feed yourself?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |

## 5.0 COMMUNICATION

- |     |  |                          |  |                          |
|-----|--|--------------------------|--|--------------------------|
| 5.1 | Is it hard for you to ask people to help you?<br>Explain:      | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 5.2 | Do you have difficulty accepting help?<br>Explain:             | <input type="checkbox"/> |  | <input type="checkbox"/> |
| 5.3 | Do you have a videotape that demonstrates your daily routines? | <input type="checkbox"/> |  | <input type="checkbox"/> |

**6.0 TRANSPORTATION AND MOBILITY**

(CHECK APPROPRIATE BOX—YES OR NO)

- |     |   | Y                        | or | N                        |
|-----|---|--------------------------|----|--------------------------|
| 6.1 | Do you need or use a wheelchair?  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.2 | Do you use a power or manual chair or both?<br>Explain:                                 | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.3 | Do you know from where and whom you got your wheelchair?<br><u>Who?</u> <u>Phone #?</u> | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.4 | How do you get your wheelchair fixed?<br>Explain:                                       | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.5 | Who pays for the repairs for the wheelchair?<br>Explain:                                | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.6 | Do you have another chair if something happens to yours?                                | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.7 | Who cleans your wheelchair and how often should that happen?<br>Explain:                | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.8 | How do you get around the community?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.9 | Do you own your own vehicle?<br>Explain: Insurance:                                     | <input type="checkbox"/> |    | <input type="checkbox"/> |

If yes, who pays for repairs?



## 6.0 TRANSPORTATION AND MOBILITY

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |   | Y                        | or | N                        |
|------|---|--------------------------|----|--------------------------|
| 6.11 | Do you use public transportation by yourself?<br>Explain:                               | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.12 | Can you go out in a regular car?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.13 | Do you feel comfortable on your own in the community?<br>Explain:                       | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.14 | Have you ever had an accident in your chair in the community?<br>Explain:               | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.17 | What would you do if your wheelchair broke down when you<br>were out alone?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 6.18 | Do you use community recreational facilities and resources?                             | <input type="checkbox"/> |    | <input type="checkbox"/> |

What

How Often

How I get there





## 8.0 MEDICATIONS

(CHECK APPROPRIATE BOX—YES OR NO)

- |     |   |             |                 |                |              | Y                        | or | N                        |
|-----|---|-------------|-----------------|----------------|--------------|--------------------------|----|--------------------------|
| 8.1 | Do you take medications?  |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
|     | <u>What</u>   | <u>When</u> | <u>What for</u> | <u>Pres by</u> | <u>Phone</u> |                          |    |                          |
| 8.2 | Where do you purchase your medications?                           |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
|     | <u>Pharmacy</u>   |             | <u>Address</u>  |                | <u>Phone</u> |                          |    |                          |
| 8.3 | Are your medications delivered or picked up at pharmacy?          |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.4 | Do you reorder your own medications?                              |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.5 | Are your medications packaged in a way that helps you keep track? |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.6 | Do you administer your medications independently?                 |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
|     | Explain:  |             |                 |                |              |                          |    |                          |
| 8.7 | Do you keep a record of medications?                              |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.8 | Do you use methods other than pills to take medications?          |             |                 |                |              | <input type="checkbox"/> |    | <input type="checkbox"/> |
|     | Explain:  |             |                 |                |              |                          |    |                          |



**8.0 MEDICATIONS**

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |  | Y                        | or | N                        |
|------|--|--------------------------|----|--------------------------|
| 8.9  | Can you give yourself shots if you have to take medicine that way?                               | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.10 | Where do you keep your medications?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.11 | Who do you want to be able to get to your medications?<br>Name:                                  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.12 | What happens if you don't take your medications?<br>Explain:                                     | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.13 | Do you have a way to get rid of the medicines you are finished with?<br>Explain:                 | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 8.14 | Do you know what to do if you take too much medication or have an allergic reaction?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |



## 9.0 HOUSEHOLD RESPONSIBILITIES

(CHECK APPROPRIATE BOX—YES OR NO)

		Y	or	N
	Are you able to do housekeeping chores by yourself?			
9.1	Kitchen? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.2	Bathroom? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.3 R	Bedroom? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.4	Living Room? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.5	Laundry Room? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.6	Yard? Explain:	<input type="checkbox"/>		<input type="checkbox"/>
9.7	What is your experience managing people who do this work for you?	<input type="checkbox"/>		<input type="checkbox"/>
9.8	How would you let your attendants know what you wanted them to do?	<input type="checkbox"/>		<input type="checkbox"/>
9.9	Do you own or are you able to get household furnishings or adaptive equipment that you need? List and explain:	<input type="checkbox"/>		<input type="checkbox"/>

**10.0 PERSONAL NEEDS**

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |   | Y                        | or | N                        |
|------|---|--------------------------|----|--------------------------|
| 10.1 | Do you like to spend time alone at home?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.2 | Have you ever hired your own Personal Assistant?  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.3 | Do you have or need funding to hire Personal Assistants?  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.4 | Have you been evaluated by any agencies, such as IHSS, to determine your attendant needs?<br><u>Agency</u> <u>Contact</u> <u>Phone</u> <u>Funding</u> <u>Date</u>   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.5 | Do you have or need to make adaptations, such as door openers, to living spaces in order for you to live independently?<br><u>What</u> <u>How &amp; Where purchased</u> <u>Who maintains</u> <u>Phone</u> | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.6 | If your living space need adaptations who will pay for them?  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.7 | Do you have or need space for a canine companion or other pet?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.8 | What are some qualities you like in a Personal Assistant?<br>Explain:   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 10.9 | What are some qualities you would not like in a Personal Assistant?<br>Explain:   | <input type="checkbox"/> |    | <input type="checkbox"/> |



## 11.0 INTERPERSONAL

(CHECK APPROPRIATE BOX—YES OR NO)

- |      |   | Y                        | or | N                        |
|------|---|--------------------------|----|--------------------------|
| 11.1 | If you have problems with someone, a roommate or assistant, for example, how do you usually resolve them?<br>Explain: | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.2 | Do you put things in writing or keep a record of agreements?<br>Explain:  | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.3 | When and where do you like privacy?<br>Explain:   | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.4 | Have you had to fire a Personal Assistant? If yes, how did you do it?<br>Explain:                                     | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.5 | Can your assistants have friends or family visit or stay with them?<br>Explain:                                       | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.6 | Who pays, how often, and how much do you pay your assistants?<br><u>Payer</u> <u>When</u> <u>Rate</u>                 | <input type="checkbox"/> |    | <input type="checkbox"/> |
| 11.7 | Have you had experience completing timecards for your Personal Assistants?<br>Explain:                                | <input type="checkbox"/> |    | <input type="checkbox"/> |

# Medical Information Checklist

Date of last physical exam? \_\_\_\_\_ What did you find out?

Was your blood pressure taken?                         Y        N        If so, what is it?

Do you have, or have you had any serious illness, disease, or have you been hospitalized? Y        N        If so, please describe:

Do you have, or have you ever had the following? (Please circle and describe under remarks)

A. rheumatic fever	Y	N	R. respiratory disease	Y	N
B. inflammatory rheumatism	Y	N	S. psychiatric treatment	Y	N
C. scarlet fever	Y	N	T. any x-rays for growths	Y	N
C. hepatitis, jaundice	Y	N	U. asthma	Y	N
E. liver disease	Y	N	V. peptic ulcer	Y	N
F. tuberculosis	Y	N	W. allergies (rash) to:		
G. high/low blood pressure	Y	N	1. penicillin	Y	N
H. venereal disease	Y	N	2. other antibiotics	Y	N
I. heart disease or stroke	Y	N	3. iodine	Y	N
J. heart murmur	Y	N	4. codeine	Y	N
K. angina pectoris	Y	N	5. local anesthetic	Y	N
L. pacemaker or parts	Y	N	(as in novacaine)		
M. hyperthyroidism	Y	N	6. aspirin	Y	N
N. epilepsy /convulsions	Y	N	7. other	Y	N
O. blood disease/as anemia	Y	N			
P. abnormal bleeding	Y	N	X. eye disease (glaucoma)	Y	N
Q. diabetes/sugar disease	Y	N	Y. contact lenses	Y	N
			Z. aids virus	Y	N

Are you taking any medications, drugs, or pills, or have you experienced an unusual reaction to any drug such as, but not limited to, the following? Please describe under remarks:

Anticoagulants (blood thinners)

as Warfarin or Courmarin	Y	N	Digitalis or Nitroglycerin	Y	N
Steroids (cortisone)	Y	N	Insulin	Y	N
Tranquilizers or sleeping pills	Y	N	Other	Y	N

Have you experienced any unfavorable reactions to previous dental treatment?         Y        N  
Do you have any disease, condition or problem not listed that we should know about? Y        N

**Remarks:**

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

Please make sure that you tell us about any changes in the above information when we review it.

REVIEWED THIS DATE \_\_\_\_\_ SIGNATURE \_\_\_\_\_

REVIEWED THIS DATE \_\_\_\_\_ SIGNATURE \_\_\_\_\_



## Listen to Me Communicate

This communication plan is designed to support people who do not use words to talk, or who have difficulty communicating in typical ways. This section is also very useful for supporting people who communicate with their behavior.

The heading **what is happening** describes the circumstances. The headings **and (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.

It's easiest to complete the communication worksheet by starting from the two inside columns first (. . . . does, we think it means) and then working out to the two outside columns (what is happening, and we should).

**What is happening**

\_\_\_\_\_ does

**We think it means**

**And we should**



## **Your Pattern of Support When You Live In Your Own Home**

Based on everything learned about the person's best week days and best week-end days, and their preferred routines and rituals, what would a pattern of support look like? When would the person be alone? When would paid support be present? What things would paid support be helping the person with or doing for the person? When would the person's natural supports be present? Remember that everyone's days are unpredictable and that supported living services strive to be flexible and offer support if and when it is needed. This schedule is only a best guess at when supports are needed.



	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6 AM							
7							
8							
9							
10							
11							
12 PM							
1							
2							
3							
4							
5							
6							
7							
8							
9							
10 PM							



## **Getting to Know You**

Planning for Services in Supported Living



Getting to Know You:  
Planning for Services in Supported Living

Part Three:  
Summing It All Up

This workbook belongs to:

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Connections for Information and Resources  
on Community Living (CIRCL)



**Getting to Know You:**  
Planning for Services in Supported Living

**Part Three:**  
**Summing It All Up**

compiled for

Connections for Information and Resources  
on Community Living (CIRCL)  
4171 Starkes Grade Road  
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by

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1999



**Summing It All Up** is a place to pull together all of the information you have gathered and organize it into a plan for support. The Plan includes the following headings:

- The People who Contributed to this Plan
- Great Things about You
- What is important to the person prioritized into two or three categories:
  - 1st priority - Non-negotiables
  - 2nd priority - Strong Preferences
  - 3rd priority - Highly Desirables

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 has been learned about the person, not what people are guessing about. What is important to the person is divided by headings that prioritize how important things are.

- Things I Want to Learn to Do
- Things We Need to Know or Do to Help the Person Get What is Important
- Other Notes, Comments, Recommendations and Things that are Unresolved



# The People who Contributed to this Plan:

Name:	Relationship to the Focus Person:
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____
11. _____	_____
12. _____	_____

**Original Date of Plan:** \_\_\_\_\_

**Revisions Made:**  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## What is Most Important?

Now, please help us prioritize the important things you told us about the people in your life, the things you like to do, your best and worst days and your rituals and routines. Be very detailed if you need assistance to have or do the things that are important to you. Prioritize these things that are important to you into three categories:

**Non-negotiables** - things you must do or have/must not do or have.

**Strong Preferences** - things that are important or very important to you.

**Highly Desireables** - things you like/dislike or things you'd like to try.



**NON-NEGOTIABLES - THE THINGS THAT \_\_\_\_\_  
MUST HAVE, DO, AND BE:**

In relationships with others

In things to do, things to have



In health, safety

In positive rituals



STRONG PREFERENCES - NEEDS OF \_\_\_\_\_

HIGHLY DESIRABLES - WANTS AND ENJOYS  
OF \_\_\_\_\_



## Things I Want to Learn to Do

Are there things you want to learn to do? The supported living services agency can teach you to do more for yourself if this is what you would like to do. The Daily Living Skills Assessment can be used to see what you already know how to do and the Personal Assistance Needs Assessment can be used to see your physical care and personal assistant/attendant management skills. The things you would like to learn can be listed here.

Things I Want to Learn to Do



## **Things We Need to Know or Do to Help the Person Get What is Important**

What do others need to know or do in order for the person to get what is important. Develop this section by looking at each thing listed as important to the person and ask yourself if there is anything that support people need to know or do in order for the person to have what is important.

What do others need to know or do so that the person has more good days and fewer bad days.

Include support the person needs or things we need to know or do about the person's "negative reputation". We all have one! Are there things that make the person upset that we need to know about? Are there concerns of relatives, friends and others who know and care about the person?

Be very detailed when the person needs physical assistance to have the routines and rituals that are important to them.

Include assistance the person will need to move toward their dreams and hopes for the future.

What Do Others Need to Know and Do?



# Things We Need to Know or Do to Help the Person Stay Healthy and Safe

## **To Help the Person Stay Healthy:**

Gather and record the information here when there are significant health issues. Describe what people need to know or do to help the person stay healthy. Information from the *Daily Living Skills Assessment* or the *Personal Assistance Assessment* would go here for people who need support to monitor and take medication.

## **To Help the Person Stay Safe:**

Describe what people need to know or do to help the person stay safe. Information from the *Daily Living Skills Assessment* or the *Personal Assistance Assessment* would be recorded here for people who need support to be safe.

This is also where we can describe things to know or do to support someone who has mental health issues.

If the supported living services will include emergency response services or on-call services describe what the person needs here.



Other Things We Need to Know and Do  
to Support Health and Safety?



**Other Notes, Comments, Recommendations  
and Things that are Unresolved**

**Other Notes, Comments, Recommendations  
and Things that are Unresolved**



## Getting to Know You

Planning for Services in Supported Living

## References for Getting to Know You

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**Supported Living Services Training Tool Box**

**Part Four:  
Tools and Applications**

**Connections for Information and Resources  
on Community Living (CIRCL)**

**April, 2001**