Future Care Planning: A Roadmap for Family Caregivers

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INTRODUCTION

Family caregivers are a valuable resource to our community. Each caregiver's experience is unique, meaningful, and ongoing. Thinking about one's personal future and the future of the family member with a developmental disability (DD) can be emotionally difficult and overwhelming. This Roadmap was made for the ***family caregiver***.

The roadmap is a journey with many twists and turns in which you will discover different roads to take. You will stop at different points in your journey and your path may change along the way. This journey will take you to areas that are unfamiliar or uncomfortable and you may need additional assistance along the way. Your journey will involve different decisions and tasks. There will be intersections that need to be solved. Along your chosen path, you can involve family, your community, and professional caregivers who have additional knowledge about legal and financial decisions, housing options, employment opportunities, and ways to encourage social engagement. The participation and input from the person with a developmental disability will be an important part of your journey and plan.

The roadmap was designed as a workbook to guide your thoughts and discussion about future care planning. It also serves as a resource for other family members and service providers so they can provide support as you go through the planning process. As you review this roadmap, you don't have to complete every section and you don't have to review each section in the order it is outlined here. Identify what areas you want to explore first and you can always return to a section or topic area at a later date.

Things to Help You Along Your Journey

1. Do not get intimidated by the length of the Roadmap – you may not need to complete every page
2. At first, quickly glance through the whole roadmap
3. Identify the sections or pages that are easiest to complete first
4. Schedule a quiet time when you can review the document more closely
5. Invite a friend or family member to go through the roadmap with you (if you will find this useful)
6. Remember that you don't have to complete every section all at once
7. Congratulate yourself on exploring the process of future care planning – *it's not an easy thing to do.*

It's Time To Begin Your Journey..........

For the Family Caregiver

This section is designed for YOU as the **family caregiver,** the person who is most involved with the daily activities and care of the person with a disability. You may or may not be living with the person with a disability but you are still intimately involved with the oversight, management, and day-to-day concerns that occur.

This map depicts a journey that can at times feels overwhelming yet meaningful. It takes you as a family caregiver and those you love to places that are both familiar and distant. Along your journey, there are friends, relatives, your community, and service providers who can provide support and direction.

Planning Your Journey

The GOAL of future care planning is to engage in a conversation and to consider options that are available in your community. It is important to begin making plans as early as possible knowing that these **plans can and will change**. The future care plan involves consideration of the needs and desires of your loved one with a disability; exploring housing options in your community; exploring meaningful work opportunities; examining financial resources; knowledge about health care resources; and finding comfort and peace of mind. The discussion about future care plans should involve the individual with the disability as much as possible. There are other individuals who have important contributions to make and they include: family members, future caregiver(s), legal guardians, community providers, and individuals from other support networks.

Early planning is key to a smooth and informed transition. It is recommended that you **review and revise your roadmap every six months or at least each year.** These plans should be readily accessible and shared with the appropriate persons.

There are several **benefits of planning early.** When planning is done before the need arises or before a crisis occurs, positive things occur:

- Individual(s) who will assume the care or oversight will understand more clearly what works well and what doesn’t work as well
- Care and service providers will be more prepared and will be ready to take over in the event of your illness or death
- Other family members will have a clearer understanding of their role, which minimizes conflict in the family
- Disputes between siblings over who should pay for what can be avoided
- You can clearly see what tasks need to be completed and what you have already accomplished
- Plans are well thought out when emotions are calmer and caregivers are not rushed to make important decisions

In the 2008 *State of the States in Developmental Disabilities* report, it was estimated that the majority of people (60%) with intellectual and developmental disabilities in the United States live with family caregivers. Of this group, 25% lived with caregivers who were age 60 and older. The lack of future planning can result in inappropriate residential placements; inadequate financial and legal safeguards; increased confusion for the person with DD; disagreements between other family members; and inadequate involvement and input of the person with developmental disabilities about their own future.

Reference: Braddock, D., Hemp, R., and Rizzolo, M.C. *The State of the States in Developmental Disabilities, 2008.* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.

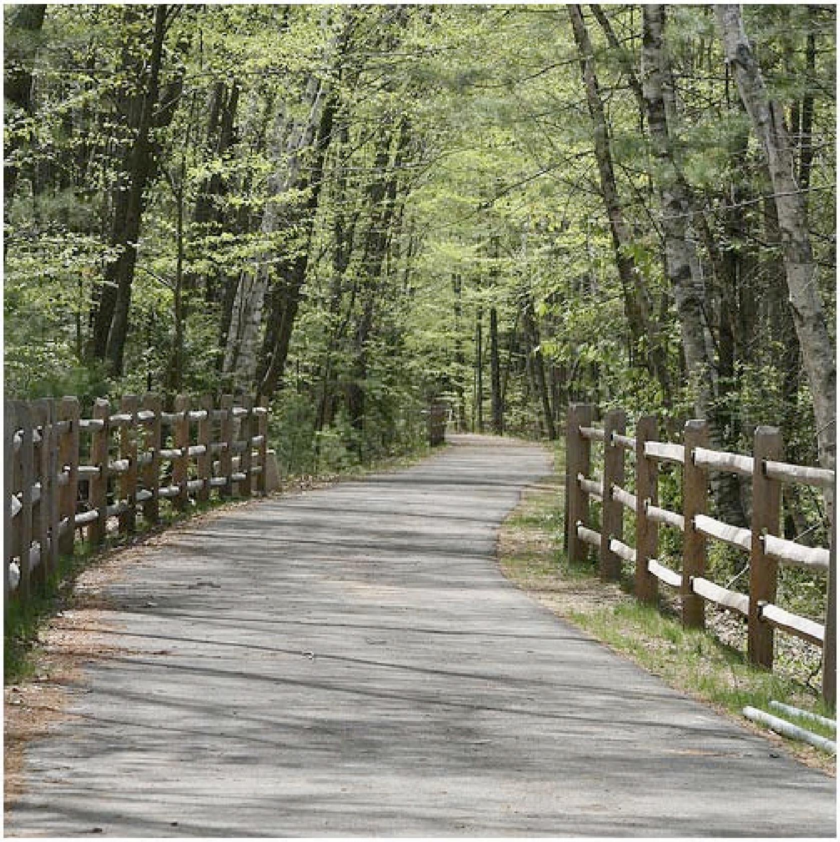
Some family caregivers find that making or talking about a future care plan for a loved one is difficult for several different reasons. Here are some of the challenges family caregivers have shared. It may or may not apply to you. Do you face some of the same challenges that other caregivers face? *By sharing your concerns, you will be better able to move forward, one step at a time.*

a. Not knowing where or how to start
b. Waiting or trying to identify the right time to start planning
c. Not knowing who to ask or include in the discussion
d. Being confused about how systems work and what they do
e. Not knowing about resources available to help
f. Having few or limited personal/family/community resources
g. Lack of close family or support systems nearby
h. Inability to obtain clear and helpful information
i. Experiencing emotional discomfort and stress when thinking about or talking about future care plans
j. Being fearful or concerned about what might happen in the future
k. Being too busy to plan
l. Being unsure of how independent the person with DD can be
m. Lack of knowledge about creative housing options

Start Planning Your Journey Now

Family caregivers often ask, **"When is the best or right time to start making future care plans?"** It is never too early to start this discussion. One family shared that it occurred to them one day when their son was restless and agitated, as if he wanted them to know that he wanted a space and house of his own. For another caregiver it was when her daughter developed a new relationship with a male and his family. For others, it can be triggered by health changes for either the family caregiver or the person with the disability.

One thing is for sure: it is best to start this discussion before a crisis because planning takes time. It is also important to make plans when both the caregiver and family member with a disability are healthy and able to contribute to the discussion. Some of the decisions to be made need to be discussed when the person reaches 18. Some of those decisions must be made and acted upon well before then.



WHO CAN HELP?

Sometimes you will need help from others and it can come in a variety of forms. Here you can identify the individuals in your family, community, or support network that can contribute to this discussion.

NAME:

1.

2.

3.

4.

5.

6.

7.

8.

Other:

How Family Can Help

It can be difficult to ask for help from family members. This section will allow you to reflect on some important questions. It may be a good time to look at family members' future relationship with the person with the disability and how they can be part of the future plan. You may be surprised to find out that there are other members who want to get involved to some degree.

The following questions will allow you to reflect on important issues to ask yourself and your family members. If and when you feel comfortable, you can share your response with family members to open up the discussion about their role and ways in which they can participate in the caregiving role. You can also ask family members and siblings to respond to the same questions.

Circle the response that identifies how you feel at this time.

I feel comfortable discussing this topic with family members

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

I have tried to have this discussion recently with a family member

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

In my discussion, we reviewed the day-to-day care activities

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

I shared my expectations about the type of or degree of care that I wanted to see provided by the family member

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

I recognized limitations the family member would have in providing care

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

The family member recognized limitations they have in providing care

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

We identified ways that the family member can be involved in providing care

1	2	3	4	5
Strongly Agree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree

There are no right or wrong answers or an appropriate score for the items above. This is an exercise where you can look at where you are now and what this all means.

Do you have enough help?

Have you asked for the help you need and want?

How Brothers and Sisters Can Help

Now is the time to explore the role of siblings. Many adult siblings are involved with providing care in various ways and degrees. If your son, daughter, grandson or granddaughter has siblings, what role do you want them to play in the future? What role do they want to play? You may be ambivalent about the degree of involvement siblings should have. You recognize the time commitment and sacrifices you have made. You may be surprised to know that siblings want to have this important conversation.

The following topics can facilitate discussion about their role and ways in which they can participate in the caregiving role. Use this page to prepare for your discussion with siblings:

- Financial costs
- Time
- Impact on relationships with friends, spouse, other family members
- Dividing responsibility among other family members
- Helping from a distance

- Health concerns of sibling with a disability

- Safety issues

- Quality of life, happiness, integration, social and physical activities

- Availability of support for sibling with DD and themselves

The research about sibling expectations of being future primary caregivers shows that:

- Siblings have some expectations that they will eventually become involved with the care of their sibling with a disability
- The role of the non-disabled sibling will depend on their involvement in disability activities, contact with their sibling, and satisfaction experienced in providing care

Resources for adult siblings:

Siblings and their role: *Rehabilitation Research and Training Center on Aging with Developmental Disabilities* at http://www.rrtcadd.org.

Online discussion group for adult siblings: http://groups.yahoo.com/group/sibnet

Personal Profile For:

Throughout the Roadmap you will be putting together pieces of a personal profile of your family member with a disability. The profile is important because it helps you apply the experience and knowledge you have with what your family member with the disability wants regarding where to live, his/her routines, what s/he wants to learn, and how s/he learns best. There will be multiple sections in the profile.

Besides demographic information, the personal profile will identify:

- What and who are important to you and your family member with a disability?
- How can my needs be met?
- How can the needs of the person with a disability be met?
- How can supports be delivered?
- Who will provide the various types of supports?
- How do I engage other family members and the community?
- What works and does not work?

Demographics and Health

Name:

Nickname:

Age and/or Birth Date:

Gender:

Primary Language Used (If sign language is used, state what type of sign):

Method of Communication (If the primary mode of communication is other than speaking: communication boards, etc.):

Diagnoses or Important Health Information:

Medications:

Speech Therapy:

Physical Therapy:

Occupational Therapy:

Art or Music Therapy:

Family History:

Physical Examinations (Date and Evaluator)

- Immunizations
- Pelvic Exam
- Mammogram
- Testicular Exam
- Prostate Exam
- Audiology Exam
- Vision Exam
- Dental Exam
- Other:

A Checklist of What _______________ Can Do

This checklist can help to identify the activities that the person with a disability can accomplish. It includes both simple and complicated activities. Not all of the activities will apply to your situation. This checklist also identifies the amount of support that is currently needed for each activity. Place a **"mark"** in the appropriate column. You can review this list alone or with your family member with a disability.

Note: * *Needs Some Help* means that a person is physically able to do the task but needs some oversight, organization, and supervision.

	Needs help all the time	**Needs some help**	**Can do it him or herself**
PERSONAL SKILLS			
Eat with a spoon			
Use knife and a fork			
Blow his/her nose			
Brush his/her teeth			
Comb his/her hair			
Take a shower			
Shave him/herself			
Use the bathroom			
Exercise			
Notes:			

	Needs help all the time	**Needs some help**	**Can do it him or herself**
KITCHEN AND COOKING SKILLS			
Pour a drink into a cup			
Make a simple meal (like toast with butter)			
Heat food in a microwave			
Make scrambled eggs			
Help set the table			
Put dishes in sink or dishwasher			
Wash dishes			
Notes:			

	Needs help all the time	**Needs some help**	**Can do it him or herself**
CLEANING SKILLS			
Take out the trash			
Make his/her bed			
Put dirty clothes into hamper			
Wash his/her clothes			
Vacuum the rug			
Sweep the floor			
Wipe off the table			
Notes:			

	Needs help all the time	Needs some help	Can do it him or herself
SHOPPING			
Make a shopping list			
Know that money has value			
Know about food groups			
Choose appropriate foods			
Push a grocery cart			
Know to ask for assistance			
Know his/her clothing size			
Purchase items with money			
Notes:			

	Needs help all the time	Needs some help	Can do it him or herself
COMMUNICATION			
Use a computerized talker			
Talk in simple phrases			
Use the phone			
Write a letter or note			
Take part in an online community			
Talk with friends			
Request help by dialing “911”			
Notes:			

	Needs help all the time	Needs some help	Can do it him or herself
COMMUNITY ACTIVITIES			
Go to restaurants			
Attend plays, movies, concerts			
Attend religious services			
Participate in sports			
Do volunteer work			
Work at a paying job			
Manage money for community activities			
Notes:			

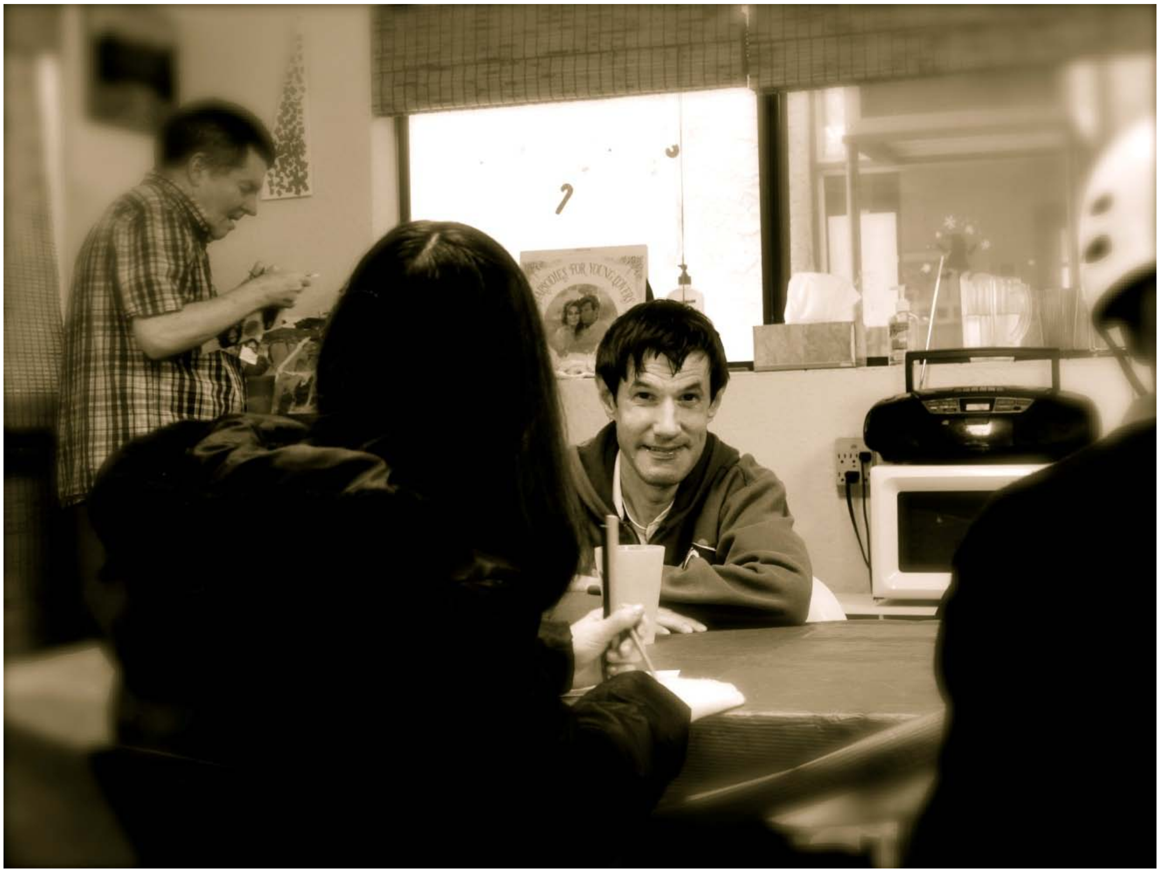
	Needs help all the time	Needs some help	Can do it him or herself
TRANSPORTATION			
Walk or push a wheelchair			
Ride in a car			
Ride in a van			
Ride the public bus system			
Read the bus schedule			
Call for a ride			
Fly in an airplane			
Notes:			

Person-Centered Planning

What is Person-Centered Planning?

Person-centered planning is a guided, systematic process that assists people in identifying the steps to make their dreams a reality. A full range of options for successful adult living is explored in partnership with important people in a person's life. Topics may include creating a vision for the future, employment, education, relationships, recreation, and health & wellness.

This section provides some information about person centered planning. One important component of this planning process is to understand what is important to the person with a disability. The following exercise is one way to help you do that. Here you will explore the difference between what is important ***to*** the person and what is important ***for*** the person. Things that are important ***to*** the person include his or her hopes and dreams, likes and dislikes, places that are important, and special interests. At the same time, you will also identify what is important ***for*** the person, such as what is needed to ensure her/his health and safety.



NEEDS and DREAMS:
Important To and Important For

(Check out the resources for Person Centered Thinking and Planning in the Appendix)

IMPORTANT *TO:* _____________ _________________ **hopes, dream, likes and dislikes, places, special interests**	**IMPORTANT *FOR:*** _____________ _________________ **what is needed to ensure health and safety**

Next Steps

Sometimes what is important to the person does not always match what is important for them. What is needed to bring the important *to* and important *for* items in better balance?

What has to be maintained, enhanced, or changed to accomplish this?

What do other people have to know or do?

What do we need to learn or figure out?

Living with Family or Living Elsewhere

One of the most important and possibly difficult decision family caregivers will make has to do with finding the most appropriate residential living arrangement. This process will take some time and planning. There are more options than in the past and some will take some creative planning. It may involve talking with other families who face similar issues and pooling together resources.

Now is the time to explore the following questions:

- What are my concerns or worries about the future living arrangement for your family member?

- What can be done to minimize or reduce my concerns or worries?

- Who can I talk to about this?

- Can smaller steps be taken to explore this option?

- How would I define success?

- What information do I need to begin exploring options?

You may try something and it may not work the first time. Let those around you know what you need and how they can be supportive. It may involve taking risks and adapting plans. Don't hesitate to tell others around you what you need.

Exploring Living Options

What living options have you explored?

- ☐ With family:
  - o Same city ___________________
  - o Different city or state ___________________
- ☐ Respite (temporary arrangement that provides a break)
- ☐ House or apartment (independently)
- ☐ House or apartment with roommate(s)
- ☐ In house or apartment with hired caregivers who provide supervision
- ☐ Apartment community that is designed and governed by people with disabilities along with family, friends, relatives and support providers (Example: Co-op)
- ☐ Adult Foster Care (another family/provider assumes care)
- ☐ Group Home (managed and run by a service provider)
- ☐ Other ____
- ☐ Have not looked at options yet

Here are additional questions to think about.

1. Have you had a discussion about the various living options with _____________ (name of child or adult) If no, reasons why:
2. Have you explored what he/she may prefer?
3. Does he/she have the skills or resources to be successful in the living arrangement?
4. What other skills or resources will allow him/her to be successful?

Finding Compatible Roommates

The following checklist can be used to identify the qualities and behaviors of current and future roommates. Matching the right roommate is a time consuming and valuable process. Identify the items/behaviors you think will be important. Your family member can also complete the checklist. After you both are done, compare and discuss your list.

Check *the qualities you and your family member with a DD should consider when finding a compatible roommate.*

Eating Habits:

☐ Likes to share food

☐ Does not like to share food

☐ Cooks own meals

☐ Cooks for roommate

☐ Requires special diets

☐ Other:

Sleeping Habits:

☐ Goes to bed early/late

☐ Gets up early/late

☐ Wakes up during the night

☐ Sleep walks

☐ Snores

☐ Takes daytime naps

☐ Other:

Interests:

☐ Enjoys sports - what sports? ____________________________________

☐ Enjoy playing games – what games? ____________________________

☐ Likes art

☐ Likes music – what kind? ____________________________________

☐ Likes to read

☐ Enjoys being outdoors

☐ Watches television – which shows? ____________________________

☐ Other:

Socialization:

☐ Needs quite time

☐ Likes to spend time with roommate

☐ Enjoys parties

☐ Enjoys inviting people over

☐ Having guests over

☐ Likes to share their things

Other:

Personal Behaviors and Temperament:

☐ Forgiving after argument

☐ When upset, does not get physical

☐ Feelings get hurt easily

☐ Likes to share belongings

☐ Likes to help by doing things

☐ Laughs a lot, has sense of humor

☐ Outgoing vs. shy/reserved

☐ Borrows things frequently

☐ Likes their area neat and tidy

☐ Enjoys hugs

☐ Smokes to relieve stress

☐ Enjoys dressing up

☐ Prefers living with same gender

☐ Prefers living with someone from same race or ethnic group

☐ Other:

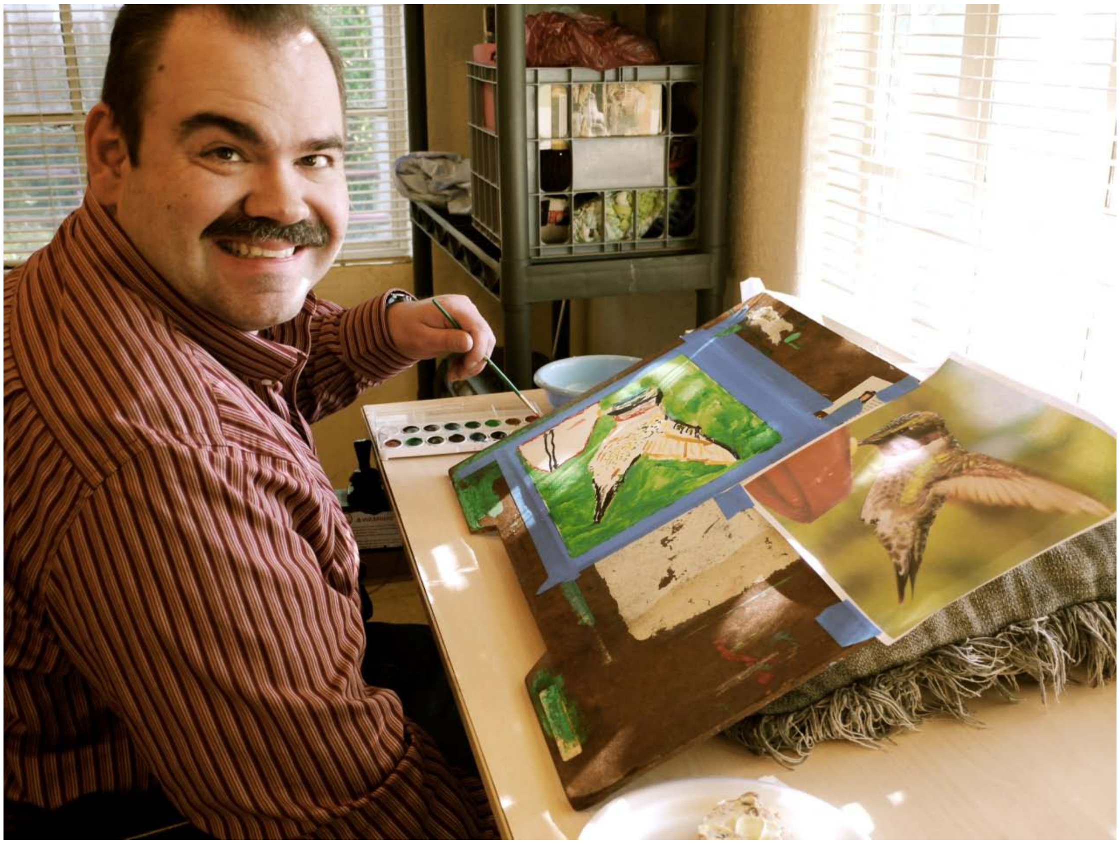
Notebook of Important Information

In case of an emergency, this notebook of information communicates and documents important information about the individual with a disability. It is sometimes referred to as a “Letter of Intent.” You may keep a separate notebook for this purpose. Be sure to tell your family or those involved in providing care and support about your notebook.

This notebook can include:

- Medical history, medications, treatments, services
- Financial considerations
- Educational history and desires
- Vocational history and desire for employment
- Individuals involved in current and future care and support
- Methods of communication (both effective and not effective)
- Likes and dislikes of the individual with a disability
- Important persons in one’s life
- Preferred activities and celebrations
- Behaviors that stimulate or calm the individual
- Cultural, religious and spiritual practices
- Other information that would help others to understand and appreciate the capabilities of and interactions with the individual with a disability.

Emotionally Speaking: Putting it All Together



The next few pages will help you put all the pieces together. Begin by reviewing what you have learned from the information gathered in the profile and the information provided by the person with a disability in the next section. Identify where you agree and disagree. These are useful points for discussion. You can invite another person to join you in the discussion. This can be helpful because they may have a more neutral and less emotional response during the discussion.

In this part of the action plan, you also compare the present (what is happening) with what should be happening. Determine what needs to be maintained/enhanced and what needs to be changed/different.

This is your opportunity to identify your hopes and desires for your family member. Jot down everything that comes to mind without worrying about whether it is attainable or not. You may be surprised as to what can be accomplished or what you have already accomplished. It will help you to identify potential steps to reach your goal.

My Hopes and Desires	**______________'s Hopes and Desires**

Reflecting and Moving Forward

Future care planning is an emotional process because caregivers have to deal with difficult personal emotions. Find a quiet time and review the following questions as best as you can.

What did you learn from this planning process about yourself and about your family member with a disability?

How did this planning process make you feel? What emotions did it trigger?

Do you feel that talking with others in a similar position will help you?

Are you willing to share your thoughts and concerns with others?

More Reflections

What will you try based on what you learned?

What do you think you can accomplish?

What will be your challenges or obstacles?

What can you do to try to minimize those challenges or overcome those obstacles?

Who can help you move forward?

For the Individual With a Disability

This section includes materials designed for the person with a disability. Some individuals will require assistance in reviewing and filling out the forms.

Chris Ortiz, ArtWorks artist, in front of his painting easel

“IMPORTANT TO” and “IMPORTANT FOR”

Your family and friends want to know what is important to you. Write about those things in the left column. In the next column, write about the things that make you feel safe and healthy.

IMPORTANT *TO:* ____________________________ **My hopes, dream, likes and dislikes, places, special interests**	**IMPORTANT *FOR:*** ____________________________ **What I need to keep me healthy and safe**

What I Can Do

This checklist will remind me and my family of what I can do now and things I still need help with. I can ask someone to help me fill this out. Some items are harder to do than others. It is okay if I cannot do everything on this list. Place a **"mark"** in the appropriate column.

Note: * *Need Some Help* means that a person is physically able to do the task but needs some executive oversight, organization, and supervision.

	Need help all the time	Need some help	Can do it myself
PERSONAL SKILLS			
Eat with a spoon			
Use knife and a fork			
Blow my nose			
Brush my teeth			
Comb my hair			
Take a shower			
Shave myself			
Use the bathroom			
Exercise			
Notes:			

	Need help all the time	Need some help	Can do it myself
KITCHEN AND COOKING SKILLS			
Pour a drink into a cup			
Make a simple meal (like toast with butter)			
Heat food in a microwave			
Make scrambled eggs			
Help set the table			
Put dishes in sink or dishwasher			
Wash dishes			
Notes:			

	Need help all the time	Need some help	Can do it myself
CLEANING SKILLS			
Take out the trash			
Make my bed			
Put dirty clothes into hamper			
Wash my clothes			
Vacuum the rug			
Sweep the floor			
Wipe off the table			
Notes:			

	Need help all the time	Need some help	Can do it myself
SHOPPING			
Make a shopping list			
Know that money has value			
Know about food groups			
Choose appropriate foods			
Push a grocery cart			
Know to ask for assistance			
Know my clothing size			
Purchase items with money			
Notes:			

	Need help all the time	Need some help	Can do it myself
COMMUNICATION			
Use a computerized talker			
Talk in simple phrases			
Use the phone			
Write a letter or note			
Take part in an online community			
Talk with friends			
Request help by dialing “911”			
Notes:			

	Need help all the time	Need some help	Can do it myself
COMMUNITY ACTIVITIES			
Go to restaurants			
Attend plays, movies, concerts			
Attend religious services			
Participate in sports			
Do volunteer work			
Work at a paying job			
Manage money for community activities			
Notes:			

	Need help all the time	Need some help	Can do it myself
TRANSPORTATION			
Walk or push a wheelchair			
Ride in a car			
Ride in a van			
Ride the public bus system			
Read the bus schedule			
Call for a ride			
Fly in an airplane			
Notes:			

Where I Want To Live

This page will help your family find the best place for you to live in the future. The decision will be based on your desires, hopes, and wishes.

Where and with whom do you want to live in the future? Write down the name of the person.

- ☐ Sister
- ☐ Brother
- ☐ Aunt
- ☐ Uncle
- ☐ Other relative: ________________________________
- ☐ Alone in my own house or apartment
- ☐ With roommate(s) in a house or apartment
- ☐ In house or apartment with hired caregivers who provide supervision
- ☐ In an apartment community that is designed and run by people with disabilities along with family, friends, relatives and support providers
- ☐ Group Home where there are several people who live there with hired caregivers
- ☐ Another place like _____________________________
- ☐ I don’t know right now

My Living Space

The following questions and sentences will make you think about the things that you want to do or have in your living space and residence. Ask yourself the questions and think about how you would answer the following. Then talk about it with your family.

How do I feel about my current living arrangement?

What works well for me right now?

What would I like to have that I don't have right now in my living space?

What will make me feel good about my living space and the people who will help me?

What do I need to be successful in a new and different place?

How do I feel about moving?

Finding A Roommate

When I am looking for a roommate, here are some of the things that are important to me.

*I will put a **mark** by the things that I am looking for in a roommate.*

Eating Habits:

☐ Likes to share food

☐ Does not like to share food

☐ Cooks own meals

☐ Cooks for roommate

☐ Requires special diets

☐ Other:

Sleeping Habits:

☐ Goes to bed early/late

☐ Gets up early/late

☐ Wakes up during the night

☐ Sleep walks

☐ Snores

☐ Takes daytime naps

☐ Other:

Interests:

☐ Enjoys sports - what sports? ______________________________

☐ Enjoy playing games – what games? ________________________

☐ Likes art

☐ Likes music – what kind? ________________________________

☐ Likes to read

☐ Enjoys being outdoors

☐ Watches television – which shows? _________________________

☐ Other:

Socialization

☐ Needs quite time

☐ Likes to spend time with roommate

☐ Enjoys parties

☐ Enjoys inviting people over

☐ Having guests over

☐ Likes to share their things

Other:

Personal Behaviors and Temperament:

- ☐ Forgiving after argument
- ☐ When upset, does not get physical
- ☐ Feelings get hurt easily
- ☐ Likes to share belongings
- ☐ Likes to help by doing things
- ☐ Laughs a lot, has sense of humor
- ☐ Outgoing vs. shy/reserved
- ☐ Borrows things frequently
- ☐ Likes their area neat and tidy
- ☐ Enjoys hugs
- ☐ Smokes to relieve stress
- ☐ Enjoys dressing up
- ☐ Prefers living with same gender
- ☐ Prefers living with someone from same race or ethnic group

My Siblings

If you have siblings, how do you want to interact with them? Answer the following items. This will help you and your family to plan activities.

What I want my siblings (brothers and sisters) to do with me.

How I would like them to help, when I get older.

What they do with me that I enjoy.

What they do with me that I don’t enjoy as much.

Is there anything I think about a lot when it comes to my family?

If I need help or support, what can they do to help me?

Have I talked to my brothers or sisters about this?

Do I feel comfortable talking with them? If no, why?

EXPLORING NEEDS AND DISCOVERING RESOURCES

The following section will help you identify some of the resources in your community.

Communicating With Your Support Coordinator

If you are receiving services through the Division of Developmental Disabilities, your support coordinator is an important resource. The purpose of this page is to identify and understand how you can best work with your support coordinator. A clear understanding of the support coordinator's role is a necessary part of planning for the future care of the individual with a disability.

The following information can serve as a resource for you. You may refer to this many times

Support Coordinator Name: ______________________________

Phone Number:

Important information to share with support coordinator:

How support coordinator can help me in the future care planning process:

Services and Opportunities

The purpose of this page is to examine 1) what services are currently in place for the person with a disability and 2) what is needed to maximize independence and quality of life for the person with a disability.

	Current	**Future (what you want)**
Adaptive Aid		
Employment		
Social		
Learning & Educational		
Physical/Exercise		
Other		

Formal Caregivers Who Provide Support

Formal caregivers are hired professionals who provide a variety of services. This worksheet identifies the values and preferences you have. It is very important to consider the strengths that the staff or provider brings and the behaviors you feel work well when caring for the person with a disability. It is helpful to share and discuss this worksheet with the person providing care.

Name:

Training:

Personal Qualities:

Communication Skills:

Ability To Understand Or Work Well With Those From Different Cultures:

Areas of Strength/Special Skills:

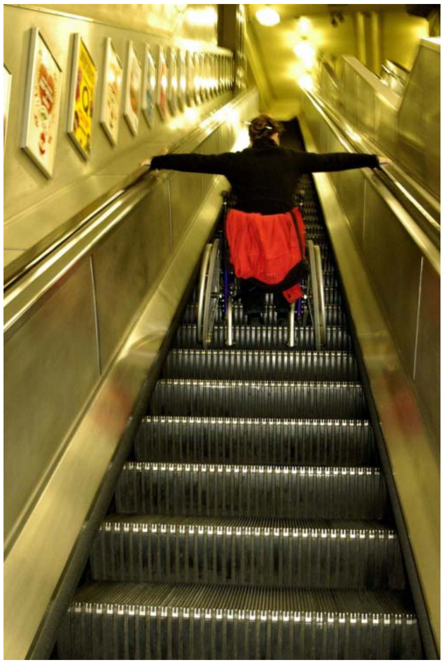
Areas to Modify or Adapt:

Behaviors that work well when working with ______________ (family member with a disability):

FINANCIAL AND LEGAL CONSIDERATIONS

Prepared by Susan McMahon, attorney

Decision Making



This section has important financial and legal information. There are a lot of things to consider when making future care plans. This section will guide you through the important step of financial planning.

When a person turns 18, he or she has all the legal rights and responsibilities of an adult. This means they can vote and sign contracts. They can also make decisions about their healthcare, living arrangement and residence, finances, and participation in school and work. Individuals with a developmental disability may need assistance or support in some areas. In order to maintain their independence as possible, it is important to understand some of the legal options available for their families, friends and caregivers.

Here are some decisions that need to be made as an adult:

- Where to live and who to live with
- Health care (physical and mental health)
- Managing finances
- Managing government benefits
- Managing eligibility for services
- Accessing services and support
- Legal issues such as a lawsuit
- Future care planning, arranging appropriate care/support
- Screening, hiring and firing staff

Special Needs Trusts

Special Needs Trusts are established to avoid the loss of (preserve) public resources and benefits for the person with a disability. You may sometimes see or hear the terms “supplemental needs” or “supplemental trusts.” These terms are used to describe the purpose of the trust and refer to the same thing.

What benefits do you want to protect? (please check all that apply)

- ☐ Social Security Income (SSI)
- ☐ Medicaid/ AHCCCS in Arizona
- ☐ Long term care benefits/ ALTCS in Arizona
- ☐ Other: ____

Who should be in charge of the Special Needs Trust (Trustee)?

- ☐ Family member: ________________________________
- ☐ Professional trustee
- ☐ Combination of people: ___________________________

Questions to discuss with your attorney who specializes in this area:

- What is the difference between a *“Self-Settled”* special needs trust and a *“Third-Party”* special needs trusts?
- What kind of trust is most appropriate for our situation and why?
- What can the Special Needs Trust BUY?
- What can the Special Needs Trust PAY for?
- Have there been any recent CHANGES in the rules that affect us?
- What are the responsibilities of the Trustee?
- Is there any PAY-BACK provisions or rules?
- How does income taxation affect the trust?
- Are there special reporting rules?
- When and how often should the trust be reviewed for changes?

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Protection of Entitlement Benefits

Many individuals with disabilities receive entitlement benefits. As a result, many families are concerned about how to protect those benefits and, at the same time, provide the quality of life they want for their son or daughter with a developmental disability.

What benefits do you want to protect? (Check all that apply)

- ☐ Social Security Income (SSI)
- ☐ Medicaid/ AHCCCS in Arizona
- ☐ Long term care benefits/ ALTCS in Arizona
- ☐ Other: ______________________________

Are there things you currently pay for or provide to your family member with a developmental disability to enhance their life? What? How much do you spend on each item per year?

☐ Clothing	$____________
☐ Vacations	$____________
☐ Recreation	$____________
☐ Transportation	$____________
☐ Gifts	$____________
☐ Other: ____________	$____________
☐ Other: ____________	$ ____________

A trust can take over many of these expenditures now and after you death.

Using Family Money to Enhance An Individual's Life

Family members can give money to a person with a disability, without jeopardizing entitlement benefits, if they do it correctly.

A trust can be created with family money and used to provide things that entitlement benefits don't cover. These trusts are frequently called *"third party" funded trusts*. People use lots of different names for these trusts. The names people use for trusts are confusing! That's why it is easier to call it a *"third party" funded trust*. That name tells where the money comes from.

- Do you have money that you would like to give to your family member?

- Will you give the money or asset to the individual now or at your death?

If you create a "*third party" funded trust* now other people can also direct that their money for the individual is deposited in the same trust.

- Is there someone else in the family who might be planning to give the person with DD money?

- A grandparent, aunt, uncle or sibling?

- Will they give the money or asset to the individual now or at their death?

If a person with DD lives with you and pays you rent you can put the money in to a third party funded trust to provide for their future. (Talk to your accountant about the effect that will have on your taxes.)

- Does the person with DD live with you?

- Does the person pay you rent?

Protecting An Individual's Own Money To Provide for Their Future While Maintaining Entitlements

When a person with DD has too much money in their own name they will lose their entitlement benefits.

Did your family member receive money from any of these sources?

☐ Inheritance

☐ Social Security back payment

☐ Personal Injury Settlement

☐ Gifts of stocks or bonds

If the right kind of trust is created for the individuals' money, their entitlements will be safe. The individual, their parent or guardian can create a "*self funded/ payback trust*". People use lots of names for these trusts. The names are confusing. It is easier to call them "*self funded" trusts*. The name describes whose money is in the trust.

When a "s*elf-funded" trust* is in place, the person with DD receives all of their entitlement benefits. The trust can be used to pay for some of the things the person needs that aren't covered by entitlements.

"Pooled trust" programs vary considerably. Not all states have pooled trust programs or may have restrictions on them. Pooled trusts provide supplemental funds for the person with a disability and protect him or her from losing important government benefits. Families set up a sub-account with a trust program and then "pools" these funds to manage as one account. It can be relatively inexpensive to set up.

Decisions to Be Made in Preparation for Creating a Trust

Who should be in charge of the trust (Trustee)?

- ☐ Family member: ______________________
- ☐ Professional trustee: ___________________
- ☐ Combination of people (two family members or a family member and a professional): ______________________

Who will take over this responsibility when the individual you appoint first is not able to continue?

- ☐ Different Family member: ______________________
- ☐ Different Professional trustee: ____________________

Whose money will be used to fund the trust?

- ☐ Individual with DD: ______________________
- ☐ Other family member: ______________________
- ☐ Other: ______________________________________

When will the money be placed in the trust?

- ☐ Immediately
- ☐ At the death of: ________________________________

Questions To Ask Your Attorney

- What does it costs to set up a trust?

- What is the difference between a *"Self-Funded"* trust and a *"Third-Party"* trust?

- What kind of trust is most appropriate for our situation and why?

- What can the Trust BUY?

- What can the Trust PAY for?

- What are the advantages / disadvantages of funding the trust immediately?

- What are the advantages / disadvantages of funding the trust at my death?

- What are the responsibilities of the Trustee?

- What are the advantages / disadvantages of having more than one trustee?

- What are the advantages / disadvantages of having a family member act as trustee?

- What are the advantages / disadvantages of having a professional trustee?

- Is there any PAY-BACK provision or rules?

- How does income taxation affect the trust?

- Are there special reporting rules?

- When and how often should the trust be reviewed for changes?

- What reports will be required for the trust?

How To Find An Attorney To Create A Trust

Finding an attorney who is knowledgeable in the rules of trusts for people with DD is essential. It is important to ask attorneys about their experience before you choose one.

Questions you could ask:

- Do you have any experience with individuals with DD?
    - Personally?
    - Professionally?

- Have you established a third party funded trust before? How many?

- Have you established a self-funded trust before? How many?

- Have you ever acted as trustee for a trust for a person with DD?

- Are you familiar with any pooled trusts?

APPENDIX:
Resources and Helpful Websites

Caregivers & Persons with Developmental Disabilities

National Family Caregivers Association
http://www.thefamilycaregiver.org/caregiving_resources/

Family Caregiver Alliance
http://www.caregiver.org/caregiver/jsp/home.jsp

The Arc of the United States
http://www.thearc.org/NetCommunity/Page.aspx?pid=183

Association of University Centers on Disabilities on Research, Education, Service
http://www.aucd.org/template/index.cfm

AZ Center for Disability Law: Legal Options Manual (English & Spanish)
http://www.acdl.com/selfguides.html

AZ Governor's Council on Developmental Disabilities
Legal Options Manual (English & Spanish)
http://www.azgovernor.gov/ddpc

Emergency Planning Guide for Persons with DD (English & Spanish)
http://www.azgovernor.gov/ddpc

Aging and Disability Resource Center
http://www.adrc-tae.org/tiki-index.php?page=HomePage

Special Needs Alliance
http://www.specialneedsalliance.com/home

Future Planning Resource Guide (2006) English and Spanish
http://www.rrtcadd.org/Resource/Publications/Caregiving/Brief/Info.html

Sonoran UCEDD (University Center of Excellence in Developmental Disabilities)
http://sonoranucedd.fcm.arizona.edu

Siblings

For more information about siblings and their role:

Rehabilitation Research and Training Center on Aging with Developmental Disabilities at http://www.rrtcadd.org.

Online discussion group for adult siblings:
http://groups.yahoo.com/group/sibnet

Person Centered Thinking and Planning

The Learning Community for Person Centered Practices
http://www.learningcommunity.us/

Responsive Systems Associates at http://thechp.syr.edu/rsa.htm
John O' Brien and Connie Lyle O'Brien

Helen Sanderson Associates: Person Centered Thinking and Planning
http://www.helensandersonassociates.co.uk/Reading_Room/reading_room.htm

Capacity Works by Beth Mount at www.capacityworks.com

Legal

Center for Special Needs Trust Administration at http://www.sntcenter.org

National Academy of Elder Law Attorneys: Locate an Elder Law Attorney at www.naela.org

Special Needs Alliance: Find an Attorney at www.specialneedsalliance.org

Special Needs Answer, a community resource provided by the Academy of Special Needs Planners http://www.specialneedsanswers.com

State Bar of Arizona at http://www.azbar.org

Legal Options Manual (2004) available through the Governor's Council on Developmental Disabilities. Available at http://www.azgovernor.gov/ddpc

Arizona Center for Disability Law at http://www.acdl.com

The ARC of Arizona at http://www.arcarizona.org/

Emergency Preparedness

National Organization on Disability (NOD) - Emergency Preparedness Initiative (EPI)

Prepare yourself –disaster readiness tips for people with disabilities:
http://www.nod.org/index.cfm?fuseaction=Page.viewPage&pageId=1564

FEMA
Accommodating People with Disabilities and Mass Disasters
http://www.fema.gov/oer/reference/

American Red Cross: People with Disabilities

Tips for People with Service Animals
http://www.prepare.org/disabilities/animaltips.htm

Preparations for People with Disabilities in Disaster
http://www.prepare.org/disabilities/disabilities.htm

Formal Caregivers and Hired Staff

The University Center for Excellence in Developmental Disabilities, Education, Research, and Service (UCEDD) for the State of Illinois (University of Illinois Chicago)

Caldwell, J., Lopez, E., DeBrine, E., Factor, A., Heller, T., & Ennis, D. (2006). Future planning resource guide for families and adults with developmental disabilities in Illinois. Family Planning Resource Guide – http://www.idhd.org/default.asp?contentID=258

Illinois Direct Support Professional Workforce Initiative. (2006). *Find Choose & Keep Great DSPs. A toolkit for people with disabilities.* http://www.idhd.org/default.asp?contentID=258

Illinois Direct Support Professional Workforce Initiative. (2006). *Find Choose & Keep Great DSPs. A toolkit for families.* http://www.idhd.org/default.asp?contentID=258

Institute on Community Integration (ICU) UCEDD – The University of Minnesota

Through Asking the Right Questions... You Can Reach Your Destination - A pocket guide containing questions for families and persons with disabilities to ask as they interview residential service providers and decide which are best suited to meet their support needs. (1999) Cost: Free, available at: http://rtc.umn.edu/questions/

How to Choose a Home Care Provider
http://www.nahc.org/Consumer/contents.html

Within this - How Do I Select the Right Home Care Provider? -
http://www.nahc.org/Consumer/hdistrhcp.html

Helping You Choose Guides -
http://www.jointcommission.org/GeneralPublic/Choices/
  Ambulatory Care
  Behavioral Health Care
  Home Care & Hospice
  Long Term Care

How to Choose a Caregiver -
http://www.sncsllc.com/youshouldknow.htm#How_to_choose_a_caregiver

Employment

Institute for Community Inclusion (ICI) - University of Massachusetts Boston and Children's Hospital Boston

- The 30-Day Placement Plan: A Road Map to Employment - http://www.communityinclusion.org/article.php?article_id=151&type=topic&id=3

- Teaching Networking Skills: Paving a Way to Jobs and Careers - http://www.communityinclusion.org/pdf/networkingmanual_F.pdf

- Networking: A Consumer Guide to an Effective Job Search - http://www.communityinclusion.org/article.php?article_id=62&type=topic&id=3

- Four Strategies to Find a Good Job: Advice from Job Seekers with Disabilities - http://www.communityinclusion.org/pdf/to18.pdf

- Employment Resources – all and more can be found here; above are a small selection - http://www.communityinclusion.org/page.php?page=get_article&id=3&type=topic&scope=all

Paul V. Sherlock Center on Disabilities – Rhode Island College

- Employment Resources and Planning: A RI Guide for Youth in Transition 1089.6 kb(PDF) – has some great checklists on what you need to know and do

- Getting the Most from Supported Employment 114.4 kb (PDF)

10 Tips for Family Caregivers

http://www.thefamilycaregiver.org/caregiving_resources/tips_and_tools.cfm

Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.

Watch out for signs of depression, and don't delay in getting professional help when you need it.

When people offer to help, **accept the offer** and suggest specific things that they can do.

Educate yourself about your loved one's condition and how to communicate effectively with physicians.

There's a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence.

Trust your instincts. Most of the time, they'll lead you in the right direction.

Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**

Grieve for your losses, and then allow yourself to **dream new dreams.**

Seek support from other caregivers. There is great strength in knowing you are not alone.

Stand up for your rights as a caregiver and citizen.

SONORAN UCEDD
Center of Excellence
In Developmental Disabilities Education, Research and Service

ACKNOWLEDGEMENTS

The University of Arizona’s Sonoran University Center of Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) thanks the caregivers who participated in the *Older Caregivers and Transitions Study*. Caregivers across Arizona taught the research staff about the issues caregivers face when thinking about, designing, and implementing a future care plan for a family member or loved one with a disability. In addition to family caregivers, service providers and professional caregivers contributed valuable information and insight.

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This Roadmap is available on the Sonoran UCEDD website at http://sonoranucedd.fcm.arizona.edu/. Please send comments or suggestions to:

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