



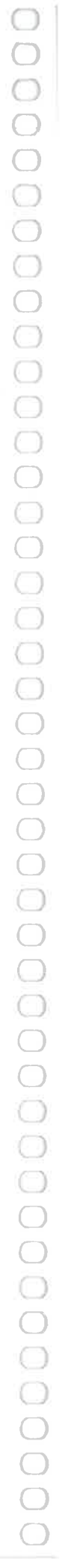
Florida
Developmental
Disabilities
Council, Inc.

PLANNING AHEAD

A GUIDE FOR PARENTS, FAMILY MEMBERS, AND
LEGAL REPRESENTATIVES OF INDIVIDUALS
WITH DEVELOPMENTAL DISABILITIES



Sponsored by the United States Department of Health and Human Services,
Administration on Intellectual and Developmental Disabilities and the
Florida Developmental Disabilities Council, Inc.



ACKNOWLEDGEMENTS

We would like to thank those who provided expertise, technical assistance, review, and administrative support in the development of the original *Planning Ahead Guide* and in the review and development of this fourth edition.

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<i>Paul Finch</i>	<i>Janice Tully</i>
<i>Bob Foley</i>	<i>Janie Whitfield</i>
<i>Janet Graham</i>	<i>Latarsha Williams</i>
<i>Margaret Hargrove</i>	

Additionally, this project would not have been possible without the participation of individuals, family members, advocates, support coordinators, service providers and the staff from the following agencies and organizations:

Agency for Health Care Administration, Division of Medicaid
Agency for Persons with Disabilities
Christy Jennings Creative
Department of Children and Families
Department of Education, Division of Vocational Rehabilitation
Department of Elder Affairs
Department of Health
Disability Rights Florida
Long Term Care Ombudsman Council
Office of Public Guardian, Inc.
Tallahassee Office of the Social Security Administration

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Fourth Edition



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INTRODUCTION

The Florida Developmental Disabilities Council developed the *Planning Ahead Guide* to give important information to people with disabilities and their families to help them engage in purposeful life planning throughout all stages of life.

When children are very young it is simple to give instructions to a babysitter to follow. For parents of a child with a disability, it may feel natural to continue this habit as the child grows into adulthood. However, there may come a time when parents will not be available to give a list of their child's "dos and don'ts" or "likes and dislikes." We may even find it difficult to think what it will mean in our own lives when we will no longer be here or become unable to care for ourselves. We should consider who will care for us, who will inherit our belongings, and where we want to be buried, for example. This type of thinking ahead is even more critical when there is a child with a disability in the family who will grow up possibly needing continuing supervision and support. It becomes very important to commit to writing what the person would like his or her future to be and to leave these instructions for new informal supports, caregivers and service providers.

The *Planning Ahead Guide* is designed to help with this planning process. It is divided into three sections:

- Section 1. The Guide
- Section 2. Resources and Forms
- Section 3. Personal Information Summary

SECTION 1. THE GUIDE

The first section of the *Planning Ahead Guide* contains nine (9) chapters of information on important topics. Extra tips and helpful advice are highlighted throughout the chapters. Also, each chapter ends with a section called "Consider This..." with space provided to write personal notes and next steps for action.

This Guide will:

- Lead you through the process of thinking about areas you need to include in planning ahead for you or your family member;

- Identify agencies and organizations in Florida that provide services to persons with developmental disabilities. The contact information for each agency mentioned in the *Guide* can be found in the Resources and Forms Section; and,
- Provide options from which to choose.

SECTION 2. RESOURCES AND FORMS

The second section of the *Planning Ahead Guide* contains a directory of services and support organizations that may be helpful in the planning process. This section also includes a list of common acronyms and sample forms.

SECTION 3. THE PERSONAL INFORMATION SUMMARY

The third section of the *Planning Ahead Guide* contains a Personal Information Summary where you can store the personal information necessary to provide direction regarding the quality of life desired by your family member. Keeping the Personal Information Summary current and relevant will require time and effort. As life changes, resources and supports change - so too should a person's long-range plans.

For more information on many of the topics introduced in the *Planning Ahead Guide*, please visit the Florida Developmental Disabilities Council's website at www.fddc.org, Resources section, or call toll free 1-800-580-7801.

The Personal Information Summary is also available in a downloadable format on www.fddc.org to make it easy for you to update information. If you are using the paper version, make several copies of the blank form located in the back of this Guide to update the information periodically.



SECTION 1: THE GUIDE

CHAPTER ONE

BEFORE YOU BEGIN

Life for individuals with disabilities today is quite different from anything that could have been imagined twenty years ago. Individuals with disabilities are making many of their own choices, living in the community, owning their own homes, holding regular jobs, and establishing and working toward their own goals.

There are four fundamental principles that should guide you and your family member in planning for the future: Self-Determination, Inclusion, Person-Centered Approaches, and Personal Outcomes.

1. SELF-DETERMINATION

Self-determination is the foundation for creating the opportunity for persons with disabilities to take control of their lives and participate in the decision-making process.

The pillars that support the principle of self-determination are defined as:

- **Freedom** – means to exercise the same rights as all citizens. Individuals with disabilities decide where they want to live, with whom they want to live, and how their time will be occupied.
- **Authority** – means to have control over the money an individual needs for his or her support, including deciding his or her priorities. This is accomplished through the development of a budget that changes as the person and his or her life circumstances change.
- **Support** – means to organize resources as determined by the person with a disability. This means that individuals do not receive “supervision” and “staffing.” Rather, individuals with disabilities may seek support and contract for any number of services that will assist them in their daily lives.
- **Responsibility** – refers to using public dollars wisely and to contributing to one’s community. The tax dollars spent on individuals with disabilities are an investment in that person’s life. And all persons, including individuals with disabilities, have a responsibility to contribute back to their communities to the fullest extent possible.

2. INCLUSION

Inclusion is making sure people with disabilities are no longer separated from those who do not have disabilities. People with disabilities participate and interact with others in the community just as everyone else. Inclusion also means accepting cultural differences.

3. PERSON-CENTERED APPROACHES

A person-centered approach to planning means planning is done by and with the individual. The planning process must be geared to the individual's desires and personal wishes. Planning responds to the needs of the individual and respects his or her personal choices. It is a consistent and ongoing approach that supports individuals in realizing their own goals and outcomes and adjusts as those goals and outcomes change.

When planning with the individual, it is important to:

- Honor what the individual wants his or her life to look like.
- Respect different ways of communicating.
- Ensure that a variety of natural and community supports are present to provide a solid foundation for the individual. Natural supports include family, friends, co-workers, religious and faith communities, civic and professional organizations.
- Provide meaningful work and leisure opportunities.
- Provide information and resources that educate the individual about options and opportunities so that he or she can choose and experience everything that life has to offer.
- Respect the individual's right as a citizen and as a human to enjoy a fulfilling, safe, and healthy life.
- Provide supports and security in finances, health, freedom from abuse, neglect and exploitation, and in making plans for the future.
- If guardianship is present in the individual's life, ensure that the guardianship is a support to the individual in realizing his or her goals. In addition, guardianship at any level should be reviewed often to determine if it is still needed and, if not, to ensure that action is taken to restore rights as needs and situations change.

4. PERSONAL OUTCOMES

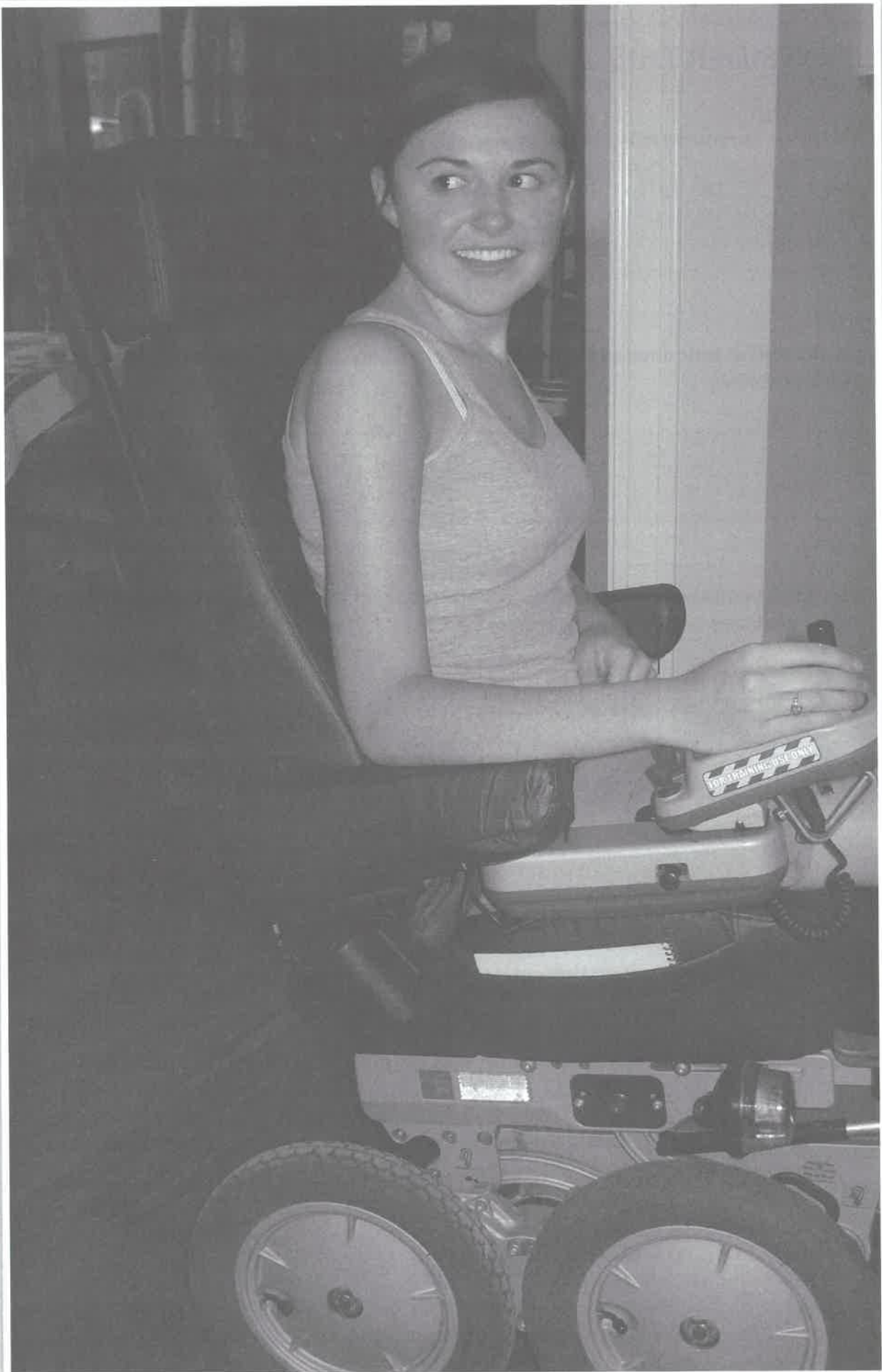
A personal outcome can be defined as the achievement of a goal or choice determined by a person. These goals form the major expectations that people have in life. Services and supports provided should be based on the personal outcomes desired by each individual to improve his or her quality of life - not outcomes decided by others.

CONSIDER THIS

1. What can you do to honor these principles in your family member's life?

2. Identify at least **three** of the **natural** and community supports available to your family member.

3. What are the **personal** outcomes that are important to the person? Have you discussed these goals and outcomes with the person?



CHAPTER TWO

CHANGING LIFE STAGES

While each person's life journey is unique to that individual, there are common stages of life we all experience. And, because we know these different stages exist, we can prepare for the changes we know will come. This chapter examines some of the common stages in life and some of the important times in life when we are all likely to experience significant change. Purposeful life planning takes into account the particular needs of each stage of life.

COMMON STAGES OF LIFE

- 1. The early years.** Birth to age four (4), before a child enters the educational system.
- 2. The school years.** From age four (4) to age 21, depending on the individual.
- 3. The work and family years.** Generally occurs between ages 22 through 64.
- 4. The retirement years.** Traditionally these years began at age 65, but now for many Americans, the retirement years begin at age 67 or later.

For individuals with developmental disabilities, the dividing line between these four stages may not appear as clearly as they do for others. The lines may blur across life stages.

Early Years

Learning the basic skills associated with the activities of daily living begins in the early years and may continue over the entire course of the person's life. Early intervention and integration have assisted persons with disabilities to make tremendous strides in recent decades. Supportive services are often introduced at this stage. Natural supports, family and friends are involved in the individual's life in a major way.

School Years

Early intervention and integration continues during the school years and schools must meet the federal requirements established under the Individuals with Disabilities Education Act (IDEA). This federal legislation also requires that schools prepare a student for reaching adulthood. The

law requires that the planning for transition from school to adult independent living begins no later than age 14 and can continue up to age 22. During the transition years, students can receive education and training in many areas including learning job skills and exploring job opportunities. These plans and goals for transition into adult independent living are recorded in the student's Individualized Education Plan (IEP), which is written by the student, the parents, teachers, any other staff involved in the student's education, and any other advocates the individual and family wishes to include in the transition process. This person-centered planning gives the student and family the opportunity to make decisions about the student's future.



Work and Family Years

The transition from school to independent living begins! During the previous life stage, individuals should have established their desires and goals for this period of their lives. Where do they want to work? Where do they want to live? What social activities and social relationships do they want to pursue? Individuals can now begin to meet these goals with the support of family members or others in their circle of support.

For everyone, this period is usually focused on where we work. Almost anyone can have a job in the community when the proper training and ongoing supports are made available. Persons with disabilities can and do hold jobs in competitive employment with or without supports. Chapter 5 discusses employment opportunities and supports.

Retirement

Most people nearing age 50 begin to think about retiring although the age of retirement is usually 62 – 67 (the age retirement benefits are available through Social Security). Ordinarily, workers start out at a low level job and through the years the nature of the work changes, or a worker moves up the employment ladder to different jobs. For persons with developmental disabilities this does not always happen. They often remain in the same job for many years, with little change in the tasks they perform. However, they may have worked enough years to have earned retirement even though there may not be retirement benefits available from the employer.

Some people do not want to retire. They may prefer to shift to another kind of work, or work only part time, leaving more free hours for leisure activities or other things they enjoy. This is equally true for persons with developmental disabilities. Individuals with disabilities may need help in discovering what retirement will mean to them. They may wish to try something new, to

do something that allows more leisure time, or to retire from employment as they have known it. If your family member really thinks he or she wants to retire, there are community retirement programs for older persons with or without developmental disabilities.

Anyone retiring should consider what life will be like without a job. Some things to consider are:

- What will I do all day every day?
- Will I be able to see my friends who are still working?
- How will I make new friends?
- Will I have enough money to do the things I want to do?
- Would I rather try a different kind of job?
- Could I reduce my work hours to have more leisure time for other activities?

An individual's circle of support can help provide information about options available locally and may even arrange for visits or exploring activities such as:

- A part-time job
- Existing recreation programs
- Volunteer activities in various settings
- Senior centers and nutrition sites
- Clubs or groups focused on a particular hobby
- Church-related activities



The retirement years can also bring physical changes. Individuals with disabilities can expect to have many of the common physical changes associated with aging. With some types of developmental disabilities aging begins to occur at an earlier chronological age. Some of the more common physical effects of the aging process are:

- **Vision loss.** More light is needed to see and glare may be a problem. Reading becomes more difficult and cataracts may occur and cloud the lens. Bifocals or reading glasses may be needed.
- **Hearing loss.** It may become more difficult to hear sounds at the low or high range of pitches and words may seem to run together. Some sounds are lost altogether. A hearing aid may be helpful to some.
- **Changes in the bones and muscles.** Bones become weaker and more brittle and osteoporosis may occur. An increase in body fat and a loss of muscle mass may cause a loss of muscle tone, strength, and stamina.

LIFE-CHANGING EVENTS

During each stage of life there are important events where significant changes can occur. It is important to anticipate and plan ahead, when possible, for these important transitional times. Six important life-changing events are:

1. **Reaching adulthood** – at age eighteen a person becomes an adult. The natural parent no longer has any legal right to speak for the person unless the person consents, except in certain circumstances.
2. **Changing vocational status** – occurs when a person changes from school to job, job to school, from one job to another, or retires.
3. **Changing place of residence** – relocating from home to a supervised living environment with new people, or living independently with one or more roommates.
4. **Changing primary caregiver** – may have great emotional impact on the person needing a caregiver. The new caregiver will need important information about the needs of the person.
5. **Changing health care needs** – the person could experience a decline or improvement in their medical condition which may require a change in level of care.
6. **Approaching end of life** – near the end of life, a person faces choices in personal and medical care and how his or her affairs will be managed once he or she is gone.



PLANNING FOR LIFE'S CHANGES

All of us face changing abilities and life circumstances as we age. It is our ability and willingness to adjust to these changes that sets us apart from one another. Whether we are moving from one stage of life to another or whether we are experiencing a significant life-changing event, it is important that we prepare ourselves to adjust as change comes.

Who Should Plan?

An individual's entire circle of support - family and friends - should be involved in planning for the future and thinking about what his or her role might be in the individual's life. It is essential that the individual with developmental disabilities has the opportunity to fully participate in the planning and, to the fullest extent possible, participate in the decision-making process regarding where to live or work, how to use free time, and who will provide the support services needed to achieve these and other desired goals.

Why Should We Plan?

We plan to make available the information about the family member including circle of support participants, financial resources currently available, and other elements necessary to plan for the quality of life desired for and by the individual, to ensure the individual lives the way he or she wants to live.

Who Can Help Us Do This?

Local advocacy groups, service providers, case managers, and friends will be invaluable in helping family members identify and plan for the future. An attorney also can be helpful in the process if he or she is knowledgeable of laws relating to persons with disabilities and familiar with, and supportive of, the principles of self-determination.

When Should We Plan?

Planning is not a one-time only event. It is a continuous process. But the process should begin today and this Guide will help you!

- Do not try to get everything done at once.
- Work gradually through each section of this Guide, review the plan frequently, and revise the plan as needed.
- Set a specific time to review and update the Personal Information Summary. It may be a birthday, a holiday when family and friends are together, or a time designated just for this purpose.

CONSIDER THIS

1. What will your family member's quality of life be when you are no longer playing a role in managing his or her care? Start by making a list of those things that really matter.

2. What type of care and supervision does your family member need?

3. Who will help with or make necessary decisions?

4. What type of home and neighborhood will your family member live in?

5. What type of employment, daily activities, and leisure activities are appropriate for your family member?

6. How does the individual define quality of life?

7. How will his or her needs be provided for financially?

8. What steps are you taking to build the person's independence?

Now that you have worked through Chapter 2, go to the Personal Information Summary and complete Section A. Person's Information, Section I. A Day In The Life Of... and Section J. Key Family and Friends. These sections ask for detailed personal information for your family member and his or her family and friends. This information is often needed to access services and is useful in identifying a person's circle of supports.

Also, remember to update the Personal Information Summary when any life-changing event occurs.

CHANGING A PRIMARY CAREGIVER

Planning for a future caregiver is especially important. Changing primary caregivers can happen suddenly and unexpectedly. Because this change can be traumatic for your family member, it should be planned for thoughtfully and carefully. When selecting a future primary caregiver, be sure to:



- 1. Discuss the reason for the change with the person.** Be sure the choice of primary caregiver is the choice of your family member with the disability. Remember that a primary caregiver is involved in many aspects of the individual's life. The caregiver should be someone who understands the individual's likes and dislikes and can comfortably communicate with the individual.
- 2. Discuss caregiving responsibilities with the potential future primary caregiver.** Be sure the potential caregiver understands the wishes and goals of your family member and is willing to pursue these same goals. Make sure the potential caregiver understands the principles discussed in Chapter 1, is willing to communicate with the family member when changes are necessary, and will try to reach mutual agreement whenever possible. Discuss the expectation of the long-term commitment required of a caregiver, the need to spend time with other family members, and whether the potential caregiver understands and is willing to make this commitment.
- 3. Discuss any additional roles the future caregiver will be expected to play.** Will the future caregiver be expected to serve as medical proxy, health care surrogate, representative payee, or guardian? What additional steps should be taken to ensure any additional roles are in place?
- 4. Obtain agreement from both the individual and the future primary caregiver.** Both the individual and the potential caregiver should understand their primary areas of responsibility.
- 5. Communicate by writing the name of the future primary caregiver in easily accessible documents.** Inform all family members and others who are important to your family member, who will be the primary caregiver, and what that person's responsibilities will involve.

Even after you have carefully selected a future primary caregiver, take a moment to think through what would happen if the future caregiver became unavailable and write those contingency plans down as well.



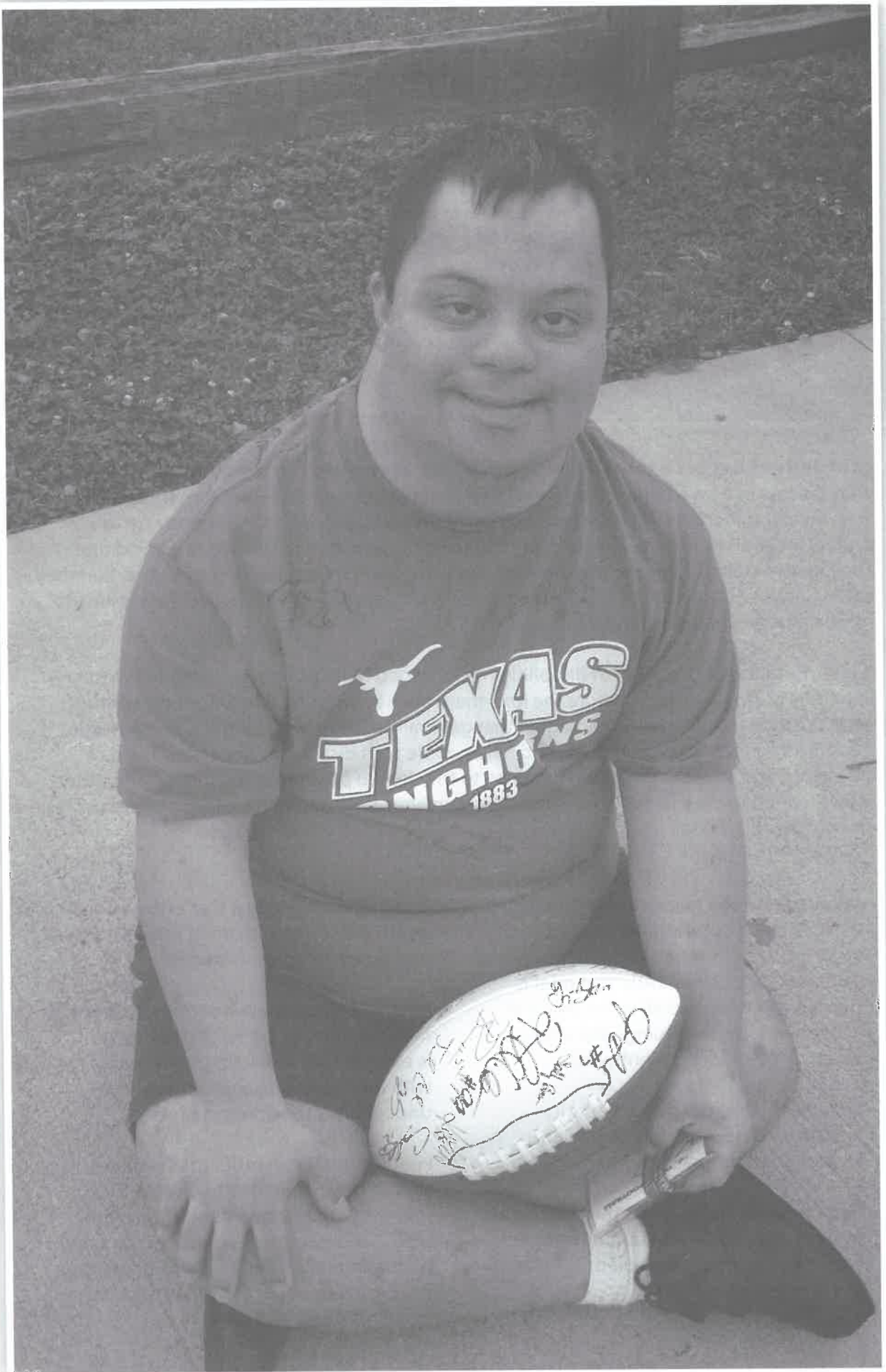
COPING WITH GRIEF AND LOSS

Death is a little discussed subject in our American culture. Many families do not encourage talking about the feelings and grief that come with the death of a loved one. Yet, all of us at sometime in our lives will deal with the death of someone close to us. This may also be a time when we begin to realize our own mortality, or it may be seen as a natural part of the cycle of life.

The ease with which we survive times of stress or personal loss depends on our coping skills. How each of us deals with stress is the result of what we have learned. People are better able to deal with the loss of a loved one if they have been given opportunities to develop these skills. Well-meaning friends, neighbors, primary caregivers, and service providers may try to protect individuals with disabilities from facing feelings related to the loss of a loved one. They may mistakenly believe that they are shielding them from upsetting emotions that they could not possibly understand. This is not true. In fact, each of us experiences losses and, to some degree, can understand death.

It is important that people with disabilities be informed of a loss and given the opportunity to handle it. This is easier if, before the loss, there have been some discussions regarding what death is and the sadness and grief that generally accompany it. If this is not possible, it is still important to communicate and help people with disabilities understand end of life events, and to allow them to participate to the degree possible in the funeral and other rituals related to the death. These rituals help survivors understand their feelings and express and process their grief.

- Allow the person to express as much grief as he or she is comfortable sharing.
- Communicate consistently that grief is normal and expected after the death of a loved one. Do not change the subject when dying or loss is mentioned.
- Be patient. Progress may be erratic, and may include times of confusion, forgetfulness, or denial.
- Communicate using terms the person can understand. Recall pleasant times shared with the person who has died.
- Remind the individual that one person's death may remind them of previous losses and bring up unresolved grief.
- Involve a spiritual advisor from the person's faith tradition or a grief therapist who is experienced in relating to persons with intellectual disabilities and who understands the grieving process.
- People who live in residential facilities should be encouraged to discuss their loss with other residents and staff. If the policy of the residential facility is to avoid discussing death and grieving, encourage the facility to begin a learning experience for all residents and staff.



CHAPTER THREE

BECOMING AN ADVOCATE

To advocate means to effectively communicate, convey, or negotiate the interests, desires, needs and rights of an individual. Advocates either have learned through experience or have been trained to provide support, advice, and assistance to others.

Some specific ways we can effectively advocate include:

- Learn as much as possible about the service or program in question, how to access the service or program, and get information about the rights and appeal process.
- Identify agency representatives who are responsible for assisting with particular types of problems.
- Be specific about the needs of the person in order to match those needs with the available services and supports.
- Request assistance from another advocate or outside source, if needed.
- Testify at legislative hearings and community forums.

SELF-ADVOCACY

Individuals with disabilities can be very persuasive in advocating for themselves. Self-advocates are most effective when they:

- Realize that all Americans have the same civil rights.
- Are encouraged to talk about their concerns as they arise.
- Ask for help.
- Don't give up.

KEYS TO EFFECTIVE ADVOCACY

A self-advocate or anyone who advocates on behalf of persons with developmental disabilities should remember these ten important steps to effective advocacy:

1. Believe In Yourself

- You are worth the effort to protect your interests and rights.
- You can do it!

2. Learn Your Rights

- You are entitled to equal rights under the law.
- Contact Disability Rights Florida to request information about your legal rights.
- Get information by using your local libraries or the Internet. Join e-mail groups, and social networking sites. Network with peer-run, family and community support programs, advocacy groups, and service providers. Attend classes or workshops.
- Contact referral or crisis hotlines.
- If you do not understand information or explanations provided, say so.

3. Discuss Your Questions and Concerns

- Prepare by writing an outline of your concerns and writing down your questions.
- Raise your questions and concerns by phone, in person or by writing a letter. Use e-mail and on-line forms to start a conversation about your concerns.
- Schedule a meeting. Speaking to someone in person can be an effective way to advocate for yourself. Plan what you are going to say. Practice with friends, with a tape recorder, or even in front of the mirror. Dress for the occasion and be on time. You may bring someone along for support.
- Be polite. Introduce yourself and anyone with you. Learn and use other people's names when you communicate. State your concerns clearly and simply. Ask politely for what you want.
- Listen carefully to the explanations and answers given. If you do not understand something, ask for clarification.
- Write down the name of each person you spoke with and their contact information.
- Send a follow up note listing your understanding of any agreements reached or next steps decided during the conversation or meeting. Keep a copy for your records.

4. Be Effective on the Phone

- Before you call someone, write down the key points you want to say and your most important questions. Stay calm and be polite. Keep your message clear and focused.
- Try to make your call in a place without distractions. If you must leave a voice message, keep it brief and make sure to include your name and a contact number where you will be available to accept a call.
- Be willing to listen. What you hear may be as important as what you say.
- Always get the name and position of the person you are talking to. Ask when he or she will get back to you or when you can expect action.
- If this person cannot help you, ask who can. Thank the person for being helpful.
- Keep a record of your call and follow up!



5. Put it in Writing

- Write a letter or send an e-mail about your request or concern. Keep it short and to the point. Begin and end your letter or e-mail by stating your request or concern and provide supporting information.
- If you need others to become aware of the situation, you may send copies of your letter or e-mail to supervisors or advocacy groups.
- Only copy your letter or e-mail to people who can assist you. Be cautious with sharing confidential information.
- When you circulate a letter or e-mail to other people, put "cc" (copies circulated) at the bottom of the letter with a list of the people you sent copies. If you are sending an e-mail, list the names of other people in the "cc" line of the e-mail.
- In some instances, you may want to contact your legislators or include them in the people you copy with your letter or e-mail.
- Keep a copy for your records.
- Contact Disability Rights Florida for sample advocacy letters.

6. Get Information and Decisions in Writing

- If someone tells you something, ask them to put it in writing or send you documentation.
- If they tell you something is a law, policy or procedure, ask for a copy or a website address.
- If you disagree with a decision, ask for it in writing along with the reasons for the decision.

7. Use the Chain Of Command

- If you feel you are not getting a straight answer, thank the person for their time and ask to speak to someone else who can address your concerns.
- Use the organization's chain of command to help you find the supervisor or other person you need to communicate with.

8. Know Your Appeal Rights and Responsibilities

- If you do not get a satisfactory decision, ask what you need to do next to resolve the dispute or appeal the decision. Most organizations and government agencies are required to have a process to review decisions.
- Request clear written information about the dispute resolution process and your right to appeal a decision you believe is wrong. Be sure you understand your responsibilities.

9. Follow Up and Say Thank You

- Keep track of key deadlines and time frames. Follow up.
- Remember to thank people along the way. Recognize those individuals who provided helpful information and good service.

10. Ask For Help

- If you need assistance resolving a dispute, contact Disability Rights Florida or another advocacy or community organization to request information or assistance.

EMPOWERMENT

An individual's circle of support can play a critical role in the planning process and in coordinating the services and supports needed by the individual. Individuals with disabilities and their family members are the true care managers and advocates.

- Individuals with disabilities are usually capable of determining their own needs and advocating for themselves.
- Individuals and their families should be empowered to develop their own resources, rather than becoming dependent on the service delivery system.

- Individuals and their families should be the ones deciding what services and supports they need.

This person-centered approach to planning is a change from the old way of planning. Allowing sons and daughters to pursue their personal goals to the greatest extent possible may be quite a change for parents of adult children who have disabilities. Some parents will find this difficult to accept, but most parents are pleased that their adult children now have the opportunity to plan for their own futures. It is important for families and professionals to work together to provide the right balance between protection and support, and to support their family member who has a disability to enjoy the same rights, responsibilities, and freedoms as their children who do not have disabilities.

For additional information and assistance with advocacy, contact Disability Rights Florida or your local legal services office by calling 1-850-385-7900 or going to <http://www.floridalegal.org>.

CONSIDER THIS

1. Are there any advocacy programs or services that you would like to learn more about?

2. Has this chapter given you ideas of any items that should be completed on the Personal Information Summary?

EXAMPLES OF ADVOCACY ORGANIZATIONS:

Partners in Policymaking

Partners in Policymaking is a Florida Developmental Disabilities Council (FDDC) leadership and advocacy training program that teaches individuals with disabilities and their family members advocacy skills so that they can encourage the best use of available dollars or seek additional local, state, and federal funding. Based on a national model, the overall goal of the program is to make all communities better places for persons with disabilities to live, work, and play by developing productive partnerships between people with disabilities and those in a position to make policy and law. For additional information, visit the Florida Developmental Disabilities Council's website, www.fddc.org, or call toll free at 1-800-580-7801.



Family Care Council

The Florida Legislature established the Family Care Council (FCC) that currently operates in each of the Agency for Persons with Disabilities (APD) service areas. These councils advise the APD on the needs of persons with developmental disabilities and their families and are charged with providing information and outreach to self-advocates and advocates. They also review the effectiveness of local service programs and make recommendations with regard to programs. For more information on Family Care Councils, go to <http://www.fccflorida.org> or call toll free 1-800-470-8101 to connect with your local council.

CHAPTER FOUR

IDENTIFYING FEDERAL, STATE, AND LOCAL AGENCY RESOURCES

Many nonprofit organizations and federal, state and local government agencies offer programs and assistance aimed at improving the quality of life for a person with a disability.

FEDERAL INCOME BENEFIT PROGRAMS

Most of us, at some point in our lives, will probably receive benefits from the federal government. Individuals with disabilities are no exception. The Social Security Administration has retirement and disability programs to benefit workers, their dependents, and, after they die, their survivors. It also administers the Supplemental Security Income (SSI) program, which provides financial assistance to certain persons, including persons with disabilities, who may have limited income and resources.

Social Security Administration (SSA)

Social Security Administration (SSA) retirement benefits are available to persons who have been employed, made financial contributions to the social security system, and reached the social security retirement age. For many years, the normal age of retirement was 65, with reduced benefits available to those who wished to retire as early as age 62. However, the age at which a person may receive full retirement benefits has changed based on the person's birthdate. A person must have worked at least 40 quarters (ten years) to qualify. For the most up-to-date information on Social Security retirement benefits, go to <http://www.ssa.gov/pubs/> or call 1-800-772-1213.

Social Security Disability Insurance Program (SSDI)

The Social Security Disability Insurance Program (SSDI) provides a monthly cash payment to workers who have met the SSA disability definition before reaching retirement age and who are now unable to continue working due to their disability. These SSDI benefit payments will continue as long as the person is unable to engage in "substantial gainful activity" or "SGA." Substantial gainful activity means working for pay at a certain level of income. There are several

important stepping stones in the process that allows people to go to work after enrolling in SSDI and to try working again for an extensive period of time while maintaining their cash payment and Medicare coverage. Many people can work and keep their SSDI payments and Medicare if they are aware of the work incentives for SSDI.

Social Security Dependents and Survivors Benefits

When a worker receives Social Security benefits, either through retirement or disability, certain family members may also receive monthly cash payments based on the worker's Social Security record if they are:

- A spouse age 62 or older,
- Minor children, or
- Adult children 18 or older who have disabilities.

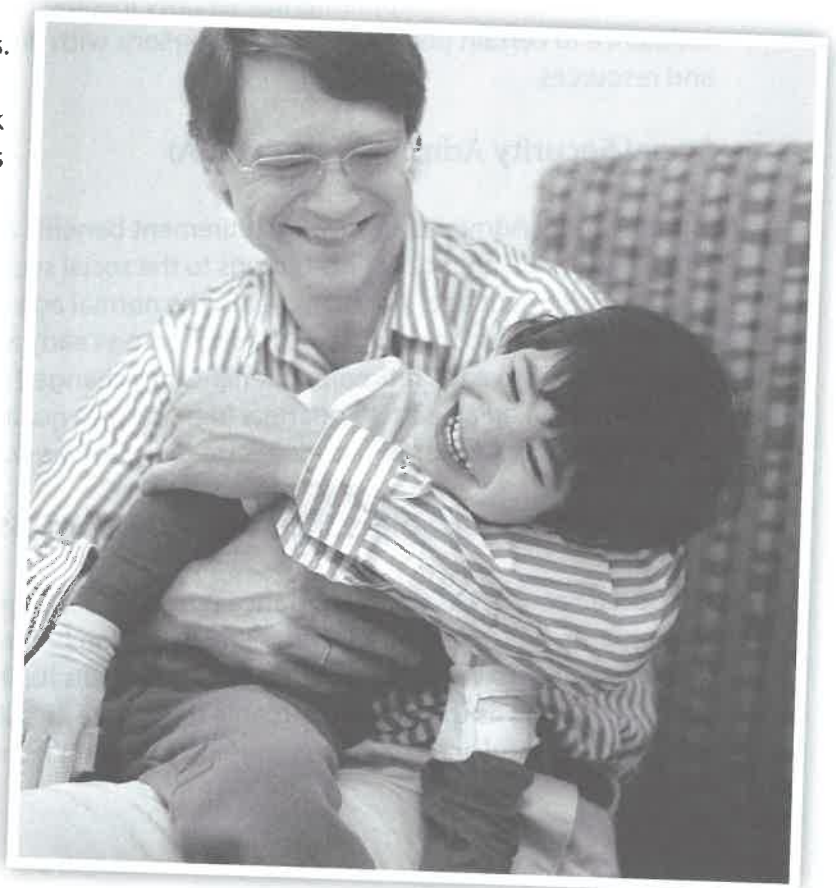
When a worker dies, survivor's benefits are paid to certain family members. Persons who can receive survivor's benefits are:

- A widow or widower age 60 or older;
- A widow or widower age 50 or older who has a disability;
- A widow or widower caring for a child under age 16 or a child with a disability;
- An unmarried child;
- A minor child or an adult child with a disability whose disability occurred before age 22 and who continues to have the disability; or,
- Parents who depended on the deceased individual for at least half of their financial support.

The amount of money each person will receive depends on how much income the worker received from employment over his or her working lifetime. To calculate how much a dependent or survivor would receive, go to <http://www.ssa.gov/planners/benefitcalculators.htm>, or call the Social Security Administration at 1-800-772-1213 and ask for a form called the "Request for Earnings and Benefits Statement."

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is based upon financial need, rather than on any earnings the individual may have received from employment or paid into the system. It provides monthly cash payments to persons who are age 65 and older, or who have blindness or another disability and who meet the financial eligibility test for resources and income. SSI is also available to children who have blindness or have a disability. Persons who reside in Florida who get



SSI are automatically eligible for Medicaid, a government health insurance program, and often are eligible for other federal programs such as SNAP, the food assistance program.

The definition of “disabled” is the same for SSI as it is for the Social Security Disability Insurance (SSDI) program. To qualify for SSI, a person must have a physical or mental disability that prohibits them from performing substantial gainful activity that is expected to last at least a year or to result in death. In order to be eligible for SSI, the person with a qualifying disability must meet age requirements and show that the value of his or her property or assets and income from any source does not exceed the maximum allowed by law, which is currently a limit of \$2,000. The basic amount paid for SSI is the same nationwide but some states add a financial supplement to that amount. Currently, Florida is not one of those states.

Persons may be able to receive both Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) payments if the amount of their SSDI benefit is smaller than the maximum amount of income that they would be entitled to receive under SSI.

How Property and Assets are Treated under SSI

Property and assets include but are not limited to real estate, certain personal belongings, bank accounts, cash, stocks and bonds. To be eligible for SSI, the total value of these items cannot be greater than \$2,000.

The following items do not count as assets or resources for purposes of SSI eligibility:

- The applicant’s home and the land it is on, provided that it is the primary residence.
- Household goods, personal property, and one car, depending on how they are used.
- Life insurance with a face value of \$1,500 or less per person.
- Up to \$1,500 in burial funds for the applicant and up to \$1,500 in burial funds for the applicant’s spouse, or burial plots for the applicant and his or her immediate family.
- Uniforms or other items required for his or her employment.

As laws and policies change often, make certain that if there are additional options for keeping assets, such as special needs trusts, that these assets have been approved by the Social Security Administration. Check with the local Social Security office or visit the agency’s website at <http://www.ssa.gov/ssi>.

How Income May Impact SSI Eligibility

Countable income can include both earned income and unearned income. This means that income which may impact the amount of the SSI payment includes money that is paid by an employer, Social Security payments, private pension payments, or some items of value that are received as gifts to pay for food, shelter or utilities.

However, certain types of income may not be counted. In 2011, this included the first \$20 of income received in a month – whether unearned or earned; plus the first \$65 per month earned from working and half of the amount over \$65; benefits from the Supplemental



Nutrition Assistance Program (SNAP), formerly known as the Food Stamp Program; most food or shelter provided by private, nonprofit organizations; and most home energy assistance.

If a person has a disability and plans to work, there are special rules known as “work incentives” which make it possible for individuals receiving Social Security or SSI to work and still receive monthly social security payments and Medicare and Medicaid.

Be sure to contact the Social Security Administration before beginning employment. ***Failure to do so could result in the loss of your benefits.***

For the latest information on what does and does not count as income for the purpose of qualifying to receive SSI, go to <http://www.ssa.gov/ssi/text-income-ussi.htm> or call 1-800-772-1213.

Appeals

If a person is denied eligibility for SSI or SSDI benefits, an appeals process is available and should be utilized. Filing instructions are printed on the back of the notice of denial. If you believe that benefits have been wrongfully denied, consult with an advocate, a knowledgeable friend, or an attorney, and seek help right away. There is a time limit on filing for reconsideration or appealing a case to the administrative court. Two fact sheets are available from the Social Security Administration with additional information regarding the appeals process. You may request the fact sheets from your local Social Security office or download them from the agency’s website.

- *The Appeals Process*, <http://www.socialsecurity.gov/pubs/10141.html>
- *Your Right to Representation*, <http://www.socialsecurity.gov/pubs/10075.html>

FEDERAL HEALTH INSURANCE PROGRAMS

For many years, there have been two medical insurance programs that are funded by tax dollars, Medicare and Medicaid. Even though both programs are funded in total or in part by the federal government and some of the services provided and the people served are the same, the purposes of the two programs are very different.

Medicare

Medicare is a federal health insurance program for persons age 65 or older or who have a disability. A person must have had that disability for at least two years before becoming eligible for Medicare. If there is proof that the person has had the disability for two years, be sure to provide this to the Social Security representative. While Medicare provides basic health insurance, it does not cover all medical expenses or the cost of long-term nursing care. When you

apply for Social Security benefits, the Social Security Administration will also help you enroll in the Medicare program.

Medicare is divided into four parts:

PART A covers most medically necessary hospital, skilled nursing facility, home health and hospice care. Part A is free if you have worked and paid Social Security taxes for at least 40 calendar quarters (10 years). Those who have worked and paid taxes for less than the required number of calendar quarters pay a monthly premium for participation in the program.

PART B covers most medically necessary doctors' services, preventive care, durable medical equipment, hospital outpatient services, laboratory tests, x-rays, mental health care, and some home health and ambulance services. A monthly premium is paid for this coverage.

PART C is not a separate benefit, but, rather, allows private health insurance companies to provide Medicare benefits to beneficiaries. These Medicare private health plans, such as HMOs and PPOs, are sometimes known as *Medicare Advantage* plans. If you wish to do so, you may choose to get your Medicare coverage through a Medicare private health plan instead of Part A or Part B.

PART D is the part of Medicare that provides outpatient prescription drug coverage. Part D is provided only through private insurance companies that have contracts with the government - it is never provided directly by the government. Part D is optional for most people. An individual's prescription medications will determine whether it is important to participate in Part D. Qualified Medicare beneficiaries (QMBs), specified low-income Medicare beneficiaries (SLMBs), and certain qualifying individuals (QIs) are automatically enrolled in a low-income subsidy (LIS) program and are not subject to the Medicare Part D premium.

1-800-MEDICARE (800-633-4227)

TTY: 877-486-2048

<http://www.medicare.gov/>

Medicaid

The Medicaid program is designed to help people with low income and few assets. *It is not the same as, nor is it a part of, Medicare.* Although the federal government funds a portion of Medicaid, each state pays a portion of the cost and sets additional rules regarding eligibility and services.

Medicaid pays for prescribed medications within certain limits. Services for children under age 18 are more inclusive than services for adults. General information is available at the Centers for Medicare & Medicaid Services website, <http://www.cms.gov/home/medicaid.asp>.

Some individuals are eligible for both Medicare and Medicaid. This is called dual eligibility. In Florida, Medicaid may pay some of the premiums and deductibles required under Medicare for a person who is dually eligible. The Federal Affordable Care Act established a new Medicare-Medicaid Coordination Office that will serve people who receive benefits from both Medicaid and Medicare. For additional information on dual eligibility, e-mail the office at MedicareMedicaidCoordination@cms.hhs.gov.

There is a special program within Medicaid for persons who work and are not eligible for SSI, but who do not have enough income to cover their medical expenses. This is known as the Chapter 16b Medicaid provision, sometimes referred to as “Protective Medicaid.” Application for this portion of the program should be made at your local Medicaid office.

In Florida, the Agency for Health Care Administration (AHCA) is responsible for Medicaid. The Department of Children and Families acts as their agent by enrolling people in Medicaid. For questions or information, you may contact the Agency for Health Care Administration by phone, toll-free at (888) 419-3456.

The eligibility criteria for Social Security benefits, Supplemental Security Income, Medicare, and Medicaid are all different. You *do not* have to choose one or the other. In fact, an individual may be eligible for more than one of the programs.

STATE PROGRAMS AND RESOURCES

Agency for Persons with Disabilities Medicaid Waivers

The Agency for Persons with Disabilities (APD) serves the needs of Floridians with developmental disabilities. The primary mission of the APD is to support persons with developmental disabilities in living, learning, and working in all aspects of community life. Each year, the Florida Legislature budgets a specific amount to provide these services. Most of these funds are allocated to Medicaid waiver programs.

The Agency has two types of services: community-based services and institutional care. Institutional care is discussed in Chapter 6. Community-Based Care Medicaid Waivers assist people with disabilities to live in their own homes or in residences located in their own communities. The majority of persons served by APD receive community-based services through one of three Medicaid Waivers:

- The Developmental Services Home and Community-Based Services Waiver (DS/HCBS Waiver),
- Consumer Directed Care Plus (CDC+), and
- The Family and Supported Living Waiver (FSL Waiver)

Eligibility for APD Services

Eligibility for APD community-based services and institutional care is explained in detail in Section 393.065, Florida Statutes. *Note: Even though the term “mental retardation” is considered out-of-date it still is used in Florida law. That is why the term is used in this section.*

Very generally the requirements are:

1. You must be a resident of the State of Florida.
2. You must:
 - be over the age of three and have a diagnosis (before the age of eighteen) of autism, cerebral palsy, Down syndrome, mental retardation, Prader-Willi syndrome, or spina bifida, as defined in Chapter 393 of the Florida Statutes, or

- be between the ages of three and five years old and at high risk of developing a developmental disability. (Children from birth to age three (3) receive services through Children’s Medical Services, if eligible.)
3. You must be eligible for Medicaid.
 4. If you are seeking institutional care, you must be financially eligible for the Institutional Care Program (ICP).
 5. You must satisfy the level of care standards for an Intermediate Care Facility for the Developmentally Disabled, and
 - have a primary diagnosis of mental retardation with an intelligence quotient (IQ) of 59 or less; or
 - have a primary diagnosis of mental retardation with an intelligence quotient (IQ) of 60-69 and at least one of the following: ambulation deficits, sensory deficits, chronic health problems, behavior problems, autism, cerebral palsy, Down syndrome, epilepsy, spina bifida, or Prader-Willi; or
 - have primary diagnosis of mental retardation with an intelligence quotient (IQ) of 60-69 and severe functional limitations in at least three of the following major life activities: self-care, understanding and use of language, learning, mobility, self-direction, or capacity for independent living; or
 - be eligible under the category of autism, cerebral palsy, Down syndrome, spina bifida, or Prader-Willi and have severe functional limitations in at least three of the following major life activities: self-care, understanding and use of language, learning, mobility, self-direction, or capacity for independent living.

All services provided by APD must be medically necessary as defined in Florida law, whether provided by an intermediate care facility or through one of APD’s waivers.

For the most up-to-date information on APD services, call 1-866-APD-CAREs (1-866-273-2273) or visit the following website for more information or to download an application for waiver services, <http://apd.myflorida.com/waiver/>.

Important Note: APD services are not transferrable when a person moves to another state.

Demand for Waiver Services

In recent years, the amount of money allocated to the Medicaid waiver has not increased. No increase in funding is expected in the near future. The limitation on funding has made it impossible for the waiver programs to keep pace with the growth in the number of people living in Florida who are in need of these services and are otherwise qualified for them. Most

applicants for Medicaid waiver services are placed on a wait list. Be sure to complete the application process even if you are told there are no funds, nor any services available. Get on the wait list as soon as possible. It is the only way the Legislature can know the true need for services around the state.

In certain crisis situations, APD will consider applications to provide services without placing the person on the wait list if certain criteria are met. Your APD area office can provide you with an application to request crisis services if you meet the following criteria:

1. The applicant is currently homeless, living in a homeless shelter, or living with relatives in an unsafe environment.
2. The applicant exhibits behaviors that, without the provision of immediate Medicaid waiver services could result in a life-threatening situation for the applicant or others, or a situation that may result in bodily harm to the applicant or others requiring emergency medical care from a physician.
3. The applicant's current caregiver is in extreme duress and is no longer able to provide for the applicant's health and safety because of illness, injury, or advanced age.

The Role of the Support Coordinator

Each person applying for services from APD is assigned a state support coordinator including persons on the waiting list for Medicaid waiver services. Anyone on a Medicaid waiver can choose a waiver support coordinator or, in some cases, a consultant. Some intermediate care facilities call the person who assists residents with their plan of care a support coordinator. Others may call them case workers, social workers, or qualified mental retardation professionals (QMRP).

In addition to conducting intake and determining eligibility, it is the responsibility of the support coordinator to help an individual and his or her family members identify service needs, develop support and cost plans, and coordinate service delivery.

The support coordinator most likely will need to obtain a great deal of information about you and your family member's circumstances before beginning to develop a support plan. It will probably be necessary to meet several times. This meeting is often held in the person's home, but it can be held in the support coordinator's office if you prefer. The information learned at these meetings will be written into your support plan.

The Support Plan

Support plans are individualized plans of supports and services that identify a person's needs, goals, outcomes, interests, and abilities. The support plan also identifies the services and supports available through APD and the community that are needed to meet the individual's needs. Support plans are developed by the individual with a disability, his or her support coordinator, and others that the individual wishes to include in the process.

Other State Agencies Serving Persons with Developmental Disabilities

Some agencies provide services that are designed for the general public but are also useful to persons with developmental disabilities. These services may be funded by various departments of state or local government. Some of these programs are:

Florida Department of Children and Families (DCF)

Adult Services Program

The Adult Services Program provides ongoing case management and in-home services through community-based services (Chapter 410, Florida Statutes). Clients who qualify for these services are adults with disabilities (18 through 59 years of age) with permanent physical or mental limitations that restrict their ability to perform normal activities of daily living and their capacity to live independently. Through case management and other in-home services, the program supports and maintains the independence of adults with disabilities and their quality of life.

Optional State Supplementation (OSS)

The Optional State Supplementation (OSS) program provides monthly cash payments to indigent elderly or individuals with disabilities who live in special noninstitutional, residential living facilities, including assisted living facilities, adult family care homes and mental health residential treatment facilities. To qualify for OSS, an individual must need assistance with the activities of daily living due to physical and/or mental conditions. The program provides a monthly check that supplements the individual's income so the person can pay the facility a provider rate established by the state.

Supplemental Nutrition Assistance Program (SNAP)

Administered by the U.S. Department of Agriculture and the Florida Department of Children and Families, the Supplemental Nutrition Assistance Program was formerly known as the Food Stamp Program. SNAP helps households with limited incomes buy food. The Electronic Benefits Transfer (EBT) card is the identification card for this program. On the back is a magnetic strip that works in grocery stores to deduct the amount of groceries purchased from the monthly benefit amount. Apply for SNAP in person at a local Department of Children and Families office or apply online at www.myflorida.com/accessflorida. If you have problems or need assistance, contact the Customer Call Center toll-free at 1-866-762-2237.

Home Care for Disabled Adults

This program provides case management services and a small financial subsidy to approved caregivers providing in-home care to adult persons (18 through 59 years of age) with disabilities who would otherwise be placed in nursing homes or institutions. Subsidy payments, though limited in amount, are intended to help offset the cost of housing, food, clothing, and incidentals, as well as those expenses related to medical, pharmaceutical, and dental services not covered by Medicare, Medicaid, or other forms of insurance. A special pre-authorized reimbursed supplemental subsidy may also assist with the purchase of equipment, supplies, and/or services when regarded as essential to the health and well being of the individual, if funding is available.

Community Care for Disabled Adults (CCDA)

The Community Care for Disabled Adults (CCDA) program assists adults (18 through 59 years of age) who have a permanent physical or mental disability that restricts their ability to perform one or more activities of daily living and impedes their capacity to live independently. Through the provision of, or linkage to, in-home services, CCDA helps these adults with disabilities live

dignified and reasonably independent lives in their own homes. Services include but are not limited to: adult day care; case management; chore service; escort service; homemaker service; and personal care. Through these services, CCDA strives to enhance the individual's quality of life, help the individual to remain in the least restrictive environment, and avoid premature or unnecessary institutionalization.

Aged and Disabled Adult Medicaid Waiver

This program assists adults with permanent disabilities (18 through 59 years of age) who are at risk of being placed in long-term care facilities. It allows adults with disabilities to be cared for in their homes, preserving their independence and ties to family and friends. To be eligible to receive services, the individual must meet Medicaid financial eligibility and level of care for nursing home placement. The Aged and Disabled Adult Waiver program provides services similar to those provided by the CCDA program listed above. Each department district is responsible for the administration of the DCF Medicaid Waiver program. Some districts, through agency staff, provide case management services and contract with community service providers for the provision of eligible services of the Medicaid Waiver program. Other districts contract with provider agencies for all services, including case management. Services include personal care, home delivered meals, homemaker services, day care, and other services.

You can find more information about the Department of Children and Families' programs and services at www.myflorida.com or call 1-850-487-1111. This is not a toll-free call.

Florida Department of Education (DOE)

Schools must meet the federal requirements established under the Individuals with Disabilities Education Act (IDEA). This federal legislation requires, among other things, that schools prepare a student for the transition from school to adult independent living. Planning for this transition begins no later than age 14 and can continue up to age 22. During the transition years, students can receive education and training in many areas including learning job skills and exploring job opportunities. These plans and goals for transition into adult independent living are recorded in the student's Individualized Education Plan (IEP), which is written by the student, the parents, teachers, any other staff involved in the student's education, and any other advocates the individual and family wishes to include in the transition process.

In addition to the assistance available in local schools, there are two divisions in the Florida Department of Education that provide services available to persons with disabilities.

- 1. The Division of Blind Services** provides orientation and mobility training, Braille reading and writing, typing, homemaking, manual arts, personal counseling, recreational services, vocational exploration and specialized vocational training to persons who are legally blind. They may also provide training in personal adjustment, eye medical services, glasses, low vision aids, and diagnostic and maintenance services. Talking Book Services provide library services for those unable to read conventional print due to a visual impairment. Individuals with developmental disabilities may be eligible for these services.
- 2. The Division of Vocational Rehabilitation** provides a comprehensive scope of services to persons with physical or mental disabilities that are an impediment to employment and

who require services to obtain employment. The Division of Vocational Rehabilitation will be discussed in *Chapter 5, Exploring Employment Opportunities*.

You can find more information about the Department of Education's programs and services at www.myflorida.com or call 1-850-245-0505. This is not a toll-free call.

LOCAL PROGRAMS AND SERVICES

Now, more than ever before, individuals and their family members must look to their community for services and supports. Many communities have a wide array of resources, supports, services, and disciplines that can impact and enhance an individual's quality of life.

- Use personal resources to secure needed services.
- Talk to other families about their experiences or join parent support groups.
- Meet with school officials or the school's exceptional education director concerning the student's needs. There are scholarships available, such as the McKay Scholarship, to assist students with disabilities.
- Contact the local university or college. Many have centers that concentrate on research and applied treatment and therapies focused on certain types of disabilities or offer services and accommodations to students with disabilities.
- Contact not-for-profit agencies to learn more about what they provide.
- Raise awareness in your church or other place of worship of the need for services and the possibility of informal networks of volunteers and services.
- Reach out to other community and civic organizations like Rotary club, Kiwanis, Scouts, and Boys and Girls Clubs for programs or services.
- Explore local government services that provide assistance to persons with developmental disabilities. The county or municipal authority may provide direct services, such as recreation, transportation, or public health services, or may choose to contract with nonprofit entities, such as councils on aging or economic development organizations, to provide these services.
- Identify private businesses and practitioners that understand your needs and have experience addressing individuals with similar needs.
- Explore eligibility for other state programs or services. Depending on age and income, other state agencies may also provide critical services. For example, programs in the Florida Department of Education can provide assistive technology resources, cover tuition and educational costs, and offer certified personnel to provide training in areas like supported employment, mobility management, and independent living skills.

- Phone 2-1-1. This is a general informational referral service that is available statewide. 2-1-1 can help you locate family support groups in your area, information on scholarships such as the McKay Scholarship, and other resources mentioned in this section.

The talents and effort of family and friends are an individual's most valuable assets. The willingness to explore the potential of community resources is essential in securing a better future.

Remember that APD is not your only option for services. Section 2 of this Guide provides even more information on agencies and organizations that provide programs and services to persons with disabilities.

CONSIDER THIS

1. Write down the programs and services that may be able to assist your family member.

2. Find the contact information for each program or service you listed above.

3. Schedule a time for you and your family member to contact at least one of these organizations to find out more information. Of course, you can contact them all if you like. When you contact the organizations, remember the Keys to Effective Advocacy discussed in Chapter 3.

Now that you have read through Chapter 4, Identifying Federal, State and Local Agency Resources, go to the Personal Information Summary and complete Section E. Benefits and Services.

CHAPTER FIVE

EXPLORING EMPLOYMENT OPPORTUNITIES

For decades people with disabilities were thought of as being unable to work. However, that notion has been proven wrong! Today people with disabilities work in the public and private sectors. Persons with disabilities are also self-employed and successfully running their own micro-enterprises.

Since the mid-1980s, people with the most severe disabilities have also been employed by using on-the-job systematic training and consistent follow-along strategies. This may require ongoing additional supports such as the assistance of supported employment coaches who help people learn new skills or help them to obtain special equipment that may be necessary to perform some tasks required by their jobs.

Having a job creates a sense of well-being and allows for the hope and true possibility of becoming self-sufficient and independent. Several programs exist to help individuals with disabilities find and keep competitive employment, provide incentives to work while maintaining employment, and protect the rights of employees with disabilities.

DIVISION OF VOCATIONAL REHABILITATION (VR)

The Department of Education, Division of Vocational Rehabilitation (VR) is a federal-state program that works with people who have physical or mental disabilities to prepare for, gain or retain employment. Examples of services that VR provides include:

- Medical and psychological assessment
- Vocational evaluation and planning
- Career counseling and guidance
- Training and education after high school
- Job-site assessment and accommodations

- Job placement
- Job coaching
- On-the-job training
- Supported employment
- Assistive technology and devices
- Time-limited medical and/or psychological treatment.

If an individual's goal is to become employed, he or she may be eligible for VR services if they meet the following criteria:

- A physical or mental disability that interferes with the ability to become employed.
- VR's help is necessary to prepare for, gain, or retain employment.

If an individual receives Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) for a disability, he or she is presumed eligible for VR services if employment is the goal.

VR defines supported employment as work that:

- Pays persons with disabilities at the same rate as other employees.
- Promotes social integration, productivity, and maximum use of a person's skills and abilities.
- Takes place in an integrated work setting.
- Assists individuals with developmental disabilities, severe and persistent mental illnesses, or other significant disabilities.
- Includes job coaching that is often provided by an employment specialist after placement on the job.
- Maintains support services to the worker for present and future employment needs.
- Builds extended ongoing supports with agencies and partners outside of VR to assist a person in maintaining employment.

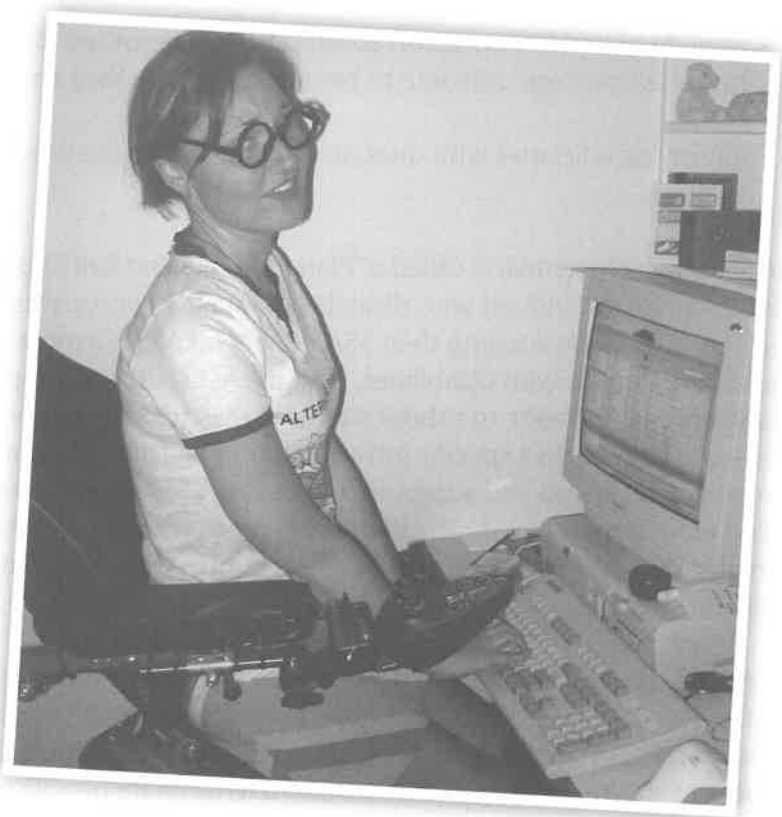
Supports may include: arranging transportation, placement, training or retraining the supported worker, developing natural supports and assistive technology, if needed, to perform job duties. An example of this type of support is a service provided by a Certified Business Technical Assistance Consultant (CBTAC). These consultants are certified to assist people with disabilities who are interested in supported employment, self-employment or in establishing new micro-enterprises.

Call 1-800-451-4327 (Voice/TDD) or visit VR's website to find an office near you or to read more about their services (<http://www.rehabworks.org/>).

WORKFORCE FLORIDA

People with disabilities may access workforce services and resources through one-stop centers located statewide or online at <https://www.employflorida.com/>. The **Employ Florida** toll free number is 1-866-FLA-2345.

Workforce Florida and regional workforce boards have been charged with providing support and special initiatives for workers with disabilities.



SOCIAL SECURITY ADMINISTRATION'S WORK INCENTIVES

Because many people with disabilities fear losing their SSA benefits and related health care due to being able to work and earn an income, they choose not to work. The SSA has made efforts to reduce this fear by creating and implementing programs known as SSA Work Incentives. Work incentives allow people who receive SSA benefits to work and earn an income while maintaining their benefits and their health insurance. There are specific conditions and requirements for each work incentive, and people must understand how the programs work, including the reporting requirements, in order to ensure proper implementation.

Work Incentives Planning and Assistance (WIPA) projects across the U.S. and the U.S. territories work with SSA beneficiaries with disabilities on job placement, benefits planning, and career development. By working with a WIPA representative, SSA beneficiaries will be better equipped to make informed choices about work. Section 2 provides current WIPA contacts in Florida. Each WIPA is staffed with Community Work Incentive Coordinators (CWICs) to:

- provide work incentives planning and assistance;
- help beneficiaries and their families determine eligibility for federal or state work incentives programs;
- refer beneficiaries with disabilities to appropriate Employment Networks or state VR agencies based on individual needs and impairment types;
- provide benefits planning and assistance services;

- provide general information about potential employer-based or federally subsidized health benefits coverage available to beneficiaries once they enter the workforce; and
- inform beneficiaries with disabilities of further protection and advocacy services available to them.

One SSA's work incentive is called a "Plan for Achieving Self Support" also known as a PASS. This plan helps individuals with disabilities obtain an occupational objective: to get a job or return to work while keeping their SSA benefits. PASS is a more formal work incentive that requires individuals with disabilities, with the assistance of a support coordinator or vocational rehabilitation counselor, to submit a written plan for saving money needed for the purpose of learning how to do a specific job and attain a specific occupational objective. When this plan is filed, reviewed and accepted, the person's SSA benefits will not be reduced as long as certain conditions are met. The plan must be submitted to and approved by the Social Security Administration before the person begins the job. A person must have a source of income to participate in PASS.

The Agency for Persons with Disabilities also recognizes that the general public is not aware of special rules that are in place that allow people with disabilities to earn more money, build assets and still maintain certain benefits. Florida Benefits Information Resources Network (FBIRN) is a network of state agency staff that is trained to facilitate people with disabilities to connect with the "right person" (federal and state workers who are certified to provide benefits assistance). Call toll-free 1-866-273-2273 or visit <http://apd.myflorida.com/employment/fbirn.htm> for additional information.

For more complete information on all of SSA's work incentives please see the 2011 Red Book published by SSA. For additional information on SSI and SSDI Employment Supports such as Impairment-Related Work Expenses (IRWE) and Property Essential to Self Support (PESS). Additionally, two publications titled *Your Ticket To Work* (Publication No. 05-10061) and *Working While Disabled—How We Can Help* (Publication No. 05-10095) will provide further information about Social Security work incentives. It is available online at www.ssa.gov or call 1-800-772-1213 to request a publication.

AMERICANS WITH DISABILITIES ACT (ADA)

Anyone new to the workforce should learn about the Americans with Disabilities Act of 1990 (ADA). The ADA is a federal civil rights law designed to prevent discrimination and assist people with disabilities to do more in their community. One fundamental principle of the ADA is that it prohibits employers of 15 or more employees from discriminating against qualified individuals with disabilities. Call 1-800-514-0301 or 1-800-514-0383 (TTY) to request a copy of *A Guide for People with Disabilities Seeking Employment*, or visit the ADA website (<http://www.ada.gov/workta.htm>) to print a copy.

As the *Guide for People with Disabilities Seeking Employment* states:

"There are more opportunities now than ever before for people who are receiving SSDI and SSI benefits to learn job skills and find permanent employment."

Visit the Florida Developmental Disabilities Council website to receive additional materials about employment: <http://www.fddc.org/publications>. Scroll down to the blue banner titled "Employment."

CONSIDER THIS....

1. What are the employment goals of your family member?

2. What supports are necessary to assist your family member in reaching his or her employment goals?

3. Is the person eligible for any of the work incentive programs?

Now that you have read Chapters 4 and 5, go to the Personal Information Summary and complete Section C. Employment/Retirement and Section F. Financial Resources.

VOLUNTEERISM

Many individuals with disabilities are choosing to spend their days engaged in meaningful volunteer positions. Volunteering offers a wide spectrum of community involvement for individuals who want to expand their experiences and also gain valuable skills that can lead to employment opportunities.

Volunteer activities may include working at a local public library, food banks, animal shelters and faith-based programs as well as for specific programs such as Goodwill and the Salvation Army. Disability-specific programs like Partners in Policymaking offer options to expand social roles through service on local, state, or national volunteer boards. Businesses also are constantly on the lookout for volunteers who can bring a fresh perspective on disability issues and in meeting the consumer needs of individuals with disabilities.

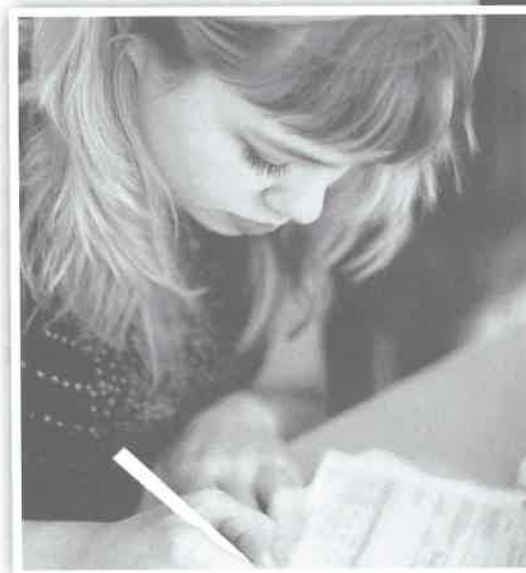
Family members, friends and other members of an individual's circle of support can assist in discovering and reaching out to find new opportunities for community involvement.

Volunteer Florida encourages volunteerism for everyone from youth to seniors to people with disabilities; promotes volunteerism for disaster preparedness and response; and helps to strengthen and expand Volunteer Centers in Florida. Please call 1-850-921-5172 or visit <http://www.volunteerflorida.org> for more information.



DISCOVERY

If you want to work but don't know what type of work you want to do, you might try using a process known as Discovery. As Florida's Project 10 Transition Education Network defines it: "Discovery is a process for getting to know a student by collecting information about his or her interests, strengths, environments or activities where they are at their best, supports that are effective for them, and present levels of performance. Information is gathered through a series of activities, interviews and observations at home, school, and in the community as well as with people who know the student well. A Vocational Profile is created to provide direction to career development activities and to share information for job development. Discovery is an alternative strategy to more traditional or standardized forms of vocational evaluation." If you are still in school, ask your teacher about Discovery or ask your vocational rehabilitation counselor about it. Often people were told that they could not work after completing traditional vocational assessments but they could indeed work after having experienced the Discovery process. Visit the Florida Center for Inclusive Communities website to learn more about Discovery and other best practices related to transition (<http://www.flcic.fmhi.usf.edu/projects/employment.htm>).

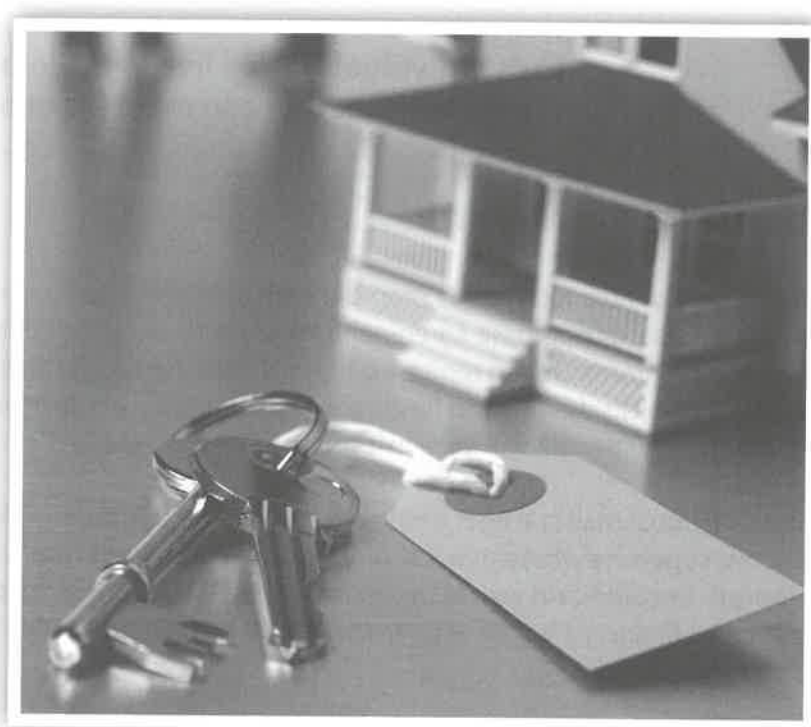


CHAPTER SIX

CHOOSING THE BEST PLACE TO LIVE

Ideas about where an individual with a disability should live have changed significantly in our country. In years past, the only options were to stay at home with family members or to enter an institution. This is no longer the case.

It may be difficult for family members to accept that their family member has the right to choose from a wide range of residential options, including living in an apartment or their own home, alone or with a roommate. These options may require supports and services which are available through the Medicaid waiver program, nonprofit organizations and the private sector.



Sometimes, out of years of habit, parents continue to make decisions for an adult child with a disability. When parents loosen the reins, they may be surprised to learn how capable their family member is at making good decisions once the person is allowed to see and experience available options.

Individuals with disabilities and their family members should identify where the individual wants to live, the supports and services that will be required to meet this goal, the local availability of these resources, and whether the individual is willing to relocate to another part of the state if services and supports are not available locally. Additional considerations include how this residential option will change the individual's current lifestyle, whether it is economically feasible, and how the change will affect relationships with friends and family.



As you and your family member discuss and consider places to live, be certain to write down those things you know your family member will want and need in order to live in the manner he or she has chosen. Learn as much as possible about each of the options available. Be certain to explore all available options in your community. Visit as many types of residential options as you can and pay particular attention to the preferences and options of your family member.

Because circumstances change, it is a good idea to plan both for the immediate future and long-term. The key to developing a long-range plan is to “be flexible.”

Each individual should live in the least restrictive environment that can meet his or her needs.

LIVING INDEPENDENTLY

It may be possible for a family member with a disability to live in a house or apartment through a rental, lease, or purchase agreement. Personal finances will determine whether it is necessary to have a roommate or to request a stipend if the person receives services from the Agency for Persons with Disabilities and funds are available. Even if a stipend is given in one year, there is no guarantee the person will receive a stipend the next year.

The individual may consider hiring a roommate or a supported living coach who can assist with chores, supervise where needed, and provide companionship. In-home supports are available through the Medicaid waiver program so that 24-hour or some other level of supervision is available. Sharing a house or apartment with other adults either with or without disabilities can also be explored.

Persons with skills, personalities, and interests that complement each other can live together. Expenses can be shared and any supervision needed can be supplied by a provider, if necessary. Up to three individuals receiving Medicaid waiver services can live in the same home. However, local zoning ordinances may impose density requirements regarding how many individuals with disabilities can live in a given area. You will want to be certain to check to see if such restrictions are in place before signing a lease.

You may wish to contact the local office of the Department of Housing and Urban Development to see if purchasing a house is an option. This agency may be able to tell you about special programs available at the federal, state or local level for potential homebuyers with disabilities.

A wide variety of supports exist to ensure that an individual can live as independently as possible with adequate services in place to make the choice successful. Some residential options are licensed by the state and must meet requirements of state law or agency rule.

Advantages

The person chooses:

- Where and with whom he or she will live.
- A daily routine.
- An independent support coordinator who assists in the development of an annual support plan to identify all needed supports and services and coordinates these services.
- All support and service providers.
- Someone who can assist in managing the person's daily life, or the person can create his or her own array of supports with the assistance of a support coordinator.
- To retain all of his or her money and may be responsible for his or her own living expenses.
- A physician and dentist. The support coordinator may coordinate any necessary appointments.

Disadvantages

- May be more expensive.
- Safety and security issues may exist.
- Community based services may be limited.

LIVING IN THE FAMILY HOME

An individual with a disability may choose to live in the family home and receive supportive services that make this possible. In addition, services may be available to elderly parents through a number of state and local agencies that will allow them to continue caring for their son or daughter. A support coordinator can assist family members in identifying and obtaining these services. Parents can will their home to a child with a disability who can continue to live there after their deaths. However, the child must be living in the family home before the death of the parent to avoid loss of eligibility for certain government benefits.

Advantages

The person chooses:

- A daily routine.
- An independent support coordinator or consultant who helps to prepare a support plan identifying all service needs, and coordinates those services.
- All support and service providers.
- Someone who can assist in managing the person's daily life, or the person can create his or her own array of supports with the assistance of a support coordinator.
- To retain all of his or her money and may be responsible for his or her own living expenses.
- A physician and dentist. The support coordinator may coordinate any necessary appointments.

Disadvantages

- Possible loss of independence.
- Possible loss of privacy.

FOSTER CARE HOMES, ASSISTED LIVING FACILITIES, GROUP HOMES, AND RESIDENTIAL HABILITATION CENTERS

Foster Care Homes

These are private homes in which a family or staff treat the individual like a member of the family. They provide all of the basic needs - food, clothing, shelter, companionship, some transportation, and participation in community activities, as well as supervision. Only three individuals with disabilities may live in a foster care home at any given time. Foster care homes are licensed by the Agency for Persons with Disabilities.

Assisted Living Facilities (ALFs)

These are residential facilities that are usually designed to meet the needs of elderly persons who require some supervision but do not need nursing care. Some ALFs are designed to meet the needs of adults with disabilities. Only those individuals who require minimal supervision should consider this option. The ALF provider and the resident determine the services and supports to be provided and the cost of that care. ALFs are licensed by the Agency for Health Care Administration.

Group Homes

These are residences in the community that provide residential care for at least four (4) but no more than 15 individuals. They may be private homes or a specially built facility. A group home must meet all of the individual's basic needs and may also provide other specialized services, such as behavioral training or medical care. Supervision is provided by employed staff and professionals. Group homes are licensed by the Agency for Persons with Disabilities.

Residential Habilitation Centers

These centers provide 24-hour supervision by employed staff and serve at least nine individuals. The law does not specify the maximum number of people they can serve. They must meet all of the individual's basic needs and may provide specialized training within the facility. Residents may also leave the facility and go to a local training center during the day. Florida has prohibited the opening of any new residential habilitation centers and existing centers may not increase the number of people they serve. Residential Habilitation Centers are licensed by the Agency for Persons with Disabilities.

Advantages

The person chooses:

- The representative payee for SSI/SSA. It can be the facility, a family member, or a guardian. Most of this money is used for room and board. A small amount is kept by the person to be used as a personal needs allowance.
- A dentist and physician. The facility operator and the support coordinator schedule appointments.
- A support coordinator who assists in the development of an annual support plan to identify all needed supports and services, and coordinates these services.
- Roommates. However, this varies by provider.



- Where to live, subject to availability. The needs of the group may affect the daily routine.
- The providers, however, the facility is primarily responsible for providing services.

Disadvantages

- Greater loss of independence.
- Greater loss of privacy.

SKILLED NURSING FACILITIES AND INTERMEDIATE CARE FACILITIES FOR THE DEVELOPMENTALLY DISABLED (ICF/DDS)

Skilled Nursing Facilities

Skilled nursing facilities provide 24-hour skilled nursing care. Generally, these facilities serve the elderly. In the event that a person with developmental disabilities develops special nursing needs that cannot be accommodated in another setting, he or she will receive both services specific to the developmental disability and to the special nursing needs. Skilled nursing facilities are licensed by the Agency for Health Care Administration.

Intermediate Care Facilities for the Developmentally Disabled (ICF/DDS)

Intermediate Care Facilities for the Developmentally Disabled (ICF/DDS) provide health and rehabilitative services to individuals with disabilities in a protected residential setting. Services include ongoing evaluation, service planning, 24-hour supervision, coordination, and integration of health/rehabilitative services to help individuals function at their greatest ability. ICF/DDS are licensed by the Agency for Health Care Administration.

ICF/DDs feature consistent training, treatment, and health services. Persons served in ICF/DDs tend to have significant impairments, including respirators and feeding tubes. ICF/DDs are designed to provide the highest level of publicly-funded intervention and supports for people with developmental disabilities.



Types of ICF/DDs

The Florida Association of Rehabilitation Facilities (Florida ARF) reported that, in 2011, 86 ICF/DDs were operating in Florida, ranging in size from six beds to 120.

- Six-bed homes operate similarly to group homes. They are located within residential neighborhoods and residents are involved in community activities.
- Cluster facilities feature three homes located in close proximity but operate as separate living units. Each home has four semi-private rooms. Clusters specialize in extensive medical care and rehabilitative services such as therapies.
- 64-bed campuses with each campus comprised of four separate living units. Each unit has eight semi-private rooms. Clusters provide deep-end care to medically fragile people that would be much more costly in institutional settings.
- Other ICF/DDs are variations of these models and have more than 12 residents per home.

How ICF/DDs differ from other long-term care programs

- ICF/DDs are 100% Medicaid funded.
- Over the last 20 years, Florida transitioned thousands of residents from ICF/DDs to waiver services; however, currently, a lack of funding limits diversion opportunities.
- ICF/DD residents have no other appropriate place to live, and some have no family, or their family members are unable to care for them.
- Individuals living in ICF/DDs participate in community activities outside of the home.
- ICF/DD residents may be non-ambulatory, have seizure disorders, have behavior problems, have a mental illness, have visual or hearing impairments, or a combination of these conditions. Nearly one in five residents requires 24-hour nursing services and a medical care plan in addition to their service plans.
- ICF/DD payment is based on a cost reimbursement model, meaning the state only pays recognized costs in pre-approved rates. Individuals contribute toward the cost of their care when assets are available.
- The ICF/DD program is regulated by the federal government with the state providing compliance oversight.

Advantages

- The skilled nursing care or ICF/DD provider is paid for with public benefits.
- All needed services are provided or coordinated by the skilled nursing facility or ICF/DD provider.

Disadvantages

- May not be able to choose roommates.
- Medical and dental services are provided by or coordinated by the facility. It can be difficult to choose a medical provider other than the one selected by the facility.
- The daily routine is usually more structured.
- A social worker or case manager is employed by the facility.

CONSIDER THIS

1. Where would the person prefer to live?

2. What daily activities such as walking, dressing, preparing meals, etc., does the person need assistance to perform? Can the needed level of assistance or supervision be provided in the residential option your family member is considering?

3. Do you have an updated personal disaster plan?

Now that you have read Chapter 6, you are ready to complete Section B. Residential History/Plans in the Personal Information Summary.

DISASTER PREPAREDNESS

Wherever the person chooses to live, it is important to plan for an emergency or disaster situation. It is important to know the individual's possible needs and what assistance the person may need before, during, and after a disaster.

Write down an emergency plan and keep it where it can be easily found. Remember to base the plan on the person's lowest anticipated level of functioning.

The Florida Developmental Disabilities Council has published *Disaster Ready*, a comprehensive emergency preparedness guide for Floridians with disabilities that includes a detailed, four-part personal disaster plan. The guide is available on the Council's website at <http://www.fddc.org/publications> or you can request a free copy by calling 1-800-580-7801 (toll free).

Disability Rights Florida also offers information on emergency preparedness. Call 1-800-342-0823 to request this information or go to <http://www.disabilityrightsflorida.org> and click on "Resources," then "Disability Topics," and then "Emergency Preparedness."



CHAPTER SEVEN

PROTECTING YOUR LEGAL RIGHTS

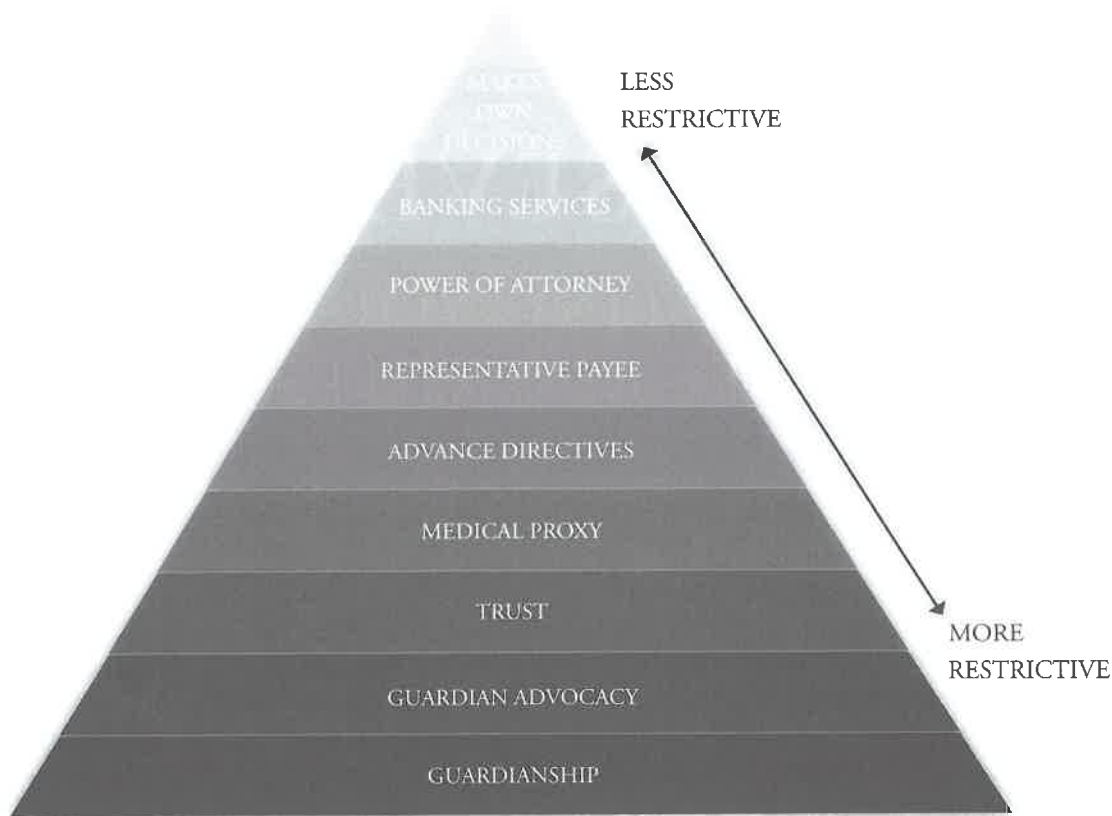
The diagnosis of a disability does not automatically mean that a person needs formal decision-making assistance. We all rely on informal decision making assistance from family, friends, co-workers, and others when we make our own decisions. Supporting individuals with disabilities and encouraging them to make their own decisions should always be first and foremost in our minds.

**The least restrictive way to protect rights
should always be considered first.**

In the past, guardianship was often the first option considered by family members of individuals with disabilities. Families were encouraged to seek guardianship by service providers, school officials and health care providers. Now, Florida law requires that alternatives to guardianship must be considered before a guardianship can be established.

Guardianship may protect an individual with a disability who lacks the capacity to manage property or to protect his or her own health and safety, but declaring a person incapacitated has a major impact on his or her civil rights. Guardianship should only be established when there is no other alternative and as the last possible resort. Guardianship should always be limited to the areas where assistance is absolutely necessary.





ALTERNATIVES TO GUARDIANSHIP

There are a number of alternatives to guardianship which can provide support for an individual while allowing him or her to exercise self-determination. These alternatives usually allow the individual to retain his or her civil rights while making decisions with the assistance of another. This means that the decision-making authority remains with the individual. Alternatives to guardianship should be carefully considered to determine whether they meet the individual's particular situation. There are advantages and disadvantages to each alternative. Seek legal advice, if necessary, to help choose what is best for you and your family member.

BANKING SERVICES

Sometimes support from family and friends can be enough to allow an individual to manage his or her own personal and financial affairs. Here are some of the ways that someone may assist an individual with managing money in a bank account:

Joint Bank Account

A joint bank account allows two or more people to have joint ownership over an account. Both persons have legal access to all of the money in the account and can make deposits and withdrawals. This arrangement allows one co-owner to pay bills for the other co-owner if he or she needs assistance in doing so.

Each person is legally entitled to all the money in the account, which has tax implications for each co-owner. All of the money in the joint account can be considered an asset of each person for the purposes of programs like SSI, Medicaid and SNAP. Because both parties are entitled to use all the money in the account as they see fit, there is some risk that financial exploitation could occur.

Co-signor on Bank Account

The person with a disability allows another person to be a signor on the account. The co-signor does not own the account but the co-signor can write checks and withdraw money from the account on behalf of the owner. The co-signor cannot use the money for any other purpose.

With the rise in the popularity of online banking and check-cards, fewer banks will allow this type of restriction and may charge for it.

Online Banking

Direct deposits and online bill payment are simple and easy ways to assist someone in managing their money.

POWERS OF ATTORNEY

A power of attorney (POA) is a legal instrument that gives one adult, called the “attorney-in-fact,” legal authority to act for another adult, called the “principal.” The principal must have legal capacity to sign a POA, in other words, the principal must understand the authority he or she is giving away. A durable power of attorney (DPOA) is a type of POA that remains effective even when the principal loses capacity in the future.

Please see an attorney to make certain your POA or DPOA, signed before October 2011, is still valid.

Powers of attorney can be used to give an agent the authority to manage money and property for the principal. Powers of attorney can also be used to give an agent authority to make medical decisions.

Many individuals choose to use standard powers of attorney that they find on the Internet. If you choose to do this, be very careful to make sure that the form you are using is valid in Florida because changes in the law may mean that “boiler-plate” powers of attorney may be out of date. For example, grants of authority with respect to wills, trusts, gifts, and property require a separate initial from the principal for each provision. If you do not do this, the document may not be valid in Florida. Seeking the advice of an attorney to help with a power of attorney is a good idea. The attorney will be able to write a power of attorney that is legal, meets your family’s specific needs, and is properly signed.

REPRESENTATIVE PAYEE

A representative payee is a person or organization appointed by the Social Security Administration to receive benefits on behalf of someone who cannot manage his or her social security benefits because they are too young or because the person cannot manage his or her property due to a mental or physical impairment. Benefits can include Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) . This “representative payee” receives

the monthly cash payment and spends the money to meet the needs of the person. The representative payee must complete a report each year that says how the money was spent for the person. If Social Security benefits are the individual's only property, this may provide enough security and stability to the person's finances that guardianship can be avoided.

One advantage of this alternative is that the annual representative payee report must give the oversight that is lacking in other alternatives. This can bring everyone involved a certain peace of mind. However, one disadvantage is that it can be difficult to convince Social Security to give control of the funds back to the individual when the person regains the ability to manage his or her social security benefits.

ADVANCE DIRECTIVES

An advance or pre-need directive is a document that becomes effective when an individual becomes incapacitated that expresses his or her desires, particularly with regard to any aspect of his or her health care, and a written form directing an anatomical donation after death are considered advance or pre-need directives. The directive is written in advance of the need, and the individual must have capacity at the time it is signed. Advance directives must be witnessed by at least two individuals. Some people write advance directives when they are diagnosed with a life-threatening illness. Others are simply planning ahead.

Living Will

A living will is a written document that directs the providing, withholding, or withdrawal of life-prolonging medical procedures in the event the individual is unable to make decisions and has a terminal illness, end-stage condition, or is in a persistent vegetative state.

Designation of Health Care Surrogate

This written document names another person as your representative to make medical decisions for you if you are unable to make them for yourself. You can include specific instructions about any treatment you want or do not want. You can also designate an alternative surrogate. If you designate a health care surrogate and alternate, be sure to ask them if they agree to take this responsibility, discuss with them how you would like matters handled, and give them a copy of the document. The health care surrogate must make decisions using substituted judgment, which means the way you would have made the decision if you had been able to make it.

Durable Power of Attorney for Health Care

This written document names another person to make medical decisions for someone whether or not the person is incapacitated. An attorney should be consulted to prepare this document.

MEDICAL PROXY

A medical proxy, also called a health care proxy, is someone who makes medical decisions for another person who lacks the ability to make his or her own medical decisions. The medical proxy takes effect automatically if the person who lacks capacity has not named a health care surrogate. Florida law gives the following order of priority of persons who can act as a medical proxy:

- legal guardian or guardian advocate,
- a spouse,

- a parent,
- an adult sibling or a majority of adult siblings,
- any other adult relative,
- a close friend, or
- a licensed clinical social worker who meets certain criteria.

A medical proxy seeking to withhold or withdraw life-prolonging procedures must follow certain procedures.

A sample living will, health care surrogate designation form and medical proxy form are located in Section 2. Resources and Forms.

TRUSTS

A trust is a legal arrangement where a trustee holds and manages property for a beneficiary according to the instructions written in the trust document. Special needs trusts are used to maintain eligibility for public benefits. An attorney should be consulted to help determine whether a trust is needed. A general description of trusts is given in Chapter 9, Making an Estate Plan.

GUARDIAN ADVOCACY

In Florida, there is an alternative to guardianship that is only available for individuals with developmental disabilities. Section 393.12, Florida Statutes, authorizes guardian advocacy.

The guardian advocacy process generally takes less time and is less expensive than a guardianship. Another significant difference is that there is no determination of incapacity in guardian advocacy, which means that many find guardian advocacy less stigmatizing.

Under the guardian advocacy law, those who demonstrate that they are able to perform some decision-making tasks keep the right to seek employment or a driver's license, and, generally, to marry or dissolve a marriage. Once a guardian advocacy is established, the duties, responsibilities, and authority of the guardian advocate are the same as those of a guardian, which are listed in Chapter 744, Florida Statutes.

If an individual who has a guardian advocate gains or regains some ability to exercise rights that were transferred to the guardian advocate, a suggestion of restoration of rights can be filed by that individual or any other interested party.

For more information on guardian advocacy, contact the Florida Developmental Disabilities Council and ask for a copy of *Lighting the Way to Guardianship and Other Decision-Making Alternatives*, or go to <http://www.fddc.org/publications>.

GUARDIANSHIP

Chapter 744, Florida Statutes, covers all persons who might need guardianship for any reason, including dementia, head trauma, mental illness, or any disability. Unlike guardian advocacy,



guardianship can only be established after a court has determined that the individual is incapacitated with respect to one or more rights. There are two basic categories of guardianships:

1. Full (plenary) Guardianship

Under full guardianship, a person is appointed by the court to exercise all delegable legal rights and powers of the person who has a disability. Many advocates for persons with developmental disabilities believe that full guardianship is necessary for very few people. It removes all rights relating to both person and property and requires that there first be an adjudication of the person as totally incapable of handling any personal decisions, money, or property. After this adjudication of incapacity another hearing is held to appoint the guardian to make all decisions for the ward.

2. Limited Guardianship

In limited guardianship proceedings, the court adjudicates the individual incapacitated in specific areas due to the fact that he or she lacks the capacity to do some, but not all, of the tasks necessary to care for his or her person or property. After the adjudicatory hearing, another hearing is held and a guardian is then authorized to handle only those rights and powers that the court finds the person incapable of handling.

Standby Guardianship

Guardians ordinarily wish to have a hand in deciding who will take over when they can no longer serve as guardian, rather than leaving it up to the court to choose. Standby guardians may operate as guardian for up to 20 days after the death or incapacity of the guardian, at which time they must have the court confirm their appointment. The court may appoint a standby guardian with the same petitioning procedures and at the same hearing as required for the basic guardianship.

Foreign Guardianship

Florida recognizes guardianships from other states, territories, and countries. Within 60 days of the person under guardianship moving to Florida, the guardian must file an authenticated order of the appointment with the Clerk of the Court in the county where the ward resides.

Any decision-making rights that are removed by the court and transferred to the guardian can no longer be made by the ward. The guardian should always consider the wishes of the ward when making these decisions.

Requirements of Guardians

To become a guardian, a person must:

- be a Florida resident over the age of 18, of sound mind and never been convicted of a felony,
- receive court-approved basic training in how to function as a guardian or guardian advocate,
- file a guardianship report annually to include the guardianship plan and an accounting of assets, and
- develop an annual guardianship plan, which includes details of the current condition and needs of the ward and how the guardian proposes to meet those needs.

Guardians are required to have an attorney. It is important to find an attorney who is knowledgeable in guardianship laws and has the experience to help you explore the most appropriate decision-making options.

The guardian has no personal financial responsibility for the care and maintenance of the person, but the guardian has a special relationship called a fiduciary responsibility to use the ward's property only for the ward and to carefully and responsibly manage the person's property.

If the cost of an attorney is an issue, your local Legal Aid office or the Florida Bar's Lawyer Referral Service may be able to assist you.

Public Guardians

Some counties in Florida have an Office of Public Guardian. If the person has limited financial resources and no family, friend, or any other person, bank, or corporation willing to serve as guardian, and there is no means to pay a professional guardian, the public guardian may become the guardian of the individual.

CRIMINAL JUSTICE CONSIDERATIONS

Florida law makes special provisions for individuals who have certain intellectual impairments or autism and who have had an encounter with the criminal justice system. The provisions for this program are found in Chapter 916, Florida Statutes. If a family member should ever have an encounter with the criminal justice system, make certain that legal representation is provided and that this attorney has experience in criminal defense of persons with disabilities. Additionally, each area office of the Agency for Persons with Disabilities has a designated "court liaison" to work with consumers of APD services who are involved in the criminal justice system. The court liaison will help make certain that the person receives all of the protections afforded under the law. Florida law contains special provisions for criminal defendants with intellectual disabilities. The program is called the Mentally Retarded Defendant's Program. Contact APD for more information.

CONSIDER THIS....

1. Do you and your family member have a living will?

2. Have you and your family member named a health care surrogate designation in a written document?

3. Have you and your family member named an alternate health care surrogate in a written document?

4. Which rights, if any, does your family member need assistance in exercising?

5. Which decision-making options could help your family member in the area of decision-making assistance?

Now that you have read through Chapter 7, you are ready to complete Section G. Decision-Making Assistance of Personal Information Summary.

CHAPTER EIGHT

DEALING WITH HEALTH CARE CONCERNS

Good health care is important to everyone. For persons with disabilities extra attention must be given to maintain good health and catch health problems early. It may be difficult for your family member to identify and convey potential health problems to you. Not understanding what will happen during a doctor's visit may cause resistance to future visits. Primary caregivers may be unaware of what each annual checkup should require or be uncertain about when a condition is an emergency. This chapter gives some suggestions about how to handle situations related to maintaining quality health care and recognizing emergencies.

When there is a family member with a disability, primary caregivers as well as medical professionals have an added responsibility to see that the individual receives quality health care. This includes understanding what quality health care is, knowing what can be anticipated because of the person's disability, and maintaining adequate records for others who will have the responsibility as care providers in the future. Federal rules through HIPAA (Health Insurance Portability Accountability Act) require individual permission regarding sharing of medical records and information with anyone.

THE BUILDING BLOCKS OF QUALITY CARE

Appropriate Communication

It is important that health care providers be skilled in dealing with individuals with disabilities. They should be able to give you and your family member confidence in their knowledge and abilities. There should be opportunities for all who are involved in the health care of the individual to communicate with health care providers regarding diagnosis, proposed treatment, and anticipated outcomes.

Both health care providers and those in the individual's circle of support should speak directly to the individual receiving care in language that the person can understand.

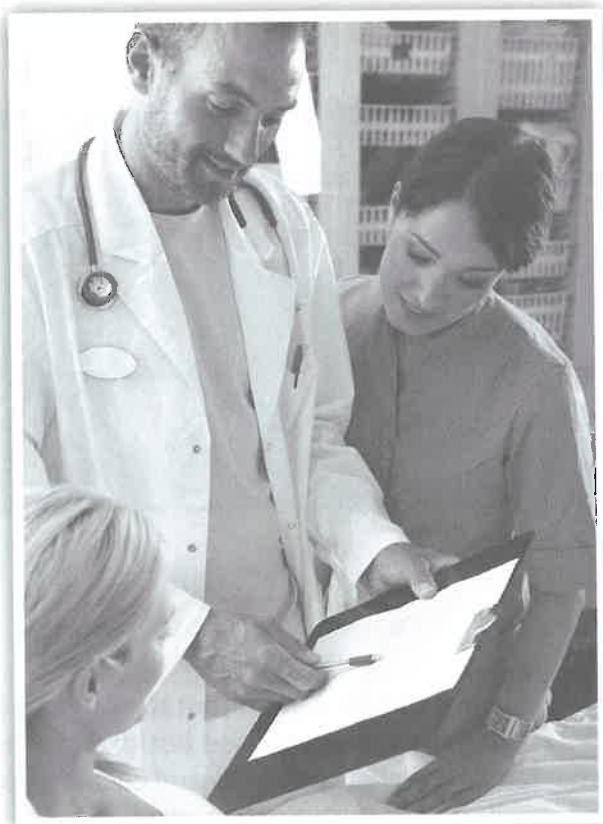
Person-Centered Care

The needs of the individual with developmental disabilities should be placed above those of health care professionals. This may require revising the method of administering treatment to

meet the special needs of the individual. For example, it is sometimes difficult for a person with cerebral palsy to lie on an examination table without special assistance. In the course of conducting physical examinations it is important that providers give simple explanations of what the patient can expect, both in terms of loss of privacy and the degree of discomfort.

Continuity of Care

Seeing the same physician, nurse, or therapist is important to a person with a disability. Keep in mind, however, there comes a time when transition from one physician to another must occur. For example, transition occurs when a referral is made from a primary care physician to a specialist when the individual moves from one primary care physician to another, or when an 18-year-old moves from a pediatrician's care to a primary care physician. Whatever the reason for the change, the reasons for the transition should be fully explained to the patient.



Comprehensiveness of Care

To the extent possible, health care should be comprehensive. Individuals with disabilities, their family members, and medical case managers should be actively involved in and take responsibility for their care. Prevention of disease and disability should be a cornerstone of comprehensive care.

Local Provider Base

Whenever possible, health care should be provided in the community where the person lives. When it is necessary to travel outside of the community, your local physician should coordinate consultations with out-of-town specialists. Any specialist should be familiar with the medical conditions and needs of the person with a disability, and be able to provide information related to the medical condition.

THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that only allows health care providers to use or disclose protected health information for treatment, payment, and health care operation purposes.

Patients can sign a HIPAA waiver allowing doctors and other health care professionals to communicate with specifically named persons about the patient's health history and current health situation. Without this authorization, doctors are prohibited by law from discussing anything about a patient with third parties, including family members, unless the individual has been determined to be incapacitated by a court or his or her physician and the person receiving

the disclosure is the guardian, guardian advocate, medical proxy, or designated health care surrogate.

Health care professionals often cite HIPAA when refusing to disclose health information to a family member, so it is a good idea to understand whether HIPAA allows you to access information you may need.

Caregivers who are paid with Medicare or Medicaid funds are not allowed to discuss any information about the persons they serve. Even the person's name is protected and should not be disclosed.

CARE PLANS

Care plans are developed for people who live in institutions to address their medical, psychological and social needs. The individual and his or her legal representative have a right to participate in the development of a care plan. The individual can also invite family members or friends to attend care plan meetings and assist in the development of the plan. Any issue or concern should be discussed at the planning meeting and documented as a part of the plan.

For information on federally funded health insurance programs, go to Chapter 4.

CONSIDER THIS....

1. Do you participate in care plan meetings with your family member? Remember the Keys to Effective Advocacy discussed in Chapter 3.

2. Has the person considered giving a trusted family member or friend a HIPAA waiver to allow someone else access to his or her medical information?

Now that you have read through Chapter 8, you are ready to complete Section D. General Health Information of the Personal Information Summary.

INDIVIDUAL EMPOWERMENT

The opinions of the individual with intellectual disabilities should be considered by medical professionals. They should recognize that, to the extent possible, adults who have a disability should make their own health care decisions. They should also understand that family members can play a critical role in making certain that a patient with intellectual disabilities understands treatment options and makes decisions in his or her best interest.



CHAPTER NINE

MAKING AN ESTATE PLAN

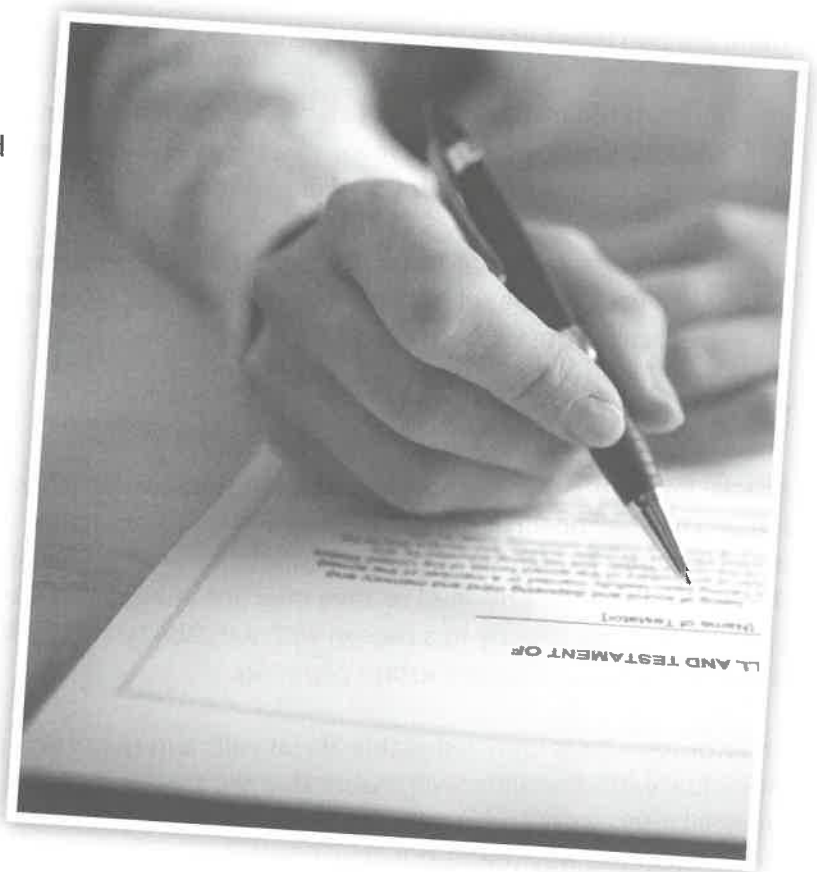
Estate planning involves making plans for transferring property after a person's death. An estate plan is important for everyone, including individuals with disabilities, who is preparing for the future. Everyone understands that estate plans are critical for those who are wealthy, but people often do not realize that they are equally important for those with fewer assets. It is important to consider estate planning even if there are very few assets to place in a trust, or leave in a will. An estate plan can help others know your wishes in the event of your death or incapacity. An estate plan can help provide the needs of a person with a disability if a primary caregiver dies or becomes incapacitated. An estate plan can help individuals with disabilities who are leading more productive lives in the workforce, plan for their future.

There are several ways to plan for the transfer of an estate upon a person's death. At least three components should be considered when making an estate plan.

- A Last Will and Testament,
- A Trust, and
- Personal Financial Planning.

LAST WILL AND TESTAMENT

Wills can range from very simple to very complex documents. They state your wishes for disposing of your assets after your death. Wills make it much easier for those you leave behind to handle your affairs. Since Florida law requires



that even the most simple wills contain certain required language, you should have an attorney prepare your will.

After your death, the person you have named in your will to be your personal representative must determine the exact value of your assets, notify your beneficiaries and creditors, and keep account of all transactions. When all probate requirements have been met, whatever assets are left are then distributed to those you have named in your will or to a trust. It is important that you give your personal representative a copy of your will. The original, signed copy of your will should be kept in a safe or safe deposit box. Some attorneys keep wills in their offices.

There are several ways to transfer property automatically upon death. Insurance policies can transfer property automatically to beneficiaries. Bank accounts titled as payable on death accounts can transfer the funds in the account automatically to a beneficiary.

You should be ready to discuss with your attorney how you want to distribute your assets after your death and who you want to receive them so that the attorney can advise you on the best way to achieve your objectives.

In Florida, if someone dies without a will, state law decides how those assets will be distributed. These laws are called intestacy statutes. It is always best to plan ahead and have a will.

TRUSTS

Trusts can be an important tool when making an estate plan. Trusts have several advantages. They can avoid some aspects of probate, protect eligibility for government benefits, and can help ensure that a person's quality of life is maintained.

There are two types of trusts: revocable or irrevocable.

- A revocable trust is one that can be changed or terminated at any time during the settlor's lifetime. Common uses of revocable trusts include inter-vivos trusts (living trusts) or trusts used in conjunction with Last Will and Testaments.
- An irrevocable trust is more permanent, and assets in an irrevocable trust cannot be taken back by the settlor in most circumstances. A special needs trust is an example of an irrevocable trust.

Special Needs Trusts

Special needs trusts, also known as supplemental trusts, allow someone to keep his or her own funds while still qualifying for or maintaining public benefits. It is important that all family members understand the importance of planning when leaving assets to a person with a disability. A well-intentioned relative may not understand the problems he or she can cause by leaving assets directly to a person with a disability. An individual's public benefits may be jeopardized without proper estate planning.

An attorney who is knowledgeable about wills and trusts that protect the interests of an individual with disabilities will ensure that the trust is properly worded and will protect the financial interests of the person. He or she will be aware of changes in federal or state law that might affect the way the trust is structured.

A trust may be created by a parent or any other family member or interested person. This person, called the “settlor,” can fund the trust by putting bank accounts, stock, or other assets in the name of the trust. The trustee is the person responsible for managing the trust fund for the benefit of the individual with the disability, known as the beneficiary.

Since the trustee is responsible for administering the trust, it is important to select a trustworthy and capable person or financial institution to serve as a trustee after your death or incapacity.

The Florida Developmental Disabilities Council’s *Lighting the Way to Guardianship and Other Decision-Making Alternatives* publication provides more detailed information about special needs trusts. It is provided free of charge upon request or can be downloaded from the council’s website at www.fddc.org.

PERSONAL FINANCIAL PLANNING

Tax Issues

Do not overlook tax issues when estate planning. Several different kinds of taxes may be imposed by the federal and state governments, including gift and estate taxes, inheritance taxes, income taxes, and capital gains taxes. Be sure to consult an attorney who specializes in tax law or a tax accountant before a plan is put in place.

Financial Planning

Financial planning involves developing ways to achieve an individual’s financial goals while the person is living and after the person’s death.

Depending on your assets, you may want to seek the services of a financial planner. A financial planner may be an accountant, broker, or insurance agent who can offer comprehensive financial planning services, including planning for the transfer of property when a person dies. Just be certain that whoever you use has you and your family member’s financial interests in mind, rather than their own. You should explore the education and certifications held by persons advertising as financial planners, as well as ask whether the financial planner has any financial interest, such as a sales commission, in any product that he or she recommends.



While most of us will benefit from consulting with a financial planner, not everyone needs one. Regardless, be certain that you have a detailed description of your own financial situation, including bank accounts and a current and complete list of assets, and liabilities.

SELECTING AN ATTORNEY

In selecting an attorney to assist you with these legal documents, select one that is familiar with wills, special needs trusts, protecting the government benefits of individuals with disabilities, guardianship and other alternatives, health and life insurance, community organizations that serve individuals with disabilities, and the particular capabilities of the person.

Disability Rights Florida is a not-for-profit, statewide corporation that provides a protection and advocacy system for individuals with disabilities. While the organization does not offer a formal lawyer referral service, it is possible that it may be able to refer you to an attorney in your area who specializes in estate planning intended to benefit persons with developmental disabilities or general disability law. Call toll free 1-800-342-0823 or go to the organization's website at <http://www.disabilityrightsflorida.org>.

The Florida Developmental Disabilities Council's *Lighting the Way to Guardianship and Other Decision Making Alternatives* publication provides more information about where to find legal assistance, as well as how to prepare for meetings with attorneys and what to do during those meetings.

CONSIDER THIS

1. Do you know an attorney who has experience working on legal issues that are common to people with disabilities?

2. Have you and your family member prepared a will and considered a trust?

3. Have you considered your own plans regarding your death and talked to your family member about his or her plans?

Now that you have read through Chapter 9, you are ready to complete Section H. Final Arrangements.



MAKING FUNERAL PLANS

It is important to plan ahead for your own funeral. If you have plans to donate your body to a medical school, discuss this with your family, obtain the necessary forms, and complete and return them now. This will make things much easier for those you leave behind.

Use a funeral facts booklet, available from any mortuary or your place of worship, to gather and record necessary information. Look at obituaries and use them as a guide to write down facts about yourself. Describe the type of funeral service you want, where it will be held and whom you would like to participate in

the ceremony. Specify whether you prefer burial or cremation and decide where you would like for your remains to be buried or distributed. Look into prepaid funeral plans and decide how you will pay for the expenses related to your death and disposition.

It is important to discuss your plans with family members, including those with intellectual disabilities. Explain why you must plan in advance and use the opportunity to talk about life and death, and what it means within the context of your own personal religious or spiritual beliefs.

After you have discussed the meaning of death and the emotions and feelings that accompany it, you may wish to ask how your family member feels about planning for the end of his or her life. You may be surprised at the level of understanding shown.

FLORIDA BAR SERVICES

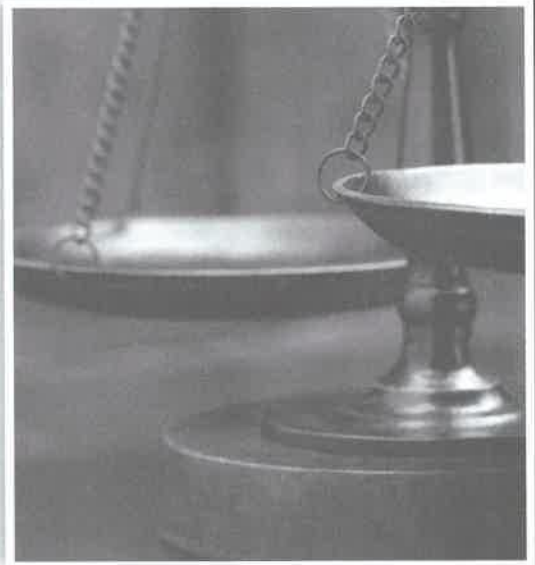
The Florida Bar Lawyer Referral Service and local bar association lawyer referral services are designed to make it easier for people to find a lawyer who specializes in their particular area of legal need. The Florida Bar Lawyer Referral Service has also established a specialty panel of attorneys who specialize in disability law known as the Disability Law Panel. If your personal circumstances qualify you for referral to one of these specialty panels, you will receive a free initial 30-minute office consultation.

If the legal issue is one that can be easily handled, the attorney's fee for additional work will be lower than the lawyer's regular rate. Participating attorneys are encouraged to use a payment plan or another method of assisting the client in paying legal fees. Unlike regular lawyer referral service programs which operate in cities with local bar association lawyer referral service offices, the Disability Law Panel operates statewide.

The Florida Bar Lawyer Referral Service

1-800-342-8011 (toll free)

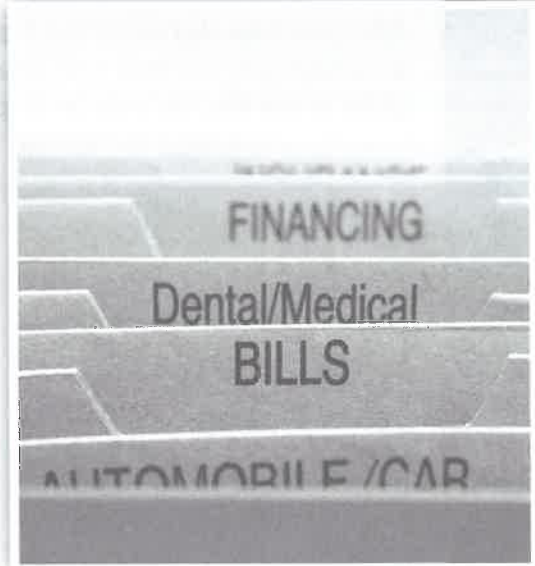
<http://www.floridabar.org> (Click on "Directories," then "Find a Lawyer," and then "Lawyer Referral Service.")



ORGANIZE IMPORTANT PAPERS

Tell trusted individuals in your circle of support where you keep important papers. Be sure to include birth certificates, marriage certificates, divorce papers, and child support orders; naturalization papers; legal agreements; a list of stocks, bonds, certificates of deposit, and other investments; property deeds; insurance policies; tax returns for the most recent seven years; financial records; guardianship papers; advance directives, living wills, and designation of health care surrogacy for both you and the person; powers of attorney for both you and the person, if appropriate; wills, and trust agreements; names and contact information of persons named in legal documents; and burial instructions. Don't forget to include this information in the Personal Information Summary!

Each estate plan is unique, designed to meet the needs of one special individual - you. Involve other family members in your planning whenever possible, including the person with a disability. Again, as stated earlier, more and more individuals with disabilities are leading productive lives in the workforce, and they, too, may need to do financial planning.





BEWARE OF UNINTENDED CONSEQUENCES

Sometimes parents or other family members leave money in a will intended for a person with a disability to another family member with instructions regarding how the money is to be spent. This may not be a wise decision.

Even if the person who receives the money uses it as intended, circumstances may arise that would prevent the money from being available to the individual. For example, if the person who receives the funds has an illness or injury that requires hospital or nursing home

care, the money will be legally considered his or hers. The hospital or nursing home - or anyone who was owed money by the person - could make a legal claim on the money. If the person who received the money dies without a will that specifies that the money go to the person with a disability, the money would go to the other person's heirs.

Leaving assets to an agency or organization with the expectation that it will care for your family member also may be ill advised. If the leadership or financial condition of the agency changes, there is no assurance that your family member will be protected.

If the person becomes dependent on government benefits, you must consider how money or property you leave to him or her as an inheritance will affect his or her eligibility for government benefits. This is particularly true when it comes to Supplemental Security Income (SSI) and Medicaid waiver eligibility. It is also important that other family members who may wish to remember a loved one with a disability in their wills take this into consideration. Without proper planning, even the most well-intentioned "gift" can quickly cause unintended, negative consequences. Often, these consequences can be avoided by using a special needs trust. Talking with and using the services of an attorney with experience in working with individuals with disabilities and their families can be a very wise investment.



SECTION 2: RESOURCES & FORMS

RESOURCES & REFERENCED MATERIAL

Agency for Persons with Disabilities State of Florida; *Decision-Making Options: Exploring ways that people with disabilities get help with making decisions*; Brochure, April 2009.

Agency for Persons with Disabilities State of Florida; *Navigating the Developmental Disabilities Program: You're The Driver- A Resource Notebook for Individuals with Developmental Disabilities and Families Receiving Services from Agency for Persons with Disabilities*; 2005-2006.

Agency for Health Care Administration; *Florida Medicaid: Developmental Disabilities Waiver Services Coverage And Limitations Handbook*; May 2010.

Association of University Centers on Disabilities; *Resources: Acronym Dictionary*; Retrieved 6/8/11 from <http://aucd.org/template/index.cfm>.

Big Bend Transition Council; *Big Bend Transition Spectrum of Services and Guide For Students with Disabilities*; June 2009.

Bragdon, Tarren; *The Case For Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities*; United Cerebral Palsy 2011.

Buchanan, M., Andresen, E. & DeFries, E.; *Florida Office On Disability And Health: Florida Disability & Health Issues Survey: Final Report*; September 8, 2008.

Consumer Directed Care Plus; *Your Life, Your Way: Roles in CDC+*; Retrieved 5/27/11 from <http://cdcplus.org/roles.html>.

Disability Rights Florida; Publications; *Transition: The Passage from youth to adulthood; Your guide to services and information that can make transition a success for young people with disabilities*; Retrieved 6/3/11 from <http://www.disabilityrightsflorida.org/>.

Federal Register; *Presidential Documents; Executive Order 13548 of July 26th, 2010; Increasing Federal Employment of Individuals with Disabilities*; Vol. 75, No. 146; July 30, 2010.

FEMA; *Preparing for Disaster for People with Disabilities and other Special Needs*; Jessup, MD; August 2004.

Florida Association of Rehabilitation Facilities, *Community Residential Living for People with Developmental Disabilities*; Retrieved 6/1/11 from <http://www.floridaarf.org/>.

Florida Developmental Disabilities Council; *Disaster Ready: Emergency Preparedness Guide for Floridians with Disabilities*; Retrieved from <http://www.fddc.org/publications>.

Florida Developmental Disabilities Council; *Lighting the Way to Guardianship and Other Decision – Making Alternatives: A Curriculum for Individuals and Families*; 2009.

Greenbaum, J.; *Life Planning for Adults with Developmental Disabilities: A Guide for Parents and Family Members*; New Harbinger Publications; Oakland CA.; 2007.

LexisNexis; *Special Needs Trusts*; Retrieved 6/1/11 from <http://trusts-estates.lawyers.com/estate-planning/special-needs-trusts>.

Lillesand, Jessica; *New POMS are potentially in the pipeline regarding Pooled Special Needs Trusts' Use of Retained Funds after Death of SSI Beneficiary*; May 25th, 2011; Retrieved 6/1/11 from <http://www.floridaspecialneedslaw.com>.

Maryland Developmental Disabilities Council; *What's Possible: 9 Stories of Changed Lives*; Retrieved 5/25/11 from http://www.md-council.org/publications/DDC_WhatsPossible_web.pdf.

National Council on Disability, *Rising Expectations: The Developmental Disabilities Act Revisited*; Washington, D.C.; 2011.

Pearpoint, J., O'Brien, J. ; *Person Centered Planning with MAPS and PATHS: A workbook for facilitators*; Inclusion Press; 2007.

Project 10: Transition Education Network; *A-Z Library of Terms and Resources*; Retrieved 6/1/11 from <http://project10.info/>.

University of South Florida; Florida Center for Inclusive Communities; University Center for Excellence in Developmental Disabilities Education, Research and Service; *Needs Assessment Report*; Submitted to: Administration on Developmental Disabilities; 2005-2010.

The Quality of Life Project; *Quality of Life for People With Developmental Disabilities*; Toronto, Canada; 1999; Retrieved 6/1/11 from <http://www.utoronto.ca/qol/pwdd.htm>.

COMMON ACRONYMS

AA

Area Administrator (Agency for Persons with Disabilities)

ABA

Applied Behavioral Analysis

ADA

Americans with Disabilities Act

ADD

Administration on Developmental Disabilities (U.S. Department of Health and Human Services)

ADL

Activities of Daily Living

ADT

Adult Day Training

AHCA

Agency for Health Care Administration

ALF

Assisted Living Facility

APD

Agency for Persons with Disabilities

APS

Adult Protective Services (Florida Department of Health)

ASD

Autism Spectrum Disorder

AT

Assistive Technology

BSCIP

Brain and Spinal Cord Injury Program

CARD

Center for Autism and Related Disabilities

CDC+

Consumer Directed Care Plus

CIL

Center for Independent Living

CMS

Centers for Medicaid and Medicare Services (U.S. Department of Health and Human Services)
or Children's Medical Services (Florida Department of Health)

CP

Cerebral Palsy

CRT

Community Residential Training

DBS

Division of Blind Services

DCF

Department of Children and Families

DD

Developmental Disabilities

DDA

Developmental Disabilities Act

DOAH

Division of Administrative Hearings

DOE

Department of Education

DOEA

Department of Elder Affairs

DVR

Division of Vocational Rehabilitation

ESE

Exceptional Student Education

FAAST

Florida Alliance for Assistive Services and Technology

FAPE

Free Appropriate Public Education

FCC

Family Care Council

FCCF

Family Care Council of Florida

FDDC

Florida Developmental Disabilities Council

FDLRS

Florida Diagnostic and Learning Resources System

FFI

Florida Freedom Initiative (APD grant)

FND

Florida Network on Disabilities

FSLW

Family and Supported Living Waiver

FSP
Family Support Plan

HCBS
Home and Community Based Services Waiver

HMO
Health Maintenance Organization

ICF/DD
Intermediate Care Facility for Persons with Developmental Disabilities

ICP
Institutional Care Program

IDEA
Individuals with Disabilities Education Act

IEP
Individualized Education Plan

IFS
Individualized Family Supports

IHP
Individualized Habilitation Plan

IPE
Individual Plan for Employment

ISP
Individualized Service Plan

ITP
Individualized Transition Plan

LEA
Local Education Agency

LRE
Least Restrictive Environment

LTRC
Long-Term Residential Care

MD
Muscular Dystrophy

MS
Muscular Sclerosis

NICHCY
National Dissemination Center for Children with Disabilities

NRSS
Non-Residential Support Services

OJT
On-the-job Training

OT
Occupational Therapy

P&A
Protection and Advocacy

PADD
Protection and Advocacy Program for Persons with Developmental Disabilities

PASS
Plan for Achieving Self-Support

PCA
Personal Care Attendant

PCP
Primary Care Physician

PDD
Pervasive Developmental Disorder

PNS
Projects of National Significance

POA
Power of Attorney

POM
Personal Outcome Measures

PSA
Prior Service Authorization (for APD services)

PT
Physical Therapy

SILA
Supported Independent Living Allowance

SLD
Specific Learning Disabilities

SPGO
Statewide Public Guardianship Office

SSA
Social Security Administration

SSDI
Social Security Disability Insurance

SSI
Supplemental Security Income

UCEDD
University Centers of Excellence in Developmental Disabilities

UCP
United Cerebral Palsy

VE
Varying Exceptionalities

VR
Vocational Rehabilitation

WSC
Waiver Support Coordinator

WSCC
Waiver Support Coordinator Consultation

DIRECTORY OF SERVICES & SUPPORT ORGANIZATIONS

Please note that telephone numbers and website addresses can change. All information is current as of the publication date.

2-1-1

In many, but not all, communities in Florida, the telephone number "2-1-1" has been designated as an information and referral line. This means that community members can dial 2-1-1 for information on a variety of community services, including crisis counseling.

<http://flairs.org/membermap.htm>

Administration on Developmental Disabilities (ADD)

In Florida, ADD provides funding to the Florida Developmental Disabilities Council, Disability Rights Florida, the Mailman Center for Child Development, the Florida Center for Inclusive Communities, and Project of National Significance Family Support 360.

Administration on Developmental Disabilities

Administration for Children and Families

U.S. Department of Health and Human Services

Mail Stop: HHH 405-D

370 L'Enfant Promenade, S.W.

Washington, D.C. 20447

1-202-690-6590 (This is not a toll-free number)

<http://www.acf.hhs.gov/programs/add/index.html>

Adult Protective Services (APS)

APS supports adults with disabilities who need assistance to remain in their homes and/or in the community. For additional questions, please contact the Adult Protective Services Program Office at 1-850-488-2881 (This is not a toll free number) or <http://www.dcf.state.fl.us/programs/aps/>

The four programs offered through the Adult Protective Services Program are: *home care for disabled adults, community care for disabled adults, Aged and Disabled Adult Medicaid Waiver services, and Consumer-Directed Care Plus (CDC+)*. These services generally are provided to those who do not receive services from other specialized sources, such as the Agency for Persons with Disabilities.

Agency for Health Care Administration (AHCA)

AHCA is responsible for licensure of health care facilities and is primarily responsible for the Florida Medicaid program.

2727 Mahan Drive
Tallahassee, FL 32308
1-888-419-3456
<http://ahca.myflorida.com>

Agency for Persons with Disabilities (APD)

APD is the primary source of state-funded services for individuals with developmental disabilities. Headquartered in Tallahassee, APD has 16 area offices.

4030 Esplanade Way
Tallahassee, FL 32399
1-866-APD-CAREs (1-866-273-2273)
<http://apd.myflorida.com>

Arc of Florida, The

The Arc of Florida advocates for people with developmental disabilities to be fully included in all aspects of their community.

2898 Mahan Drive, Suite 1
Tallahassee, FL 32308
1-850-921-0460
1-800-226-1151 (toll free)
<http://www.arcflorida.org>

Center for Autism & Related Disabilities (CARD)

CARD provides support and assistance with the goal of optimizing the potential of people with autism and related disabilities.

1-800-769-7926
<http://autism.fsu.edu/regionalCARDs.php>

Centers for Independent Living (CILs)

CILs are non-profit organizations that assist persons with significant disabilities in living successfully in their communities. CILs operate to promote and assist individuals with disabilities in achieving or maintaining independent living. The statewide association website includes an interactive map that will link you to CILs in your area.

Florida Association of Centers for Independent Living (FACIL)
325 John Knox Rd, Bldg C, Ste 132
Tallahassee, FL 32303
1-850-575-6004
1-866-575-6004 (toll-free)
<http://floridacils.org>

Centers for Medicare & Medicaid Services (CMS)

CMS, a branch of the U.S. Department of Health and Human Services, is the federal agency that administers the Medicare program and monitors the Medicaid programs offered by each state.

7500 Security Boulevard
Baltimore MD 21244-1850
1-800-MEDICARE
MyMedicare.gov

Children's Medical Services (CMS) provides care for children with special health care needs and their families through two divisions, the CMS Network and CMS Prevention and Intervention.

1-800-654-4440

<http://www.cms-kids.com>

Early Steps System is Florida's early intervention system, offering services to eligible infants and toddlers (birth to 36 months) with significant delays or a condition likely to result in a developmental delay. Early intervention is provided to support families and caregivers in developing the competence and confidence to help their child learn and develop. For additional information on Florida's Early Steps System, go to http://www.cms-kids.com/families/early_steps

Additionally, each of Florida's 67 counties has a local county public health department which provides a variety of services to residents. For a complete listing of services provided by each of the county health departments and contact information, go to

<http://www.doh.state.fl.us/chdsitelist.htm>

Department of Children and Families (DCF)

DCF's ACCESS Florida Food, Medical Assistance, and Cash website is your link to public assistance. DCF is the agency responsible for public assistance eligibility determination and ongoing case management of Food Assistance, Temporary Cash Assistance, and Medicaid.

866-762-2237-Customer Call Center

<http://www.dcf.state.fl.us/programs/access>

Department of Children and Families-Florida Abuse Hotline

(To report suspected abuse, neglect, or exploitation of children, the elderly or a vulnerable adult.)

1-800-962-2873 or 1-800-96-ABUSE

Telecommunications Device for the Deaf (TDD) 1-800-453-5145

<http://www.dcf.state.fl.us/abuse/report/>

Department of Education (DOE)

There are two divisions and one bureau in the Florida Department of Education that provide services to persons with disabilities.

The Division of Blind Services provides services and support to ensure that Floridians with visual impairments are able to achieve success in life.

1-800-342-1828

<http://dbs.myflorida.com>

The Division of Vocational Rehabilitation serves as an employment resource for businesses and people with disabilities.

1-800-451-4327

<http://www.rehabworks.org>

The Bureau of Exceptional Education and Student Services administers programs for students with disabilities and for gifted students.

1-850-245-0475

<http://www.fldoe.org/ese>

Department of Elder Affairs (DOEA)

DOEA was created to meet the needs of older Floridians and to help them to remain independent and self-sufficient as long as possible. The focus is to enable those with the greatest need to maintain their independence and self-sufficiency.

1-800-963-5337

http://elderaffairs.state.fl.us/english/programs_services.php

Department of Housing and Urban Development (HUD)

People with low incomes are eligible to receive rental assistance from various programs administered by HUD. This includes privately owned subsidized housing, public housing and the Housing Choice Voucher Program better known as "Section 8." Individuals are encouraged to make application for housing through the voucher program even if there's a waiting list for housing.

1-800-569-4287.

<http://hud.gov>

Disability.gov

This website provides an interactive, community-driven information network of disability-related programs, services, laws and benefits. New resources are added daily across 10 main subject areas: benefits, civil rights, community life, education, emergency preparedness, employment, health, housing, technology, and transportation.

<https://www.disability.gov>

Disability Rights Florida

Disability Rights Florida is the designated protection and advocacy system for individuals with disabilities in the State of Florida. Its mission is to advance the quality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities through collaboration, education, advocacy, as well as legal and legislative strategies.

2728 Centerview Drive

Forrest Building, Suite 102

Tallahassee, FL 32301

1-850-488-9071 or 1-800-342-0823 (toll free)

<http://www.disabilityrightsflorida.org>

Down Syndrome Organizations in Florida

http://www.dsfflorida.org/Florida_DS_Organizations.html

Family Café

The Annual Family Café is a statewide event designed to meet the informational and networking needs of individuals with disabilities or special health care needs and their families.

1-888-309-2233 (toll free)

<http://familycafe.net>

Family Care Council (FCCF)

The purpose of the Family Care Council is to bring together individuals with disabilities and their family members so that they may join together to advocate, educate and empower themselves and others. The FCCF works in partnership with the APD to bring quality services to individuals with dignity and choice.

1-800-470-8101

<http://www.fccflorida.org>

Family Network on Disabilities of Florida, Inc. (FND)

FND is a statewide network of families, professionals, concerned citizens and individuals of all ages who may be at-risk, have disabilities or have special needs.

(800) 825-5736

<http://www.fndfl.org/>

Florida Alliance for Assistive Services and Technology (FAAST)

FAAST provides demonstrations, trainings and assists people in obtaining assistive technology.

3333 W Pensacola Street, Building 100, Suite 140

Tallahassee, FL 32304-2800

1-850-487-3278

1-888-788-9216 (toll free)

<http://www.faast.org/>

Florida Bar Lawyer Referral Service

This service refers the public to attorneys who provide low cost or free initial consultations.

1-800-342-8011 (toll free)

<http://www.floridabar.org>

Florida Center for Inclusive Communities

The Florida Center for Inclusive Communities works to expand and improve services available to people with disabilities and their families through research and capacity building. This is a University Center for Excellence in Developmental Disabilities (UCEDD).

13301 Bruce B. Downs Blvd., MHC 2113A

Tampa, FL 33612-3807

1-813-974-3126 or 1-866-818-4797 (toll free)

<http://www.flcic.org>

Florida Commission for the Transportation Disadvantaged

The Commission is responsible for developing policies to coordinate transportation services.

605 Suwannee Street, MS-49

Tallahassee, FL 32399-0450

1-850-410-5700 (This is not a toll-free number)

<http://www.dot.state.fl.us/ctd/contacts/ctcsbycounty.htm>

Florida Developmental Disabilities Council, Inc.

The Council advocates and promotes meaningful participation in all aspects of life for Floridians with developmental disabilities.

124 Marriott Drive, Suite 203

Tallahassee, Florida 32301-2981

1-800-580-7801 (toll free)

By Telecommunication Device for the Deaf:

1-888-488-8633 (TDD toll free)

www.fddc.org

Florida Developmental Disabilities Resources

(Resource sponsored by the Delmarva Foundation and the Agency for Health Care Administration in cooperation with the Agency for Persons with Disabilities)

1-866-254-2075 (toll free) Delmarva Foundation

www.fddresources.org

This resource helps individuals with developmental disabilities find a provider who best meets their needs.

Florida Diagnostic & Learning Resources System (FDLRS)

FDLRS provides diagnostic, instructional, and technology support services to district exceptional education programs and families of students with disabilities.

<http://www.fdlrs.org>

Florida Law Help

Attorneys in legal aid offices around the state provide free or low-cost legal assistance to moderate and low-income Floridians. The Florida Law Help website can help you find assistance in your area. Legal Services of North Florida, Inc., administers this website and may be able to direct you to services if you do not have Internet access.

1-850-385-9007 (This is not a toll-free number)

<http://floridalawhelp.org>

Florida Self-Advocates NetworkED (FL SAND)

FL SAND is a statewide self-advocacy organization sponsored by the Florida Developmental Disabilities Council that works for systems change.

1-315-443-3851 (This is not a toll-free number)

<http://www.floridaselfadvocacy.com>

Florida Statutes

The Florida Statutes is the collection of laws passed by the Florida Legislature. You may search the Florida Statutes by subject area or statute number.

<http://www.leg.state.fl.us>

Florida Work Incentives Planning and Assistance (WIPA) Projects

WIPA Projects work with Social Security beneficiaries with disabilities on job placement, benefits planning, and career development.

Abilities of Florida

(Citrus, DeSoto, Hardee, Hernando, Highlands, Hillsborough, Levy, Manatee, Pasco, Pinellas, Polk, Sarasota, and Sumter counties)

2735 Whitney Road

Clearwater, FL 33758

1-727-538-7370, ext. 365

1-800-259-5709, ext. 306 (toll free)

<http://www.servicesource.org/services-by-state/florida>

Goodwill Industries of North Florida, Inc.

(Alachua, Bay, Bradford, Calhoun, Columbia, Dixie, Escambia, Franklin, Gilchrist, Gulf, Holmes, Lafayette, Liberty, Marion, Okaloosa, Santa Rosa, Suwannee, Taylor, Union, Walton, and Washington counties)

4527 Lenox Avenue

Jacksonville, FL 32205

1-352-335-1311

1-877-346-3349 (toll free)

<http://www.goodwilljax.org/>

Independent Living Resource Center of NE Florida Opportunity Development, Inc.

(Baker, Clay, Duval, Gadsden, Hamilton, Jackson, Jefferson, Leon, Madison, Nassau, Wakulla, and St. Johns counties)

2709 Art Museum Drive

Jacksonville, FL 32207

1-904-399-8484

1-888-427-4313 (toll free)

www.cilj.com

Brevard Achievement Center, Inc.

(Brevard, Flagler, Indian River, Lake, Martin, Okeechobee, Orange, Osceola, Palm Beach, Putnam, Seminole, St. Lucie, and Volusia counties)

1845 Cogswell Street

Rockledge, FL 32955

1-888-310-6525, Ext. 5207 (toll free)

<http://bacbrevard.com>

Center for Independent Living in Central Florida

(Broward, Charlotte, Collier, Glades, Hendry, Lee, Miami-Dade, and Monroe counties)

720 N. Denning Drive

Winter Park, FL 32789

1-407-590-6336 (This is not a toll-free number)

<http://www.cilorlando.org/>

Mailman Center for Child Development

This organization addresses special health care needs of persons with developmental disabilities through research, training, and advocacy. This is a University Center for Excellence in Developmental Disabilities (UCEDD).

University of Miami Miller School of Medicine

Department of Pediatrics (D-820)

P.O. Box 016820

Miami, FL 33101

1-305-243-6801 (This is not a toll-free number)

<http://mailmancenter.org>

Projects of National Significance (PNS)

PNS' promote and increase the independence, productivity, inclusion and integration into the community of persons with developmental disabilities.

<http://www.acf.hhs.gov/programs/add/pns/pns.html>

Project 10: Transition Education Network

The Network assists school districts in providing appropriate and timely transition services and programs to assist youth with disabilities in their transition to adulthood.

University of South Florida St. Petersburg

140 7th Avenue South, SVB 108

St. Petersburg, FL 33701

1-727-873-4661 (This is not a toll-free number)

<http://www.project10.info>

Self-Advocates Becoming Empowered (SABE)

SABE is a national self-advocacy organization that is working toward the full inclusion of people with developmental disabilities in the community

P.O. Box 30142

Kansas City, MO 64112

<http://www.sabeusa.org>

Social Security Administration (SSA)

The SSA can provide information on federal financial assistance that is available to persons with developmental disabilities.

1-800-772-1213

<http://www.ssa.gov>

Special Needs Registry

The Registry provides contact information for each county's special needs shelter.
1-850-413-9969 (This is not a toll free number)
<http://floridadisaster.org/disability/snshelterlist.html>

The Spina Bifida Association, The (SBA)

The SBA serves persons with spina bifida through education and advocacy.
<http://www.spinabifidaassociation.org> (follow link for Florida Affiliates)

Statewide Public Guardianship Office (SPGO)

SPGO oversees and monitors public guardians and is responsible for the registration of professional guardians.
1-850-414-2381
1-800-963-5337 (toll free)
<http://elderaffairs.state.fl.us/english/spgo.php>

Substance Abuse and Mental Health (SAMH) Program

The agency's Mental Health Program Office oversees Adult Mental Health Services and Children's Mental Health Services. If a person with a developmental disability needs either substance abuse or mental health services and is refused by either of these programs, involvement on the part of the support coordinator or other advocate involvement is essential.
1-850-487-1111 (This is not a toll-free number)
<http://www.dcf.state.fl.us/samh/index.shtml>

United Cerebral Palsy (UCP)

UCP educates, advocates, and provides support services to people with cerebral palsy and other disabilities.
1660 L Street NW, Suite 700
Washington, DC 20036
1-800-872-5827 / 1-202-776-0406
<http://www.ucp.org/> (follow link for Florida Affiliates)

U.S. Department of Justice

This agency provides information on the Americans with Disabilities Act.
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Rights Section - NYA
Washington, D.C. 20530
1-800-514-0301 (voice)
1-800-514-0383 (TTY)
www.ada.gov

Volunteer Florida

The Elliot Building
401 South Monroe Street
Tallahassee, FL 32301
1-850-921-5172 (This is not a toll-free number)
<http://www.volunteerflorida.org/disability/index.html>

Workforce Florida, Inc.

1580 Waldo Palmer Lane, Suite 1
Tallahassee, FL 32308
1-850-921-1119
TTY (via the Florida Relay Service) 711
<http://www.workforceflorida.com>



Designation of Health Care Surrogate

Name: _____

In the event that I have been determined to be incapacitated to provide informed consent for medical treatment and surgical and diagnostic procedures, I wish to designate as my surrogate for health care decisions:

Name _____

Street Address _____

City _____ State _____

Phone _____ Phone: _____

If my surrogate is unwilling or unable to perform his or her duties, I wish to designate as my alternate surrogate:

Name _____

Street Address _____

City _____ State _____

Phone _____ Phone: _____

I fully understand that this designation will permit my designee to make health care decisions and to provide, withhold, or withdraw consent on my behalf; or apply for public benefits to defray the cost of health care; and to authorize my admission to or transfer from a health care facility. Additional instructions (optional):

I further affirm that this designation is not being made as a condition of treatment or admission to a health care facility. I will notify and send a copy of this document to the following persons other than my surrogate, so they may know who my surrogate is.

Name _____

Name _____

Signed _____

Date _____

Witnesses

1. _____

2. _____

At least one witness must not be a husband or wife or a blood relative of the principal.

Declaration of Medical Proxy

Under Florida Statute 765.401, a medical proxy can be appointed to make health care decisions for an "incapacitated or developmentally disabled patient" if there is no executed advance directive, if there is no designated surrogate or alternate surrogate to execute an advance directive, or if the designated or alternate surrogate is no longer available to make health care decisions.

Health care decision means providing informed consent, refusal of consent or withdrawal of consent to any and all health care; decisions concerning private, public, government, or veteran's benefits to defray the cost of health care and the right of access to all records of the principal reasonably necessary for a medical proxy to make decisions involving health care. Health care decisions may be made for the patient by any of the following individuals, in the following order of priority, if no individual in a prior class is reasonably available, willing, or competent to act. Please check the appropriate proxy category you are signing under:

- A court appointed guardian or guardian advocate;
- The patient's spouse;
- An adult child of the patient or the majority thereof;
- A parent of the patient;
- An adult sibling of the patient or the majority thereof;
- An adult relative of the patient who has exhibited special care and concern for the patient;
- A close friend of the patient; or
- A licensed clinical social worker or a clinical social worker who is a graduate of a court-approved guardianship program selected by a bioethics committee.

The patient's attending physician should evaluate the patient's capacity and if the physician concludes the patient has capacity to make health care decisions, the attending physician should enter that evaluation in the patient's record. If the attending physician questions capacity, a second physician can also be consulted.

I, _____, medical proxy, confirm that the above conditions have been met for the patient, _____, and that there are no available surrogates to be considered from a prior class according to this statute. Therefore, I accept the designation of Medical Proxy for the patient named above. I agree to make health care decisions based upon what I reasonably believe the patient would make under the circumstances. I accept the responsibilities of Medical Proxy as authorized under Florida Statute 765.401.

Medical Proxy Signature

Date

STATE OF FLORIDA COUNTY OF _____

Sworn to (or affirmed) and subscribed before me this ____ day of _____, _____,
by _____

Notary Public Signature

Print, Type or Stamp Commissioned Name of Notary

Personally Known _____ OR Produced Identification _____
Type of Identification Produced _____

SECTION 3:

PERSONAL INFORMATION SUMMARY

Personal Information Summary

For: _____

Prepared By: _____

Date Last Completed: _____

Section A. Person's Information

Directions: Write information about the person with a disability. Provide as much detail as possible.

Full Legal Name _____ Nickname or Aliases _____

Current Mailing Address _____

Current Physical Address _____

Home Telephone Number _____ Work Telephone Number _____

Mobile Telephone Number _____ Email Address _____

Gender _____ Race _____ Height _____ Weight _____ Eye Color _____

Hair Color _____ Primary Spoken Language _____

Date of Birth _____ City and State of Birth _____

U.S. Citizenship Status _____

Religious Affiliation _____

Driver's License No. (or State Identification No.) _____

Social Security No.: _____

Marital Status _____ Spouse's Legal Name _____

Voting

Registered to Vote (Yes / No) Date Registered _____

Registered Selective Service (Yes / No) _____

Religious Affiliation

Regularly attends religious services (Yes / No)

These services are held at _____

Address _____

Phone _____

Usually attends on _____ (Day) _____ AM _____ PM

Is a member (Yes / No)

Requires assistance to attend (Yes / No)

Attends church related activities _____

Education

School Records

Last school attended _____

Name _____ Phone Number _____

Address _____

Classes: Regular Diploma Track (Yes / No)

Special Diploma Track (Yes / No)

Other Special Program _____

Relationship with peers (Excellent / Good / Fair / Poor)

Learning Style

Adapts to new situation easily (Yes / No)

Becomes upset/agitated in new situation (Yes / No)

Becomes destructive or self abusive when agitated (Yes / No)

Describe behaviors _____

What calms person when agitated? _____

Overly friendly/affectionate to strangers (Yes / No)

Has age appropriate manners (Yes / No)

Section B. Residential History/Plans

Describe the type of home or residence where the person has lived in the past, where he lives now, and how he would like to live in the future.

Currently lives in _____
(Own Apartment, Shared Home/Apartment, Family Home, Assisted Living Facility, Foster Home, Group Home, IDF/DD, Residential Habilitation Center, Skilled Nursing Home)

Other (describe) _____

Requires the following support services to live there: _____

Lives with _____

Optimal level of supervision required (Low / Medium / High)

Other _____

Monthly cost is _____ Paid by _____

Caregivers with whom the person has lived previously (start with most current):

Name	Address	Reason for Leaving
_____	_____	_____
_____	_____	_____
_____	_____	_____

In the future, the particular type of home the individual prefers is _____
(Own Apartment, Shared Home/Apartment, Family Home, Assisted Living Facility, Foster Home, Group Home, IDF/DD, Residential Habilitation Center, Skilled Nursing Home)

Other (describe) _____

If the person prefers a group setting, preference for number of residents who live there is _____

If the person prefers living with family or friends, arrangements (have/have not) already been made with:

Name	Address	Phone Number
_____	_____	_____
_____	_____	_____
_____	_____	_____

The type of neighborhood preferred is (Urban / Suburban / Rural)

The home should be near (Bus Stop / Grocery Store / Work Place / Hospital / Church / Family Members)

Other _____

Can use this kind of transportation:	Bus	Train	Taxi
With help:	(Yes / No)	(Yes / No)	(Yes / No)

Other _____

Section D. General Health Information

Provide a Brief Summary of Diagnoses and Medical History _____

This section deals with health issues of the person with a disability. First gather all current medications and medical records, past and present. Addresses and phone numbers for health care providers are also needed, so have them handy. Provide as much detail as possible.

Birth Date _____ Age _____ Height _____ Feet _____ Inches

Weight (Average / Overweight / Underweight) _____

Special Diet _____

Blood Type _____ Blood Disorder _____

Name of Physician _____ Phone Number _____

Date of Last Physical _____

Who has person's medical records? Name _____

Address _____ Phone Number _____

Health Insurance

Medicare No. _____ Medicaid No. _____

Private Insurance Co. _____ Plan No. _____

Prescription Plan Provider. _____ Plan No. _____

Other Insurance _____

Does person smoke? (Yes / No) Amount _____

Drinks alcohol? (Yes / No) Amount _____

Use recreational drugs? (Yes / No) Drug Used _____

Frequency _____

Current Physicians

Name	Profession	Phone Number	Date Last Seen
------	------------	--------------	----------------

Primary Physician

Dentist

Optometrist/Ophthalmologist

Specialists and other health care providers (Therapists, Nutritionist, Nurse Practitioner, Psychologist, etc.)

Allergies (Food, Medicine or Substances)

List

When an allergic reaction occurs, this is what happens, and this is what should be done:

Medications

Able to take medication without assistance (Yes / No)

Describe assistance needed or special way required (e.g. crushed, with food, etc)

Knows names of own medications (Yes / No)

Recognizes own medications (Yes / No)

Knows purposes of own medications (Yes / No)

Prescription Medicines

Look at the bottles of medicines now being taken for the following information.

Copy this information on the form provided on the following page.

Remember to update when changes are made to medications.

MEDICATIONS (Prescription and Over-The-Counter)

Name of Medicine	For What Condition	Amount Given (Dosage)/ When & How Often	Side Effects	Doctor's Name/Ph#	Pharmacy Ph#

Other Health Information

Use special equipment, assistive device(s) or consumable medical product(s):

Device/Item	Vendor	Phone#	Method of Payment
-------------	--------	--------	-------------------

Signs own consent forms for health care? (Yes / No) Copies are located at _____

Has signed an advance directive? (Yes / No) Copies are located at _____

Living Will? (Yes /No) Copies are located at _____

Health Care Surrogate Name _____ Copies are located at _____

Do not resuscitate order? (Yes / No) Copies are located at _____

Carries copies in wallet or purse? (Yes / No) *Attach copies with this Personal Information Summary

Has signed an organ/tissue donation card? (Yes / No)

Has been admitted to a hospital within the past five (5) years? (Yes / No)

Reason	Emergency (Yes / No)	Hospital (Location)	Date
--------	----------------------	---------------------	------

Has had any surgical procedures (an operation)?

Reason	Name of Surgeon	Hospital (Location)	Date
--------	-----------------	---------------------	------

Presently receiving physical, occupational therapy or speech?

Type of Therapy	Therapist's Name	How Often	Date Started
-----------------	------------------	-----------	--------------

Presently receiving mental health services?

Type of Services	Physician's Name	How Often	Date Started
------------------	------------------	-----------	--------------

The following activity (such as, being overheated) results in seizures:

Certain activities can cause other problems (such as, ear infections). Activity and problem that results:

List preference for performing health and hygiene routines in special ways:

Task Needed	How Performed
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

List Immunizations:

Name of Immunization	Date	Booster(s) Date
Tetanus and Diptheria	<hr/>	<hr/>
Measles	<hr/>	<hr/>
Hepatitis B	<hr/>	<hr/>
Flu Shot (Influenza)	<hr/>	<hr/>
Pneumonia (pneumonococcus)	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>

Provide any special diet requirements:

Special food preparation:

List functions sometimes requiring assistance:

Life Area			Help Needed
Seeing/Vision	Normal	Normal with Glasses	_____
	Last Eye Exam	_____	_____
	Frequency Required	_____	_____
Hearing	Normal	Normal with Hearing Aid	_____
	Hypersensitive	Impaired	_____
	Deaf		_____
Speech	Normal	Uses Sign Language	_____
	Impaired	Uses Communication Device	_____
Mobility	Normal	Wheelchair	_____
	Special Shoes	Impaired	_____
	Uses Walker	Uses Artificial Limb	_____
	Uses other Orthopedic Devices (List)		_____

Periodic health screenings are an important way to stay healthy. Indicate the most current medical examinations:

Examination	Date	Examination	Date
Mammogram		Dental Checkup	
Vision Check		Blood Pressure Check	
Gynecological Exam, Pap Smear		Annual Physical Checkup	
Hearing Check		Glaucoma (Family history)	
Prostate			

A doctor has recommended that the person have the following special checkups regularly:

Prescribed by	Where Administered	For What Problem	Frequency Required	Duration
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Frequency of bowel movement _____

Problems with constipation (Yes / No) Remedy _____

Problems with urination (Yes / No) Remedy _____

Urinary Infections _____ Frequent Urination _____ Bladder Leakage (Frequency) _____

Section E. Benefits and Services

APD Services

Write information about services received from the Agency for Persons with Disabilities

If APD services not yet received, give date APD application submitted _____

APD District _____ Phone # _____

Support Coordinator Name _____

Support Coordinator Mailing Address _____

Support Coordinator Email Address _____

Support Coordinator Work Telephone Number _____

Support Coordinator Emergency Telephone Number _____

Fax _____

Date of Annual Support Plan _____

Remember to attach support plan to the Personal Information Summary

See Next Page For Table - Name And Service Provided By APD

APD Services

Name Of Service Provided Through APD	Service Provider Name	Mailing Address	Telephone	Email	Fax

Attach cost plan and/or I-Budget.

Section E. Other Programs and Services

Write information about services received from government agencies and community resources.

Description Of Services	Source	Contact Person	Mailing Address	Email Address	Work	Telephone / Fax

Section F. Financial Resources

Income

Please list all financial resources available to the person, such as wages, Social Security income (include name of Social Security program), SNAP/Food Stamps, OSS, interest income.

Source of Income	Income Amount	How Often Received

Banking and Brokerage Accounts

Name of Bank or Brokerage Acct.	Name(s) on Account (Signature Authority)	Acct. Number	Type (Savings, Checking, Brokerage)

Other Assets

Real Estate

Property Value

Personal Property

Property Value

Trusts Where Person Is A Named Beneficiary

Trustee Contact Information

Automobiles

Value

Insurance Policies

Value

Safe Deposit Box

Location

Other

Future Benefits

Is person named as beneficiary of another person's policies or accounts? (Yes / No)

Policy Holder

Name

Address

Phone Number

Insurance Company (Name)

Address

Policy Number

Section G. Decision-Making Assistance

This section describes the financial arrangements that have been made to benefit the person and protect legal rights. Be sure that the names of any financial advisors are included as well as copies of court orders or other legal papers.

Banking Services

Person needs assistance with (circle all that apply):

Banking Paying Bills Making Purchases
Counting Money Recognizing Denominations of Money

List assistance currently in use (such as co-signer on bank account) _____

Power of Attorney

Has this person given a Power of Attorney or Durable Power of Attorney to someone else? (Yes / No)

Name of Attorney-in-Fact _____

Address _____

Phone Number _____

Representative Payee

Has Social Security assigned a representative payee? (Yes / No)

Name and contact information of the representative payee? _____

Living Will

Has the person signed a living will? (Yes / No)

The living will documents are located: _____

Health Care Surrogate Designation/Durable Power of Attorney for HealthCare

Has the person named a Health Care Surrogate or Power of Attorney for Health Care? (Yes / No)

What is the name of the Health Care Surrogate/Power of Attorney for Health Care?

Is there an alternate Health Care Surrogate/Power of Attorney for Health Care? (Yes / No)

What is the name of the alternate Health Care Surrogate/Power of Attorney for Health Care?

Medical Proxy

If the person has no health care advance directive and the person cannot make his or her medical decisions, who can serve as medical proxy? (See Planning Ahead Guide, page 92, for list of order of priority.)

Trust

Name of Trust _____

This trust is: Revocable _____ Special Needs _____ Irrevocable _____

Trustees: Names Address(es) Phone Number(s)

Current _____

Successors _____

Copy of the trust can be found at _____

Guardian Advocacy and Guardianship

A guardian or guardian advocate has been appointed (Yes / No)

Type of guardianship: Plenary Guardian Limited Guardian Guardian Advocate

Date of appointment _____ County _____ State _____

Court Case No. _____

A copy of the guardianship court order is located at _____

Name of Guardian _____ Relationship _____

Address _____ Phone Number _____

Name of Guardian Advocate _____ Relationship _____

Address _____ Phone Number _____

Name of Co-Guardian/ Advocate (if any) _____ Relationship _____

Address _____ Phone Number _____

Name areas for which guardian/guardian advocate must give consent:

Has a standby guardian/guardian advocate been appointed? (Yes / No)

Name _____

Address _____

Name and telephone number of attorney who prepared guardianship:

Section H. Final Arrangements

Last Will and Testament

The Person's Personal Representative named in the will:

Name

Address

Name of Attorney who prepared will: _____ Phone Number _____

Address _____

A copy of the will is located at: _____

The person is named as a beneficiary in other wills (Yes / No)

Testator(s) Name

Address

Phone Number

Copy of this will can be found at _____

Life Insurance Coverage

The person is covered by the following insurance policy:

Type of Policy

Policy Number

Company

Address

Life

Other

Identification cards are with

Name Address Phone Number

Premiums are paid by

Name Address Phone Number

Copies of policy(ies) are with

Name Address Phone Number

Awareness of Death

Have you discussed your own death with the person? (Yes / No)

Have you discussed the person's death with him/her? (Yes / No)

Has the person experienced the death of a loved one? (Yes / No)

Has the person experienced the death of a pet? (Yes / No)

Has the person visited a funeral home? (Yes / No)

Has the person visited a cemetery? (Yes / No)

Have you discussed the person's desires regarding organ or tissue donation? (Yes / No)

What are the person's wishes? _____

Any concerns expressed by the person about end-of-life discussions? _____

List the members of the immediate family who have died during the person's lifetime. Indicate their relationships (uncle, grandmother, etc.), and date when each death occurred.

Relative who Died	Who told about the death	Date of Death	Attended funeral (Yes/No)
-------------------	--------------------------	---------------	---------------------------

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

How did the person grieve these losses? Describe their behaviors.

Did the person ever undergo grief counseling? (Yes / No)

Name others who were close to the person and left either to retire, relocate or for other reasons. List these persons and their relationships.

Name	Relationship	Can be reached at
------	--------------	-------------------

_____	_____	_____
_____	_____	_____
_____	_____	_____

Funeral Arrangements

Person to contact at time of death:

Name	Address	Phone Number	Relationship (Personal, co-worker, neighbor, other)
------	---------	--------------	--

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Funeral and burial arrangements have been made (Yes / No)

If prepaid, policies/contracts can be found _____

Preferred funeral company _____

Address _____ Phone Number _____

BURIAL:

Burial Plot Purchased (Yes / No) Headstone/Marker (Yes / No)

Type of Marker preferred and epitaph _____

Cemetery/Mausoleum Name _____

Address _____ Other _____

CREMATION:

Burial /Interment of Ashes Scattering of Ashes

Ashes are to be scattered at: _____

Memorial Service? (Yes / No) Location _____

Special content of service (Yes / No) Describe _____

Flowers? (Yes / No) Memorial donations can be made to: _____

Songs to be played _____

Invite these persons to the service

Preferred Clergy/Eulogist _____ Phone Number _____

Address _____

Section I. A Day In The Life Of...

A DAY IN THE LIFE OF (Name) _____

Arises at _____ (AM) _____

List morning medications _____

Needs assistance with: Hygiene Dressing Grooming
Prefers (Shower/ Bath) Taken _____ (PM) _____ (AM)

Aids or appliances used to get around include (circle all that apply):

Braces Special Shoes Walker Wheelchair Crutches Positioning Aids
Other _____

Uses: Eyeglasses Contact Lens Hearing Aids
 Telecommunication Devices (TDD) Communication Board

Other Communication Devices _____

Able to eat without help (Yes / No) If No, needs help with _____
 Special Plate Special Utensils Special Cup Straw

Has problems with choking (Yes / No)

Dietary Restrictions:

Is able to drink: Thin Liquids _____
 Thickened Liquids _____

Usually ready to start the day at _____ (AM) By going to _____

Transported by _____

Bedtime Preparation

List bedtime medications _____

List any routine activities performed at bedtime _____

Usual bedtime _____ (PM) Is there a quiet time/meditation (Yes / No) If Yes, describe

Help needed getting to sleep (Yes / No) Describe sleep pattern (how well, how long usually sleeps)

Use of CPAP or BPAP? _____

Safety Precautions

Can the person be left unsupervised? (Yes / No)

For how long? _____ (Minutes) _____ (Hours) _____ (Days)

Recognizes danger of (circle all that apply): Heat Sources Poisonous Materials
 Electricity Open Windows Sharp Objects Water Traffic Strangers

Can evacuate building on hearing alarm? (Yes / No)

Needs physical/verbal prompt to evacuate building? (Yes / No)

Likes and Dislikes

Favorite People to live with:

Name	Address	Phone Number
_____	_____	_____
_____	_____	_____
_____	_____	_____

Favorite People to spend time with:

Name	Address	Phone Number
_____	_____	_____
_____	_____	_____
_____	_____	_____

Favorite Pets:

Name	Type
_____	_____
_____	_____

Favorite Color _____

Favorite clothing or possessions:

Clothing	Possessions
_____	_____
_____	_____
_____	_____

A DAY IN THE LIFE OF (Name) _____ (cont.)

Favorite foods, drinks, restaurants:

Foods

Drinks

Restaurants

Recipe for favorite food may be found _____

Favorite recreation

TV Shows

Movies

Music

Sports

Hobbies

Others

When is the person most happy? _____

Dislikes living with _____

Dislikes spending time with _____

Disliked pets

Name

Type

Disliked clothing/possessions

Clothing

Possessions

Disliked recreation

TV Shows

Movies

Music

Sports

Hobbies

Others

A DAY IN THE LIFE OF (Name) _____ **(cont.)**

Do violent or sexually suggestive TV, movies, music, sports activities lead to behavior problems? (Yes / No)

When has the person been most unhappy?

Fears and Phobias

Afraid of	Strange People	Enclosed Spaces	Buses	Animals
	Open Spaces	Loud Noises	Heights	The Dark
	Cars	Other _____		

Comments

Special Occasions

Special dates usually observed _____

Holidays observed _____

Recognizes the special dates of others:

Name	Occasions	Date
_____	_____	_____
_____	_____	_____

Usually buys cards (Yes / No)

Attends Party (Yes / No)

Usually buys gifts (Yes / No)

Price Range \$ _____ - \$ _____

Social and Recreational Activities

Activities enjoyed:	Arts&Crafts	Fishing	Visiting Neighbors
Senior Center Activities	Community Outings	A Hobby	Sporting Activities
Movies/Concerts	Going to Recreation Parks	Specialized Camps	Shopping

Other _____

Describe current social and recreational activities: _____

Vacations and Travel

Travel Enjoyed (circle all that apply): Specialized Camps Group Day Trips
Going on Vacation Visiting Family/Friends
Other _____

Travel Enjoyed by (circle all that apply): Car Bus Train
Plane Boat/Ship

Usual travel companion is _____

Favorite vacation destinations _____

Frequency of trips _____ Planned by _____

Unpleasant vacation experiences in the past _____

Has spending money for vacation? (Yes / No) Amt. range \$ _____ - \$ _____

Section J. Key Family and Friends

Spouse's Information

Directions: Write information about the person with a disability's spouse.

Spouse's Legal Name _____

Address, if different than the person's: _____

Date of Birth: _____

Telephone: Home _____ Work _____ Mobile _____

Email Address _____

Citizen Status _____

Social Security No. _____ Medicare No. _____

Military Status and Date of Discharge, if applicable _____

Date of Marriage _____ Date of Divorce _____

Parents Information

Directions: Write information about the person with a disability's parents.

Mother's Legal Name _____

Mother's Maiden Name _____ Name at time of Person's Birth _____

Mother's Date of Birth _____ Mother's Place of Birth _____

Mother's Current Address _____

Mother's Current Home Telephone Number _____

Work Telephone Number _____ Mobile Telephone Number _____

Mother's Email Address _____

Mother's U.S. Citizenship Status _____

Mother's Social Security Number _____ Mother's Medicare Number _____

Mother's Military Status and Date of Discharge, if applicable _____

If Deceased, Date and Place _____

Date of Marriage _____ Date of Divorce _____

Date Retired _____ Source of Any Retirement Benefits _____

Mother's Blood Type _____

Current primary caregiver (yes or no) _____

Father's Legal Name _____

Father's Date of Birth _____ Father's Place of Birth _____

Father's Current Address _____

Father's Current Home Telephone Number _____

Work Telephone Number _____ Mobile Telephone Number _____

Father's Email Address _____

Father's U.S. Citizenship Status _____

Father's Social Security Number _____ Father's Medicare Number _____

Father's Military Status and Date of Discharge, if applicable _____

If Deceased, Date and Place _____

Date of Marriage _____ Date of Divorce _____

Date Retired _____ Source of Any Retirement Benefits _____

Father's Blood Type _____

Current primary caregiver (yes or no) _____

Other Important Individuals

List relatives who are emotionally closest to the person:

Name	Address	Phone No.	Email	Relationship
------	---------	-----------	-------	--------------

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

List other relatives who know and care about the family member:

Name	Address	Phone No.	Email	Relationship
------	---------	-----------	-------	--------------

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

List special friends who are well known and liked by the person:

Name	Address	Phone No.	Email	Relationship/Length of Relationship <small>(Personal, co-worker, neighbor, other/ years)</small>
------	---------	-----------	-------	---

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

The following individual(s) has at times been an advocate helping get needed services and supports:

Name	Address	Phone No.	Email	Relationship <small>(Personal, co-worker, neighbor, other)</small>
------	---------	-----------	-------	---

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Has a circle of friends (Organized Social Group) (Yes / No)

Name of organized social group _____

Contact person _____

Address _____

Phone Number _____

Frequency of Meetings _____ Weekly _____ Monthly _____ Other

Other _____

EXHIBIT H- Consumers

CONSUMER SATISFACTION SURVEY

The Federal Developmental Disabilities Act of 2000 requires all Developmental Disabilities Councils to report on customer satisfaction with Council-supported activities. The information that you are providing in this survey will be incorporated into an annual report that is submitted to the Administration on Developmental Disabilities. We value your appraisal of this activity. Your reply is important. Please complete the information below and return it to the Provider or mail it to: Florida Developmental Disabilities Council, 124 Marriott Drive, Suite 203, Tallahassee, Florida 32301

Activity: Planning Ahead Guide: 4th Edition

Check the category that best describes you:

- Individual with a disability Family member Public policy maker
 Member of Community Organization or Association
 Representative of Public Agency or Private Agency

Name of city where you live: _____

Please check the box that best reflects your opinion of this activity.

I Consumer Satisfaction with Council Activities

STATEMENT	YES	NO
Respect: I (or my family member) was treated with respect during project activity.	<input type="checkbox"/>	<input type="checkbox"/>
Choice: I (or my family member) have more choice and control as a result of project activity.	<input type="checkbox"/>	<input type="checkbox"/>
Community: I (or my family member) can do more things in my community as a result of this project.	<input type="checkbox"/>	<input type="checkbox"/>
Rights: Because of this project activity, I (or my family member) know my rights.	<input type="checkbox"/>	<input type="checkbox"/>
Safe: I (or my family member) am more able to be safe and protect myself from harm as a result of this activity.	<input type="checkbox"/>	<input type="checkbox"/>

STATEMENT	Strongly Agree	Agree	Disagree	Strongly Disagree
Satisfied: I am satisfied with project activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Better Life: My life is better because of project activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

II. What has been helpful or not helpful about this project activity?

(Fold)

STAMP

Florida Developmental Disabilities Council, Inc.
124 Marriott Drive, Suite 203
Tallahassee, Florida 32301

(Fold)





Florida
Developmental
Disabilities
Council, Inc.



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