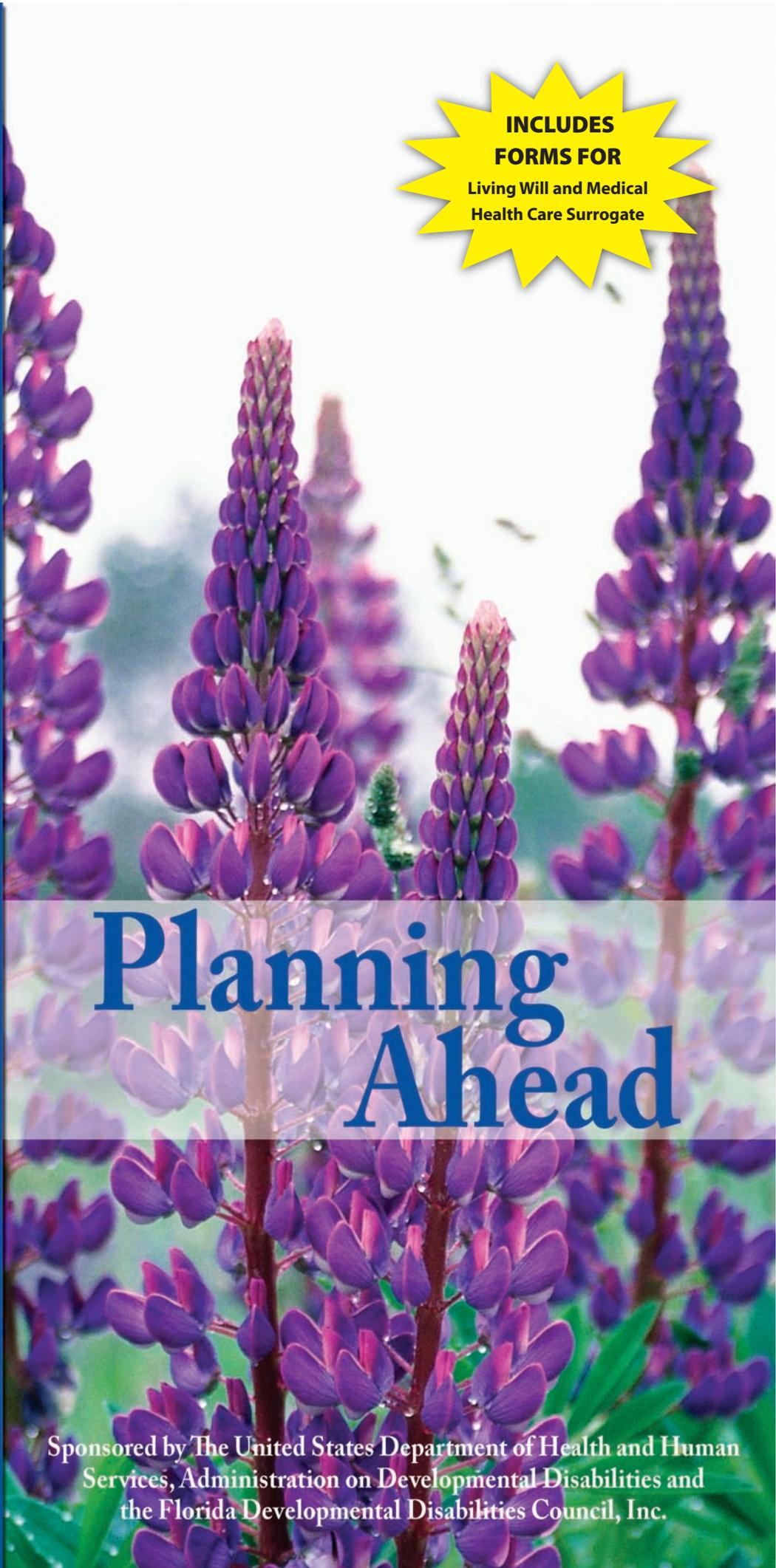




Florida Developmental
Disabilities Council, Inc.



**INCLUDES
FORMS FOR**
Living Will and Medical
Health Care Surrogate



Planning Ahead

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



SPECIAL ACKNOWLEDGEMENT

*T*he Florida Developmental Disabilities Council dedicates this handbook to the memory of Janice Tully. Janice worked for many years on grants from the Council to the Department of Children and Families, Developmental Disabilities Program. She had a natural ability to organize many people and much information and could make it look so easy. Her work is reflected in this document, and although she left us before it was finished, we think she would approve. All of us who knew and worked with Janice miss her unique talents and tender ways. It seems fitting to dedicate, to her memory, information to help organize your life to ensure your loved one's needs are addressed, as she was the most dependable, caring and organized individual most of us ever encountered. We miss her deeply.

Acknowledgements

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Adult Services

Economic Self-Sufficiency

Family Safety and Preservation

Mental Health

Substance Abuse

Department of Education/Vocational Rehabilitation

Department of Elder Affairs

Department of Health

Florida Protection and Advocacy Center

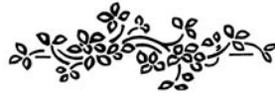
Long Term Care Ombudsman Council

Tallahassee Office of the Social Security Administration



A very special thanks is extended to the individuals, family members, advocates, support coordinators, and providers of services who gave us your time in reviewing the handbook. Your suggestions truly helped us in providing needed improvements so all users can be more fully empowered when navigating the vast array of systems and practices they face.

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SECTION 1

THE HANDBOOK



Developmental Disabilities Council, Inc.

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Administration on Developmental Disabilities and the Florida Developmental Disabilities Council, Inc.

CHAPTER ONE



Getting Started

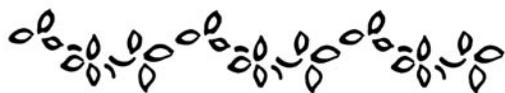
*W*hen children are very young it is simple to leave instructions for the babysitter to follow. For parents of a child with a disability, it is natural to continue this as the child grows. However, as this child reaches adulthood, while leaving instructions may continue, it is often difficult to plan ahead to a time when we will not be available to leave the list of “do’s and don’ts” or “likes and dislikes.” We even find it difficult to plan ahead for the time when we will no longer be here – who will inherit what, where we want to be buried, etc. This planning ahead is even more critical when there is a child with a disability in the family who will grow up continuing to possibly need supervision and support in a few or many areas of their life. It becomes very important to commit to writing what we would like the future to be, to leave a verbal picture for new supports and caregivers.

Planning ahead today is quite different from anything that could have been imagined twenty years ago. We would never have believed that so many persons with disabilities could be making many of their own choices, living in the community, owning their own homes, holding regular jobs, establishing and working toward their own goals. As you study the handbook and complete the **Personal Information Summary** with your family member, keep these thoughts in mind so that whatever plan you believe is best now won’t prevent that person from moving forward far beyond present expectations. Words you will be hearing often, and four primary principles to remember are:

Inclusion – People with disabilities are no longer separated from those who are not disabled. They participate and interact with others in the community just as you and I do. Inclusion also includes addressing cultural diversity.

Self Determination – People with disabilities take control of their own lives, make choices and exercise their rights.

Person-centered Approaches & Planning – The focus of planning is done by and with the individual. The planning process must be geared to the individual’s particular desires and personal wishes. Planning is on-going and responds to the needs of the individual and respects their personal choices. Person Centered Planning is not a quick solution or just a written document to address problems – it is a consistent and on-going approach to support the individual



in realizing goals and outcomes he has set for himself and responds as goals and outcomes change. A few areas to think about when planning with the individual:

- Honoring the individual's voice and vision of what he wants his life and future to look like and supporting him to realize his vision
- Respecting diverse ways of communication;
- Insuring that a variety of natural and community supports are present to provide a solid foundation for the individual including spiritual, civic and other community alliances, and that family, friends and other connections are nurtured;
- Providing meaningful and stimulating opportunities through work, where one lives and leisure opportunities;
- Providing information and resources including educating the individual about options and opportunities so he can choose and experience a wide variety of what life has to offer;
- Respecting the individual's right as a citizen and as a human to enjoy a fulfilling, safe and healthy life;
- Providing supports and security in the form of financial, health, freedom from abuse, neglect and exploitation and in making plans for their future.

If guardianship is present in the individual's life, insure that the guardianship is a support to the individual in realizing his preferences and choices. In addition, guardianship at any level should be frequently reviewed to determine if it is still needed and, if not, to ensure action is taken to restore rights as needs and situations change.

Personal Outcomes – Services and supports provided should be based on the personal outcomes desired by each individual to improve that individual's quality of life. A listing of "My Personal Outcomes" can be found in the Helpful Attachments section of this handbook and additional information is located at www.thecouncil.org.

THE PRINCIPLES OF SELF DETERMINATION

The Principles of Self Determination and movement are founded on four basic American principles:

Freedom – the exercise of the same rights as all citizens. People with disabilities, with assistance when necessary, will establish where they want to live, with whom they want to live and how their time will be occupied. They do not have to trade their inalienable rights guaranteed under the Constitution for supports or services.

Authority – the control over whatever sums of money are needed for one's own support, including the re-prioritizing of these dollars when necessary. This is accomplished through the development of an individual budget that "moves" with the person.

Support – the organization of these 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 companionship for support and contract for any number of discrete tasks for which they need assistance.



Responsibility – the wise use of public dollars. Dollars are now being used as an investment in a person’s life and not handled as resources to purchase services or slots. Responsibility includes the ordinary obligations of American citizens and allows individuals to contribute to their communities in meaningful ways.

It is critical to think of these and many other values when completing the **Personal Information Summary** and when addressing decision-making needs. Focus should always be on individuals’ abilities rather than disabilities and the least restrictive alternatives to guardianship. Guardianship can be a very expensive legal process. In the past it has been viewed as a means to “protect” the individual, but recent thought and practice focuses on the least restrictive means of providing assistance with decision-making. Far too often a full guardianship is sought to solve a single issue or problem that could have been addressed in a much simpler and appropriate fashion through alternative decision-making methods. These alternatives are also typically much less expensive. In the **Helpful Attachments** section you will find a chart that provides guidance to individuals and their family members to assist in determining if and what areas the individual may need assistance with decision-making. Chapter 8 also provides more information on decision-making options and guardianship.

Currently in Florida the Southern Movement for Independence is leading efforts to build a strong self-determination foundation for self advocates. More information on this movement can be obtained by contacting the Florida Developmental Disabilities Council or by going to their website at www.fddc.org. Readers can find links at this site to self-advocacy and other critical information.

Planning Ahead is divided into three sections:

1. The Handbook
2. The Personal Information Summary for Your Family Member
3. Helpful Attachments

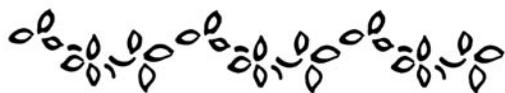
SECTION 1

THE HANDBOOK

*T*he Handbook section of this guidebook contains eleven chapters. It is designed to provide you with information that will help you identify and plan for everything that should be written in the **Personal Information Summary** section. Work through this summary one area at a time. If you can’t decide about a certain part, go on to the next part and come back later to the uncompleted information.

The Handbook will:

- Guide you through the process of thinking through everything that should be included, and how you might go about making these decisions;
- Help you understand how the service delivery system works, and how you can make the system work for you;



- Identify agencies and organizations in the State of Florida that provide services to persons with developmental disabilities; and
- Provide you with options from which to choose.

Reference to the individual with the disability may reflect “him” without intending to specify gender.

SECTION 2

THE PERSONAL INFORMATION SUMMARY

*T*he **Personal Information Summary** is an evolving long-term plan that will provide direction regarding the quality of life desired by your family member and you. Those who survive you will then have guidance regarding how to reach and maintain this quality of life. It will require ongoing review and revision, as resources and ideas of supports change. It will take some time on your part, and it will require you to keep in mind that as things change for you, the long range plans for your family member must be reviewed and updated also.

The **Personal Information Summary** is prepared by and with your family member and gives a roadmap for all the things others may need to know when you are no longer around. Although it seems to be very long, it will make the task of assembling all the necessary information easier. Do not try to complete it all at once. Start with the personal things that you know very well but others would not know. Before you know it, you will have made a good start on identifying and providing a framework of the things that are necessary to insure the continuity of a meaningful life after you are no longer around.

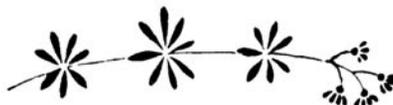
The summary will give you an organized and comprehensive format in which to identify decisions you and your family member make about the future. Attached to it should be photographs and a current copy of the latest Support and Cost Plans (the Agency for Persons with Disabilities’ documents that authorize services). It should be stored in a safe place and used as you work with others who are planning with and providing services to your family member.

SECTION 3

HELPFUL ATTACHMENTS

*I*ncluded in the handbook are a number of important attachments that relate back to information provided in the handbook as well as additional information you may find helpful.

CHAPTER TWO



Preparing Yourself and Others

*W*hat will the quality of life be for your family member when you are gone? Start by making a list of those things that matter — perhaps things you have never thought of as needing long-range planning. Here's a list for starters:

- Type of care and supervision needed
- Who will help/make necessary decisions
- Type of residence, including the neighborhood in which he will live
- Type of employment/daily activities
- Quality of life/leisure time activities
- How all needs will be provided/financed

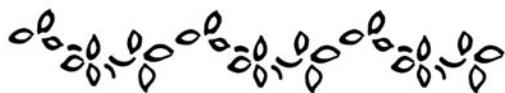
Who Should Plan?

Not only the individual's parents but the entire family and friends should be involved in planning for the future, and thinking about what the role of each might be in the life of the person with the disability.

Why Should We Plan?

To make available the elements necessary to achieve the quality of life desired for and by the individual.

To insure that the individual has the opportunity to fully participate in and direct the decision-making regarding where to live or work, how to use free time, and who will provide the support and services needed to achieve these and other desired goals.



TO BE SURE YOU HAVE ACCESSED ALL AVAILABLE BENEFITS.

Who Can Help Us Do This?

Local advocacy groups, service providers, case managers and friends will be invaluable in helping you and your family member identify and plan for the future. Your attorney is another important consideration, and should be one who is knowledgeable of laws relating to persons with disabilities. This person should also be familiar with the **principles of self-determination**.

When Should We Plan?

As soon as possible and continually thereafter. Do not try to get everything done at once. Get started, work gradually through each section, review frequently, and revise the plan as needed. Set a specific time for your family member and you to review and update the **Personal Information Summary**. It might be a birthday, a holiday when family and friends are together, or a time designated to **JUST DO IT!**

TRANSITION

There are four transitional points that are significant in any person's life, but which will have a more significant impact on a person with a developmental disability. These are:

1. **Reaching the age of majority.** In Florida this is age 18 when one becomes an adult and the natural parent has no legal right to speak for the person.
2. **Changing vocational status,** whether from school to job, job to school or from one job to another.
3. **Changing place of residence** – from home to a supervised living environment with new people, or on your own in an independent living situation with one or two roommates.
4. **Changing primary caregiver,** which may have great emotional impact on the person needing a caregiver.

You can anticipate and usually plan ahead for the first three points. Sometimes you can plan ahead or believe you have planned ahead for the future primary caregiver but this may not always be the case. Since this may be the most traumatic and sometimes unexpected, be sure you have covered all the bases. When selecting a future primary caregiver, be sure to:

Discuss this with the individual with the disability. Be sure your choice of primary caregiver is also the choice of your family member with the disability. Remember that this person could be involved in many aspects of the individual's life and it should be someone who understands the individual's likes and dislikes and can comfortably communicate with the individual.

Discuss this with the potential future primary caregiver. Specifically discuss care-giving responsibilities. Be sure this person understands the wishes and goals of you and your family member, and is willing to pursue these same goals, or to communicate with the family member when changes are necessary and will try to reach mutual agreement whenever possible. Discuss especially the long-term commitment required of a caregiver, the need to spend time together with other family



members, and whether the potential caregiver understands and is willing to make this commitment.

Obtain agreement from both the individual and the future primary caregiver.

THEN...

Communicate by writing the name of the future primary caregiver(s) in easily accessible documents. Inform all family members and others who are important to your family member, advising them who will be the primary caregiver, and what that person's responsibilities will include.

Be sure the name, current address and telephone number of the future primary caregiver are written:

- In the **Personal Information Summary**
- In the Letter of Intent (should be attached to your Will),
- In the order for a standby guardian (when guardianship is appropriate),
- In the individual's central record in the Agency for Persons with Disabilities and with the support coordinator,
- With the attorney and/or anyone who has a copy of your will, guardianship and other important papers.

Who's in Charge?

Be sure primary caregivers are familiar with WHO is responsible for WHAT and understand their specific roles. Make certain these roles and responsibilities are delineated and written in the Personal Information Summary.

REMINDER: NOW LOOK AT THE PERSONAL INFORMATION SUMMARY ON PAGE 55 AND FILL IN THE NEW INFORMATION.

CHAPTER THREE



Using Government Benefits

Being able to maximize the use of governmental agencies that provide benefits is critical for individuals with disabilities. Some agencies are federal, others are state but funded by federal monies, some are state funded, and others may be local or private agencies available only in your community.

SOCIAL SECURITY

Most of us, sometime in our lives, will receive government benefits from our federal government. Individuals with disabilities usually receive them earlier than others, perhaps all of their lives. Several of these programs are accessed through the Social Security Administration.

Retirement Benefits: The most familiar program is Social Security, which we look to for retirement benefits. This is for persons who have been employed and are now ready to retire. The usual age of retirement is 65, with reduced benefits available if you wish to retire as early as age 62. At the present time the age at which a person receives full benefits (age 65) is gradually going up until by the year 2007 one must be age 67 in order to receive full benefits, but this may change. A person must have worked at least 40 quarters to qualify. (Each year is divided into quarters.)

Disability Benefits: A disability benefit is not usually the type of Social Security benefit received by persons with developmental disabilities. Social security provides disability benefits to persons who have worked but became disabled before reaching age 65 and are unable to continue working before reaching age 65. To be eligible for disability benefits they must have worked a certain number of years but for some reason became disabled (that is, had a severe mental or physical condition that prevents them from continuing to work). These benefits can continue as long as the person is unable to work.

Dependents: When a worker receives Social Security benefits either through retirement or disability, spouses age 62 or older and minor children as well as children 18 or older who are severely disabled may also receive benefits on the parent's Social Security record.



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

- A widow/widower age 60 or older
- A widow/widower age 50 or older and disabled
- A widow/widower caring for a child under age 16 or a disabled child
- An unmarried child
- A disabled child of any age who was disabled before age 22 and remains disabled
- Parents who were dependent upon the deceased for at least half of their support

The amount of money each person will receive is dependent upon how much income the wage earner has received from employment over his working lifetime. To learn how much you and your dependent would receive, call the Social Security Administration at 1-800-772-1213 and ask for a form called "Request for Earnings and Benefits Statement." Within approximately six weeks they will advise you what your estimated benefits will be.

SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income (SSI) is another federal program but is based upon a person's financial need. It pays monthly checks to persons who are 65 or older, blind, or have a disability, and who meet the financial eligibility test for resources and income. It is also available to children who are blind or disabled. Persons who get SSI are also eligible for Medicaid (a health insurance program) and often are eligible for other federal programs such as food stamps.

The basic amount paid for SSI is the same nationwide, but some states add money for certain things to the basic amount. The Social Security office advises about these supplements when a person applies for SSI.

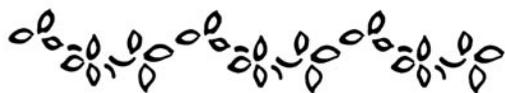
Persons may be able to receive both Social Security benefits and SSI if the amount of their Social Security benefits is smaller than the maximum amount that they would be entitled to receive under SSI.

SSI eligibility depends on a person's age, blindness or disability, the value of property or assets owned and income the person has from any source.

Disabled (the same as with Social Security benefits) means that a person has physical or mental problems that prevent him or her from working and the disability is expected to last at least a year or to result in death.

Income means money obtained from wages, Social Security checks, pensions or any items received such as food, clothing or shelter. However, currently certain things are not counted:

- The first \$20 of income per month
- The first \$65 per month earned from working and half the amount over \$65
- Food stamps
- Most food, clothing or shelter you get from private nonprofit organizations
- Most home energy assistance



Property or assets mean real estate, certain personal belongings, bank accounts, cash, stocks and bonds. To be eligible for SSI, these items cannot total in value over \$2,000.

As laws and policies change often, make certain you determine if there are additional options for asset accumulation that the Social Security Administration has approved. You can check with your local Social Security office.

Things that do NOT count:

- The home the person owns (if he lives in it) and the land it is on;
- Personal and household goods, and life insurance policies, depending on their value;
- One car;
- Burial plots;
- Up to \$1500 in burial funds for the person and up to \$1500 for a spouse;
- If blind or disabled, some things necessary (such as uniforms) if the person plans to work.

Rules Relating to Employment: If you are disabled and plan to work, special rules may apply. Be sure to consult with the Social Security administration regarding your plans. **Failure to do this could result in the loss of your benefits.**

How to Sign Up: Contact your local Social Security Office, or call 1-800-772-1213 for an appointment with a Social Security representative who will help you. (Although Supplemental Security Income [SSI] is different from Social Security Benefits, it is handled by the same office.) When a person with a disability reaches the age of 18, he needs to be certain to apply for SSI.

What to Have with you:

- Social Security card or a record of the Social Security number;
- Birth certificate or other proof of age;
- Information about residence—including mortgage or lease, and landlord's name;
- Payroll slips, bank books, insurance policies, car registration, burial fund records and any other information about income and things owned;
- If disabled, the names, addresses and telephone numbers of doctors, hospitals and clinics that have been seen.

Payments: After application is made, SSI benefit payments begin the sixth month after Social Security determines the person disabled.

Appeals: If a person is denied eligibility for SSI or Social Security benefits, an appeal process is available. Instructions for filing this appeal are on the back of the notice of denial received. If benefits are denied and you believe the person is eligible, consult with an advocate, friend, or attorney and seek help in filing an appeal. You may contact your local county bar association for a listing of attorneys who will accept SSI appeals on a contingency basis. To learn more about the appeals process ask any Social Security office for the fact sheet **The Appeals Process** (Publication No. 05-10041). You should also ask for the fact sheet **Your Right to Representation** (Publication No. 05-10075), as the person has a right to be represented by a qualified person of your choice.



MEDICAL INSURANCE

There are two medical insurance programs that are government funded. These are Medicare and Medicaid. Even though they are both federally funded, and some of the services provided and the people served are the same, the programs and purposes are different.

Medicare: Medicare is a federal health insurance program for persons age 65 or older, and for persons who have a disability. 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, that office will help you also enroll in the Medicare program. A disabled person must have been disabled for two years before becoming eligible for Medicare. If there is proof that the person has been disabled for two years, be sure to show this to the Social Security representative.

Medicare is divided into two parts: Hospital Insurance (Part A) and Medical Insurance (Part B).

Hospital Insurance (referred to as “Part A”) pays for hospital care. Everyone receiving Medicare is enrolled in this part. There is no charge or monthly premium for Part A coverage. It covers all hospital services for the first sixty (60) days, except for an annual “deductible” which requires you to pay a certain amount of the bill first, before Medicare begins payment. After sixty (60) days in the hospital, you must pay a daily coinsurance amount which varies depending on the length of the hospital stay. This coverage is for up to one hundred fifty (150) days for each hospital stay. Other services also included in hospital insurance are such services as time limited skilled nursing care, home health care and hospice care.

Medical Insurance (referred to as “Part B”) pays for doctors’ services and many other services such as outpatient hospital care, laboratory tests and X-rays. Recent legislative changes in Medicare include Drug Discount Cards for participants in Medicare Part B. There are several types of cards available and each type of card provides a different level of discount on the price of medications. Additional changes to Part B are planned in future years. If you choose to participate in Part B you are required to pay a monthly premium. This insurance premium is usually deducted from your retirement or disability Social Security benefits. Medical insurance requires that you pay a “deductible” each year. This is the part of your medical bills that you must pay before Medicare begins paying. After you have “met the deductible,” Medicare usually pays eighty (80) percent of the approved charges for covered services for the remainder of the year.

Medicaid: This is a federal medical insurance program administered by the state. It is designed to help people with low income and little or no resources. It is NOT the same as, nor a part of, Medicare. Although the federal government funds a portion of Medicaid, each state pays a portion of the cost, and sets its own rules as to who is eligible for this health insurance and what services will be covered.

Medicaid pays for prescribed medications within certain limits. Services for children under 18 are more inclusive than services for adults. The Social Security Administration can explain the differences.

A person may be eligible for both Medicare and Medicaid. In this case, in the State of Florida, Medicaid will pay the premiums and deductibles required under Medicare.



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

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. You may be eligible for only one, or two, or maybe ALL FOUR. The Social Security office can advise you which you are eligible to receive.

OTHER AGENCIES SERVING PERSONS WITH DEVELOPMENTAL DISABILITIES

There are many services that are not specialized for people with disabilities but are for the general population. They may be funded by, and services provided through various other departments of state or local government. Many of these services used by all citizens are also useful to persons with developmental disabilities. Some of the programs used by the general population are:

Adult Services Program: This program is in the Department of Children and Families and provides limited in-home support services including: adult day care, adult day health care, case management, chore services, emergency alert/response, escort service, group activity therapy, home delivered meals, home health aide, homemaker, home nursing services, interpreters, medical equipment/supplies, personal care, physical and/or mental examination, transportation and medical therapeutic services. These services are usually provided to individuals who do not receive services from other specialized sources, such as the Agency for Persons with Disabilities. However, some persons with developmental disabilities live in homes licensed as an Adult Living Facility if the home best meets those persons needs.

Food Stamp Program: The Food Stamp Program is a federally funded program that provides food stamps that may be used like cash to purchase food. Certain items are excluded, such as candy, sodas and paper goods. People who have a low income are eligible for assistance. In most cases, people who receive SSI would be eligible. The Food Stamp Program is in the Department of Children and Families, Office of Economic Self-Sufficiency.

The Substance Abuse Program and Mental Health Program: The Substance Abuse Program provides help to people who abuse alcohol or other drugs. The Mental Health Program provides assistance to people who have mental health problems. If the person with a developmental disability needs either substance abuse or mental health services and is refused by either of these programs the support coordinator or other advocate involvement is essential in accessing these programs to meet the needs of the individual. Both the Substance Abuse Program and Mental Health Program are in the Department of Children and Families.

Housing Assistance: People with low-income are eligible to receive rental assistance from various programs administered by the U. S. Department of Housing and Urban Development (HUD) through local housing authorities. This may be in housing projects which are govern-



ment owned with rent based on income. There is also a program that provides subsidies to persons who rent privately owned property and is referred to as Section 8 housing. This provides assistance when the landlord is willing to participate in the Section 8 program and the place to be rented has been approved by the appropriate local housing authority. In this program a person must be approved for a rental subsidy after which he pays only a portion of the rent (the amount determined based on a percentage of the individual's income) and the housing authority pays the balance of the rent to the landlord. To receive such a subsidy the person must meet the eligibility criteria and the building or apartment to be rented must meet established standards. The landlord cannot charge more rent than the amount that the housing authority has found to be fair in the local area. Individuals are encouraged to make application for Section 8 even if you will be placed on a waiting list. Your local Housing Authority can provide you with additional information. Also, the Department of Community Affairs and the Florida Housing Coalition, Inc. are additional resources to obtain more information on financing options and opportunities for housing for individuals with developmental disabilities.

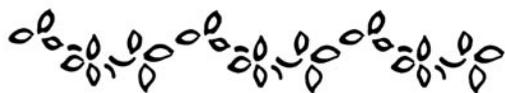
Department of Education: There are two divisions in the Department of Education that provide services available to persons with disabilities.

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.

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 scope of these services may include medical, psychological or vocational assessments, vocational or career planning, counseling to support the exercise of informed choice in the development of the Individual Plan for Employment (IPE) which includes the services required to achieve the person's employment goals. Services will enable students to transition from school to work, and assist eligible adults of working age. If the person has a developmental disability and is a consumer of the Agency for Persons with Disabilities, services from the Division of Vocational Rehabilitation should always be coordinated through the support coordinator.

Local school districts provide a wide range of services for school-age children with developmental disabilities. Every year, each school district must submit a plan to the Department of Education outlining the special programs they plan to provide for exceptional students (this designation includes persons with mental retardation and other developmental disabilities).

Annual funding is provided by the state based on each county's plan. Educational services may be available through public schools and special education classes in hospitals, homes or other non-educational facilities. Districts will sometimes assign special education teachers to preschool and day care programs to work with children with disabilities. The Department of Education may also offer vocational education to individuals with disabilities. To learn more about the educational programs in your area, contact your local county school district office and your Agency for Persons with Disabilities support coordinator.



Department of Elder Affairs: The Department of Elder Affairs is designed to meet the needs of elders, helping them 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. An elderly parent or caregiver may be able to receive services from the Department of Elder Affairs, making it possible to remain in the home with a developmentally disabled person, thus allowing both to remain in their home and community. Both the Department of Elder Affairs and the Agency for Persons with Disabilities may offer many of the same services, and it is possible that a person with a developmental disorder and the caregiver may be receiving like services from different departments, or sometimes one department may be able to provide for both. It is important that the support coordinator be aware of the dual needs so that the two departments can work together to maximize the potential for both the elderly parent or primary caregiver and the person with a developmental disorder.

As the person with a developmental disability becomes older, there may be specialized programs only in the Department of Elder Affairs that can meet certain needs, such as programs dealing with Alzheimer's and dementia. Therefore, it is important that the availability of services in both programs should be considered in order to better meet the consumers' needs and maximize the use of valuable resources.

For assistance please contact the Elder Helpline at 1-800-963-5337 or online at <http://elderaffairs.state.fl.us>.

Department of Health: Each county in Florida has a County Health Department. These programs provide a variety of services that may differ among counties. The Children's Medical Services Program (CMS) in the Department of Health provides early intervention services to high-risk children ages 0-3. Contact your local county health department to learn what health services are available.

REMINDER: NOW REVIEW THE PERSONAL INFORMATION SUMMARY. IS THERE ANY INFORMATION THAT SHOULD BE RECORDED THERE, OR ANY CHANGES MADE? IF SO, NOW IS THE TIME TO IT!!!

CHAPTER FOUR



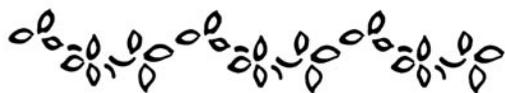
Understanding Florida's Social Service System for Individuals with Developmental Disabilities

Chapter 393, Florida Statutes, is the enabling legislation authorizing services that may be provided to persons with developmental disabilities. These services are administered by the newly formed Agency for Persons with Disabilities. The Agency for Persons with Disabilities is the primary source of state funded services for persons with developmental disabilities. We encourage you to read and become familiar with Chapter 393.

The state is currently divided into geographic areas, with 14 offices located around the state. The current configuration of these areas may change due to the new agency's formation during the 2004 legislative session (check your local phone book or the Agency's website for updated information). This program is funded to provide a comprehensive range of services and allows several options for how services may be obtained. Services may be provided to persons three years of age or older with a diagnosis of retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome. Children who are ages four and five who are at high risk for a developmental disability are also eligible for the program, but in order to keep receiving services after age five, the person must have a specific diagnosis of one of the disabilities listed above. Children with special needs who are birth to age three are served by Children's Medical Services in the Department of Health. Additional eligibility requirements must be met for some services.

APPLICATION FOR SERVICES

For an individual to become a consumer of the Agency for Persons with Disabilities, a written application must be completed. This application for services may be initiated by a phone call from the person needing service, by a parent or guardian, or by visiting a local Agency for Persons with Disabilities Office. The offices are open Monday through Friday from 8:00 a.m. to 5:00 p.m. The application process, called intake, is conducted by the Agency for Persons with Disabilities. Basic information such as name, address, nature of the disability and service needs are recorded.



Be sure to complete the application process even if you are informed there are no funds, nor any services available. The Agency maintains a waitlist for services – get on this waitlist as soon as possible – it is the only way the Legislature can know the true need around the State!

ELIGIBILITY

Eligibility for the program must be determined before any services can be provided. This requires an evaluation to document that the person has a developmental disability designated in Chapter 393, Florida Statutes. This evaluation must have been completed by the appropriate professional before the person is 18 years old. The appropriate professional would be:

- Retardation A psychologist
- Cerebral Palsy..... A physician
- Autism A psychiatrist or psychologist
- Spina Bifida A physician
- Prader-Willi Syndrome..... A physician

These reports may be existing evaluations from health care organizations, educational records or reports from other agencies. If no previous reports are available, the Agency for Persons with Disabilities will obtain the evaluation necessary to determine eligibility. There are other criteria for eligibility for Waivers and other programs administered by the Agency for Persons with Disabilities. Again, check on your status as policies and laws may change. During this process it is important for the applicant to keep all appointments made by the Agency for Persons with Disabilities. If assistance is needed to keep an appointment, be sure to tell the agency staff so they can help the applicant keep appointments.

Once eligible, you should receive a copy of “Navigating the Developmental Disabilities Program – You’re the Driver” (also known as the “Yellow Notebook”) to assist you in traveling through the Agency for Persons with Disabilities and related systems.

SUPPORT COORDINATION

Each person applying for services to the agency is assigned a support coordinator. In addition to conducting intake and determining eligibility, it is the responsibility of the support coordinator to help you and your family member identify service needs, develop support and cost plans, and coordinate service delivery.

Although a support coordinator is assigned when the individual first applies for services, a request for a change can be made if for any reason the individual is not satisfied. Before changing support coordinators, first advise the Agency for Persons with Disabilities so that a smooth transition can be made.

SUPPORT PLANNING

An individualized plan of supports and services that identifies needs, goals and outcomes, interests, and abilities is prepared for each person with a developmental disability. This support plan



identifies the services and supports (generic and paid) needed to meet identified individualized needs. It will be developed by the individual with the disability, the support coordinator and those identified by the individual whom they wish to participate including family, friends and providers of services, just to mention a few.

The support coordinator may need to obtain a great deal of information to supplement that already given. There will probably be several times when it will be necessary to meet together. This is often done in the home, but could be done in the office if you prefer.

All of the information provided will be written into the support plan. This is a plan for one year. It states goals that have been set, and describes the supports and services that will be necessary to reach these goals. This planning will take into account the personal outcomes desired. When this plan is completed, the cost of requested services will be calculated and submitted as the cost plan to the staff of the Agency for Persons with Disabilities for approval.

After the cost plan is approved, the support coordinator will provide you with a copy of both your support plan and approved cost plan so you can interview and select providers to deliver your services. There may be a waiting period, and sometimes exactly what had been requested might not be available. In such instances, the support coordinator may identify available alternatives for consideration.

There is a wide range of services funded from a number of sources, both state and federal, available through the Agency for Persons with Disabilities. Do not hesitate to identify whatever services your family member needs or desires. Funding could be available from various sources and in unique ways.

If a person needs some where to live, this request should be made to the support coordinator who will make any necessary revisions to the support plan, and help find the most appropriate and least restrictive place that can meet the needs of the individual.

The support plan may be revised at any time, but must be reviewed and updated at least annually. When individual needs change the support coordinator should always be contacted immediately.

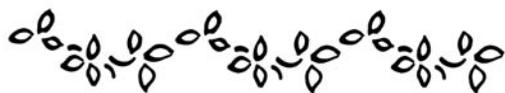
The support coordinator will also know of other federal, state and local agencies that provide services to the general community as well as to elderly persons or those with other disabilities. Thus, the support coordinator may be able to help you combine services from several agencies to meet the specialized needs of various family members if this is necessary to maintain a home for the family member with a disability.

For the most current information about supports and services available through the Agency for Persons with Disabilities you should go to their website (www.apd.myflorida.com) or, if you are already a client, refer to your Yellow Notebook (**Navigating the DD Program: You're the Driver!**).

SUPPORTS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

There are currently two primary funding sources available through the Agency for Persons with Disabilities. They are:

- The Developmental Services Home and Community-Based Services Waiver (DS/HCBS Waiver), and;
- The Family and Supported Living Waiver (FSL Waiver)



Most services provided to persons with developmental disabilities through the Agency for Persons with Disabilities are funded through the Developmental Services Home & Community Based Services Waiver. Under both the DS/HCBS waiver and the FSL waiver, individuals can live within their local communities and are able to choose their support coordinators, as well as the providers for each of their needed services.

Each waiver as well as specific provider qualifications and limitations are fully defined in the Waiver Services Directory. Both the DS/HCBS and FSL waiver have a directory. You can obtain a copy from your local Agency for Persons with Disabilities office or access it from the Internet at <http://apd.myflorida.com>.

The Consumer-Directed Care Plus Waiver and the Florida Freedom Initiative are available to a limited number of people at this time. Hopefully they will be available to more people once the federal government gives the state of Florida approval to expand the programs. The diversity of funding types has grown significantly over the last several years. Consumers and their family members should check the Agency's website or review the Agency's Yellow Notebook to determine what's currently available.

There may also be other services available through alternative funding sources or additional programs from other state agencies and departments.

Examples of other supports include:

- Natural supports through family and friends,
- Community supports such as church programs,
- Other State and Federal programs such as Medicaid State Plan services.

For further information, including information about enrollment requirements for any of these services, contact your local office of the Agency for Persons with Disabilities.

CHAMPS – CITIZEN MONITORING

The intent of the CHAMPS program, "Citizens Helping to Assess, Maintain and Provide Supports," is to provide a feedback mechanism for people who receive services from the Agency for Persons with Disabilities and their family, friends, acquaintances or others. It is designed to aid the Agency, self-advocates, advocate groups, family members, providers, and volunteers to collaborate in partnership to enhance a person-centered quality of life. It establishes a formal communication link between recipients of services, their families and advocates and the Agency for Persons with Disabilities. The program ensures that individuals with developmental disabilities, family members and citizens in the community have an opportunity to express concerns, compliments, promote effective practices, or make suggestions in improving quality of care for those receiving services. CHAMPS is not intended to replace the Florida Abuse Hotline. For more information on this program you can call toll free at 1-800-470-8101 or email www.CHAMPS@dcf.state.fl.us



LEGAL PROTECTIONS

Sometimes things happen in our lives for which we have never planned. One of those could be involvement with the criminal justice system. In addition to the Bill of Rights for Persons With Developmental Disabilities (see Helpful Attachments section), persons with retardation or autism who become involved with the criminal justice system have additional protections under the law. This law is found in Chapter 916, Florida Statutes. If your family member should ever have an encounter with the criminal justice system, make certain that legal representation is provided and that this person is familiar with Chapter 916, Florida Statutes. There are a number of publications available through the Florida DD Council that can be used as resources and guides for legal protection. Also, each area office of the Agency for Persons with Disabilities has a person designated as the “court liaison”. In the event of involvement with the criminal justice system, it is advised that you work closely with this individual in addressing protections under the law.

OTHER INFORMATION

Efforts have been made in recent years to revise the service delivery system. A brief overview of these redesign initiatives are being addressed by the Agency for Persons with Disabilities. Refer to the Helpful Attachments section for more detailed information, or go to the Agency’s website (apd@myflorida.com).

REMINDER: IF YOU HAVE NOT APPLIED TO BECOME A CONSUMER OF THE AGENCY FOR PERSONS WITH DISABILITIES, REMEMBER THAT THIS APPLICATION MAY BE INITIATED BY VISITING A LOCAL AGENCY OFFICE OR BY A PHONE CALL FROM THE PERSON NEEDING SERVICE, A PARENT OR GUARDIAN.

CHAPTER FIVE



Advocating and Coordinating Care

To prepare for learning about advocacy and coordination, let's review a few key points from chapter 4.

HOW SERVICES AND EXPENDITURES ARE AUTHORIZED

The Agency for Persons with Disabilities is the primary source for obtaining basic services for persons with developmental disabilities. To receive services:

- A person must be determined eligible by having a disorder or syndrome attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi and that constitutes a substantial handicap which can reasonably be expected to continue indefinitely.
- A support plan, which identifies the needs of the individual, must be developed.
- A cost plan that justifies and authorizes the cost of these services must be approved.

The support and cost plans must be reviewed at least annually, and service needs may be updated at any time. If needs change before the end of the year, the family and consumer should consult with their support coordinator who can arrange to update the plan.

Much of the information referenced in this Chapter relates to the DS/HCBS Waiver as it is the primary funding source for services from the Agency for Persons with Disabilities. If you are served through a different waiver or general revenue, please consult with APD for further direction and information.

STAFF WITH RESPONSIBILITY TO CHANGE PLANS

The support coordinator will be a person representing the Agency for Persons with Disabilities with responsibility to advocate for the individual. This person will also be involved in helping the individual and family members identify needed services, their priority for delivery, and will be involved in the development of the cost plan. The individual is not eligible to receive any ser-



vices that are not included in these two plans. It may seem simple to contact the service provider and ask for a service or support to be changed, but service providers cannot add, alter or discontinue services until the support plan has been approved to reflect this need and communicated in writing to the service provider. Therefore, when the individual or family believes that other or additional services are necessary, the support coordinator must initiate the change process. This person can arrange for revision of both the support and cost plans. Remember that the support plan is the governing document and must be accompanied by an approved cost plan. Its authority for services stays in place, even if the support coordinator changes.

EMPOWERMENT

Although the support coordinator plays a critical role in guiding individuals through the service delivery system and in coordinating service delivery, the individual and the family are the most important life managers. Individuals with disabilities and their families are empowered to take more control of their own lives. The main points of this concept are:

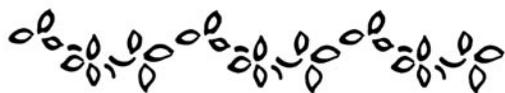
- Individuals with disabilities are usually capable of determining their own needs.
- Individuals and their families should be empowered to develop their own resources, rather than becoming dependent on the service delivery system.
- Individuals and their families should be the ones deciding what services and supports they need.

This person-centered way of planning is a change from the old way of providing services. Allowing their sons or daughters to pursue their personal goals to the greatest extent possible may be quite a change for parents of adult children. Some parents will find this difficult to accept, but most parents are pleased that their family members can now have the opportunity to plan for their own future. It is important for families and professionals to work together to provide the right balance between protection and support, and to create new options for providing the necessary support to the family member with a disability.

FOLLOW THE LINE OF AUTHORITY

If you have a problem that you have not been able to resolve, it is best to follow the line of authority to attempt resolution. Some tips are:

- Discuss your problem with your support coordinator.
- Gather all the facts about steps you have taken so far. Write down dates, names, titles and phone numbers of people to whom you have talked.
- Put this information in writing to the provider or agency with whom you have been communicating. Be sure to first describe the nature of the problem and the desired resolution. Give a date by which you wish a response. Copy your support coordinator. Keep a copy.
- If you have received no response by the chosen date, write a letter to the Agency for Persons with Disabilities Program Administrator in the area in which your



family member receives services. Describe the problem and efforts you have taken to reach resolution. Again include information about dates, names and titles of persons you have contacted as well as a copy of your original letter describing your problem. Credibility and good communication are essential, but keep the information in the letter brief and to the point. Be sure to include a phone number where you can be reached.

- In the letter, ask for something specific. Be clear about what you wish to have done. Ask for a written response by a certain date. (Ten working days is usually a fair amount of time.) A written answer is important because this usually is the start date for any negotiation or appeal process.
- Mark on your calendar the date you expect a response. If you don't receive one, follow up with a phone call to that person. Make written notes of the date and time you call, the person with whom you speak, and key conversation points.
- If you do not receive a response within ten working days, work your way up to the next level of supervision. (In the Agency for Persons with Disabilities this would be a position at the Central Office in Tallahassee - you can obtain the name and title of this person by calling 850-488-4877). Write that person advising him of efforts you have made to reach resolution. Always put your request in writing, keeping a copy of all details.
- It will usually not be necessary to go to higher levels. If your issue is related to statewide legislation or funding, you may wish to contact your local state legislator or the Governor's office. Sometimes as a last resort the media might be helpful.
- Remember, in some situations, you may win only in the sense that you have your voice heard and you get on the record with your complaint. If you exhaust all of the measures described above to no avail, it would be time to ask the Advocacy Center for Persons with Disabilities or your own attorney to get involved. Provide them with all of the detailed information you have been accumulating.

DUE PROCESS RIGHTS

You may appeal any decision made by the Agency for Persons with Disabilities under two authorities:

- Chapter 120, F.S., which provides "administrative hearings," and
- Chapter 42, §431.200, Code of Federal Regulations, which is used to challenge appeals relating to Medicaid services.

Administrative hearings under Chapter 120, F.S., are available whenever the Agency for Persons with Disabilities denies a service or fails to act on a request you made for assistance. To obtain an administrative hearing you must request the hearing, preferably in writing, to the Agency for Persons with Disabilities Administrator in the area where your family member resides, or you may appeal to the Office of Appeal Hearings in Tallahassee. You must request this hearing no later than ninety (90) days from the date you received notice of the Agency's actions. The support coordinator or the local Agency for Persons with Disabilities office will help you make your request.



A fair hearing under Chapter 42, §431.200, is used ONLY when the service in question is being paid through the federal Medicaid program. You may request a fair hearing when requested services are denied, when the Department fails to act on a request for services within ninety (90) days of request, or when services have been suspended, terminated or reduced. Your support coordinator can advise you which appeal would be most appropriate and will assist you in the process. Legal representation is advised when appealing.

ADVOCACY

The dictionary defines “to advocate” as “to speak in favor of, to defend a cause, or to plead on another’s behalf.” Within the social service system, advocacy usually has a goal of making a change in a policy, a program, or a service. Advocacy takes place at various levels—the agency, local, state or even federal level.

Within the system which provides for services to individuals with disabilities, an advocate could be a person or an organization that helps these individuals and their families receive needed services. Advocates are trained to provide support, advice and assistance, and may express their position in a formal setting. This type of advocate is usually a person or agency outside the immediate situation. The goal of the advocate is to seek resolution of conflict and obtain needed services. Some examples are local Family Care Councils (FCC’s) and Local Advocacy Councils (LAC’s).

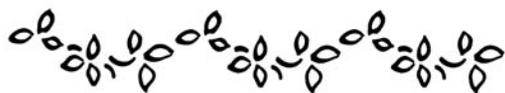
A family member usually is the first to assume the role of advocate. Some specific ways family and friends can effectively advocate include:

- Learn as much as possible about the service or program in question, including getting information about the rights and appeal process and how to utilize this process.
- Identify which agency professionals are responsible for assisting with which types of problems.
- Name the service(s) you and your family member need/do not need.
- Request assistance from an outside source if resolution is not reached.

SELF-ADVOCACY

The person with a disability can be very persuasive by advocating for himself. The following are steps that a self-advocate may find helpful:

- Believe in yourself. You are worth the effort it takes to protect your interest and rights.
- Realize you do have rights. You should be treated equally, according to law. Get information you need by asking questions.
- Talk about your concerns. Speak directly with the person and record his name when you are having a problem. You can do this by telephone, personal visit, or letter. If you go in person be sure to bring someone else along to listen and support you.
- Get the facts in writing. Ask for a copy of any policies, rules or regulations that affect your situation. This is important because what you understood them to say and what is in writing may not be the same.



- Use the chain of command. If you have difficulty with a worker, go to the next level supervisor. Ask to speak to that person. Always confirm conversations, whether personal or by phone, in writing to the person making a commitment. Keep notes recording all names and dates.
- Know how to appeal the decision. Get clear and written information on how to make a formal appeal.
- Don't give up. Be clear in what you say. Keep after what you want. Don't let people talk you out of something that is important to you, but do avoid arguing with them. Follow up with visits, letters, or phone calls.
- Use good skills in talking with and listening to others. Have a plan to tell about your problem and what you want. Stay calm and speak clearly. Try to avoid becoming emotional. Listen to what people say to you. What you hear may be as important as what you say.
- Ask for help. Get in touch with advocacy organizations. They can give you information about getting services. Local support groups will be of help also.
- Don't forget to follow up. If you don't hear from a person and it is past the time when they said they would contact you, be assertive and call them.
- Thank those who help you. When others help you or solve a problem for you, be sure to thank them.

INFORMAL ADVOCACY GROUPS

Advocacy is much larger than merely dealing with one individual's problem. To improve programs and funding, it is necessary for people with similar problems to come together as a group in order to organize and direct efforts to particular issues. It is not unusual to find that if you are having a serious problem you cannot get resolved, others are having similar problems. Some general suggestions for getting started are:

- Define your issues,
- Develop your vision,
- Share the workload,
- Involve your friends and elected officials,
- Understand the legislative process and work through it to get better legislation and funding,
- Communicate clearly with policymakers about what needs to be done,
- Involve the media,
- Become familiar with all the advocacy organizations; work together with them,
- Be creative with your approaches and solutions.

REMINDER: HAS THIS INFORMATION ALERTED YOU TO ANYTHING YOU SHOULD PUT IN THE PERSONAL INFORMATION SUMMARY?

CHAPTER SIX



Choosing the Best Place to Live

*I*deas about where an individual with a disability should live have changed significantly in our lifetime. Early options were either to stay at home with the family or enter an institution. Many families have not yet reached full acceptance of having the family member make a choice from a wide range of options. Such options require supports and services—choices that were never available before. Now it is incumbent upon parents to look anew at what may be available to their family member, consider with him whether one of these new ideas might not be a better plan for the future, and support the decision he makes.

This chapter will discuss only places to live. It is understood that services and supports will also be necessary, and these will vary depending on the selection made regarding where to live as well as the specialized needs of the family member.

A new concept for some parents will be that the individual can make a choice of where and how he wants to live. It is then the responsibility of family to help and support him.

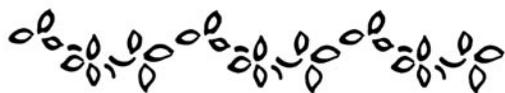
STEPS TO TAKE

Identify

- Where the individual wants to live
- What supports and services will be required to meet this goal
- Availability of this resource locally
- Whether he is willing to relocate to obtain his choice

Understand

- How this will change the current lifestyle
- Whether this is economically feasible
- How this will change friends, family contacts, and availability of activities



Choose

Your family member may make some of these choices NOW for the immediate future, with you offering guidance and support. You may still want to identify in your long-range plan some flexibility based on future developments of an ever-changing program, and write this possibility in **the Personal Information Summary**.

Write it Down

Include all the things you know your family member will want/need to live in the manner he has chosen. Your golden rule is "Each individual should live in the least restrictive situation that can meet his needs." Therefore, you must learn as much about all options as you can. With your family member, visit different kinds of places to live. Pay particular attention to the preferences and options of your family member. Sometimes from years of habit, parents continue to make decisions for the family member and are surprised to learn how much and how well he can make good decisions for himself when he has an opportunity to see and experience the options available. Remember, options include all available options, not just looking at three or four group homes, but truly reviewing each living environment including supported living. Supported living now offers a wide variety of supports to insure the individual can live as independently as possible with adequate services in place to make the choice successful.

Some of the options are licensed by the state and must meet particular requirements. You may want to talk to someone about these licenses what they are required to provide prior to making your final decision. Also AHCA has a report card on certain types of licensed facilities and that is just another resource to consider in making your decision.

OPTIONS AVAILABLE FROM LEAST TO MOST RESTRICTIVE

1. Living in your own home

A family member may wish to live in a house or apartment through rental, lease or purchase. This might be possible by:

- Hiring a roommate or a supported living coach who can assist with chores, supervise where needed, and provide companionship. Many individuals use the service of in-home supports through the waiver so that 24 hours or some other level of supervision is available;
- Sharing a house or apartment with other adults with or without disabilities. Persons with skills, personalities and interests that compliment each other can live together. In this way expenses could be shared and supervision (if needed) supplied by a provider. Up to three individuals receiving services can live in the same home. There are also density requirements regarding how many individuals with disabilities can live in the same area. (Contact your local agency staff person to discuss this before entering into a rental agreement).
- Purchasing a house. This is possible through new and innovative housing and financing options at federal, state and local levels. (Refer to Chapter 3 under Housing Assistance for contacts to learn more about these options).

(Supported living is a name given to any of these options, and it merely means that by purchasing necessary services, assistance and supervision is provided which supports a person to live in his own home.)



2. Family Home

A family member may continue to live with his family and receive the services that enable him to stay there. In addition to the services necessary for him to live at home, services needed by elderly parents may also be made available if they are necessary for them to continue caring for their family member. Such services could be obtained through other agencies such as the Area Agency on Aging, Adult Services Program in the Department of Children and Families and the Department of Elder Affairs as well as other state and local agencies that offer services in specialized areas (such as County Health Departments). Your family member's support coordinator can help you obtain these services.

With the expansion of available services and supports, parents can now will their home to a family member who can continue to live there after his parents' death. But remember the family member must LIVE in the house or it may become an asset that could cause loss of eligibility for certain government benefits. This was discussed in Chapter 3, Understanding Government Benefits.

3. Foster Home

This is a private home 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, participation in community activities, as well as supervision. Only three persons in addition to the family may live in a foster homes at one time. Foster home are licensed through the Agency for Persons with Disabilities.

4. Assisted Living Facility

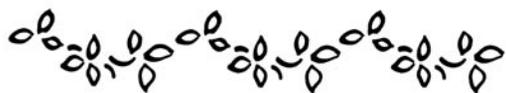
This is a residential facility that is usually designed for elderly persons who require some supervision but do not need nursing care. Sometimes an assisted living facility may be designed especially to meet the needs of adult persons with developmental disabilities. Only those persons who require minimal supervision would live here. Any training needed would be obtained outside the facility. Assisted Living Facilities are licensed through the Agency for Health Care Administration.

5. Group Home

Florida statute describes this as a residence in the community that provides residential care for at least four but no more than fifteen individuals. It may be a private home 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 may be provided by employed staff and professionals. Group homes are licensed by the Agency for Persons with Disabilities.

6. Residential Habilitation Center

This residence provides 24-hour supervision and must serve at least nine individuals. Supervision is by employed staff. The facility must meet all of the person's basic needs and may provide specialized training within the facility. However, residents may also go outside the facility to a local training center for training during the day. Although there is no set maximum number of people they can serve, under statute no new residential habilitation centers may be opened, and none may increase the number of people they currently serve. Residential Habilitation Centers are licensed by the Agency for Persons with Disabilities.



7. Skilled Nursing Home

Skilled nursing homes provide 24-hour skilled nursing care. This is a program usually needed by elderly persons. It is not customary for persons with developmental disabilities to live in a skilled nursing home unless they have specialized nursing needs that cannot be met anywhere else, in which case the specialized programs needed due to their developmental disability must also be provided in the skilled nursing facility. Skilled Nursing Homes are licensed by the Agency for Health Care Administration.

REMINDER: REMEMBER TO COMPLETE INFORMATION IN THE PERSONAL INFORMATION SUMMARY REGARDING RESIDENTIAL PREFERENCES.

CHAPTER SEVEN



Work and Retirement

LIFE STAGES

People go through four periods in their lifetime:

The Early Period—Birth to 5 years

The School Period—3-21 years

The Work and Family Period—22-64 years

The Retirement Period—65 and up

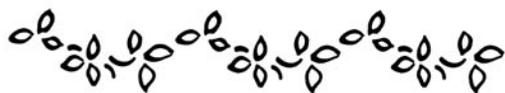
EARLY INTERVENTION AND SCHOOL

Things learned in the Early Period will prepare a person for the School Period. A significant portion of the School Period prepares us for the Work Period. We may think of the Work Period as consuming at least half of our lives. Retirement provides the opportunity to rest and enjoy things we have not had time to do during the years of the Work Period.

For individuals with developmental disabilities, these four periods may not be as evident; however, early intervention and integration have assisted persons with disabilities to make tremendous strides in recent decades.

Learning the basic daily living skills will begin in the Early Period and may extend for the full life span. Therefore, the blend of school (work preparation) and work may seem to extend indefinitely.

The past decade or more has provided an emphasized effort to support individuals with disabilities to participate appropriately in the Work Period. Today, the opportunity to hold a job should be available to everyone with a disability who wishes to work. Since the mid-1980's, over 200,000 people with "the most severe" disabilities have been employed by using on-the-job systematic training and consistent follow along strategies. This may require ongoing additional supports such as supported employment coaches who help the person learn new skills or obtain special equipment that may be necessary to perform some tasks.



There are now more opportunities for persons with developmental disabilities to be gainfully employed. However, this means that planning must start very early. The school should begin planning with the student for a transition from school to work in the early teens, perhaps as early as 12 or 13 years of age. Mandated legislation, the Individuals with Disabilities Education Act (IDEA), requires that planning for the transition from school to the community (employment) must begin no later than age 14. This gives the family and school possibly six years, or until the student's 22nd year, to help the student learn job skills and, in many instances, graduate or exit school with a job in the competitive work force. Check with your local Vocational Rehabilitation office to determine at what age and what specific services they can begin providing – it is never too early to start. Also inquire about their eligibility requirements.

These plans for transition 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 transition, and any other advocates the family wishes to have there. The plan addresses such things as areas of learning required to hold a job, appropriate job opportunities and how the transition will be made from school to work. This person-centered planning gives the student and family the opportunity to make decisions about the student's future.

Almost anyone can have a job in the community when the proper training and ongoing supports are made available. Opportunities provided through the Agency for Persons with Disabilities may include the traditional work training programs and sheltered employment, as well as supported employment or a regular competitive job.

THE WORK AND FAMILY PERIOD

Supported Employment may be a full or part time job in the community. Each individual will select a job coach, employment specialist or employment consultant who helps him learn the job and the social skills required for the job. The job coach continues to provide this support as long as it is needed, working with both the employee and the employer.

When a person with a disability chooses to become employed, the job coach examines the individual's interests, abilities and strengths. He then approaches businesses to find a job that fits the interests and abilities the individual has to offer. Other factors considered are: how close the job is to the person's home, transportation, the salary, and hours to be worked.

After finding a match between the job and the person seeking employment, the job coach may go to the place of employment and train the person on the job, if the business and individual wish the job coach to do this. The coach also teaches the person to use appropriate transportation to get to work and return home, as well as use any equipment or perform the tasks necessary to do the job. Over time, contacts with the job coach become less and less frequent, depending on the needs of the individual, but support is always available to the extent the person or the employer wishes or needs assistance.

As a result of this program, employers have found that many persons with disabilities make excellent and dependable employees. As with any "good employee," people with disabilities have demonstrated they can be punctual, reliable and loyal, and are safety conscious and willing to work. For the employer this means lower staff turnover, which saves money. As a result, employers often help expand opportunities for persons with disabilities by telling other employers how successful the program has been for them.



For some persons in supported employment, the Division of Vocational Rehabilitation (VR) may also become involved in funding supports and services to help find and maintain a job. The support coordinator will usually be the person who coordinates these referrals and works out the details of how Vocational Rehabilitation and the Agency for Persons with Disabilities will work together.

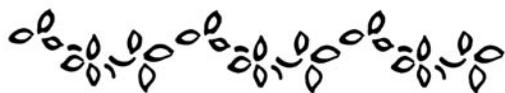
If a person has been determined disabled and is receiving Social Security benefits (SSA) or Supplemental Security Income (SSI) it is very important that the person contact the Social Security Administration so that SSA or SSI benefits will not be reduced because of earnings from employment. Social Security has a special program called Plan for Achieving Self Support (PASS) that requires the person (with the assistance of a support coordinator or VR counselor) to submit a plan for learning a job. When this plan is filed and accepted, benefits will not be reduced as long as certain conditions are met. Remember that the plan must be submitted to the Social Security Administration and approved by them before employment begins.

Volunteering offers a wide spectrum of community involvement for individuals who are looking to expand their experiences. Many individuals are choosing to spend their day activities in meaningful volunteer positions. Oftentimes these volunteer activities can result in employment opportunities. Some examples of volunteer activities can include working at your local public library, food banks, animal shelters, church programs as well as for specific programs such as Goodwill and the Salvation Army. Disability specific programs also offer options to expand social roles by applying to participate in Partners in Policymaking (go to www.fddc.org for more information and an application), serving on local, state or national volunteer boards thus opening doors to expand. Businesses also seek volunteers who can bring a fresh perspective on disability issues and in meeting the consumer needs of individuals with disabilities. Work with your support coordinator and others in your support network on reaching out to new innovative approaches to meaningful activities.

RETIREMENT

Most people nearing age 50 begin to think about retiring although the actual age of retirement is usually 62-65 (the age when retirement benefits are available through Social Security). We may have started out at a low level job and through the years the nature of our work changes, or we move 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 deviation in the tasks they perform—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 activity or other things they enjoy. This is equally true for persons with developmental disabilities. However, retirement has only been an option for persons with disabilities in recent years. Individuals with disabilities may not have a good understanding of exactly what “retirement” will mean to them. They may need help in discovering that they only wish to try something new, to do something that gives more leisure time, or to retire from employment as they have known it (e.g. doing the same repetitive job for many years.)



If your family member really thinks he wants to retire, there are community retirement programs for older persons with or without developmental disabilities. Anyone retiring should look carefully at leaving employment to retire and carefully 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?

BUT, don't overlook exploring a new part-time job. Maybe all that is really needed is a new challenge. This may be especially true when the family member is in good health and has not really reached the age of retirement.

Your Support Coordinator can help provide information about options available locally, and may even arrange for visits or exploring activities such as:

- Existing recreation programs
- Volunteer activities in various settings
- Senior Centers and nutrition sites
- Clubs or groups around a particular hobby
- Church related activities

The Support Coordinator also will help with the transition from regular employment to new activities. These may include transportation, joining one of these programs, meeting other participants, learning new routines and schedules as well as new skills.

Remember that selecting retirement requires a major life adjustment. There will be significant changes in daily life activities as well as change in friends and income. Be sure that both the person and the caregiver are knowledgeable of and ready to make the adjustments necessary for retirement.

REMINDER: REMEMBER TO DESCRIBE EMPLOYMENT AND PLANS FOR RETIREMENT IN THE PERSONAL INFORMATION SUMMARY.

CHAPTER EIGHT



Legal Ways of Protecting Rights

*G*uardianship may be the only way to protect a developmentally disabled family member's rights and insure his health and safety. However, there are alternative ways to avoid this more drastic action if adequate support, training and supervision are given to the person in need of protection. These alternatives may be more cumbersome to the advocate/decision-maker but could be well worth the effort if the individual is allowed to make those decisions that he is able to make, thus achieving a greater degree of independence. The least restrictive way to protect rights is always best.

Usually whether a person can give consent to a decision depends on the complexity and the seriousness of the decision to be made. In some cases, help with evaluating options and outcomes is all that is needed. With this guidance, the person may be able to reach his own decision. Those who can recognize their own need for help with decision-making may not require guardianship, but only advice, information, and assurance when evaluating other options that may be available rather than pursuing guardianship.

ALTERNATIVES TO GUARDIANSHIP

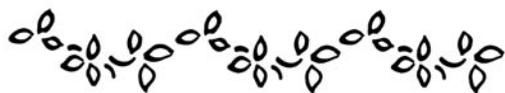
Guardianship takes away a person's right to choose in those areas in which the court has decided the person is not competent to make decisions. Whenever possible, the least stringent options for decision making are always the best course to pursue. Some alternatives to guardianship that should be considered are:

FAMILY AND FRIENDS

Sometimes attentive support from family and friends can be enough to allow the person to manage his own personal and financial affairs.

ADVANCE DIRECTIVE

A document that expresses a person's desires concerning any aspect of his or her health care, or a written form directing an anatomical donation after death is considered as an advance or



pre-need directive. As the term indicates, this option is written in advance of the need and the person must be competent at the time he signs the directive. Some people write them when they are diagnosed with a life-threatening illness. Examples of these directives include:

- **Durable Power of Attorney** – Legally competent adults who are disabled but who are capable of giving informed consent may give durable power of attorney to another adult. This legal document gives the designated person the legal authority to make decisions on specific matters for the person who is disabled. A DURABLE power of attorney can be exercised until the death of the person who gave it, even if the person becomes incapacitated.
- **Living Will** – a written document that directs the providing, withholding, or withdrawal of life-prolonging medical procedures if you are unable to make your own decisions and you have a terminal illness or are in a persistent vegetative state.
- **Health Care Surrogate** – a written document naming another person as your representative to make medical decisions for you if you are unable to make them yourself. You can include instructions about any treatment you want or do not want, similar to a living will. 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 how you would like matters handled, and give them a copy of the document.

It is important that any advance directive be witnessed by at least two individuals. Laws on health care advance directives are in Chapter 765 of the Florida Statutes (*available at your local library or at www.leg.state.fl.us. The **Helpful Attachments** Chapter includes sample documents of a living will, designation of health care surrogate, and donor of anatomical gifts.*)

FAQ's About Living Wills & Health Care Advance Directives:

The information in this section of the guidebook has been prepared by the Consumer Protection Law Committee of The Florida Bar and the Bar's Public Information Office and is offered as a courtesy of The Florida Bar and the Florida Medical Association.

The Florida Legislature has recognized that every competent person has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment or procedures which would only prolong life when a terminal condition exists. This right, however, is subject to certain interests of society, such as the protection of human life and the preservation of ethical standards in the medical profession. To ensure that this right is not lost or diminished by virtue of later physical or mental incapacity, and if desired, to designate another person to act on his or her behalf and make necessary medical decisions upon such incapacity.

What is a Living Will?

Every competent adult has the right to make a written declaration commonly known as a "Living Will." The purpose of this document is to direct the provision, the withholding or withdrawal of life prolonging procedures in the event one should have a terminal condition. The suggested form of this instrument has been provided by the Legislature within Florida Statutes Section 765.303. In Florida, the definition of "life prolonging procedures" has been expanded by the Legislature to include the provision of food and water to terminally ill patients.



What is the difference between a Living Will and a legal will?

A Living Will should not be confused with a person's legal will, which disposes of personal property on or after his or her death, and appoints a personal representative or revokes or revises another will.

How do I make my Living Will effective?

Under Florida law, a Living Will must be signed by its maker in the presence of two witnesses, at least one of whom is neither the spouse nor a blood relative of the maker. If the maker is physically unable to sign the living will, one of the witnesses can sign in the presence and at the direction of the maker. Florida will recognize a Living Will, which has been signed in another state, if that Living Will was signed in compliance with the laws of that state, or in compliance with the laws of Florida.

After I sign a Living Will, what is next?

Once a Living Will has been signed, it is the maker's responsibility to provide notification to the physician of its existence. It is a good idea to provide a copy of the Living Will to the maker's physician and hospital, to be placed within the medical records.

What is a Health Care Surrogate?

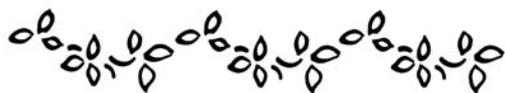
Any competent adult may also designate authority to a Health Care Surrogate to make all health care decisions during any period of incapacity. During the maker's incapacity, the Health Care Surrogate has the duty to consult expeditiously, with appropriate health care providers. The surrogate also provides informed consent and makes only health care decisions for the maker, which he or she believes the maker would have made under the circumstances if the maker were capable of making such decisions. If there is no indication of what the maker would have chosen, the Surrogate may consider the maker's best interest in deciding on a course of treatment. The suggested form of this instrument has been provided by the Legislature within Florida Statutes Section 765.203.

How do I designate a Health Care Surrogate?

Under Florida law, designation of a Health Care Surrogate should be made through a written document, and should be signed in the presence of two witnesses, at least one of whom is neither the spouse nor a blood relative of the maker. The person designated as Surrogate cannot act as a witness to the signing of the document.

Can I have more than one Health Care Surrogate?

The maker can also explicitly designate an Alternate Surrogate. The Alternate Surrogate may assume the duties as Surrogate if the original Surrogate is unwilling or unable to perform his or her duties. If the maker is physically unable to sign the designation, he or she may, in the presence of witnesses, direct that another person sign the document. An exact copy of the designation must be provided to the Health Care Surrogate. Unless the designation states a time of termination, the designation will remain in effect until revoked by its maker.



Can the Living Will and the Health Care Surrogate designation be revoked?

Both the Living Will and the Designation of Health Care Surrogate may be revoked by the maker at any time by a signed and dated letter of revocation; by physically canceling or destroying the original document; by an oral expression of one's intent to revoke; or by means of a later executed document which is materially different from the former document. It is very important to tell the attending physician that the Living Will and Designation of Health Care Surrogate has been revoked.

Where can I go to obtain legal advice on this issue?

If you believe you need legal advice, call your attorney. If you do not have an attorney, call The Florida Bar Lawyer Referral Service at 1-800-342-8011, or the local lawyer referral service or legal aid office listed in the yellow pages of your telephone book.

CLIENT ADVOCATE

Section 393.0651, F.S., allows the Support Planning Committee of the Agency for Persons with Disabilities to appoint a family member or friend of the individual to become an official client advocate when the need for this is recognized. Client advocates may assume a variety of roles depending on the needs and wishes of each individual client. They may serve as guides and advisors in developing the support plan, identifying appropriate services, considering the costs of those services, or help the individual with any decisions related to services to be provided through the Agency for Persons with Disabilities. However, they have no legislative authority.

Co-signer of Bank Accounts

This is a way to exercise some degree of control over decision-making in expenditures by requiring more than one signature on the check. It is an effective way to teach as well as supervise the individual and can prevent financial exploitation by others. Provisions should be made for the money in the account to be accessed if any of the signatories should die.

Representative Payee

An individual may be given authority by the Social Security Administration to receive and manage Social Security (SSA) or Supplemental Security (SSI) benefits for another person found unable to manage his own money. The representative payee receives the benefit payment and spends the funds to meet the needs of the individual. The representative payee is required to account annually for expenditures made on behalf of the person for whom the money is intended.

If none of these alternatives are adequate for your family member, then you may need to consider some level of guardianship.

GUARDIANSHIP

When a court appoints a person as a guardian, the person is then called his "ward".

Remember that you should only take away those rights that the person cannot handle. The statutes require that even when a right has been taken from the individual and given to a guardian or guardian advocate, the guardian is still required, to the extent possible, to consult



with the ward regarding his wishes, and allow the ward to participate as fully as possible in making the decisions affecting him.

Four areas in which persons with developmental disabilities are most likely to have difficulty and require a guardian are:

- Consenting to medical, dental and surgical procedures;
- Managing money or property;
- Applying for governmental benefits and entitlement; and
- Deciding on residential choices.

LAWS IN FLORIDA WHICH ADDRESS GUARDIANSHIP

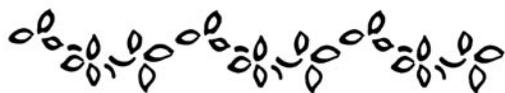
Chapter 393, F.S., Developmental Disabilities, is specifically designed to determine the degree of incapacity and to meet the unique needs of persons with developmental disabilities. This special type of guardianship is addressed in section 393.12, F.S., and the guardian is called a guardian advocate. Even though the name is different from the name “guardian” given in Chapter 744, F.S., the authority given by the court is the same.

A petition is filed asking that a guardian advocate be appointed to perform those rights that the developmentally disabled person cannot perform. Attached to this petition are reports, evaluations, support plans, individual education plans, and/or habilitation plans which indicate the degree and areas of incapacity.

This statute does not require a separate hearing to determine incapacity, and there is no adjudication of incapacity. In fact, Section 393.12, F.S., specifically denies requirements for an adjudication of incompetence. It also dictates that the hearing must be conducted in a manner consistent with due process. At the hearing to appoint the guardian advocate, the Circuit Court reviews the reports, evaluations and support plans submitted by the petitioner(s), and appoints a guardian advocate to perform those functions that the person is unable to perform. Only those rights the person cannot managed are removed.

This is the least restrictive, less costly and much preferred type of guardianship for persons with developmental disabilities because it offers the following procedural and financial advantages:

- The appropriate professionals are used to evaluate the individual, determine the degree of incapacity and identify rights that should be removed. These are professionals who have knowledge of the disability and the individual as well as the person’s potential for improvement through training.
- Existing plans identifying needs (support plan, individual education plan, or habilitation plan) may be used to identify service needs related to rights the individual cannot handle. Each client of the Agency for Persons with Disabilities has a support plan developed by appropriate professionals who know the person.
- The professional evaluation is completed by the Agency for Persons with Disabilities as part of the determination of eligibility for the program at no cost to the applicant. There is not an examining committee of 3 professionals as is required in Ch. 744, thus reducing this cost.
- This process consumes less court time, reducing the cost to courts and attorneys.



Although it is not required by statute, it is advisable to always have a standby guardian advocate appointed at the time the guardian advocate is appointed. This person should be named in the petition and would be identified in the order.

After the guardian advocate order is issued, stating which rights are removed from the ward and given to the guardian advocate, **all other actions and requirements are the same as those stated in Chapter 744, F.S., Guardianship.**

Chapter 744, F.S., (Guardianship)

Chapter 744, F.S., (Guardianship) covers all persons who might need guardianship for any reason (e.g. dementia, head trauma, mental illness, or any disability). It can be an expensive procedure and requires costly evaluations by professionals who may not be experienced or appropriate to evaluate persons with developmental disabilities.

The types of guardianship found in Section 744.102(8)(b), F.S., are:

- **Full (Plenary) Guardianship** (Section 744.102(8)(b), F.S.). A person is appointed by the court to exercise all delegable legal rights and powers of the person who has a disability. Full (plenary) guardianship is necessary for very few people. It removes all rights relating to both person and property. It 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.
- **Limited Guardianship** (Section 744.102(8)(a), F.S.). The court adjudicates the individual incapacitated in specific areas due to the fact that he lacks the capacity to do some but not all of the tasks necessary to care for his 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.
- **Emergency Temporary Guardianship** (Section 744.3031, F.S.). In emergency situations a guardian may be appointed for the person and/or property of an alleged incapacitated person prior to the appointment of a full guardian. This is done after a petition for incapacity has been filed when there appears to be imminent danger to the person. (e.g. there is no one to make a critical medical decision that must be made immediately.)
- **Voluntary Guardianship** (Section 744.341, F.S.). If the court determines that the individual is not incapacitated, but the individual files a voluntary petition for guardianship, the court may appoint a guardian or co-guardians of the property of a person who, though otherwise mentally competent, is unable to manage property. A voluntary guardianship may be terminated by the ward.
- **Standby Guardianship** (Section 744.304, F.S.). Guardians ordinarily wish to have a hand in deciding who shall take over when they die rather than have the court choose. Standbys may operate as guardian for 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. It is helpful to also have this information included in the guardian's will.



- **Foreign Guardian** (Section 744.306, F.S.). Florida recognizes guardianships from other states, territories and countries. The guardian must file an authenticated order of the appointment with the Clerk of the Court in the county where the ward resides.

Plenary and Limited guardianships are the types usually used for persons who are disabled, elderly, mentally ill, or otherwise incapacitated. The process requires a petition for determining incapacity, a hearing to determine the degree of incapacity which is based upon the reports from three court appointed professionals who have evaluated the person, only one which must be an expert in the area of the disability. Members of this committee must not have known the incapacitated person. After an adjudication of incapacity another hearing is held to appoint a guardian.

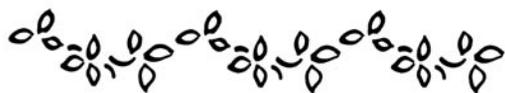
A FEW WORDS ABOUT THE PROCESS

Any Florida resident over the age of eighteen, who is of sound mind and who has not been convicted of a felony, is eligible to serve as a guardian (or co-guardian), as is a non-profit corporation organized for religious or charitable purposes. (For exceptions refer to ARC Florida Guardianship Handbook or Chapter 744, F.S.).

Each guardian is required to:

- Receive basic training in how to function as a guardian or guardian advocate. This training is provided at various sites. Training may be waived with sufficient evidence that the guardian already has this knowledge;
- File a guardianship report annually to include the guardianship plan and an accounting of assets (unless this accounting is waived by the court, which may occur if the court accepts the support plan in lieu of a guardianship report);
- Develop and implement the annual guardianship plan, which must include details on the current condition and needs of the ward and how the guardian proposes to meet those needs;
- Account annually to the court (unless waived by the court when the ward has no estate) on all receipts, disbursements, cash deposited in any institution, and property on hand at the end of the accounting period. When income is solely from governmental benefits or the person's own earned income, the annual accounting may be waived unless the ward's financial situation changes.

For both a guardian advocate (under Chapter 393, F.S.), or a guardian (under Chapter 744, F.S.), you will need an attorney. It is all right to shop for an attorney, both for fee per hour and in the area of experience in this very specialized field. It is important if you wish to use the guardian advocate process (Section 393.12, F.S.) to have an attorney familiar with this particular statute and procedure. Most attorneys who have done guardianships use Chapter 744, which is more appropriate for elderly people and children as well as total incompetency procedures for people with other disabilities. Fewer attorneys have done limited guardianships under the Guardian Advocate procedures. In some situations if the cost of the attorney is a problem, the local Legal Aid Office or Legal Referral Service may be able to help.



The potential ward, if capable of understanding the need for someone to make or help make decisions, may be the petitioner or one of the petitioners, thus from the start being represented by an attorney presumably acting in the ward's best interest, and avoiding the cost of two attorneys.

The guardian has no personal financial responsibility for the care and maintenance of the ward. A guardian may resign but can only be relieved of guardianship duties with the approval of the court.

Public Guardian

Some counties in Florida have an Office of the Public Guardian. If the person has no family, friend or any other person, bank or corporation willing to serve as guardian, and there is no means to compensate a private guardian, the public guardian may become the guardian of the incapacitated person. To be eligible to have a public guardian appointed, the potential ward must meet the asset criteria for Medicaid eligibility. At the present time all public guardianships are under Chapter 744.

A public guardian would never be appointed unless all less restrictive or intrusive methods were not sufficient for meeting the incapacitated individual's needs.

[Some states are using unique and innovative means to address decision-making assistance. The web offers readers a mechanism to research and explore more information about these and other alternatives.]

REMINDER: ANY DECISION RIGHTS THAT ARE REMOVED BY THE COURT AND TRANSFERRED TO THE GUARDIAN ADVOCATE/ GUARDIAN CAN NO LONGER BE MADE BY THE CONSUMER. THE GUARDIAN ADVOCATE/GUARDIAN SHOULD ALWAYS CONSIDER THE WISHES OF THE PERSON WITH THE DISABILITY AS WELL AS WHAT HE PERCEIVES TO BE THE WARD'S BEST INTEREST WHEN MAKING THESE DECISIONS.

CHAPTER NINE



Making an Estate Plan

An estate plan is important for everyone who is preparing for the future of a person with a developmental disability. It should consist of three components:

- a will with letter of intent,
- a special needs trust, and
- personal financial planning.

Everyone understands that estate plans are critical for those who are affluent, but often do not realize that they are equally important for less affluent persons. There are important things to consider even if you believe you have very little to put in a trust, or leave in a will.

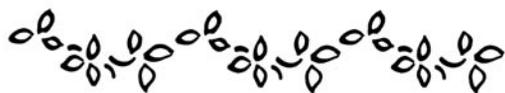
WILLS

Wills can range from very simple to very complex documents. They state your wishes for disposing of your assets after your death and are important, even if you think you do not have many assets to leave. Wills make it much easier for your descendants to handle your affairs after your death.

You should have an attorney prepare your will. After your death, the person you have named to be your personal representative (executor or executrix) 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, your estate is then distributed to those you have named in your will or to your trust.

Things that you have already designated as belonging to others would not be included in your will. This includes such things as joint bank accounts (with the name on the joint account then owning the account if the account states right of survivorship), life insurance, retirement benefits, annuities or trusts where you have described how assets must be used or passed on.

If you die without a will and leave assets, the decision as to division is set by law. For example, if you are married, have children, and die without a will, your probate estate will be divided between your spouse and your children. This may not be the way you would wish things to be, so it is best to plan ahead and have a will.



LETTERS OF INTENT

In addition to having an attorney prepare a will for you, you should write a Letter of Intent. This is a letter to familiarize others with your family member and with your expectations. It is in some ways similar to the Personal Information Summary in this document, but usually with a broader level of information in the Letter of Intent. It should cover the things you do and do not desire. The Letter of Intent should cover information regarding expectations and preferences regarding the future of your family member, such as:

- Living arrangement
- Education
- Employment or other daily activities
- Supports and services needed
- Important relationships to maintain
- Medical history, health care needs
- Abilities and needs regarding communication, independence in daily living and personal care, money management and decision making
- Likes/dislikes and preferences in social and recreational activities, religion, foods
- Effective ways to work with and support your family member
- Financial information: government benefits, bank accounts, trust, life insurance, health insurance
- Names, addresses and phone numbers of important people or agencies involved with your family member
- Anything else that will be important for others to know about your family member

CAUTION

Sometimes parents or other family members leave money intended for the person with the disability to another family member with instructions for them to “spend X amount of this money for the benefit of the family member with the disability.” This is not always the wisest decision to make. Even if the person receiving the money uses it as intended, things could happen that would prevent the money being available to the family member with the disability. Some examples are:

- If the person receiving the funds were to require nursing care, the money would be required to pay for nursing home care—legally it would be considered that person’s money.
- Creditors could take the money to satisfy claims.
- If the keeper of the money died, the money would then go to his heirs rather than to the person with a disability.

Leaving assets to an agency or organization with expectations that the agency will care for your family member for the rest of his life may not be safe or reasonable. If the leadership of



the organization or financial condition of the agency changes there is no assurance your family member will be protected.

Give careful consideration to how anything you leave as an inheritance will affect your family member's eligibility for government benefits. For example, there are financial limits (which change frequently) regarding eligibility for Supplemental Security Income (SSI). Leaving assets in excess of that amount could make the family member ineligible for SSI, and possibly Medicaid as well.

TRUSTS

One way to avoid ineligibility for government benefits due to excessive assets is to establish a supplemental or special needs trust. A properly worded trust would protect against exceeding the limited assets requirements for SSI or other similar governmental programs based on "need." The trust funds would not be available directly to your family member, so the government benefits would continue without interruption. Remember to always check with current laws and regulations before proceeding as Congress can change policies that impact government benefits and personal finances.

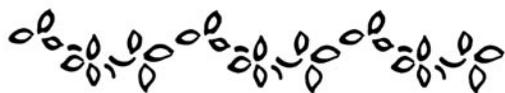
A trust is a legal document that provides a way for assets to be handled for someone else, including money or property. A supplemental needs trust is a trust created to supplement government benefits the person with a disability is receiving without jeopardizing the benefits. This trust specifically states that the funds are to be used to supplement, but not supplant or replace government benefits. You would also state in the trust who should receive the remaining funds in the trust after your family member dies.

A trust may be created by a parent or any other family member or interested person. This person, called the "grantor" can fund the trust by titling 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 person with the disability, called the beneficiary. The grantor may also be the trustee while alive or capable. Co-trustees may, with differing skills and interests in the person with the disability, be a safer choice than one trustee.

Trusts may be revocable or irrevocable. A revocable trust is one that can be changed or terminated at any time during the grantor's lifetime. The assets in a revocable trust are still considered to belong to the grantor and the grantor can regain possession of them. An irrevocable trust is more permanent and cannot be changed or revoked. The assets in the irrevocable trust cannot be taken back as they are no longer considered the assets of the grantor.

Trusts should always be drawn up by an attorney experienced in preparing trusts for persons with disabilities. Trusts have several advantages: they avoid some aspects of probate, can protect government benefits, and help insure that the family member's quality of life can be maintained.

Since the trustee is responsible for administering the trust, it is important to select someone as trustee after your death, or if you become incapable, who has the ability to administer the trust properly, and whom you believe will handle the funds competently. Sometimes a family member or friend is chosen to be the trustee; sometimes a financial institution is selected. Financial institutions usually manage trusts of larger amounts, do not monitor the personal welfare of the person, and charge fees for services based on the amount of the trust. Such charges can significantly reduce or even consume the assets in the trust. If a friend or family member is named, the trust may address financial compensation for the trustee's time and service.



TAX ISSUES

In your planning, do not overlook tax issues. There are several different kinds of taxes that may be imposed—gift and estate taxes, inheritance taxes, income taxes and capital gains taxes. In your planning, consult your attorney or a tax accountant regarding these issues.

SELECTING AN ATTORNEY

In selecting an attorney to assist you with these legal documents, select one that is familiar with:

- Wills
- Special Needs Trusts, other trust options and tax implications
- Public benefits: SSI, SSA, Medicaid and Medicare
- Other sources of income (e.g. pensions, survivor benefits, annuities)
- Guardianship and other alternatives
- Health Insurance
- Life Insurance
- The capabilities and needs of your family member with a disability, and a general awareness of community service options for people with disabilities



OTHER HELPFUL TIPS

Financial planning usually involves developing ways to achieve your financial goals. A financial planner may be an accountant, broker, or insurance agent who can offer comprehensive financial planning services. Select one with the same expectations you have for selecting an attorney.

Not everyone will need a financial planner, but whether you do or not, be sure to compile and be familiar with your own individual financial situation. You will need to review your total financial picture and develop income goals that are most advantageous to you.

Organize your important papers so they can be easily found. Be sure to include:

- Birth certificates, marriage certificates, divorce papers, child support orders
- Naturalization papers
- Any other legal agreements
- Stocks, bonds, CDs, IRAs, other investments
- Deeds
- Insurance Policies
- Income tax returns
- Financial records
- Guardianship papers



- Advance Directives/Living Will and Health Care Surrogate for both you and your family member
- Power of Attorney for both you and your family member, if appropriate
- Wills
- Letter of Intent
- Trust Agreement
- Names and addresses of people named in Power of Attorney, Trusts, Wills
- Burial instructions

Each estate plan is unique, designed to meet the needs of one special individual. Involve other family members in your planning whenever possible. To the extent of his capabilities, include your family member with a disability as you plan for his future.

REMINDER: BE SURE OTHER PERSONS WHO ARE SIGNIFICANT IN YOUR FAMILY MEMBER'S LIFE KNOW WHERE THE LEGAL DOCUMENTS ARE KEPT.

CHAPTER TEN



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. New rules through HIPAA (Health Insurance Portability and Accountability Act) require individual permission regarding sharing of medical records and information.

There are often medical conditions that are associated with particular developmental disabilities. Discuss this with your doctor to be sure that you can identify these conditions early.

QUALITY HEALTH CARE

We all would like to receive quality health care. This involves more than the medical care administered by professionals and may be difficult to obtain for a person with a disability. It includes:

Appropriate Communication. It is important to have a skilled physician with an understanding of persons with developmental disabilities. He should be able to give confidence not only to the caregiver but to the patient as well. There should be opportunities for all who are involved in the health care of the person to communicate clearly to the patient and family as well as to other professionals. Explanations of the problem, treatment and expected outcome should be understood by the patient and the family. Everyone should speak directly to the patient in simple language that he can understand.



Person-Centered Care. The needs of the family member should be placed above those of the health care professionals. This may require revising the method of administering treatment to meet the special needs of the family member. (For example, sometimes it is difficult for a person with cerebral palsy to lie on the examination table without special assistance.) Conducting examinations may require 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. When referral must be made to specialists, the transition should be coordinated by the doctor and his staff, and be fully explained to the patient and the family.

Comprehensiveness of Care. Health care, to the extent possible, should be comprehensive. Medical care should not be isolated from other aspects of the person's life. It should be the responsibility of the person and family members, or a medical case manager, with the assistance of medical professionals to see that medical care is incorporated into the home, work and social aspects of the patient's life. It should also address preventative health care using guidelines for age specific examinations.

A Community Base. Whenever possible health care should be provided in the community where the person lives. When it is necessary to travel out of the community, the local physician should communicate with these out-of-town specialists regarding the needs caused by the disability, as well as provide information related to the medical condition.

Individual Empowerment. The opinions of both the individual and the involved family member(s) should be considered by the medical professionals. They should recognize that to the extent possible the adult with a disability should make his own decisions, although the family has a critical role to play in assuring that the patient understands options and makes decisions in his best interest. There may be times when a legal process such as limited guardianship may be required, especially when medical problems are very serious.

SOME COMMON EFFECTS OF AGING

As they age, persons with developmental 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; glare may be a problem. Words more than twelve inches away become more difficult to read; sharpness declines. Cataracts may occur and cloud the lens. Bifocals may be needed.

Hearing Loss – Can't hear sounds at low levels or at high pitches; words seem to run together. Some sounds are lost altogether. A hearing aid may help somewhat.

Changes in the Bones and Muscles – Bones are weaker, more brittle; osteoporosis may occur. More body fat and a loss of muscle cells cause a loss of muscle tone, strength and stamina.

Persons with Down Syndrome tend to experience certain aspects of aging earlier than most individuals. After age 40 changes in sleeping, eating, and behavioral patterns as well as forgetfulness should be monitored and may need to be evaluated by the family physician.

REMINDER: BE SURE TO ADDRESS HEALTH CARE CONCERNS IN THE PERSONAL INFORMATION SUMMARY!

CHAPTER ELEVEN



Coping with Changes and Losses

Death is a little discussed subject in our American culture; discussion of our feelings and grief are not encouraged, and yet sometime in our lives each one of us must deal with the death of someone close to us. This may be when we begin to realize our own immortality and see death as a natural part of life. The ease with which we survive times of stress or personal loss is dependent upon one's coping skills. How each of us deals with stress is the result of what we have learned. People with retardation will be able to deal better with the loss of a loved one if they have been given opportunities to develop these coping skills. This learning may come from family experiences, religious teaching, educational training, or simply through association with friends and neighbors. It is important that people with developmental disabilities be given an opportunity to develop successful coping skills that result in good mental health and acceptable behavior.

DEALING WITH PERSONAL LOSS

Friends, neighbors, primary caregivers and service providers, although well intentioned, may try to protect the person from facing his feelings at the loss of a family member or friend. They may mistakenly believe that they are saving the person from upsetting emotions that he could not possibly understand. All persons experience losses and to some degree, can understand death. It is important that the person be informed of the loss, and is given the opportunity to handle it. This is more easily done if, before the loss, there have been some discussions regarding what death is, and how one is likely to feel sad and grieve over the loss. If this is not possible, it is still essential to inform, help with understanding, and allow the person to participate to the degree possible in the funeral and/or other rituals related to the death. Remember that these rituals are for the purpose of helping survivors understand their feelings and express their grief.

GRIEVING

Individuals who have difficulty communicating their emotions may express them through changes in behavior. This may be misinterpreted and discouraged, rather than being an opportunity to help the person more appropriately express grief and sadness, often dictated by learned behavior from ethnic examples or cultural norms. By recognizing the reason for the behavior, friends and caregivers may have an opportunity to help the person work through his feelings of loss and grief, thus avoiding long lasting behavioral and emotional problems. Using



medication or behavior programs directed at the behavior is not in the person's best interest unless the situation causing the behavior is first addressed.

Sometimes a person with retardation may not react immediately to a severe loss. Therefore, the family or a caregiver may not always recognize that an unexplained sadness, despondency or inappropriate behavior is relative to a death or other severe loss that occurred in the past.

Remember that grieving takes time. This period can last from a few weeks to years. Be patient and understanding. The best way to help a person through such a loss is to recognize the loss, understand his feelings, and help him express them. With this knowledge and support the pain of grief will gradually diminish. There are things you can do to help the person with retardation cope with changes and loss.

- Tell the individual immediately when a family member or friend dies. Be sensitive in selecting who informs him and how it is done. Remember that abstract thoughts are difficult for him to understand, so be as concrete as possible in describing what death means.
- Encourage the individual to participate in any family rituals, e.g., attending the wake, the funeral and interacting with family and visitors.
- Allow the person to express as much grief as he is comfortable sharing. Remember, grieving takes time – weeks, months, and even years.
- Communicate with the person on a consistent basis about the acceptability of grieving. Don't avoid the person, or change the subject when dying or loss is mentioned.
- Be patient. The individual's progress may be erratic, and include times of confusion, forgetfulness, or denial.
- Communicate in a way and on the level that the person can understand. Recall pleasant times together that they have shared.
- Realize that one person's death may remind the individual of previous losses and unresolved grief.
- If possible, call upon an appropriate spiritual advisor who recognizes the need to grieve and is experienced in relating to persons with disabilities.

If your family member does not live with your family, but is in a residential facility, discuss with staff and friends what has happened and encourage them to talk with him about his sadness and about the deceased person and their relationship. You will need to be a good listener as he tries to express his feelings. If the policy of the residential facility has been to avoid discussing death and grieving, encourage them to initiate a learning experience for the group.

PROVIDING LEARNING OPPORTUNITIES

Teaching about life and death may be done individually at a time that is appropriate, or in small groups as part of a continuing project. Suggestions for these activities are:

- Explain that death is the final outcome of the aging process for all of us. It is a part of life. Show that fatal injuries and incurable diseases can shorten life.



- Arrange visits to an area funeral home, cemetery and church. Invite undertakers, doctors, and clergy to come and speak about the subject of death. Be sure these professionals understand the learning limitations of persons in the group.
- Teach community standards of conduct at funerals and cemeteries, just as other forms of appropriate behavior are taught.
- Explain public displays of grief over the death of a family member which are acceptable. When a relative or an acquaintance has a terminal illness, or has been sick for a long time, discuss how your feelings may be different. He might feel relief, which can be an acceptable reaction when someone who has suffered great pain dies.
- Explain some popular euphemisms for death, such as, kicked the bucket, passed on, bought it, etc., as well as other death words they might hear that are new to them, like hearse, pallbearer, etc.
- Be careful in using the following phrases because they imply a cause of death: went to the hospital and died, died in his sleep, or got sick and died.



These activities may be conducted weekly over a period of a month or two. This will allow time for participants to think about and discuss their own feelings at each get together.

MAKING FUNERAL PLANS

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, complete and return them now. Completing these plans now will simplify the family's post-mortem duties.

- Use a funeral facts booklet (these are available from any funeral establishment, or your county Cooperative Extension Service listed under county government in your telephone directory) to gather and record necessary information.
- Look at obituaries in the newspaper and use them as a guide to write down facts about yourself. This helps the family remember the names and addresses of people to be included.
- Describe your funeral service: Where will it be? Who will participate?
- Kind of burial: Burial/cremation; Where?
- Plan for necessary payment: Prepaid? If not, how?

Now discuss these plans with your family member with a disability. Give him an opportunity to understand why you must plan this now. Use this as an 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, emotions and feelings that will be experienced,



and how we learn to cope with them, and have discussed plans for your own funeral, you may wish to learn how the person feels about planning for the end of his own life. Discuss who he would like to have attend the funeral, such as friends, co-workers, or neighbors. Learn if he has a special spiritual advisor he would like to have involved in the service. Make note of any favorite songs or stories that may be meaningful. Decide whether you will pre-arrange the funeral. Don't forget to indicate method of payment.

This is not easy to do, but PLAN AHEAD, DISCUSS WITH YOUR FAMILY MEMBER, SHARE WITH YOUR FAMILY; AND WRITE IT ALL DOWN.

REMINDER: HAVE YOU MADE A WILL? COMPLETED FINAL BURIAL ARRANGEMENTS? TALKED TO YOUR FAMILY? WRITE IT DOWN.







SECTION 2

THE PERSONAL INFORMATION SUMMARY



Developmental Disabilities Council, Inc.

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

PERSONAL INFORMATION SUMMARY

FOR:

Prepared by:

**Check or circle appropriate choices.
When necessary to add written answers, give as much detail as possible.**

Name:			Nickname:			
Social Security Number:		Medicare #:		Medicaid #:		
Date of Birth:		Place of Birth:				
Gender:	Male	Female		Race:		
Height:	Weight:		Eye Color:	Hair Color:		
US Citizen:	Yes	No		Registered to Vote:	Yes	No
Registered Selective Service:	Yes	No		Date Registered:		
Primary Spoken Language:						

BENEFITS AND SERVICES

**This section deals with government benefits and services provided to the person.
Check any that apply. Use reverse side or attach extra pages as needed.
Refer to the Financial Section for details regarding funding benefits.**

Person is now receiving:					
Social Security Benefits as:		Worker <input type="checkbox"/>		Dependent <input type="checkbox"/>	
Food Stamps	Housing Assistance	Medicare	Supplemental Security Income (SSI)	Medicaid	
Other Benefits:					

Takes part in the following programs:			
Program	Name of Provider	Phone Number	Paid By
Residential Habilitation			
Day Training (ADT)			
Sheltered Workshop			
Supported Living			
Supported Employment			
Respite Care			
Day Care			

Senior Center			
Homemaker			
Personal Care			
Transportation			
Other (Name)			

A consumer in the Developmental Disabilities Program?	Yes	No
On the Developmental Disabilities Home and Community-Based Medicaid Waiver?	Yes	No

District Phone #	Address

Support Coordinator is: (Name)	Address	Phone Number

Other Social Worker(s) Involved: (Name)	Address	Phone Number

RELIGIOUS AFFILIATION

Regularly attends religious services:	Yes	No
These services are held at:		
Address:		Phone Number:
Usually attends on:	(day)	AM PM
Is a member:	Yes	No
Requires assistance to attend:	Yes	No
Attends church related activities:	Yes	No

FAMILY and FRIENDS of MOTHER

Name:		
Current Address:		
Phone Number: (Home)	(Work)	Social Security No.:
Date of Birth:	Place of Birth:	Where Reared:
If Deceased, Date:		

Race:	Blood Type:	Religion:	US Citizen:	Yes	No
Served in Military:	Yes	No	Railroad Employee:	Yes	No
Number of Brothers:			Sisters:		
Marital Status:	Married	Widowed	Separated	Divorced	Single
Primary Spoken Language:					

Spouse (beginning with current):		
NAME	DATE OF MARRIAGE	DATE OF DEATH (D) OR DIVORCE (DI)

FAMILY and FRIENDS of FATHER

Name:					
Current Address:					
Phone Number: (Home)	(Work)	Social Security No.:			
Date of Birth:	Place of Birth:	Where Reared:			
If Deceased, Date:					
Race:	Blood Type:	Religion:	US Citizen:	Yes	No
Served in Military:	Yes	No	Railroad Employee:	Yes	No
Number of Brothers:			Sisters:		
Marital Status:	Married	Widowed	Separated	Divorced	Single
Primary Spoken Language:					
Spouses (beginning with current):					
NAME	DATE OF MARRIAGE	DATE OF DEATH (D) OR DIVORCE (DI)			

FAMILY and FRIENDS of BROTHERS AND SISTERS

NAME	ADDRESS	PHONE NUMBER	DATE OF BIRTH

List relatives who are emotionally closest to the person:

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

NAME	ADDRESS	PHONE NUMBER	RELATIONSHIP

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

NAME	ADDRESS	PHONE NUMBER	RELATIONSHIP (Personal, co-worker, neighbor, other)	LENGTH OF RELATIONSHIP (YEARS)

The following individual(s) has at times been an advocate helping get needed services and supports: (Identify with * if named official client advocate by the Developmental Disabilities Program.)

NAME	ADDRESS	PHONE NUMBER	RELATIONSHIP (Personal, co-worker, neighbor, other)

The person has _____ has not _____ learned self-advocacy skills.

HAS A CIRCLE OF FRIENDS (ORGANIZED SOCIAL GROUP):				YES	NO
Contact Person for Circle of Friends	Name		Address	Phone Number	
Frequency of Meetings:	Weekly	Monthly	Other		

A DAY IN THE LIFE OF: _____
(NAME)

List morning medications:						
Arises at:	AM					
Needs assistance with:	Hygiene		Dressing		Grooming	
Prefer:	Shower	Bath	Taken:		PM	AM
Aids or appliances used to get around include:						
Braces	Special shoes	Walker	Wheelchair	Crutches	Positioning aids	Other
Uses:						
Eyeglasses	Contact lens	Hearing aids	Telecommunication devices (TDD)		Communication board	
Other Communication Devices (list):						

Able to eat without help:	YES	NO	If No, needs help with:			
Uses:	Special plate	Special utensils	Special cup	Straw		
Has problems with choking:	YES		NO			
Is able to drink:	Thin Liquids		Thickened Liquids			
Usually ready to start the day at:	AM		By going to:			
Transported by:						

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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)						
SAFETY PRECAUTIONS						
Can the person be left unsupervised:			Yes		No	
For how long?	Minutes		Hours		Days	

Recognizes danger of: (Circle those that apply)			
Heat Sources	Poisonous Materials	Open Windows	
Sharp Objects	Hot Water	Traffic	
Can evacuate building on hearing alarm?		Yes	No
Needs physical/verbal prompt to evacuate building?		Yes	No

LIKES AND DISLIKES		
Likes		
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

LIKES AND DISLIKES		
Likes (con't.)		
Favorite foods, drinks, restaurants:		
FOODS	DRINKS	RESTAURANTS

Recipe for favorite foods may be found:

Favorite recreation:				
TV SHOWS	MOVIES	MUSIC	SPORTS	HOBBIES
OTHER:				

Dislikes	
Dislikes living with:	
Dislikes spending time with:	
Disliked pets:	
NAME	TYPE
Disliked clothing/possessions:	
CLOTHING	TYPE

Disliked recreation:				
TV SHOWS	MOVIES	MUSIC	SPORTS	HOBBIES
OTHER:				

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: (Circle those that apply)		
Strange people	Enclosed spaces	Buses
Animals	Open spaces	Loud noises
Heights	The dark	Cars
Other		

COMMENTS:

SPECIAL OCCASIONS					
Special dates usually observed:					
Holidays (Name which):					
Birthdays (Name and date):					
NAME			DATE		
Usually buys cards:	Yes	No	Attends party:	Yes	No
Usually buys gifts:	Yes	No	Price Range:	\$	\$

VACATIONS				
Activities enjoyed: (Circle those that apply)				
Group Day Trips	Arts and Crafts	Fishing	Visiting Neighbors	
Senior Center Activities	Community Outings	A Hobby	Taking Trips	
Visiting Family/Friend	Going to Recreation Parks	Specialized Camps		
Other (Describe):				
Traveling enjoyed:				
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	Amount range:	\$	\$	

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 Home Apartment	Shared Home Apartment	Family Home	Assisted Living Facility	Foster Home
Group Home	ICF/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	Med	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 we prefer is:

Own Home/ Apartment	Shared Home/ Apartment	Family Home	Assisted Living Facility	Foster Home
Group Home	ICF/DD	Residential Habilitation Center	Skilled Nursing Home	

Other (Describe):

If a group setting, preference for number of residents who live there is:

If 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:	Yes / No		

SPECIAL OCCASIONS			
Cannot use:			
Bus	Train	Taxi	Other:

EDUCATION					
School Records					
Last school attended:					
Name:				Phone Number:	
Address:					
Classes: Regular	Yes	No	Mainstreamed Special Education:	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 situations:	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

Continued on next page

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

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 these behaviors.

Did the person ever undergo grief counseling?	Yes	No
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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:

EMPLOYMENT/RETIREMENT						
During the day goes to:						
A regular job		Full time			Part time	
Activities program	Sheltered workshop		Service center		Volunteer	
Other:						
Receives health benefits:	Yes	No	Dress for work:	Uniform	Casual	Dress
Has a job coach:	Yes	No	Name		Phone Number	
Complete employment table on the next page if person has an employment record.						
It is anticipated that the person will be ready to retire by:						

Additional Notes:



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Continued on next page

GENERAL HEALTH INFORMATION

Provide a brief summary of 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 number 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:		

DISABILITY INFORMATION

Primary Diagnosis:	Cause, if known:
Secondary Diagnosis:	Cause, if known:

Other Chronic Health Conditions:	Yes	No
CONDITION	TREATMENT/MEDICATION	

Does person smoke?	Yes	No	Amount:	
Drinks alcohol?	Yes	No	Amount:	
Use recreational drugs?	Yes	No	Drug Used:	Frequency:

CURRENT PHYSICIAN

Name	Profession	Phone Number	Date Last Seen
	Primary physician		
	Dentist		
	Optometrist/Ophthalmologist		

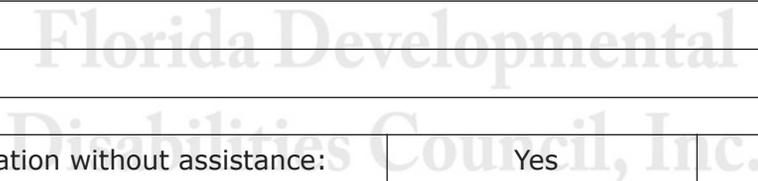
Specialists and other health care providers (speech/physical therapist, nutritionist, nurse practitioner, psychologist, etc.):

ALLERGIES (Food, Medicine or Substances)

List:

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

Non-prescription (over-the-counter) medicines taken for headaches, colds, constipation, skin problems, indigestion, etc. Indicate whether as needed or regularly and for what condition:



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 medication:	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.

Special equipment or assistive device(s):				
Device	Purchased at:	Maintained at:	Phone Number	Method of Payment

Signs own consent forms for health care:	Yes	No	Copies are located:
Has signed an advance directive:	Yes	No	Copies are located:
Living Will:	Yes	No	Copies are located:
Health Care Surrogate: Name	Copies are located:		
Do not resuscitate order:	Yes	No	Copies are located:
Carries a copy in wallet or purse	Yes	No	*Attach a copy 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:

Reason	Emergency (Yes or No)	Hospital (Location)	Date

Surgery (an operation):			
Reason	Name of Surgeon	Hospital (Location)	Date

Presently receiving physical or occupational therapy:			
Type of Therapy	Therapist's Name	How Often	Date Started

Receiving Mental Health service:			
Type of Services	Physician's Name	How Often	Date Started

The following activity (e.g., being overheated) results in seizures:

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

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

Task Needed	How Performed

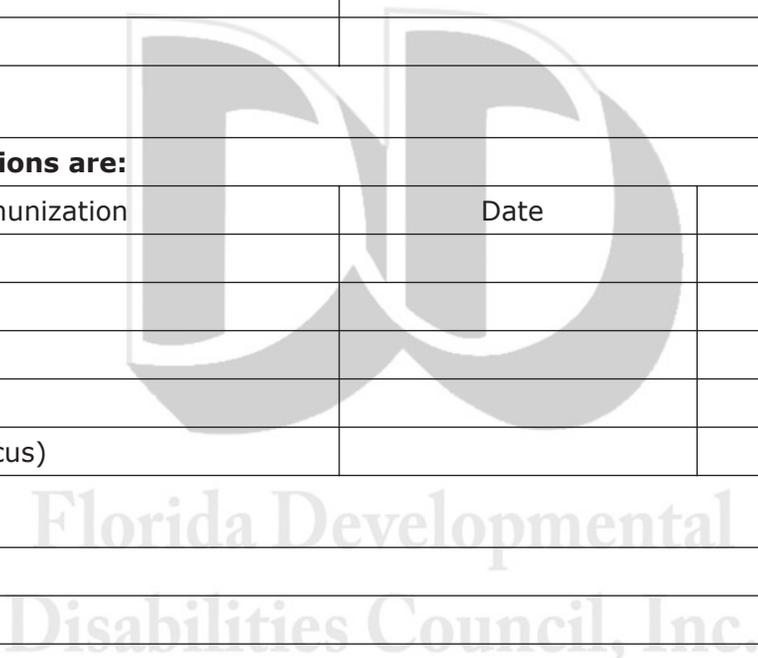
Date of adult immunizations are:

Name of Immunization	Date	Booster(s) Date
Tetanus and Diphtheria		
Measles		
Hepatitis B		
Flu Shot (Influenza)		
Pneumonia (pneumococcus)		

Special Diet:

Special Food Preparation:

Functions sometimes requiring assistance:



Life Area			Help Needed
<i>Thinking / Understanding</i>			
<i>Seeing / Vision</i>	Normal	Normal with Glasses	
	Impaired	Legally Blind	
	Last Eye Exam:		
	Frequency Required:		
<i>Hearing</i>	Normal	Normal with hearing aid	
	Hypersensitive	Impaired	
	Deaf		
<i>Speech</i>	Normal	Uses sign language	
	Impaired	Uses Communication Device	
<i>Mobility</i>	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 Check-up	
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:			
Urinary Infections	Frequent Urination		Bladder Leakage (Frequency):

PROTECTING LEGAL RIGHTS AND FINANCIAL STATUS

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.

Person needs assistance with:				
Banking	Paying Bills	Making Purchases	Counting Money	Recognizing Denominations of Money

Financial Safeguards:		
Two Signature Checking Accounts	Representative Payee	A Trust
Other (Describe):		

Name of Trust:			
This trust is:	Revocable	Special Needs	Irrevocable

TRUSTEES	NAME(S)	ADDRESS(ES)	PHONE NUMBER(S)
Current			
Successors			
Copy of the trust can be found:			

POWER OF ATTORNEY				
Has power of attorney been given to anyone:	Yes	No	Limited	Durable
If Yes, Name:			Phone Number:	
Address:				

REPRESENTATIVE PAYEE		
Does a representative payee receive benefits for the person?	Yes	No
Name:		Phone Number:
Address:		

Does the person receive?	Yes/No	Amount Per Month
A pension / retirement income?		
Trust income		
Social Security benefits		
Supplemental Security income		
Other benefits / income (specify):		

BANKING INFORMATION			
Name of Bank	Name (s) on Account (Signature Authority)	Account #	Type (Savings, Checking, Joint)

FUTURE BENEFITS		
Is person named as beneficiary of another's person's policies or accounts?	Yes	No
Policy Holder:		
Name	Address	Phone Number

Insurance Company (Name)	Address	Policy Number

GUARDIANSHIP				
A guardian has been appointed.	Yes	No		
Type of guardianship:				
Plenary Guardian	Limited Guardian	Guardian Advocate	Co-Guardian	Co-Guardian Advocate
Date of appointment:	City	County	State	

A copy of the guardianship court order, and/or case number can be found (name, place or person)			
Name of Guardian, Guardian Advocate, and Co-Guardian	Relationship	Address	Phone Number

Name areas for which guardian must give consent:

Has a standby guardian been appointed?	Yes	No
--	-----	----

Name	Address

**PARENT/FAMILY WILLS
Responsible Party Information**

In my will, I have named the following to be the personal representative of my estate:

Name	Address

Attorney's name:

Address: _____ Phone Number: _____

Disabled person has made a will? Yes No

Attorney's name:

Address: _____ Phone Number: _____

The disabled person is named as beneficiary in other wills: Yes No

Testator(s) Name	Address	Phone Number

Copy of this will can be found:

Name	Address

Florida Developmental
Disabilities Council, Inc.

INSURANCE COVERAGE

The person is also covered by the following insurance:

Type of Policy	Policy Number	Company	Address
Life			
Health			
Dental			
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

FINAL ARRANGMENTS					
Persons 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	Prepaid:	Yes No
Burial plot purchased:		Yes	No	Headstone/Marker	Yes No
Type of Marker preferred and epitaph:					
If prepaid, policies/contracts can be found:					

Florida Developmental Disabilities Council, Inc.

Cemetery/Mausoleum Name:	Address	Other:

Preferred funeral company (if applicable):		
Name:	Address	Phone Number

Cremation:		
Burial of ashes		Internment of Ashes
Ashes Given to:	Name	Address

Memorial Service:	Yes	No	Location:
Special content of service:	Yes	No	Describe:
Flowers	Yes	No	Specified donations:
Songs to be played:			

Invite these persons to the service:		
Preferred Clergy/ Eulogist	Address	Phone Number

QUICK REFERENCE			
Is currently known to the following developmental disabilities professionals:			
Social Worker:		Phone Number:	
Support Coordinator:		Phone Number:	
Other professional (coach, supervisor, etc.):			
Agency Title:		Phone Number:	
Needed services or benefits that have not been provided are:			
Name of Service (Benefit)	On Waiting List		
	Yes	No	

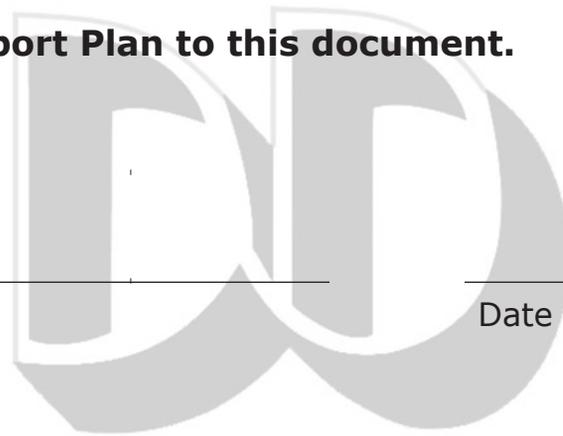
The current support plan is attached to this Information Summary.	Yes	No
The date(s) when the next Support Plan is due is:	____/____/____	____/____/____
____/____/____	____/____/____	____/____/____

Date Personal Information Summary has been updated:		
Page	Date of Change	Signature

Page	Date of Change	Signature

Include current photograph.

Attach Support Plan to this document.



Authority Signature

Date

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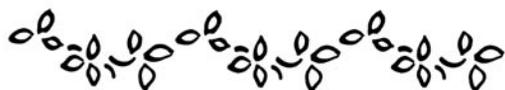
SECTION 3

HELPFUL ATTACHMENTS



Developmental Disabilities Council, Inc.

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



Suggested form of a Living Will, Florida Statutes Section 765.303.

A living will may, BUT NEED NOT, be in the following form:

LIVING WILL

Declaration made this _____ day of _____ 2_____, I _____
Willfully and voluntarily make known my desire that my dying not be artificially prolonged
under the circumstances set forth below, and I do hereby declare that, if at any time I am
incapacitated and

_____ (initial) I have a terminal condition.

or _____ (initial) I have an end stage condition.

or _____ (initial) I am in a persistent vegetative state.

and if my attending or treating physician and another consulting physician have determined
that there is no reasonable medical probability of my recovery from such condition, I direct
that life-prolonging procedures be withheld for withdrawn when the application of such proce-
dures would serve only to prolong artificially the process of dying, and that I be permitted to
die naturally with only the administration of medication or the performances of any medical
procedure deemed necessary to provide me with comfort care or to alleviate pain.

It is my intention that this declaration be honored by my family and physician as the final
expression of my legal right to refuse medical or surgical treatment and to accept the conse-
quences for such refusal.

In the event that I have been determined to be unable to provide express and informed con-
sent regarding the withholding, withdrawal, or continuation of life-prolonging procedures, I
wish to designate, as my surrogate to carry out the provisions of this declaration:

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

I understand the full import of this declaration, and I am emotionally and mentally competent
to make this declaration.

Additional Instructions (optional):

(Signed): _____

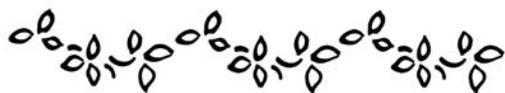
Witness _____ Witness _____

Street Address _____ Street Address _____

City, State, Zip _____ City, State, Zip _____

Phone _____ Phone _____

*The principal's failure to designate a surrogate shall not invalidate the living will
~ This form offered as a courtesy of The Florida bar and the Florida Medical Association ~*



Suggested form of a Health Care Surrogate, Florida Statutes Section 765.203

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 _____ Zip _____

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 _____ Zip _____

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: _____

Witnesses
1. _____
2. _____

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

~ This form offered as a courtesy of The Florida Bar and the Florida Medical Association ~



My Personal Outcomes

WHO AM I?

What goals have I set for myself?

Where and with whom do I want to live?

What do I want to do for my work?

Who is closest to me?

How satisfied am I with the services and supports I receive?

How satisfied am I with my personal life situation?

MY SPACE

What are my preferred daily routines?

Do I have the time, space and opportunity for the privacy I need?

Am I in control of who knows personal information about me?

Do my home, work and other environments support me to do what I want and need to do?

MY COMMUNITY

Do I have access to the places I want to be?

Do I participate in what happens in my community?

Am I pleased with the type and extent of my interaction with other people in my community?

Am I known for the different social roles I play?

Do I have enough friends?

Am I respected by others?

MY SUCCESSES

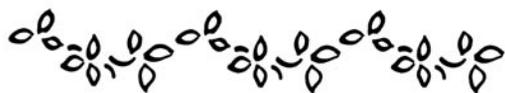
Are the supports and services I receive the ones I want?

Have I realized any of my personal goals?

MY SAFEGUARDS

Am I connected to the people who support me most?

Am I safe?



MY RIGHTS

Do I exercise the rights that are important to me?

Do I feel that I am treated fairly?

MY HEALTH

Is my health as good as I can make it?

Am I free from abuse and neglect?

Do I have a sense of continuity and security?

The Personal Outcome Measures (often referred to as the “POMs”) are 25 areas of a person’s life that are used to discover who you are and what is important to you. Support Coordinators and providers are encouraged to discuss with you the POMs and other person-centered approaches to discover important aspects of your life. The POMs also look at very critical foundations in your life such as

- health and safety,
- continuity and security,
- rights and fair treatment,
- abuse, neglect and exploitation, and
- respect.

The Council on Quality & Leadership developed the Personal Outcome Measures. You can find out more about the Personal Outcomes by visiting the Council’s website at **www.thecouncil.org**.

(Footnotes)

¹ **The Personal Outcome Measures are copyrighted by the Council on Quality and Leadership.**



Bill Of Rights

*I*n June of 1975 the Governor of Florida signed in to law the “Bill of Rights”. The purpose of this law is to give importance to rights for individuals with developmental disabilities who are citizens of Florida. These rights include:

The Right to dignity, privacy and humane care,

The Right to religious freedom and practice,

The unrestricted Right to communication,

The Right to personal possessions and effects,

The Right to education and training,

The Right to participate in community activities and to social interaction,

The Right to prompt and appropriate medical care and treatment,

The Right to behavioral and leisure time activities,

The Right to physical exercise,

The Right to humane discipline,

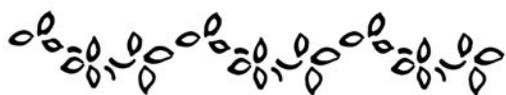
The Right to physical examination prior to subjection to a treatment program to eliminate bizarre or unusual behaviors,

The Right to minimum wage protection and fair compensation,

The Right to vote,

The Right to be free from physical restraint, and

The Right to a central record.



Redesign Initiatives – A Brief Overview

*I*n February 2002 the Department of Children and Families, Developmental Disabilities Program, now the Agency for Persons with Disabilities, began working with the Agency for Health Care Administration and stakeholders ~ individuals with developmental disabilities, their family members, service providers and other advocates ~ on a system of redesign of the Home & Community Based Waiver. That redesign addressed seven components:

- appropriate assessment,
- individual budgets,
- flexible services,
- fair and equitable rates,
- a redefined role of support coordinators,
- direct billing for providers, and
- communication.

The appropriate assessment developed for use by the Developmental Disabilities Program is called the Individual Cost Guidelines (ICG) and replaces the Florida Status Tracking Survey. It is a tool for predicting a person's individualized costs and may only be administered by someone who is trained and certified in its use. In September, 2003 the program began using this new tool which serves as the first step in the support planning process.

The individual budget is based on the results of each person's ICG, and is considered the second step in the support planning process. Using the individual's needs identified on the ICG, and incorporating the standardized statewide rates for services, the state is able to approximate one's individual budget. Another tool that was developed for use during this part of the process was the Personal Budget Worksheet, which can be used to identify costs related to ALL needs and preferences for the person. It can serve as an aid during the planning and decision-making process.

A system of flexible services was proposed that would make it easier for individuals to move their approved cost plan dollars around and change services based on the changing needs of their lives. The 32 current waiver services were collapsed into eight broad categories of similar services. The implementation of this component is still in the development stage.

In July 2003 the Developmental Disabilities Program instituted a new statewide standardized rate system for all Medicaid Waiver providers. The purpose of the rate system was to establish statewide rate consistency and to accommodate current and long-term system funding needs. These new rates are driven by direct care staff salaries and provide multiple fixed rates with limited exceptions.



Stakeholders requested a change in the responsibilities of waiver support coordinators so that they could increase assistance to individuals. Direct-provider billing allowed Medicaid Waiver providers to submit invoices for payment directly to Medicaid. That change eliminated that task from the responsibility of waiver support coordinators. With the introduction of standardized rates, support coordinators no longer needed to be involved in rate negotiations.

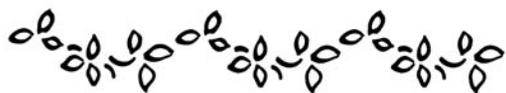
Another change in support coordination includes the creation of a limited support coordination option. Individuals who live with families can now opt for less support from the support coordinator. The agency has established a specific policy for limited support coordination. If you feel you are interested in limited support coordination, you should thoroughly review and research this alternative and talk with your support coordinator or staff at the agency before making this change.

The final component of the system redesign is improved communication:

- Regularly send E-Bulletins
- Conduct district forums
- Improve the DD website
- Expand Choice Counseling to all individuals receiving services from the agency (previously only available to persons in ICFs)
- Strengthen the role of the Family Care Councils, and
- Implement web-based training

The Developmental Disabilities Program began regularly sending E-Bulletins to anyone interested in keeping up with the changes and learning more about services and supports. Their web site was updated and expanded. It continues to be a source of up-to-date information about the program. The web-site address is **www.apd.myflorida.com**.

The system redesign that began in 2002 was the beginning of changes that are meant to improve the program for individuals with developmental disabilities. Following the 2003 legislative session, the Consumer Directed Care Plus Waiver was approved by CMS as a Florida waiver. It allows Florida to continue the Robert Wood Johnson Consumer Direct Care pilot project and is open to individuals who were part of the experimental project and those who were participating in the Choice and Control pilot. Further expansion of this waiver has not been determined yet. During the 2004 session, the Florida Legislature expanded the Family Supported Living waiver and opened it to children, as well as adults. Five services are available through this waiver and it will be offered to people who are on the waiting list for services. In addition, the Legislature created the Agency for Persons with Disabilities. The new agency will take responsibility for the Developmental Disabilities Program and the Developmental Services Institutions (including the Mentally Retarded Defendant Program ((MRDP)) on October 1, 2004. A Blue Ribbon Task Force was formed to address the many aspects of forming the Agency for Persons with Disabilities. The final report from this task force is available on the APD website. Users of this guide are highly encouraged to visit the referenced web site for updates and changes.



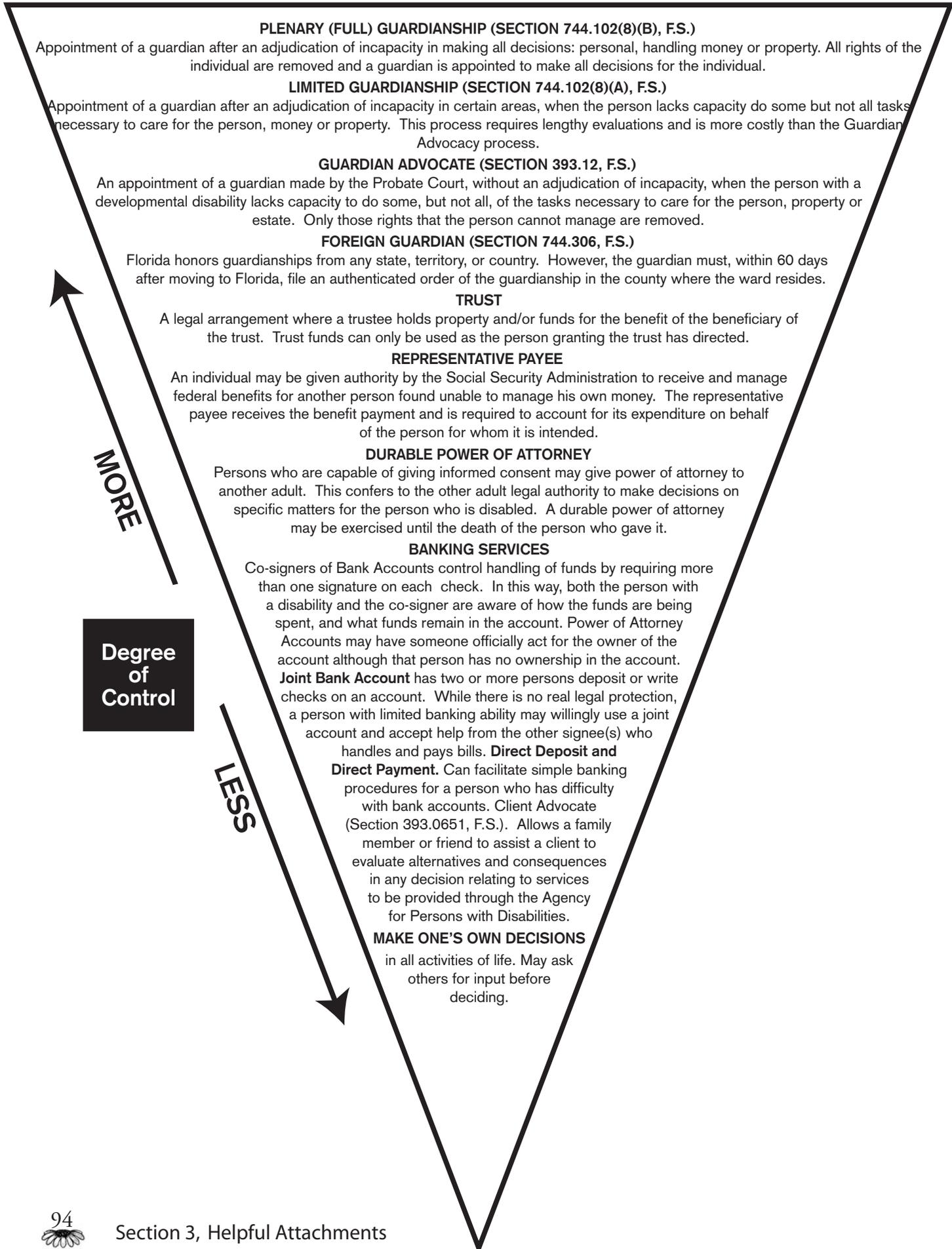
A Comparison Of Guardianship Statutes

Chapter 393	Chapter 744
<p>Petition to determine incapacity: NONE</p>	<p>Petition to determine incapacity: Petitioner alleges person to be incapacitated, specifying information on which belief is based; states which rights enumerated in statute is incapable of exercising. The petition for appointment of a guardian must be filed WITH this petition</p>
<p>Examining Committee: NONE. Existing evaluations that have been performed by the appropriate professionals for the alleged disability are used, as well as any other existing evaluations and support plans that exhibit the need for appointment of a guardian. These are usually evaluations that have been used to determine eligibility for services in the Developmental Disabilities Program and plans identifying which services are needed.</p>	<p>Examining Committee to determine incapacity: 3 members – One must be psychiatrist or other physician; one may be either a psychologist, gerontologist, another psychiatrist or other physician, a registered nurse, nurse practitioner or licensed social worker; one may be any of the above. One member of the committee must have knowledge of the alleged disability. Members of the committee may not be related to or associated with one another or with the petitioner or alleged incapacitated person. Petitioner or family physician MAY NOT be on committee. However, if the family physician is available, the committee MUST consult with him/her.</p>



<p>Adjudicatory hearing to determine incapacity:</p> <p>NONE</p>	<p>Adjudicatory hearing to determine incapacity:</p> <p>Alleged incapacitated person must be present unless waived by him/her. Partial or total incapacity must be established by clear and convincing evidence.</p>
<p>Petition for appointment of guardian advocate:</p> <p>Must state name, age, address of petitioner and relationship to person with DD, specify why person needs a guardian advocate and areas of incapacity; state name of proposed guardian advocate.</p>	<p>Petition for appointment of guardian:</p> <p>Must be filed with petition to determine incapacity.</p>
<p>Removal of rights:</p> <p>Only those rights that evaluations and testimony of witnesses have identified are delegated to the appointed guardian advocate.</p>	<p>Removal of rights:</p> <p>Rights the committee has identified as those the individual cannot perform are removed and given to the appointed guardian advocate.</p>
<p>Fees:</p> <p>NONE. (If person with the developmental disability cannot afford counsel, the court shall appoint one to represent the person.)</p>	<p>Fees:</p> <p>Examining committee and attorney appointed are paid from general fund of the county and county has a creditor's claim against guardianship property.</p>
<p>Hearing for appointment of guardian advocate:</p> <p>Is held as soon as practicable after petition is filed, but reasonable delay for investigation, discovery, or procuring counsel or witnesses shall be appointed.</p>	<p>Hearing for appointment of guardian:</p> <p>May be held at conclusion of hearing on incapacity.</p>

LEGAL WAYS OF PROTECTING RIGHTS





Guardianship To-Do List

(Step-by-Step Procedure)

This is a short reminder list – like your grocery list – of what you can expect to be involved in IF you decide that you NEED to seek guardianship. It is based on what you have learned from Chapter 8 of PLANNING AHEAD.

1. Determine what is the least restrictive and most appropriate action you need to take:
 - Durable power of attorney
 - 393.12 – Guardian Advocate
 - 744 – Guardian

2. It is assumed that you have decided that need to become a guardian advocate as found in Chapter 393, F.S.
 - Select an attorney (with input from the “potential ward” to the extent possible)

3. Engage your selected attorney and provide him/her with the most current evaluations from:
 - School
 - Agency for Persons with Developmental Disabilities
 - Psychologists, Physicians, or Others who can document incapacity

4. Discuss with your attorney who you wish, and who is willing, to be **standby guardian**.

5. Involve the potential ward in the process helping him/her understand what the outcome will be, the process for getting there, and what his/her role will be.

6. Sign the petition for guardian advocate (393.12, F.S.)

7. With the potential ward, attend the hearing and be prepared to testify if requested by your attorney.

8. When court order is received, read it. Make certain it is clearly understandable. Notify appropriate service providers, offices, and agencies by providing them with a copy of the order when appropriate.

9. Annually provide the court with an annual report for the past year as well as a guardianship plan for the following year.

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