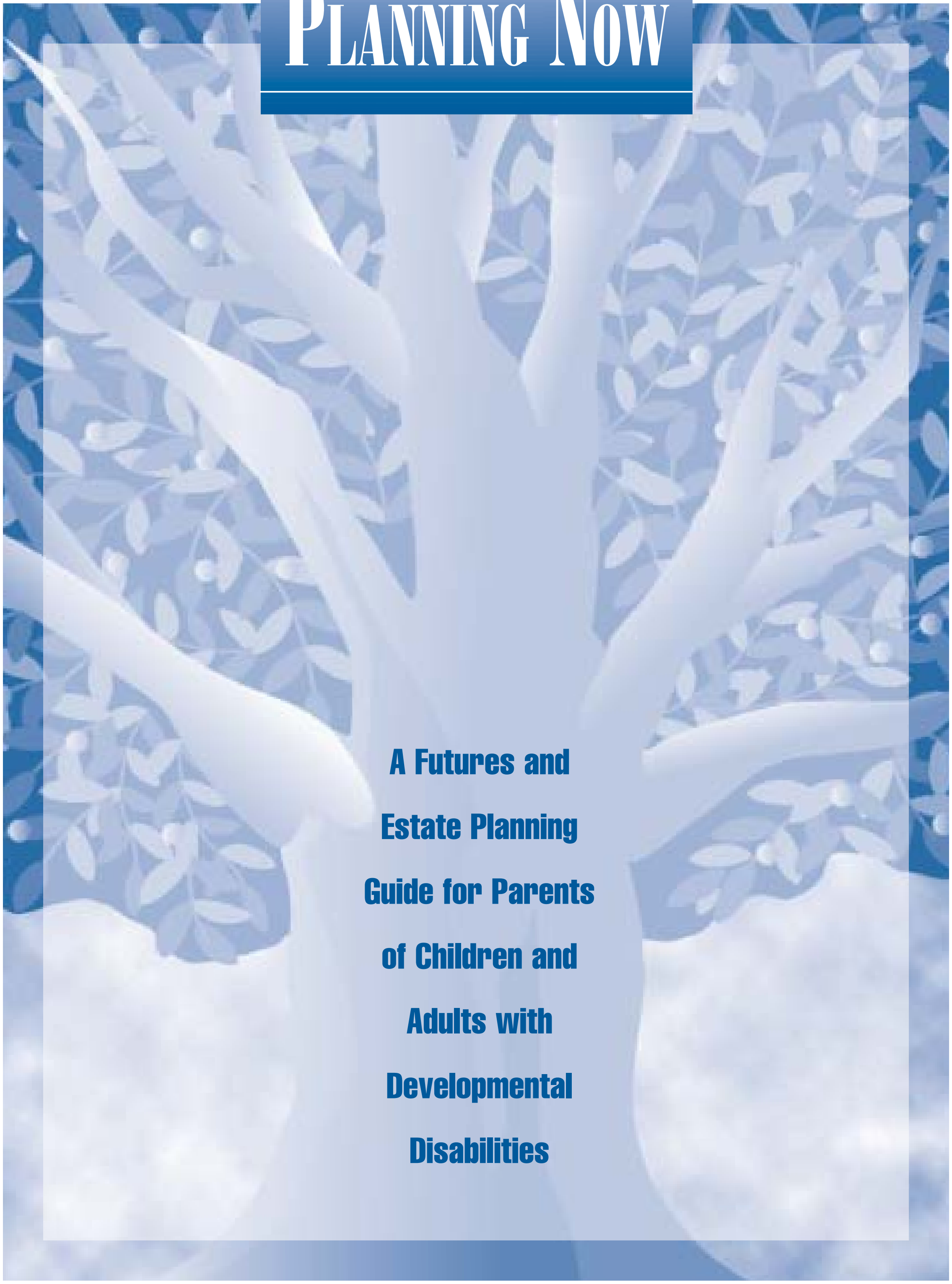
PLANNING NOW



A Futures and Estate Planning Guide for Parents of Children and Adults with Developmental Disabilities

MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

PLANNING NOW

The Maryland Developmental Disabilities Council encourages you to copy and share the information in *Planning Now: A Futures and Estate Planning Guide for Parents of Children and Adults with Developmental Disabilities*. We ask that you credit the Council.

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A Message from the Maryland Developmental Disabilities Council

Raising any child to adulthood is full of challenges. For parents of children with disabilities, concerns about their sons' and daughters' futures are magnified. Some people with developmental disabilities will have a high degree of independence and others will need one or more advocates looking out for their interests all of their lives. Many people with developmental disabilities need support with some areas of their lives.

It is often difficult for parents to envision the future of their children with disabilities. However, with adequate planning and the right combination of support from a network of family, friends, and the disability service system, your son or daughter can lead a productive, satisfying life. Failing to plan could leave your child in an emergency situation with your hard-earned money not being used the way you intended.

Families in greater numbers than ever before are interested in planning for their minor children or their adult children with disabilities: where they will live, how they will receive needed support, and how the costs will be covered. Comprehensive planning should begin now. Review your plan and change it as your child grows older and circumstances change. As your child gets older it is important to plan with him or her. There are many things families can do to envision a desired future and to take steps to realize their vision.

Having a vision for your child's future (and helping your child develop his or her own vision as he or she gets older) and planning for that future are very important regardless of the type and severity of your child's disability, the make up of your family, or the amount of money you may have to plan with. Some goals may only be accomplished with a certain amount of money, but other wishes can be realized in other ways.

By planning, you can better assure that your child's personal and financial future is what you — and your child — desire and need. Your planning will help maximize your child's independence and dignity and the control he has over his own life. Through this planning, you can picture the involvement of your friends, relatives and service providers and direct any resources you may want to help. And you can picture your child in a community of people, with friends, a job or other meaningful activities and with needs and wishes fulfilled. This can happen with families whose children have significant disabilities, as well as those whose children have milder disabilities.

Picking up this guide may have been your first step. *Planning Now: A Guide for Parents of Children and Adults with Developmental Disabilities* will help you along the way.

Jeff Rivers
Council Chairperson

Brian Cox
Executive Director

Overview of the Guide

Planning Now considers some basic questions:

- How can families assist their adult children now, or their minor children in the future when they enter adulthood, to live where and with whom they want with the support they need?
- How can parents, during their lifetimes, assist their adult children to access a typical life outside the family home?
- How can parents or other relatives plan to help their loved one with a disability upon their death?
- How can they assist their family member to rent or buy a home?
- How can they design, establish and afford necessary support?
- How can they avoid jeopardizing essential public medical and financial benefits (like Supplemental Security Income and Medicaid)?

Planning Now discusses the importance of planning; provides essential information, suggestions, and a framework for planning; and then explains various tools and resources to assist you. We also talk about the types of professionals who can help, and provide useful worksheets and additional resources in the appendix.

You can use this information to develop a plan for helping your child become more independent and grow into an adult lifestyle while you are alive. You can also use this guide to design a plan for your child that others implement after your death.

There are as many individual circumstances as there are families with a child who has a disability. All financial, legal and planning options should be considered in order to work toward the vision you, your family, and your child have for the future.

We encourage you to review this entire guide, and other resources provided in the appendices, as you begin your planning and choose the pieces that apply to your family. Contact information on all organizations and resources referred to in *Planning Now* can be found in *Appendix B*.

Good luck!

About this Guide

Planning Now is not a do-it-yourself guide. Rather it is intended to explain important issues and ideas for you to consider; provide a basic understanding of financial, legal and planning tools that may help you organize and develop your plan; and assist you to select and work effectively with planning professionals. This guide is not intended to take the place of appropriate professional assistance.

Planning Now was written for parents who have a son or daughter of any age with a disability. It will be useful, as well, for other family members, close friends, and professionals like service coordinators, financial planners, attorneys and others who help families plan.

The guide is intended to provide information and ideas that are useful to families, regardless of how many, or how few, assets they may have.

For readability, we use the word “your child” to refer to adults and minor children. We also occasionally use “he” and “she” interchangeably but are always referring to both boys and girls, and men and women.

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All information is correct to the best of our knowledge as of April 1999. However, because government benefits, laws, regulations and programs change, we urge you to verify information when you begin planning.

This publication is designed to provide accurate information regarding the subject matter covered. It is provided with the understanding that the authors and publisher are not engaged in rendering legal, financial or other professional service. Some information may be specific to Maryland.

Families are strongly encouraged to consult with an attorney and other professionals who have knowledge and expertise in estate planning as it pertains to the particular needs of people with disabilities.

Acknowledgments

Planning Now would not have been possible without the contribution of time, talent and ideas of many people. Early on, Delegate Sandy Rosenberg, Lorraine Sheehan, Naznin Adams, Kathy Cooper, Marge Gold, Nancy Kirchner, Susan Tager, and David Tomlinson took time to help us consider pertinent issues and set our course for this guide.

We thank Cathy Raggio for insight and contributions to the text and Sue Kullen for ideas about creative planning. We also appreciate contributions to the text by Cathy Lyle, Polly Huston and Berenda Riedl, and Paul Margolis of Smith Barney who contributed to the section on trusts.

Our source for the Financial Planning section and related materials in the appendix was *Facts About Financial Planners* by the American Association of Retired Persons, with additional information from the Institute of Certified Financial Planners, the International Association for Financial Planning, and Merrill Lynch. We appreciate AARP's willingness to share its well-reasoned guidance and thank Liz Oates of Merrill Lynch for our discussions on this topic.

Other guides that served as sources of information and/or ideas are *A Family Handbook on Future Planning* by The Arc of the United States, the *Community Supported Living Series* by the Wisconsin D.D. Council, and *The Fair Housing Act: Opening Doors for People with Disabilities* by the Bazelon Center for Mental Health Law.

Research of publications and pertinent activities throughout the country helped us formulate our ideas for *Planning Now*. We thank Meg Grigal for gathering and synthesizing this information. We also acknowledge Ralph Moore's work on an Estate Planning guide written for the Council in the 1980s when little information existed and his valuable feedback on this guide.

Louise Gonzales, Eileen Hislop, Gretchen Holtzinger, Catriona Johnson, Becky Laatsch, Sara and Sheldon Larmore, Pam Miller, Linda Nelson, Jane Pierson, and Ethel Zelenske provided careful review and valuable feedback on drafts. Likewise, Ken Brown of the Social Security Administration helped assure the accuracy of our information.

This publication could never have materialized from an early idea of a planning guide to this substantial work without the commitment and vision of Brian Cox. The Council is indebted to him for his longstanding work, energy, and expertise.

Finally, we thank the parents who, with sincere generosity, shared their personal stories with us, as this helped guide our work. This included Susan and Doug Holland, Jackie and Michael Golden, Kathy Cooper, Bill and Ann Buchanan, and countless others over the years.

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Introduction to Futures Planning and Estate Planning

What are “futures planning” and “estate planning” and why might they apply to you? Why should you plan and how do you start? These and many other questions are answered as we address myths about planning for the future and help guide you through the process.

“Nobody can really guarantee the future. The best we can do is size up the chances, calculate the risks involved, estimate our ability to deal with them and make our plans with confidence.”

— Henry Ford

Introduction to Futures Planning and Estate Planning

What are Futures Planning and Estate Planning?

"Futures planning" encompasses many things. Typically it refers to envisioning a desired future for yourself, a family member, or a friend and then identifying the people, resources and services needed to make all, or part, of the plan a reality. When planning with your child, the focus can be on the future while you are still living, as well as for after your death.

"Estate planning" generally refers to steps individuals or couples take to direct what will happen to their money and other assets after death and is one aspect of futures planning. Estate planning can help people in all types of financial situations. Most people want to direct how their money or assets will be distributed, minimize taxes, and choose who will care for their minor children. Parents may name people who will provide support for an adult family member with a disability who needs assistance. They may accomplish this by setting up a plan that includes a will, letter of intent, supplemental needs trust and/or other pertinent documents.

When we think of planning for the future, we often think of financial planning. Financial planning is actually the means to an end and should come after you've envisioned a desired future. As a part of the financial planning process, you will identify costs associated with the plan, evaluate your resources, consider what you can accumulate through investments, and identify other resources that might help. It is similar to planning for retirement. You know you need to save money but the amount depends on at least a general notion of what you want to do in your retirement.

The same approach applies to planning for your child with a disability. Prior to considering your resources, you need to reflect on the key elements of your child's current lifestyle that are important to maintain in the future, what you and your child want in the future, and what supports will likely be needed to make this happen. Keep in mind that it is natural for plans to change over time.

A good futures plan has a financial component that structures how assets are to be managed and spent on behalf of a person with a disability and names who will have authority to handle the assets. It may outline who will help the individual with a disability make other life decisions, if necessary, such as where he or she will live or what type of health care he or she will receive. It may also name a coordinator who will be available to advocate for the person with a disability, to make sure that appropriate supports and other services are provided, and that those supports are updated as the individual's needs change.

Parents who have a child with a disability may encounter special issues related to their family member's care and support. These issues may range from obtaining public benefits, communication devices, education, employment, housing, and transportation to ensuring such things as favorite foods, recreation and visits with friends.

The most important part of a futures plan is that it is created for each particular family's situation and offers guidelines, but is also flexible enough to be used in the future. It encourages the person with a disability to make decisions as he or she becomes an adult, while providing guidance only as needed. No one knows what the future holds, but it is very empowering and comforting to have thought about the possibilities for your child and to have planned accordingly.

Families should seek an attorney who understands not only estate planning issues but who also is knowledgeable about government benefits and understands, and is sensitive to, the needs of people with disabilities. The futures plan may also require the services of a financial planner, accountant, or life insurance broker to accomplish your goals. It may also depend on family members, friends and other advocates who are familiar with the service system as well as public and private resources available in the community.

Why Plan for the Future?

People with disabilities may need significant assistance and support from others, so changes involving the important people in their lives can be especially disruptive. A futures plan enables parents or others currently providing support to set up alternatives in the event something happens that will make them unable to continue in a supportive role. Generally speaking, we make better and more comprehensive decisions when we plan rather than acting in the midst of a crisis.

The purpose of any plan is to gain some control over what will happen if (or when) some significant event occurs. While the future is unknown, we know some things will happen, such as the eventual loss of a parent.

Many other major life changes, however, come as a surprise. For example, if a mother who has supported her son for his entire life suddenly becomes incapacitated or dies, someone else may have to help support her son. Her son will have the difficulty of coping with the loss of his mother while he is also getting used to new people in his life. If his mother has established a futures plan, she will have arranged for people in his life to help with the transition. She may have lined up support services through programs familiar with her son's needs and interests. Ideally, these people can step in, according to the prearranged plan, so that the transition will be smoother and less traumatic.

Government benefits — both financial assistance and health care benefits — are very important for many people with disabilities. Many parents have thought, or been told, that they should not leave money to their child with a disability or their child will lose public benefits such as Supplemental Security Income (SSI) or Medicaid. On the contrary, the fact that someone is receiving benefits should be an incentive to begin planning. A plan can ensure that a person keeps needed benefits and is able to use the additional assistance from family to purchase items that government benefits do not cover to enrich his or her quality of life.

Lack of Planning = Undesirable Outcomes

According to state law, if you die without a will, your children will directly inherit money and other assets. If your child with a disability receives SSI and Medicaid (or could qualify for these benefits when he or she becomes an adult), the following is likely:

1. Your child will lose his benefits and have to use the inheritance for daily living costs and health care. Few inheritances are large enough to cover these costs for long. The needs you intended to meet with your money could go unmet.

2. If your child receives services funded by the Developmental Disabilities Administration (e.g., residential and day/employment services), the inheritance can be claimed by the state to cover the cost of these services until it is depleted. These services typically cost tens of thousands of dollars a year for one person.

Some individuals have disabilities that affect their capacity to manage money or make financial decisions. A futures plan can name someone to manage assets on behalf of a person with a disability. A plan can be very structured or somewhat flexible, but should be made while keeping in mind the physical and emotional needs of your child, as well as his or her assets and government benefits. Parents can leave assets to a trustee acting on behalf of their child with a disability, while preserving their child's eligibility for public benefits. A trust can also own a house, cash from savings or life insurance proceeds, or other property.

A futures or estate plan cannot make the future predictable, but it can establish a framework to deal with the changes and minimize the disruptions and transitions. Setting up a plan now can enable your family to make informed decisions together, taking into consideration all options, rather than having to act under pressure or having a court make those decisions. It also allows you to act before a key person dies or cannot participate due to illness or other unexpected changes.

When Should You Start Planning?

It is never "too early" to start planning. And it is never "too late" either. However, the earlier you start, the more options you are likely to have. The decisions that are part of futures planning are not only legal and financial decisions but also those that will determine what your child's life will be like when you or other providers of support are no longer available. Planning can help your child live where, and with whom, he or she chooses. It is wise to establish a plan early in your child's life, and to adapt it as his or her needs and capabilities change. Parents of minor children who do not receive government benefits may believe that they do not need to establish a futures plan until their child becomes an adult or becomes entitled to benefits. But futures planning looks at the "big picture" which entails more than finances.

A futures plan requires you to consider your child's life now and envision what you and your child want it to be as he or she gets older. It requires you to ask yourself what you need to do to ensure that important supports will be there for your child to help him or her have the life you both envision. If you have not started early in your child's life, evaluate where you are and start now.

Remember that a futures plan may involve many parts that work together. Some parts of the plan may be somewhat informal such as communicating to other family members about your ideals for your child through a "letter of intent." Other parts, such as trusts and wills, are very technical and usually require the assistance of an attorney knowledgeable about disability related issues. We discuss all of these tools later.

One Plan Does Not Fit All

Each individual and each family is unique. Therefore, each futures plan also will be unique. Important thoughts while you are setting up a futures plan may include:

- Do you have other children, and if so, what are their current and future needs?
- What assets do you want to leave to your child with a disability and/or to your other children?
- What types of support does your child need?
- How can you maximize your child's independence and ability to enjoy the highest quality of life possible?
- Who else in your child's life should be involved in the planning process?

For each person asking these questions, the answers will vary widely. Your attorney will have certain legal issues to address, but should listen to your goals and expectations and work them into the plan as fully as possible. Similarly, the other professionals you consult should be willing to consider all possible planning options rather than fitting your family situation into a "one-size-fits-all" plan.

Myths and Realities

A lot of myths exist that lead us to avoid planning. Let's discuss some of these myths.

Myth: ***I have little money or assets so I don't need to plan.***
Reality: Planning involves much more than finances. It is important even when there is little or no money involved in order to increase the likelihood that your wishes are carried out.

Myth: ***There is no guarantee that services will be available when we need them, and the service system keeps changing, so we shouldn't plan.***
Reality: If the exact support you specify isn't the same when it comes time to implement your plan, others can work with your child to change details within the framework you've built.

Myth: ***I should disinherit my child so she does not lose her government benefits.***
Reality: You could set up a special needs trust in your will so that your child's inheritance is held by the trust and does not jeopardize her benefits.

Myth: ***After I die, my child will receive government benefits, which will provide everything she needs.***
Reality: Government benefits cover basic necessities, such as food, clothing, shelter and medical care. Usually, other items that impact quality of life, such as vacations, special equipment, and personal and household items are not covered.

Myth: ***I have left everything to my other children who will take care of my child with a disability.***
Reality: While you may have faith in your other children, if you leave them money with the expectation that they will care for your child with a disability, you have no way to control how they actually spend the money. In addition, they could be taxed on the money you leave them and, if they die, the money could pass to their heirs.

Myth: ***If my child is not eligible or does not yet qualify to receive services from the Developmental Disabilities Administration, there's nothing I can do.***
Reality: Some families are able to help their children become more independent with little or no DDA services, particularly when support needs aren't very great. Some help their child by renting an apartment and assisting with the costs of supports. Others leave their house to their child when they die.

Some people may not be able to get services now, but will when their parents can no longer provide support. Planning with them will help direct how services should be provided when they do become available.

Myth: ***I'm too old (too young) to start planning.***
Reality: Futures planning is an ongoing process. The earlier you start thinking about a futures plan, the better prepared you and your child with a disability will be for what the future may bring. However, it is never too late.

Myth: ***I shouldn't establish a futures plan in case the laws change.***
Reality: It is true that laws change, but a good plan is flexible enough to adapt to any changes. Also, plans should be reviewed and revised periodically. If you die without a will, the state decides where your money will go and this distribution could affect your child's ability to collect important public benefits.

Getting Your Plan on Paper

Hopefully, the myths and barriers that kept you from planning have been addressed sufficiently to let you get started. So where do you start? Start with a picture of your present life, looking at your child's abilities and needs. Then think about the future.

There are a variety of questions that might be useful in your futures planning. We included a list in *Appendix E* to get you started. These questions help people examine their wishes and needs for the future. Use your answers to these questions to guide your planning.

The appropriateness of each question will depend on things like your child's age, the impact of his or her disability on independence and decision-making, and other individual circumstances.

Your plan will also be affected by whether you are planning for the near future or distant future. Some issues might be acted upon now while others are just identified for future attention — either during your lifetime or after your death. If your child is young, it may not be possible, or appropriate, to make specific plans about adulthood issues like employment and support services. However, as your child approaches adulthood, you can develop a more detailed plan that incorporates adult issues.

You may hear people refer to "personal futures planning," "essential lifestyle planning," or other person-centered planning techniques that provide structured formats that help people with disabilities and their families plan (see *Appendix F* for details). The particular process you use to plan is not significant as long as you plan thoroughly and consider all important issues.

> Remember to involve your child whenever, and however, possible. Ask your child the same questions you ask yourself and incorporate his or her answers. There is a saying many advocates with disabilities use that is worth remembering: "Nothing about me without me."

Whether or not you develop a detailed plan like these, and regardless of how young your child is, you should write a "letter of intent". This familiarizes others with your child and expresses your expectations and wishes for his or her life. Planning early can also help you with decisions about financial planning, wills, trusts, and guardianship.

Finding Help with Planning

Sometimes families want assistance with planning, or just need ideas and guidance. Other parents of children with disabilities can be a great source of help, as can advocates, service providers and other professionals. This may take a bit of networking so start by talking with people you know. You'll find a list of advocacy agencies and other contacts who may also be of assistance in *Appendix B*. Their ability to assist your family may depend on their staffing, funding, and geographic area of service.

What Else Do I Need to Know and Who Can Help Me?

We have touched on important planning tools and issues that can help you map out the various pieces of a plan for your family. The other sections in this guide provide detailed information:

- ***Common Principles and Trends*** will help you plan and evaluate services by better understanding the most progressive ways people with developmental disabilities are supported in our communities.
- ***Government Financial and Health Care Benefits*** will make sense of Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare, which help many people with developmental disabilities with their daily living costs and medical care.
- ***Decision-Making*** will help you understand guardianship and less-costly, less-restrictive alternatives so you can decide how to best assist your child if he or she needs assistance making important decisions.
- ***Wills and Letters of Intent*** discusses these two types of documents in detail so you can use them effectively in planning for your family.
- ***Trusts*** explains how you can set aside money and other assets for your child's benefit without jeopardizing vital government financial and health care benefits.
- ***Other Planning Considerations*** covers tax issues, long-term disability insurance and how to work effectively with professionals to assist you in reaching your planning goals.
- ***Financial Planning*** will help you determine if you need financial planning assistance, what to expect, and how to reach your financial goals.
- ***Services in Maryland*** are described to assist you in identifying and locating needed services that are available to people with disabilities through major state agencies.
- ***Planning Checklist*** is a summary of important steps to review so that you consider all of the critical issues involved in planning with your son or daughter.
- ***Appendix*** information includes resources, information, and forms that will assist you through each step of your planning and implementation.

Common Principles and Trends

UNDERSTANDING TRENDS AND PRINCIPLES THAT AFFECT HOW PEOPLE WITH DEVELOPMENTAL DISABILITIES ARE SUPPORTED CAN HELP YOU BETTER PLAN WITH YOUR SON OR DAUGHTER. THIS KNOWLEDGE CAN ALSO ASSIST YOU IN ASSESSING THE QUALITY OF SERVICES YOU CONSIDER.

"The future belongs to those who believe in the beauty of their dreams."

— Eleanor Roosevelt

Common Principles and Trends

Some positive principles and trends have emerged that guide the way people with developmental disabilities are supported in our communities. These include:

Inclusion and Integration: People with disabilities are no longer separated from people who do not have disabilities. They can live, work and play in typical homes, communities and workplaces when needed supports and services are made available. All people should have the right to be included in the community regardless of their abilities or disabilities. Quality services assist people with disabilities to not just "be" in their communities but to "be a part" of their communities by helping them develop friendships, use typical community services, and participate in chosen activities. This applies to all people, including those with the most significant disabilities.

Self-determination: Self-determination refers to people having control over the services they receive and how those services are provided. It includes taking control of your life, trying out choices, having the power to exercise adult rights and responsibilities, and deciding how to spend the money that is available to you for supports. In 1997, the Developmental Disabilities Administration started an initiative to transform the manner in which the services it funds are provided to encompass these self-determination principles.

Person-centered planning: Planning about people's lives must include them every step of the way and they should drive all decisions, as their abilities allow. We shouldn't plan for people, we should plan with them. Person-centered planning focuses on people's talents, skills and abilities rather than on weaknesses and lack of abilities.

Personal outcomes: Inherent in the principles of self-determination and person-centered planning is a focus on outcomes that the person with a disability — as an individual — desires. Services should improve quality of life. The quality of services and supports is measured by looking at things such as:

IDENTITY	People choose personal goals. People choose where and with whom they live. People choose where they work or other meaningful activity. People have intimate relationships. People are satisfied with services. People are satisfied with their personal life situations.
AUTONOMY	People choose their daily routines; and make decisions regarding everyday matters. People have time, space, and opportunity for privacy. People decide when, and with whom, to share personal information.
AFFILIATION	People live, work, and play in integrated environments. People participate in the life of the community. People interact with other members of the community. People perform different social roles. People have friends. People are respected.

ATTAINMENT	People choose services. People attain personal goals.
SAFEGUARDS	People are connected to natural support networks. People are safe.
RIGHTS	People exercise rights and responsibilities. People are treated fairly.
HEALTH & WELLNESS	People have the best possible health. People are free from abuse and neglect. People experience continuity and security.

These are outcome measures developed by the Council on Quality and Leadership in Supports for People with Disabilities (with slight modifications). They serve as one example of the focus on the individual with a disability and the impact of services on his or her life. Other personal outcome measures exist.

Dignity of risk: Taking risks is a natural way for us — disabled or not — to learn and grow, and to fully experience many of life's opportunities. We learn from experience — both successes and mistakes. Risk taking is balanced with health and safety concerns, but people with disabilities should have typical experiences, even when reasonable risk is involved. We gain a sense of dignity from trying, even if we don't always succeed. People with disabilities should have these opportunities, as well.

Natural supports: These are supports provided by people who are naturally in the lives of an individual with a disability as compared to supports provided by paid staff. This includes care and support provided by family, friends, neighbors, co-workers, church members, store clerks, etc. Natural supports should be maximized and paid services should build on them.

It is important to encourage and support friendships for people with disabilities beginning when they are young, including friendships with people who do not have disabilities. Friendships provide us with enduring support and enrich our lives in many ways, offering us opportunities for growth and new experiences. These friendships can play a critical role in supporting people with developmental disabilities to live full lives.

Generic services: Generic services are services that are available to the general community compared to services that are specialized and only available to people with disabilities. They include things like public transportation, recreation, and health care. Whenever possible, people with disabilities should have the opportunity to use the same services that everyone in their community uses. Accommodations should be made as needed. This way people with disabilities have a broader range of choices, have experiences similar to their neighbors, and have opportunities to meet friends and interact with others in the community.

For more information: Refer to the D.D. Council's publication, "Best and Promising Practices" and People on the Go's publication, "Signs of Quality" *(Appendix D).*

Each of Us Wants a Life Where We are Supported by and Contribute to Our Communities

(adapted from Abraham Maslow's work by:
Michael Smull, Support Development Associates)

Affecting People's Lives

Guided by these principles, services that support people with developmental disabilities to live, work, play and participate as they desire in the community are continually evolving. The trend is toward greater flexibility in how services are provided and maximum choice and control over services by the people who need them. While this is not currently available to everyone, it represents the most progressive practices in supporting people in the community and is the direction services are moving. Our hope is that this gives you ideas for planning and a picture of what to expect of services for your son or daughter.

Some examples of how this affects people's lives include:

Where, and with whom, you live...

More flexible, individually designed services funded by the Developmental Disabilities Administration[1] allow people to have greater choice over where they live, who they live with (if anyone), how supports are provided, and who provides it. A person with developmental disabilities doesn't have to live in a group home to receive adequate supports — those supports can be provided in the person's own home. This is happening for people regardless of the type or degree of disability they have.

Instead of staying at home with parents or living in housing owned and controlled by service providers, more and more people with developmental disabilities (including people with significant

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[1] DDA is the state agency in Maryland that funds the majority of ongoing services for people with developmental disabilities.

disabilities and substantial support needs) are renting their own apartments and buying their own homes — sometimes alone and sometimes with others to share costs. Families and housing programs help make this more affordable. This includes Section 8 certificates and vouchers which assist low-income people with the cost of rent. It also includes down payment and closing cost assistance and low interest mortgages that make buying a home more affordable.

Affordable housing programs vary from county to county and, as with most publicly financed programs, there are often waiting lists. However, people with disabilities do use them successfully.

For more information about:

Section 8 rental subsidies: see "Rental Assistance Programs" in *Appendix B*
Homeownership for people with disabilities: contact the Maryland Home of Your Own Coalition c/o the Maryland Developmental Disabilities Council; 800-305-6441
Individualized planning around housing and other needs: see "Service Planning/Futures Planning" in *Appendix B*

Where you work or how you spend your day in other activities that are meaningful to you...

It used to be that the only opportunity for people with disabilities to earn income was to work in a sheltered workshop, apart from people who don't have disabilities. People who were thought unable to work attended segregated day programs where they learned "independent living skills" and engaged in other activities. Now services in Maryland are generally focused on helping people get and keep regular jobs in the community, with support as needed. This is known as "supported employment." Other people are supported to engage in activities that are meaningful to them like volunteering, learning new skills and participating in community activities.

For more information about:

Supported employment and other day services: contact the Developmental Disabilities Administration or Division of Rehabilitation Services listed under "Maryland State Agencies" in *Appendix B* and refer to the "Services in Maryland" section later in this guide.

Other families with a member with a developmental disability, advocates, and service providers can provide you with more details on these principles and trends. Use this information as you read through *Planning Now* to plan with your child in a meaningful way about all the possibilities for his or her life.

Government Financial and Health Care Benefits

Many people with developmental disabilities are eligible for public financial assistance and health care benefits to meet basic living needs. These benefits are often essential in meeting a person's daily cost of living. Having a clear understanding of these benefits is vital to assuring that your child receives them, if eligible, and retains them as needed.

> *"Do what you can, with what you have, where you are."*
>
> *— Theodore Roosevelt*

Government Financial and Health Care Benefits

Federal government programs that provide benefits to people with disabilities can usually be grouped into two main categories: "means-tested" programs and "insurance" programs. Means-tested benefits are based on need and, therefore, are available only to individuals with disabilities who have very little, or no, money or other assets. Supplemental Security Income and Medicaid are examples of means-tested government benefits. Government insurance programs, such as Social Security Disability Insurance and Medicare, are based on the individual's work record or his parents' work record, and are available to all eligible people, regardless of their assets.

Supplemental Security Income (SSI)

What is SSI?

Supplemental Security Income (SSI) is a major source of monthly income to people with disabilities. It is a federal entitlement program administered by the Social Security Administration. Entitlement means that everyone who is eligible receives the benefit, and there is no waiting list.

SSI is a cash benefit intended to cover food, clothing and shelter. It is available to people who have disabilities, are elderly, or are blind, and have very little income and assets. Children with disabilities, as well as adults, can receive SSI. Social Security defines disability as a mental or physical condition that keeps the individual from working (for adults) or results in severe functional limitations (for children) and is expected to last at least a year. If a person is under 18, his or her parents' income and assets are usually considered in determining eligibility.

To receive SSI, an individual may not have more than $2,000 in assets and a couple may not have more than $3,000. Assets that are considered include cash, bank accounts, stocks and bonds, personal belongings, real estate and any other item of value that a person owns.

Social Security, however, does not count everything a person owns in determining eligibility. Things that are not counted include: the home the person lives in, his car up to a certain value, burial plots, and personal and household goods and insurance policies depending on their value.

Property is only counted if you own it and have the right to sell it. For example, if someone buys furniture and lets you use it, but you do not own it, it is not considered an asset. There may be other excluded resources depending on the situation so each person's situation must be evaluated individually.

Amount of Benefits

The amount of SSI a person receives is affected by how much other income he or she has from other sources, including earnings. The maximum monthly SSI benefit in 2003 was $552 for an individual and $829 for a couple.

If an eligible person has no income at all, he or she will receive the maximum amount. A person receives less if he or she has income or receives other types of support for food, clothing or shelter. For example, if your adult daughter qualifies for SSI and she lives in your home, you are providing shelter to her at no cost. You would also be providing shelter for her if you paid her rent in an apartment. The value of this shelter is considered when calculating SSI eligibility.

In some cases, it makes sense to allow SSI to be reduced because the overall result, including the food, clothing and/or shelter being provided at reduced or no cost (called "in-kind support"), is better for the SSI recipient. This is because SSI rules generally do not reduce benefits by the full value of the in-kind support. The amount of the reduction depends on whether the SSI recipient is considered to be living in his own household or the household of another.

When an individual is living with a parent or someone else who owns or rents the home, but he doesn't pay his fair share of shelter and food costs, he or she is considered **living in the household of another.** In this situation, SSI will reduce his benefits by 1/3 of the maximum SSI payment ($184 in 2003), *regardless of the actual value of the support he receives*. This occurs even if the actual value is less than $184, so it may only be worth providing in-kind support if it is worth more than the 1/3 reduction.

When an individual is **living in his or her own household,** SSI counts the value of in-kind support up to a "presumed maximum value" (PMV), *regardless of it's actual value*. The PMV is 1/3 of the maximum SSI payment plus $20 ($204 for and individual in 2003). However, if there is no other income than SSI, the reduction is only $184. If you can prove that the actual value of an in-kind support is less than the PMV, only the actual value will be considered.

(Please note: These are general descriptions and a variety of criteria and exemptions apply so be sure to consult a knowledgeable advocate or attorney when planning regarding public benefits.)

Examples

- Your son lives in his own apartment with a rent of $450/month. You (or a trust) directly pay the landlord $300, while your son pays $150. You also give your son about $50 worth of groceries a month. The $350 you provide is in-kind support, but SSI only counts $204, which is the presumed maximum value. Your son's SSI check will be reduced by $204. However, if you give your son money rather than paying the landlord and grocery store, SSI will consider the full $350 as income.

- You, or a trust, make a $15,000 down payment on a condominium for your daughter. You make your payment directly to the lender. This is considered income to your daughter in the month she settles on her home, but only up to the PMV amount. Her SSI is reduced $186.66 that month. If you opted to pay mortgage payments each month to the lender rather than a lump-sum down payment, your daughter's SSI check will be reduced $204 each month.

- Your daughter rents an affordable apartment using a rental assistance program. She covers all of her expenses except for her heating bill, which you pay. The amount is $100. SSI considers this in-kind support and will reduce your daughter's SSI check by $204. If you show that the actual benefit to your daughter is only $100, SSI will reduce her check by that amount.

If the amount of in-kind support counted against a person causes them to lose all of their SSI, it may not be worth it, even if the value of the support is significant, because they will also lose Medicaid. Many people with disabilities rely heavily on Medicaid as their health insurance, and may need it more than the SSI cash payments.

Example

- Your son has a part-time job that does not pay for health insurance. Because of his income, his SSI payment is only $125/month. You pay his landlord $300/month toward rent. Your son's SSI is reduced by the presumed maximum value of $184. Since he only had $125 in SSI, he loses it altogether. He will likely also lose his Medicaid.

The reduction for living in the household of another and the presumed maximum value reduction only apply once per month. Once the reduction is taken, additional in-kind support received that month has no additional affect on SSI.

If you are helping to pay food, shelter or clothing costs that are considered in-kind support, it is generally better to pay a greater amount in a single month whenever possible, rather than smaller amounts in numerous months. It is also best to pay as many bills in the same month as possible. This is because the presumed maximum value reduction to SSI applies each month in which the SSI recipient receives in-kind support. For example, if you or a trust pays your child's water bill in October and his heating bill in November, his SSI will be reduced in both months. If you pay them both in November and no bills in October, a reduction will only be taken for one month.

A lump-sum payment you or a trust makes for an ongoing cost generally will be averaged over the months it applies to, if it is for future expenses (e.g., future rent). It will affect the SSI recipient's benefits in each of those months. A lump-sum payment for a past expense that has accumulated over months will generally only count in the month the bill is paid. In comparison, an SSI recipient can prepay expenses with their own funds without a reduction in benefits.

What Support Affects SSI Benefits?

The Social Security Administration considers the following things shelter costs, and therefore, subject to the above rules if provided as in-kind support: rent, mortgage payments, property taxes, property insurance if required by the lender, heating, gas and electric, water, sewerage, and garbage collection.

Things you, or a trust, can provide or pay for without affecting your child's SSI and Medicaid include:

- medical and supportive services, supplies, and equipment
- vocational and other training
- phone and cable and insurance bills
- other services like haircuts, housekeeper, lawyer, home maintenance (e.g., plumber, electrician, appliance repair, painter)
- loans not retained into the following month
- airline and other transportation tickets (domestic travel)
- things that SSI excludes from asset consideration like a car, furniture and other household goods up to a certain value
- in-kind food, shelter and clothing once the amount for living in the household of another or the presumed maximum value has been deducted from the SSI payment

Consult with your local Social Security office or a knowledgeable advocate or attorney for more information about assets that are not counted in determining eligibility and to assess how potential assistance given to your child for food, clothing or shelter will affect his or her benefits.

Income from a Roommate

Some people who receive SSI own a home and rent to a roommate to share costs. The money they receive for rent is not counted as income if it covers the renter's share of the mortgage interest (not principal), taxes, utilities, and maintenance. If the rent exceeds the cost of the renter's fair share of these costs, the excess is considered income and SSI will be reduced.

Medicaid (also known as Medical Assistance)

Medicaid covers the medical expenses of people with disabilities who have very low income and assets. Medicaid is a very complex program, with very strict rules determining who is eligible and what services are covered.

In Maryland, SSI recipients are automatically covered by Medicaid. This link is possible because SSI has the same income and asset tests as Medicaid. If a person does not receive SSI, there are other ways to become eligible for Medicaid.

Some individuals who have disabilities have high medical bills, and sometimes those bills are as much or more than their income. If a person has low or moderate income (though not low enough to qualify for SSI) and high medical bills, Medicaid will keep track of what the person has paid for those bills and when he or she reaches a certain level, Medicaid will cover the remaining bills.

Other people with disabilities in Maryland who are not eligible for SSI may receive Medicaid if they qualify for Developmental Disabilities Administration services through DDA's "Home and Community-Based Waiver." We will not discuss the details of the waiver here, but DDA can provide you with more information. In addition to becoming eligible for Medicaid through DDA's "Home and Community Based Waiver," it is also possible for eligible individuals to access Medicaid through other Medicaid waivers (e.g., Autism Waiver, Attendant Care Waiver). Consult a knowledgeable advocate for details.

Like SSI, the Medicaid program exempts assets such as the home, car, limited life insurance policies and burial plots in determining eligibility.

Social Security Disability Insurance

The Social Security Administration also oversees Social Security Disability Insurance (SSDI), which is a cash benefit paid to individuals with disabilities and their parents who have worked enough to be covered by the system.

Adults with developmental disabilities who have not paid enough into the Social Security system may receive *dependents'* benefits under a parent's work record if the parent worked enough to be covered and has a disability or is retired. Or, a person can qualify under a parent's work record if the parent has died, under the *survivors'* benefits program. In order to receive dependents' or survivors' benefits, the person's disability must have begun before he or she was 22 years old and be expected to last for at least a year.

The amount a person receives in SSDI depends on how much he, or his parent, earned while working. If a person receives SSDI on his own work record, SSDI determines the amount he receives based on that work record. If a person receives dependents' or survivors' benefits, the amount is usually a percentage of the covered parent's disability or retirement amount.

The amount of assets a person has does not affect his SSDI benefit. However, income may affect SSDI benefits, depending on whether the income is earned or unearned. *Unearned* **income, such as**

a pension or annuity, is not considered in determining SSDI eligibility. *Earned* **income is treated differently because if a person can work and earn a significant amount of income — more than $800 per month in 2003 — he or she will not meet the disability test and will not be eligible for SSDI benefits. Work incentives exist that can, in certain circumstances, help people retain eligibility for SSDI if they make more than $800 (see the Benefits INfoSource in** *Appendix B***). Earned income that is less than $800 per month does not affect SSDI benefits.**

If a person receiving SSI begins receiving SSDI, they could lose their SSI. This would happen if the SSDI benefit is $20 or more than the SSI amount (if there is no other income). Financially, this should not be an issue since the income from benefits would not decrease — just the source. Of concern would be the loss of Medicaid. However, people who receive SSDI based on their parent's work record rather than their own, retain their Medicaid, even if the SSI payments stop.

Medicare

Medicare is the federal health insurance program for individuals receiving Social Security Disability Insurance or Social Security Retirement benefits. A person automatically receives Medicare after getting SSDI for two years, whether qualifying on his own or through a parent's work record. In addition, everyone 65 and older who receives Social Security Retirement benefits is eligible for Medicare.

Medicare Part A covers hospitalizations and related services while Medicare Part B covers outpatient treatment and physician services. Part B requires eligible people to pay a premium but Part A does not. In addition to the premiums that must be paid on a monthly basis, recipients typically have a co-pay for a portion of their care because Medicare may only pay 80 percent or may start paying only after a recipient has paid a deductible. In some cases, Medicare pays 100 percent or has different deductibles.

Because Medicare does not cover the entire cost of recipients' care, people may purchase private insurance to pay the co-payments and deductibles. This type of insurance is referred to as "supplemental," "secondary" or "Medi-gap" insurance and only covers the portion Medicare does not cover.

As you can see, government financial and health care programs can be very beneficial to people with disabilities, but the conditions and rules can be somewhat complicated. A person may be eligible for any one, or all, of these benefits at the same time.

See "Public Benefits" in *Appendix B* and *Appendix D* for additional information on these benefit programs and to find out where to apply. Consult with an informed advocate or professional, or with the Social Security Administration (through a local office or its national toll-free number) if you have questions.

Decision-Making

Minor children and some adults with disabilities need other people to make personal, financial, and/or health care decisions on their behalf. This can be done informally or formally. We discuss different approaches and when each might be appropriate.

"A journey of a thousand miles must start with a single step."

—Chinese proverb

Decision-Making

We make hundreds of decisions every day, ranging from relatively minor decisions such as what to have for lunch, to very big decisions like where we will live or work. We may take our ability to make our own decisions for granted, never even thinking about what it would be like to be unable to make life decisions or what it would be like to have the right to make our decisions taken away.

Minor children have the ability to make some decisions, and this ability usually increases as they mature. While they are minors, their parents have the legal right to make major decisions for them.

All adults are entitled to make their own decisions. Some adults may need help making some decisions, but can still make others on their own. Other adults are not able to make decisions at all. Ideally, people are responsible for as many life decisions as possible, relying on others only for those decisions too big or complex for them to handle alone.

Minor children and *some* adults with disabilities need others to make personal, financial, and/or health care decisions on their behalf. This can be done informally or formally.

Making Decisions for Others

Parents have legal authority to make decisions for their minor children (under 18 years old). They are the “natural guardians” of their minor children and have this authority without a court order or any other special documentation.

Adults are presumed to be competent to make their own decisions as to their personal well-being and their money unless a court determines that they are not competent. Sometimes, individuals with disabilities cannot make decisions for themselves so others help by making decisions for them. These decisions are often made informally. In other families, the parent’s or other family member’s authority is through a formal process, such as a trust or power of attorney.

Families, along with their attorneys, should consider all informal and formal options before considering guardianship. Legal restrictions on the decision-making ability of a person with a disability must use the “least restrictive alternative.” If none of the less-restrictive decision-making alternatives is possible, the family may pursue guardianship, which involves going to court and having a judge decide whether to give some or most of a person’s decision-making rights to someone else, who is then accountable to the judge.

Guardianship can be broad enough to cover all decisions or limited to certain kinds of decisions. It is vital to a person’s independence to obtain guardianship only if necessary and to limit the guardianship to the decisions needed. For example, a limited guardianship may give a guardian authority to make medical decisions or to make financial decisions pertaining to a person’s home while the individual continues to make other decisions.

A person does not need a guardian simply because he or she has a disability or makes mistakes or choices that others may think are unwise. If someone seeks guardianship of an adult with a disability, he or she must prove to a judge that the person cannot make responsible decisions concerning issues like food, clothing, shelter, or health care or decisions related to his or her money or property because of a disability, and that no less restrictive method is possible.

Although guardianship is available to enable others to make decisions on behalf of people with disabilities, it should be used only as a last resort, after considering all of the options. Some of the options are outlined below.

Making Personal Decisions

Advance Directives

A "health care agent" can make health care decisions on behalf of another person. A person names his or her own health care agent in an "advance directive." Advance directives can also be used to communicate one's wishes regarding medical treatment and other health care issues. Advance directives may include instructions to the agent regarding whether to provide, withhold or withdraw certain medical treatments, often referred to as life-sustaining treatment. Examples include artificial nutrition and hydration (tube feeding) and mechanical ventilation.

An advance directive may also be called a "health care power of attorney," "medical power of attorney," or "living will." Advance directives are usually written but may be made orally, and both written and oral advance directives must be witnessed. The person signing the advance directive must be over age 18, competent to make an advance directive, and able to communicate his or her health care wishes.

A competent individual is one who is capable of making a decision about the issue presented. You are capable of making such a medical decision if you can understand the nature or the result of the treatment, are able to evaluate the risks and benefits of the treatment, and are able to communicate your decision related to the treatment.

Advance directives can be written with the assistance of an attorney or made by completing forms available from the Office of the Attorney General in Maryland. These forms are based on a sample provided in Maryland law. An attorney can draft an advance directive that is more detailed or individualized than the sample, if you want to express your wishes more fully.

An advance directive can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own health care decisions.

Surrogate Decision-Making

If an individual is not competent to execute an advance directive (and did not sign one in the past), a surrogate can make health care decisions on that person's behalf, in certain circumstances. Maryland law stipulates who may act as surrogates. In order for a surrogate to be able to make health care decisions, two physicians must sign a certification stating that the individual is unable to make informed decisions.

A surrogate must make decisions based on the wishes of the individual, if they are known. If the wishes are not known, the surrogate must consider issues like the individual's diagnosis, his or her wishes regarding life-sustaining treatment, and religious or moral beliefs.

According to Maryland law, the following individuals or groups, in the priority order listed, may make decisions (without going to court) about health care for a person who has been certified to be incapable of making an informed decision and who has not appointed a health care agent. A person may make a decision only if all higher priority people are unavailable or unwilling to assume that role:

1. A guardian, if one has been appointed
2. Spouse
3. An adult child of the patient
4. Parent
5. An adult brother or sister of the patient
6. A friend or relative (must demonstrate that they have maintained contact sufficient to be familiar with the patient's activities, health and personal beliefs)

Informal Arrangements

Often, family members and friends of people with disabilities step into the role of "advocate," sometimes without even realizing they are doing so. This role is typically very informal, as it requires no documents or court hearings. In spite of its informality, an advocate can have a tremendous impact on an individual with a disability and his or her quality of life. Many people with disabilities may choose who they want to advocate on their behalf.

An advocate may participate in planning meetings, help a person choose, acquire and monitor supports and services and help a person make life decisions. To be most effective, the advocate should become familiar with the resources available in the community and eligibility criteria for benefits, as well as the needs and preferences of the person with a disability.

Making Financial Decisions

Durable Power of Attorney

A competent adult can execute a durable power of attorney (DPOA) which appoints someone to act on his or her behalf to make legal and financial decisions. The DPOA must be in writing and must be witnessed and notarized. The DPOA can be broad or it can be limited so that the agent can only make certain types of decisions, such as write checks from a checking account or sell the individual's home.

A power of attorney is "durable" if it remains effective after the individual becomes incapable of making his or her own financial and legal decisions. The DPOA can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own financial decisions.

Trusts

A parent, family member, or other person can establish a trust with money or assets to benefit an individual with a disability. A "trustee" is named to manage some or all of the assets. The trustee has full authority to make all decisions regarding assets in the trust, including how to invest and spend the trust money.

Trusts can vary widely, so that they can be worded to meet your intent and the beneficiary's needs. While they provide a management tool that can eliminate the need for guardianship of the property, they have other uses as well. In particular, they are a mechanism that allows someone to leave money and assets to another person without jeopardizing vital public financial and health care benefits. We discuss trusts in detail in a later section.

Representative Payee

If a person who receives financial benefits from the federal government, such as SSI or SSDI, needs help with depositing the checks, paying bills, and managing money, the government may appoint someone to act as “representative payee.”

A representative payee must complete some forms and have a doctor establish that the person with a disability is unable to manage his or her assets. The government will then issue the checks in the name of the representative payee and will require that the representative payee open an account into which the checks are deposited. The representative payee must spend the money only for the benefit of the person with a disability and keep accurate records of how the government benefits are spent.

Informal Options

Joint accounts offer an informal means of assisting a person with a disability in managing his or her money. If a person with a disability owns a joint bank account with another person, either owner may access the account. For example, if a father and his son with a disability are co-owners of the son’s account, the father can deposit checks, pay bills and make other decisions related to that account.

Unfortunately, joint accounts involve some drawbacks that you should consider. One drawback is that the joint owner is not required to account for how the money is spent, so there is nothing to assure that the money is used for the benefit of the individual with a disability.

Another limitation is that even though a joint owner can make financial decisions for a person with a disability, the person with a disability can make withdrawals even if he or she makes poor judgments in spending the money. Also, the joint account is counted in determining government benefit eligibility for the person with a disability.

Another type of informal arrangement is one in which a family member holds money for a person with a disability. The money may have come from a parent or from the individual with a disability. There may be some moral obligation to use the money for the individual, but there is no way to make sure the holder of the funds spends the money as intended. Even if the family member has the best intentions, the heirs or creditors of the person holding the money may claim it. This would deprive the person with a disability of his or her money with no way of getting it back.

Guardianship

The most restrictive way to assist a person with decision-making is through guardianship. A “guardian of the person” can generally make personal decisions such as where a person will live, what kinds of health care he or she will receive and where he or she will go to school or work. A “guardian of the property” determines how a person’s money is invested and spent. An individual may need a guardian of the person but not a guardian of property, or vice versa.

If a minor child’s parents die, a guardian will be needed to make personal decisions like where the child will live and go to school. This is true regardless of whether the child has a disability. If the parents’ will named someone to act as guardian of the person, that person can serve as guardian without having to go to court. The court will appoint someone to serve as guardian of the person if the parents did not name a guardian in their will.

If a child has money that should be managed and spent for his or her benefit, the court will appoint a guardian of property. This may be the same individual as the guardian of the person. If the child is at least 14 years old, he or she may tell the court who he or she wants as guardian. The guardianship of the minor will end when the child turns 18, just as if the parents were still alive.

If you have minor children, and you would like a family member or friend to serve as guardian after your death, you should name the person in your will. If the person you name accepts the responsibility, he or she will become guardian if both parents die before your child turns 18.

Because guardianship is a big responsibility, it is a good idea to discuss what it would involve and make sure that the person you choose is willing to take on the responsibility. You should consider the person's relationship with your child and his or her other responsibilities or commitments. The proposed guardian may change his or her mind or be unable to assume the responsibility as planned, so it is a good idea to name an alternate guardian, as well.

Is Guardianship Needed for an Adult?

In order to determine whether guardianship is needed for an adult with a disability, family members should ask three questions:

1. **Must a decision be made related to my child's money, assets or property (guardianship of property) or must a personal decision be made related to my child (guardianship of the person)?**
   If no, there is no need for a guardian.
   If yes, proceed to #2.

2. **Is my child able to make the decision for himself or herself?**
   If yes, the individual should make the decision.
   If no, proceed to #3.

3. **Have all other options been thoroughly explored?**
   If no, consider all options with the goal of using the "least restrictive alternative."
   If yes, proceed to guardianship.

Guardianship of the Person

A court will appoint a guardian of the person for an adult if the adult has a disability that makes him or her unable to make responsible personal decisions. Examples of personal decisions include decisions relating to safety, shelter or health care. When a court appoints a guardian of the person for an adult, he or she becomes known as the "ward." The appointment of a guardian of the person does not take away an individual's civil rights.

Sometimes, family members or friends seek guardianship so they can make health care decisions on behalf of a person with a disability. In most cases in which there is no advance directive, a health care surrogate should be able to make all medical decisions, including decisions about life-sustaining treatment, without having to become a court-appointed guardian.

If a health care decision must be made and it cannot be made any other way, guardianship may be the only option. Individuals and families may need the services of an attorney who is familiar with the Maryland Health Care Decision Act (which governs advance directives and surrogate decision making) as well as guardianship in order to make an informed choice of options.

Under Maryland law, the true guardian of the person is the court. The court appoints the guardian and delegates him or her authority to act on behalf of the individual, yet requires the guardian to obtain permission before making certain decisions. For example, the guardian must get court approval to take such steps as changing the person's type of residence or authorizing psychotropic medications.

If a medical procedure involves a "substantial risk to life," the guardian must ask the court for special permission related to the procedure. This is true whether the guardian wants the individual to have the procedure or wants to withhold the procedure. In some situations, if a close family member is the guardian, the court will give him or her the authority to make all decisions related to life-sustaining procedures when the guardianship is established. Otherwise, the guardian must make a special request to the court. A person under guardianship may still make certain day-to-day decisions, such as what to wear and who to have as friends.

Guardianship of the Property

A guardian of the property is necessary if decisions need to be made related to a person's property or money but that person cannot make those decisions due to a mental disability. A guardian of property can only make decisions about an individual's property and money, such as selling property, paying bills, or buying things. As in guardianship of the person, the court is the ultimate guardian and delegates only certain powers to the guardian of the property. The guardian must give the court an annual accounting of how he or she spent the individual's money.

Once a guardian of property is appointed, the guardian may spend the individual's funds for his or her daily support or care. The guardian may also spend the ward's funds to support people legally dependent on the ward, such as a minor child or spouse. If the guardian wants to spend the individual's money for anyone else or make gifts from the individual's money, the guardian must make a request to the court.

How to Become a Guardian

When guardianship is the last and least restrictive option, and someone wants to become guardian for a person with a disability, he or she must submit a document called a "petition" to the court. The person seeking guardianship is known as the "petitioner." Usually, the petitioner is represented by an attorney who prepares the legal documentation.

The petition must state why the petitioner is seeking guardianship, the relationship between the petitioner and the person with a disability, and what kinds of decisions the petitioner wants to make. The petition must also include written statements from two physicians which describe the person's disability.

When the court receives the petition, it appoints another attorney to represent the person with a disability. The attorney usually meets with the person, reviews all available records, talks with people involved in his or her life, and determines whether the person has the ability to make personal and/or financial decisions. The attorney should also ask the person how he or she feels about the guardianship and the proposed guardian.

The petitioner and both attorneys must attend a hearing in court. The person with a disability may attend if he or she chooses to do so. The petitioner must prove that the person is "disabled" within the meaning of the law, that the person needs a guardian, and that the petitioner is the best person to be the guardian. The judge then determines whether a guardianship is necessary, who should be guardian, and rules on other requests in the petition.

Unless there is a life-threatening emergency, it may take up to several months to set up a guardianship. It takes time to gather information to prepare the petition, interview the appropriate people and schedule the hearing. Also, it can be expensive because the attorneys representing the petitioner and the person with a disability must be paid and there are court costs for filing a petition.

The guardian must keep records of all actions taken in his or her role as guardian. After the guardianship is established, annual reports must be filed documenting a guardian of the person's decisions and how a guardian of the property has spent the individual's funds. If court permission is required to make a certain decision, the guardian must request authorization from the court and should not act until the court has issued an order authorizing the action. Sometimes, guardians rely on attorneys to help them with these reports and motions.

Wills and Letters of Intent

A will helps assure that your wishes are carried out regarding what happens to your money, property and other belongings when you die. How you create a will, what assets are covered, and what happens if you die without a will are important.

A letter of intent familiarizes other people with your child and expresses your expectations and wishes for his or her life. A letter of intent is a key part of effective planning.

> *"Only those who will risk going too far can possibly find out how far one can go."*
>
> *— T.S. Eliot*

Wills

What is a Will?

Many people have wills (or at least have thought about writing one) and know that they take effect when they die. Many know why they have (or should have) a will and the will's general content.

What many people don't know is that wills can range from very simple to very complex documents that outline your wishes after death and that wills are important even if you don't have a lot of money or other belongings ("assets"). Wills should outline your wishes and include certain language so that your affairs are wrapped up properly and efficiently. They must be signed and witnessed.

In your will, you set out many instructions that will take place after your death. Your will should state who will receive your assets, which make up your "estate," after your death. The people who receive your estate are called "beneficiaries" (or "legatees"), and you can spell out how you want your estate divided among them.

It should also name a "personal representative" (formerly called an "executor") who will handle your estate and make sure that it passes to your beneficiaries as you have instructed. If someone dies without a will, or the person named in the will is unable to serve as the personal representative, then someone who is willing to serve may petition the court to be appointed personal representative. The court will consider the person's relationship to the deceased individual in making the appointment.

Your will can serve some other important functions, such as naming a guardian for your minor or disabled children. If you have a minor child, you can state in your will who you want to serve as guardian after the death of both parents. If you have been named the guardian of your adult child with a disability, you should also state in your will who you want to be his or her guardian upon your death. Unless there are unusual circumstances, the court will comply with your wishes. Even if you have not been appointed guardian, you should also specify who you would want to take on that role if guardianship becomes necessary after your death.

Your will can also state that a trust will be created for your child or someone else and that it will take effect when you die. This option is very important if you are planning for someone who has a disability, especially if he or she receives government benefits. A supplemental needs trust can receive that child's share of your estate so that his or her benefits will not be jeopardized.

If you decide to revise a will, you should consult a lawyer to assure that your desired changes are made in compliance with legal requirements to assure that your will is not invalidated.

How Do You Create a Will?

In order to sign, or "execute," a will, you must be competent in that you understand what assets you own and who will receive your assets when you die. You must sign the will in the presence of two witnesses. The witnesses must then sign the will in your presence. Remember that if your wishes or situation changes, you can revoke or change your will.

You should hire an attorney to prepare your will. The attorney should meet with you and discuss your wishes as to your personal representative, beneficiaries, guardians, how your estate will be distributed, and any other stipulations that may be included in your will. After your attorney drafts your will, you should not hesitate to ask for clarification of the legal provisions it contains.

Some people who have few assets write their own wills, using form books or sample wills. However, we do not recommend "do-it-yourself" wills because if your will is not written correctly, your plans and wishes may not be carried out and you could inadvertently make your child ineligible for needed financial and health care benefits.

If you already have a will and are unsure of whether it is sufficient, have an attorney familiar with disability planning review it. If you want to include a trust, have a large number or variety of assets, or have other issues that should be covered in your will, it is better to hire an attorney who has the training and expertise to address issues important to your personal situation. This is especially important if you or a family member has disability issues that should be addressed in your will.

Anyone who prepares your will for you should be an attorney. Friends, family members or other professionals who are not attorneys should not prepare a will or any other legal document for you.

What Assets Does a Will Cover?

If you die with assets in your name alone, those assets usually become part of your "probate estate" and are distributed according to your will. Your personal representative will open your probate estate and file the necessary documentation with the Register of Wills in your county. Your estate will have to be kept open for a certain period of time, usually six to nine months.

During that time, your personal representative must determine the exact value of your assets, notify your beneficiaries and creditors that an estate has been opened, and keep an accounting of all estate transactions for the Register of Wills. When all probate requirements have been met, your estate may be distributed to the people (or trusts) you have named in your will. Assets subject to this process are called "probate assets."

Assets that are not subject to this process are called "non-probate assets." These are assets you own while you are alive but that are distributed to others automatically upon your death, rather than through probate. Examples of non-probate assets are joint bank accounts, life insurance, retirement plans, annuities, and property owned by a living trust (described in the next section). If you die owning assets jointly with another person, those assets may pass to him or her at the time of your death.

If a jointly-owned asset is titled as "joint tenants with right of survivorship" or "tenants by the entireties" (for married couples only), the asset will pass to the surviving person, without becoming part of the probate estate. By contrast, if you own assets as "tenants in common" with someone else, your share will become part of your probate estate upon your death rather than pass to your joint owner.

If you own life insurance or retirement plans, the beneficiary you have named will receive the assets upon your death. Non-probate assets do not become part of your probate estate and are not controlled by your will. *For this reason, you must be careful in naming beneficiaries and make sure that your estate plan covers your non-probate assets, as well as your probate assets, so the passing of your non-probate assets is consistent with your estate plan.*

Avoiding probate may be simple and you may not have to give up much control while you are still able to make your own decisions. However, some steps required to avoid probate will limit your ability to make decisions regarding your assets. For example, you may want to retitle your savings account so that it is co-owned by you and your daughter, intending that the account will pass to her upon your death, as a non-probate asset. However, this will give your daughter the right to withdraw money while you are alive so you will have given up a significant amount of security over your finances. In addition, if your daughter has a disability and receives government benefits, co-owning a bank account could jeopardize her eligibility for the benefits. Actions that will affect how your assets will be handled during your lifetime and upon your death should be considered carefully, with the advice of an attorney.

What Can Happen if You Don't Have a Will?

If you die without a will and you have assets in your probate estate, you will die "intestate" and those assets will pass by the law of "intestate succession." This law lists who in your family will receive your estate and the order in which they will receive it.

For example, many married individuals want their estates to go to their spouse, and to their children only if their spouse is no longer living. However, the law stipulates that if you are married and have children and you die without a will, your probate estate will be divided between your spouse and your children. Distributing your estate this way may not only be against your wishes, but may present some or all of the problems we have discussed regarding benefit eligibility and covering the cost of care if you have a child with a disability.

A will enables you to direct who will receive assets and in what amounts, and whether a trust will be created for a child or other family member with a disability. It also gives you the opportunity to choose who will fill important roles related to both your money and your family member's well-being, such as your personal representative, trustee and guardian (if needed). Your will should be consistent with, and done in conjunction with, a letter of intent.

Letters of Intent

A "letter of intent" is a letter that you write to familiarize people with your child and your expectations. It does not have to meet the special requirements of a will or other legal documents and is not legally binding. However, it should be coordinated with your will so that it clearly communicates information to the appropriate people, such as a personal representative, trustee, guardian, or service provider to help them make important decisions on behalf of your child.

Use plain language, rather than technical language, when you write your letter of intent. You should ask your attorney to review your letter to make sure that it does not contradict your will in any way and to make sure that it is thorough and easy to understand.

It is a good idea to make the drafting of a letter of intent a group effort, including input from your child for whom the planning is done, family members and close friends. The purpose is to provide guidance to others who may provide care, support, or other assistance for your child. Times change and it is impossible to foresee the future so a general outline of your expectations, hopes and wishes may be better than rigid requirements.

A letter of intent should describe your child now and explain your, and your child's, expectations and preferences regarding his or her future in a variety of areas:

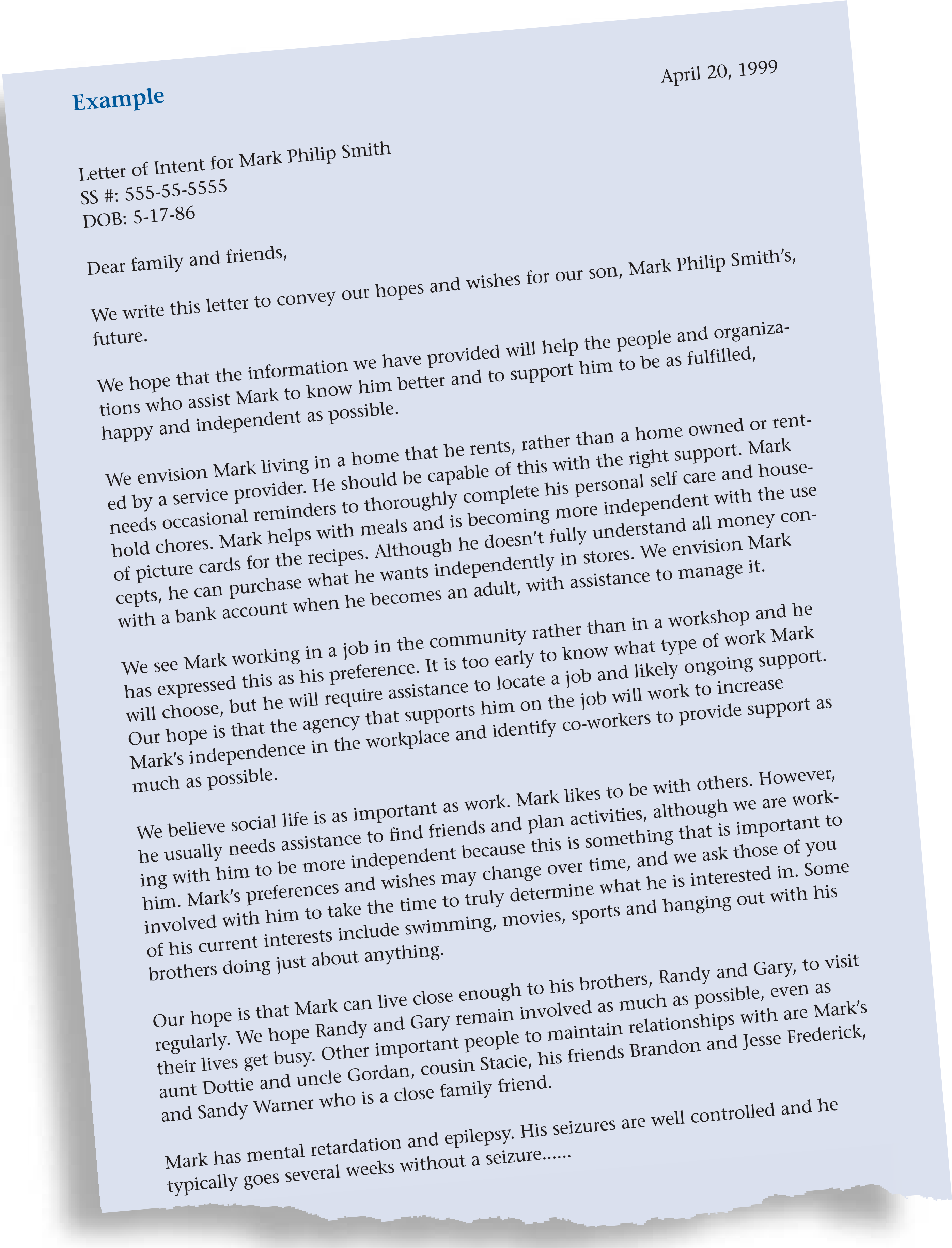
- Living arrangement
- Education
- Employment or other meaningful daytime activity
- Supports and services needed in all aspects of life
- Important relationships to maintain
- Medical history, health care needs, medication, and therapies
- Abilities and needs regarding things like communication, independence in daily living and personal care, money management, and decision-making
- Likes/dislikes and preferences (e.g., social/recreational activities, religion, and foods)
- Effective ways to work with, and support, your child
- Financial information: government benefits, bank accounts, trust, life insurance
- Other "important things to know" about your child (e.g., habits, behavior, wishes)

See *Appendix E* for a list of specific questions to consider.

The information you cover and the degree of detail you provide will depend upon your child's ability to clearly communicate his or her own wishes and likes and dislikes. Include your child's name and date of birth in the letter.

Also, attach a list to the letter that includes the names and phone number of important people or agencies involved in your child's life. This might include doctors and therapists; service providers; a guardian; trustee; representative payee for benefits; and people who are important to maintain relationships with. Also include the location of important documents *(see Appendix I).*

Your should periodically review and update your letter of intent when significant changes occur. Some parents review their letter of intent around the time of their child's birthday each year. Sign your letter and make certain that important people in your life either have a copy of your letter or know where to locate it.



Example

April 20, 1999

Letter of Intent for Mark Philip Smith
SS #: 555-55-5555
DOB: 5-17-86

Dear family and friends,

We write this letter to convey our hopes and wishes for our son, Mark Philip Smith's, future.

We hope that the information we have provided will help the people and organizations who assist Mark to know him better and to support him to be as fulfilled, happy and independent as possible.

We envision Mark living in a home that he rents, rather than a home owned or rented by a service provider. He should be capable of this with the right support. Mark needs occasional reminders to thoroughly complete his personal self care and household chores. Mark helps with meals and is becoming more independent with the use of picture cards for the recipes. Although he doesn't fully understand all money concepts, he can purchase what he wants independently in stores. We envision Mark with a bank account when he becomes an adult, with assistance to manage it.

We see Mark working in a job in the community rather than in a workshop and he has expressed this as his preference. It is too early to know what type of work Mark will choose, but he will require assistance to locate a job and likely ongoing support. Our hope is that the agency that supports him on the job will work to increase Mark's independence in the workplace and identify co-workers to provide support as much as possible.

We believe social life is as important as work. Mark likes to be with others. However, he usually needs assistance to find friends and plan activities, although we are working with him to be more independent because this is something that is important to him. Mark's preferences and wishes may change over time, and we ask those of you involved with him to take the time to truly determine what he is interested in. Some of his current interests include swimming, movies, sports and hanging out with his brothers doing just about anything.

Our hope is that Mark can live close enough to his brothers, Randy and Gary, to visit regularly. We hope Randy and Gary remain involved as much as possible, even as their lives get busy. Other important people to maintain relationships with are Mark's aunt Dottie and uncle Gordan, cousin Stacie, his friends Brandon and Jesse Frederick, and Sandy Warner who is a close family friend.

Mark has mental retardation and epilepsy. His seizures are well controlled and he typically goes several weeks without a seizure......

Planning Options

If you would like to leave assets to your child or someone else, you may name that person in your will, or name him or her as a beneficiary of a non-probate asset, such as a life insurance policy. When you die, the person will become the owner of the money or assets and may spend them, invest them, or give them away. If the person has a guardian of property, the guardian will be responsible for investing and managing the money. If your beneficiary has a disability that affects his or her decision-making, but does not have a guardian of property, giving him or her money may not be the best option.

Even if a responsible and caring guardian has been appointed, another important consideration is how the inheritance will affect the person's government benefits. If the person is receiving SSI and/or Medicaid, even an extremely small inheritance may reduce or stop the benefits. The person can reapply for benefits after the inheritance has been spent, but in the meantime he or she must spend the inheritance for food, medical care, services or other items that the benefits were covering. This would leave the person with little or no means to meet other needs or wishes.

What do you do if you want to leave money to your child with a disability but you feel that he or she does not have the skills to handle the money and/or you don't want to affect his or her government benefits? Without adequate information, some people decide to "disinherit" their child, leaving him or her nothing in the will. Unfortunately, people who receive government benefits are making due with bare necessities and even a modest inheritance placed in trust would improve the quality of their lives.

You have the option of creating and funding a supplemental needs trust so that a trustee will be responsible for investing and spending the funds for your child's benefit. The trust funds will not be directly available to your child so his or her government benefits will continue without interruption. You can decide who will receive the funds remaining in the trust after your child dies.

In some cases, parents or other family members leave money intended for a person with a disability to someone else, such as the person's brother or sister, with informal instructions to spend the money for the person's benefit. Even if the "keeper" of the money for someone with a disability used the money as intended, things could happen to take the money out of that person's control. If the "keeper" entered a nursing home, the money would be used to pay the nursing home bill and the person with a disability would not have the right to any part of it. Also, other creditors would be able to take the money to satisfy claims. If the person died, the money would pass on to his or her heirs rather than to the person with a disability.

In summary, there are various options that must be analyzed to determine which is best for you, your family members, and your financial situation.

The Financial Statement worksheet in *Appendix J* can assist you in considering all the resources you may wish to plan with.

Trusts

ESTABLISHING A TRUST PROVIDES A WAY TO SET ASIDE MONEY AND OTHER ASSETS FOR YOUR CHILD'S BENEFIT — DURING YOUR LIFETIME OR AFTER YOUR DEATH — WITHOUT JEOPARDIZING GOVERNMENT BENEFITS THAT MAY BE NEEDED. CREATING AND FUNDING A TRUST MUST BE DONE PROPERLY TO ASSURE THAT YOUR GOALS ARE MET.

"Start by doing what's necessary, then what's possible, and suddenly you are doing the impossible."

—Saint Francis of Assisi

Trusts

What is a Trust?

A trust is a legal document that provides a way for someone to take care of assets, including money or property, for someone else. Trusts are not just an option for wealthy families — if set up early, even small, regular contributions can grow into a trust fund that can greatly enhance a person's quality of life, if planning is done properly.

Trusts can be created for many different reasons. If a person with a disability cannot make responsible financial decisions, a trust can direct who will handle those decisions, including how to invest and spend the trust money. Some people set up trusts to avoid probate, the process followed after a person dies owning assets.

Trusts can also be created to supplement the government benefits a person with a disability may be receiving (or later become eligible for as an adult) such as SSI, SSDI, Medicaid, or Medicare, without jeopardizing the benefits. These trusts are called "supplemental needs trusts," "discretionary trusts," or "special care trusts" and will be the focus of our discussion on trusts.

There are many different types of trusts. If your family member has SSI and Medicaid — and you don't want him or her to lose it — you must use a trust that is designed to supplement, but not supplant or replace, government benefits.

Even when you are able to leave money and/or other assets to your child, public financial assistance and health insurance are typically still vital to cover daily living costs and medical care. The money you leave in trust can supplement what the public benefits cover. Even if the SSI payment is not needed, the Medicaid will be needed unless your child becomes employed with health benefits or you can pay for private health insurance.

If you leave assets directly to your child that result in him becoming ineligible for SSI, he will most likely also lose Medicaid. If this occurs, the money you left your child may have to cover health insurance and support needs. This can be avoided with a supplemental needs trust.

How to Create a Trust

A trust is created by a "grantor" who may be the parent of a person with a disability, another family member or other interested person. The grantor or others can fund the trust, which is done by titling bank accounts, stocks, or other assets in the name of the trust.

The "trustee" is the person named to be responsible for managing the trust fund for the benefit of someone else, the "beneficiary." In our discussion, the beneficiary is the person with a disability. The grantor may serve as trustee while alive or name someone else.

Trusts are usually created by a will or "trust agreement." They name the grantor, trustee(s), and beneficiary, and tell the trustee(s) how money should be spent for the beneficiary.

Trusts created by a will are called "testamentary" trusts and become effective upon your death. Your will can include all the information needed to direct where your estate will go when you die, including language setting up a trust and stating which assets will be owned by the trust.

You can change the trust terms any time you change or update your will. After you die, the trust terms cannot be changed and the trust will be created and administered using the language in your will.

Trusts that take effect while you are alive are called “inter vivos” trusts or “living trusts” and are created by a trust agreement. The trust agreement names the trustee and beneficiary, tells the trustee how to spend the trust funds, describes what will cause the trust to end and who is to receive the trust funds when it ends, and includes other information necessary to maintain the trust.

You can fund a living trust while you are alive, either all at once or a little at a time. You can also state in your will that some or all of your estate will be used to fund your living trust when you die. Other people can make contributions to the trust while they are alive or upon their deaths, through their wills.

Revocable vs. Irrevocable

Living trusts can be “revocable” or “irrevocable.” A revocable trust is one that you can change or terminate at any time during your lifetime, as long as you have the mental capacity to make the changes. The assets in a revocable trust are still considered to be yours since you can regain possession of them. This may be important should your own situation change due to disability, health, job status or other circumstances.

An irrevocable trust is more permanent because you cannot change or revoke it. When you transfer your assets into an irrevocable trust for someone else, you cannot take those assets back so they are no longer considered your assets. Your attorney can assist you in considering your needs and your child’s needs, and any tax implications, so you can decide whether a revocable or irrevocable trust is most appropriate.

Trusts are very complicated but can be very useful tools in setting up your estate plan. Whether a revocable or irrevocable trust is appropriate can be determined by an attorney, considering issues such as tax planning, protection of assets, long-term care planning, and probate issues. Be sure to use an attorney who is familiar with estate and tax planning techniques, as well as disability issues like government benefits.

Supplemental Needs Trusts

If a person who is eligible for means-tested government benefits (e.g., SSI and Medicaid) directly receives money or other assets, through a gift, inheritance or some other way, and the additional assets put the person over the total allowable asset limit, he or she could lose benefits. If this occurs, the individual typically must spend the assets until they are below the asset limit and then re-apply for benefits. Sometimes, people with disabilities have housing, medical or other personal expenses that are so high that they spend the additional money very fast. A properly worded and administered supplemental needs trust avoids this. The individual may also create a “payback trust” or join a “pooled trust” with his assets. These are described in this section, including there advantages and disadvantages.

If a gift or inheritance is paid to a supplemental needs trust, rather than directly to your child, you can avoid the loss of benefits. Instead of spending the money on living and/or medical expenses, the gift or inheritance can be used to improve your child’s quality of life.

This might include things like an electric wheelchair or communication device not covered by insurance, a computer, vacations, visits to and from family, and other personal needs. The trustee must be careful in spending the trust funds on the beneficiary’s behalf, because expenditures for items that are covered by public benefits may jeopardize the beneficiary’s eligibility for those benefits.

Like most trusts, supplemental needs trusts vary widely and range from relatively simple planning tools to manage modest sums of money, to intricate agreements making up only a single piece of a complex estate plan. Supplemental needs trusts (SNTs) can be divided into three categories: (1) SNTs created and funded by someone other than the beneficiary; (2) SNTs funded with a disabled individual's own assets; and (3) Pooled SNTs.

Trusts Created and Funded by Someone Else

A trust that is created and funded by someone for the benefit of person with a disability is often called a "third-party SNT." If you create and fund a third-party SNT, the assets can go directly to the trust and never be owned by the beneficiary. Because the SNT will own the assets, the beneficiary will not become ineligible for government benefits. The trust funds can be used for the individual's benefit until his or her death, when any assets left in the trust will pass to whoever you named in the trust agreement or will.

Your attorney must determine the exact provisions for your SNT. He or she must consider information about you and your child and how you want the trust funds used. Your attorney should base his or her recommendations on your child's age, what benefits your child is receiving, the eligibility requirements for benefits, and the kind and amount of assets you plan to place in the trust.

Trusts Funded with a Person with a Disability's Own Money

Sometimes things happen unexpectedly and money is paid directly to a person with a disability rather than into a trust. This may happen through an inheritance from a family member, life insurance proceeds, or a personal injury settlement. If a person receives money or property in an amount that makes him or her lose benefits, there is a planning option that can help set aside some, or all, of the money for supplemental needs and allow the person to reapply for benefits quickly.

If an individual with a disability receives a sum of money or property, certain people (the individual's parents, grandparents, guardian or the court) can create a supplemental needs trust for the individual. The trust must have special language that guarantees that after the beneficiary dies the remaining trust funds will be used to pay back the State of Maryland for services paid for by Medicaid (including health care and community services). This trust is called a "payback trust," "OBRA trust," or "d4A trust". The Maryland Office of the Attorney General must approve all payback trusts to make sure that they meet the standards in the law. After the state is paid back, the assets left in the trust can pass to the people chosen by the grantor.

Pooled Supplemental Needs Trusts

A "pooled supplemental needs trust" can provide a way to benefit from a supplemental needs trust without creating one yourself. A nonprofit agency creates a pooled trust and selects a trustee. Individual people have separate accounts, but all the money is pooled together and invested by the trustee. Individual beneficiaries get the services of a professional trustee and more investment options because there is more money overall.

If a person receives money from a gift, inheritance or settlement which causes the loss of government benefits, he or she can put the money in a pooled trust account and reapply for benefits. Accounts in pooled trusts can be created by an individual's parent, grandparent, guardian or a court. An attorney is not needed to establish an account in a pooled trust.

The account is funded initially with the individual's own money. After the trust is created and initially funded, others can make contributions to the trust. It is important to note that if someone does contribute to the trust, the terms of the trust govern that money.

Unlike a payback trust, after the beneficiary dies, the trust can keep the beneficiary's share. If the trust does not keep it, the assets left in the beneficiary's account must be used to pay back the state for all Medicaid funds spent for that particular beneficiary. After the state is paid back, any remaining assets can go to other people named by the person who created the account for the beneficiary. The Maryland Attorney General's Office must also approve all pooled trusts.

Trust Considerations

SNTs are only one type of trust and there are many variations of SNTs. If you are considering setting up a SNT, you must cover several key issues with your attorney. You must decide whether the SNT will become effective while you are alive or take effect upon your death, whether it will be funded with the beneficiary's assets or someone else's assets, how much discretion the trustee will have and who will serve as trustee. Your attorney must be able to explain each of the options to you, including their pros and cons.

We have provided a list of questions in *Appendix H* to consider when evaluating a trust.

Estimating How Much Money is Needed to Fund Your Trust

In estimating your child's annual supplemental needs, you may want to consider the many different possible costs that may be incurred. Realize that you may not be able to address all of your child's needs through the trust, either because of the expense or other reasons. It is still worth planning. All of us, with or without disabilities, have goals — some are attainable and some not. Likewise, we all prioritize our needs.

Some things to consider are:

- Educational or vocational expenses
- Costs for living supports and advocacy services that are not otherwise covered
- Equipment and assistive technology (e.g., wheelchairs, communication devices, computers)
- Medical and dental expenses not covered by government benefits
- Expenses related to the upkeep and maintenance of a home
- Miscellaneous emergency reserves
- Expenses related to hobbies, vacations, recreation, and seeing friends and relatives
- Other items like TVs, stereos, and furniture (often you can avoid affecting government benefits by having the trust own these items and allowing the beneficiary to use them)
- Other personal expenses

Your plan will be based on estimates as there is no way for you to know exact costs, especially for future needs. This is still useful information for your plan. Once you have estimates of your child's needs and potential costs, you can calculate how much money and/or assets you should put into the trust. A financial planner can be of assistance in helping calculate rates of return on different investments and developing an effective financial plan to fund your trust.

Funding the Trust

Several different types of assets can be used to fund a trust. Cash and/or investments such as certificates of deposit and stocks can fund a trust. You can give your trustee the authority to decide which investments, if any, he or she will buy with the trust's assets. If someone transfers one type of investment into the trust, unless otherwise stipulated, the trustee can decide to change the type of investment. The trustee is expected to make responsible investments.

Parents can purchase life insurance policies on one or both of their lives and stipulate that when the insured parent dies, the trust becomes the owner of the life insurance proceeds. Life insurance proceeds can be payable to a living trust already in existence or to a testamentary trust that only becomes effective when the parent dies. The amount of coverage and the type of policy you should choose depends on several factors, such as your age, your child's needs, and how much money will be needed to provide for those needs.

Funding a Trust

Most people don't have tens of thousands of dollars readily available to fund a trust. That's okay — you don't have to fund a trust all at once. Following are some examples of ways to fund a trust.

Caution: Consult an attorney or tax advisor about your individual circumstances. For instance, there may be tax consequences donors should consider.

Assets that can fund a trust include:

- cash, savings and certificates of deposit (CDs)
- stocks and bonds
- mutual funds
- life insurance
- pension plans
- real estate and personal property

Some options for building up funds in a trust include:

- Start with a lump sum that you are willing and able to contribute. This could be a modest amount or a large amount.
- Direct subsequent gifts to the trust. Others (perhaps grandparents) may wish to do the same.
- Make systematic investments. Contribute a set amount every month or every other month. Have an amount automatically transferred from your bank account.
- Make the trust the beneficiary of your life insurance.

Helping with Housing Costs

A trust can own a home. Money and other assets in the trust can be used for the home's upkeep. This option can offer a long-term living arrangement. When adequate supports are properly planned for and provided, people with disabilities can continue living in their own homes.

You can transfer your home into a trust, either while you are alive or upon your death. You can also create a trust that authorizes the trustee to use the trust funds to buy a home for your son or daughter. If you have sufficient assets, the trust can buy the house outright. If not, trust funds could be used toward down payment and closing costs and/or to help pay the mortgage payments. The trust could also loan money to your son or daughter for a down payment or rent a home to your child if that would have the least detrimental affect on his or her benefits. Individual circumstances will determine the best option.

SSI considers a person to have an ownership interest in a home held in trust for his or her benefit because the home is used to provide the person a place to live. Therefore, a home owned by a supplemental needs trust should not be considered a resource to the individual and should not result in a reduction or loss of SSI.

However, mortgage payments and property taxes paid by a trust could be counted and reduce your child's SSI. Other costs like gas and electric and water bills paid by the trust will result in a reduction of SSI in the months they are paid. As discussed in the Government Benefits section, it could be worth taking the reduction in order to receive this assistance.

There are housing costs that you or a trust can cover that will not affect SSI and Medicaid. It might be easier to have the trust pay for these and have your son or daughter pay for direct shelter costs, if he or she can afford them. Examples include: telephone and cable bills, home maintenance and repairs, and furniture and appliances within a $2,000 limit. Remember that payment must be made directly to the store or vendor. If you give money to your child for any purpose, it will be considered income and reduce his or her SSI dollar for dollar.

Please also note that transferring real estate to a trust may have significant tax implications for you and/or the beneficiary. For these reasons, when considering homeownership as an option, be sure to have a careful review by an attorney knowledgeable about these issues.

Please note that you must carefully plan how you will assist with housing costs to avoid, or minimize, the effect on your child's public benefits, specifically SSI. SSI policy is not always clear. Refer to the "Government Benefits" section for more details.

Choosing a Trustee

The trustee is responsible for administering the trust, so you must select your trustee very carefully. You should also name a "successor trustee" to take over if your trustee is unable, or unwilling, to continue.

The will or trust agreement that creates the trust should include instructions for the trustee as to how and when to give money to the beneficiary. It may give the trustee guidelines but allow him or her to decide how exactly the trust fund will be spent. The trustee has other responsibilities, including managing and investing the trust money, filing tax returns for the trust, and keeping track of how money is spent for the beneficiary.

The trustee must be someone who can administer the trust properly, so as not to jeopardize government benefits. Benefits can be negatively affected even with the best worded trust, if the trustee distributes trust funds incorrectly.

A trustee should be capable of managing the amount of money in the trust. A trustee should also be familiar with ways to invest money, even though many trustees seek professional investment advise. Even trusts with relatively small amounts may be invested, although the investment strategy may be fairly straightforward.

It is helpful if the trustee is familiar with the beneficiary's needs and preferences. It is also important for the trustee to share your vision for your child, especially because the trustee will make important decisions after your death.

Maryland law, as well as the trust document, require the trustee to spend the trust money for the beneficiary rather than the trustee's own benefit. Even though these legal protections are available, you should still be very careful in choosing who will serve as trustee.

Some grantors choose a family member or friend to be a trustee, while others name a bank or other financial institution. Financial institutions may only manage trusts over a certain minimum — sometimes as high as $500,000 — and charge fees for their services that may be based on the amount in the trust or the amount of income the trust generates. Friends or family members serving as trustee may be willing to do so at little, or no, cost. A trust can be written to financially compensate the trustee for his or her time and service, even if you name a friend or family member.

Other Planning Considerations

There are several other important issues to consider when planning how to leave money or other assets to your family. These include minimizing the impact of taxes, planning for potential long-term care needs you may have, and working effectively with professionals.

"Little by little does the trick."

— Aesop

Other Planning Considerations

Futures planning must be comprehensive in that it considers you within the context of your life and your goals; it considers you as an individual, spouse, parent, and/or other family member. It cannot be done in a vacuum. Of course, the discussions about supplemental needs trusts, decision-making and benefits for your family member with a disability are of primary concern in futures planning. However, these discussions may be accompanied by some related planning issues, such as working with professionals, tax planning and long-term care planning.

Your planning issues will vary depending on many factors, including whether you are married, how much money you have saved, how many children you have, and your children's needs. Your health status and age also are important factors to consider when beginning a futures plan, especially if you may have long-term care needs.

This section will alert you to some things you should consider as you plan for your family member with a disability.

Tax Issues

The tax laws in this area have changed significantly and the information contained in this section is no longer accurate. The tax laws continue to be in a state of flux. For further information, contact an attorney or tax professional.

There are several different taxes imposed by federal and state governments, including *gift and estate taxes, inheritance taxes, income taxes, and capital gains taxes*. These taxes may apply to you whether you are planning for a person with a disability or not. You should become aware of when each tax is applied and whether it applies to your situation. You may need the assistance of an attorney, accountant and/or financial planner to analyze your situation to determine whether taxes can be reduced or avoided.

Gift and Estate Taxes

Federal gift and estate taxes get a lot of attention because the tax rates are high, up to 55 percent in some estates. For this reason, many individuals and couples seek ways to reduce or avoid gift and estate taxes. Federal law allows each of us to transfer up to $650,000 in assets to other people without having to pay federal gift or estate taxes. This can be done through lifetime gifts and transfers occurring at death and is known as the "applicable exclusion amount." The amount that can be protected will gradually increase to $1 million by 2006.

You can use the applicable exclusion amount a little at a time and apply it to gift and/or estate taxes. For example, if Dad gave $300,000 in assets to his daughter in 1996, he used up some of his applicable exclusion amount. If he died in 1999, he would have $350,000 of his applicable exclusion amount left. If he left $500,000 in assets to his son, then $350,000 in assets would be protected by the remaining applicable exclusion amount and only the excess $150,000 would be subject to estate tax.

If your assets total $650,000 or more, or will in the future, some estate planning options may enable you to avoid or reduce gift and estate taxes. Some assets cannot be gifted, so you should consult an attorney or financial planner.

Some other points to consider regarding gift and estate taxes include:

- You can avoid gift taxes through the "annual exclusion." This allows you to give away a limited amount to as many individuals and couples as you like, every year, without using any part of your applicable exclusion amount or paying federal gift taxes. The limit is a gift of $10,000 per individual and $20,000 per married couple, each year.

- Irrevocable life insurance trusts can own insurance on a person and when the person dies, the insurance proceeds are not considered part of his or her estate.

- Married couples have increased options available because federal gift and estate tax does not apply to gifts or estate transfers to spouses. Also, married couples can have wills that create trusts to make sure each spouse can use the applicable exclusion amount to transfer assets tax-free.

Inheritance Tax

State inheritance tax is assessed upon death regardless of how much is in an estate. It applies to all probate assets and most non-probate assets. The tax rate is one percent for estate assets passing to spouses, parents, children, grandchildren, great grandchildren, etc. and ten percent to anyone else, except charities. Some special exemptions apply to assets passing to spouses. Inheritance tax on probate assets and some non-probate assets must be paid before an estate can be closed.

Income Tax and Capital Gains Tax

Income tax considerations are important for trusts, as well. The assets transferred into a trust are not taxed but the income the trust earns will be taxed. Once created, some trusts must obtain a tax identification number and file tax returns.

Capital gains taxes must be considered when giving away certain property during your lifetime, such as real estate and stocks. If the property value has increased since it was purchased, the increase is a capital gain and will be subject to capital gains taxes when the property is sold.

Tax issues are extremely complicated and should be approached only with the assistance of an accountant or attorney who has tax experience or other tax advisor. Additionally, he or she should know about special provisions that may be available to people with disabilities or high medical expenses.

Long-Term Care Needs

To avoid depleting your savings that you may want to leave to your children, you might want to consider the long term care needs you may have later in life. People receive long-term care in their own homes, assisted living facilities and in nursing homes. No matter where it is provided, it is usually very expensive. We all hope we will never need long-term care. Unfortunately, it is becoming more likely as people are living longer and fewer family members seem to be available to care for elderly relatives.

One way to plan for long-term care is to buy long-term care insurance. There are many types of long-term care insurance policies and the decisions can be very confusing. It is important to work with an insurance broker who is well-informed about long-term care insurance in general and the insurance companies and policies that are available to you.

Like most insurance, long-term care insurance becomes more expensive as you get older. People who already have certain illnesses may have to pay very high premiums or may not be able to qualify for a policy. Also, people with modest incomes and/or other expenses may not be able to afford any additional premium. For these reasons, long-term care insurance is not the answer for everyone.

Some individuals can pay for their long-term care through their savings or income, or a combination of the two. Because long-term care is so expensive, many individuals and couples must rely on Medicaid to cover some or all of the cost. Medicaid covers long-term care in nursing homes and has special rules to protect the spouse who continues to live at home. Medicaid also allows people to transfer certain assets to individuals with disabilities (or to trusts for individuals with disabilities) without jeopardizing the Medicaid long-term care eligibility of the person transferring the assets.

Because Medicaid law is so complex and changes frequently, each case must be evaluated considering the current law and facts of the situation. In order to learn about special protections and to make sure that you do not take steps to disqualify yourself or your spouse from Medicaid, consult an attorney who is familiar with Medicaid's rules for long-term care.

Arranging Your Assets: Meet the Smith Family

Planning for someone with a disability must be done in the context of his or her family. Of course, each family has unique circumstances and a unique history. Parents usually begin futures planning in relation to their child with a disability, but also provide for their other children. If you want to leave assets to a family member with a disability and to other family members, there are several different arrangements that may work for you.

The Smith family examples are outlined to give you ideas about some of the planning options you may use. However, they do not represent all possible scenarios or solutions. Because each person and family is unique, it is crucial that you consult an attorney who has experience with estate planning to determine the best plan for you and your family.

Mr. and Mrs. Smith ("Mom and Dad") have 3 adult children, Mike, Sally and Jake. Jake has a developmental disability and lives at home with Mom and Dad. Mike and Sally are both married with children. Mom and Dad want to plan for their entire family, making sure that Jake will live as independently as possible while continuing to receive SSI benefits.

Scenario 1: Mom and Dad own $300,000 in assets. Dad dies first and Mom then owns all assets. When Mom dies, the estate will be divided so that one-third (1/3) passes to Mike, one-third to Sally, and one-third to a supplemental needs trust (SNT) for Jake. When Jake dies, the assets left in the trust will be divided between Mike and Sally, as stipulated in the trust.

Scenario 2: Mom and Dad own $300,000 in assets. Upon the death of the first spouse, the surviving spouse will own all assets. When the surviving spouse dies, the entire estate will be distributed into a SNT for Jake. When Jake dies, the assets left in the trust will be divided so that half passes to Mike and half to Sally.

Scenario 3: Mom and Dad have $10,000 in assets, and they have purchased a "second to die" life insurance policy that will pay out proceeds when the second spouse dies. On the death of the second spouse, the insurance proceeds will be paid into a SNT for Jake. When Jake dies, the assets left in the trust will be divided so that half passes to Mike and half to Sally.

Scenario 4: Mom and Dad own a home and $60,000 in other assets. Upon the death of the first spouse, the surviving spouse will own all assets. When the surviving spouse dies, the home and $30,000 will be distributed to a SNT for Jake so that Jake may continue living in his home with support. Mike and Sally will each receive $15,000. When Jake dies, any assets left in the trust, including the home, will be divided between Mike and Sally.

Working with Professionals

We have mentioned the need to work with attorneys, financial advisors and other professionals throughout the preceding chapters. Finding the right professional who has the right technical skills is the first step, and can be a difficult one. Then, you must make sure you trust him or her, because you will be working together on very important issues and your relationship may be very long-term.

You may start by looking for an attorney who can address the needs of your family member with a disability, while considering your own needs and those of your other family members. Many families begin with an attorney who can prepare wills, trusts and other legal documents. Some need an attorney because government benefits have been denied or stopped. Futures/estate planning and advocacy for persons with disabilities is not a well-defined “practice area” like family law or medical malpractice. For this reason, it may take some research to find the right lawyer.

Like anyone you hire for services, you may start through “word of mouth.” If you decide you need to replace your roof, you talk to your neighbor who had his roof replaced last year. You ask your neighbor if the roofer did a good job, what he charged, how long the process took and whether your neighbor considered any other roofers and if she would use the roofer again. You may then talk to your electrician to find out if he could recommend a roofer with whom he had worked. When you get several names of roofers, you call them and “interview” them over the phone and may set up a time to meet to assess the job.

Talking to other parents who have already begun planning, such as other parents of a person with a disability, can give you a tremendous head start. Your child’s teachers, service coordinators, advocates or employer also may provide good referrals. Agencies serving individuals with disabilities may also know of attorneys familiar with benefits, estate planning and futures planning.

A list of attorneys in Maryland who have expressed an interest in estate planning with families who have a member with a disability has been compiled by an organization called Service Coordination. Contact Service Coordination at 410-882-4710 for the list.

Hiring an attorney can seem intimidating if you are unfamiliar with the legal terms or the documents you may need for your situation. For this reason, the more you do in advance to learn about estate planning, the better prepared you will be to evaluate the attorney and decide whether you want to retain him or her. Reading, attending seminars, and “networking” with other families will help you prepare to begin futures and estate planning.

You may be concerned that an attorney will be too expensive or that you will not know what to expect regarding costs. When you contact an attorney, you should ask what he or she will charge for the first meeting. The attorney should give you an estimate of his or her fees for representing you. If you decide to retain the attorney, he or she may require an advance payment, called a “retainer fee,” or may bill you when the work is finished. He or she may bill you based on a flat fee for the entire job or based on his or her hourly rate.

A qualified attorney should discuss with you the amount and type of assets to pass to your child with a disability and may recommend establishing a trust to receive the assets. The attorney may evaluate whether your child will qualify for benefits, either currently or in the future, and how the existence of a trust would affect those benefits.

It is important to think about short-term and long-term goals for your child, and to communicate those goals to your attorney. Then, he or she can help you create a plan that provides a good framework for the future, but is flexible enough so that it can be changed as your child’s needs change.

Your Attorney Should be Knowledgeable in these Areas in Order to Effectively Plan for a Person with a Disability:

☑ Wills

☑ Special Needs Trusts, other trust options, and tax implications

☑ Public Benefits: SSI, SSDI, Medicaid and Medicare

☑ Other sources of income (for example: Pensions, Survivor Benefits, Annuities)

☑ Guardianship and other alternatives

☑ Health insurance

☑ Life insurance

☑ Understanding of the capabilities and needs of people with disabilities and their families, and a general awareness of community service options for people with disabilities.

In addition to working with an attorney, you may require the services of other planning professionals, such as accountants, financial planners or insurance brokers. The search for these professionals will be similar to your search for an attorney.

As you undoubtedly have gathered from the earlier chapters, because each individual's and family's situation is different, each futures plan is different. Some basic areas may be common to most plans, but when it comes to actually developing a plan for your child, your attorney and other planning professionals must learn the details of your situation, identify the issues that require attention, and decide with you which steps to take to address those issues.

Financial Planning

Effective financial planning, with or without professional assistance, can be key in maximizing your assets. Setting goals, looking at your financial status, and understanding what financial planners do and how to select one will help you in this process.

"The man who has done nothing but wait for his ship to come in has already missed the boat."

— unknown

Financial Planning

Financial planning generally involves evaluating and recommending strategies to achieve your financial goals. Planning advice should be objective and comprehensive. The title, "financial planner" and "financial advisor" are used by a variety of people — accountants, brokers, insurance agents, and others — to indicate that they offer comprehensive financial planning services.

Not everyone needs the advice of a financial planner. By reading publications or taking courses, you may decide to undertake your own financial planning. Even if you decide to hire a financial planner, you still need to know as much as you can about your own individual financial situation. Without that knowledge, it is nearly impossible to evaluate whether a planner's recommendations make sense.

A good financial planner will review your total financial picture and offer advice about how to make your money work for you in the most advantageous ways — given your income, goals, and attitude toward financial risk.

Decide If You Need a Financial Planner

To decide if you want to contact a financial planner, go through some of the same preliminary steps a good financial planner would take you through. Though this may require some time and effort, it is a necessary part of the financial planning process. You will have a clearer picture of your financial profile and will have laid the foundation for future investment decisions. You may determine you are doing very well on your own or you may decide to confer with a financial expert to get more information or to find out if you have other investment options to consider.

Set Long-Term Goals

Before you consider any specific investments, think hard about what is important to you. If you have a spouse, try thinking first alone and then together. Writing down these ideas may help. When you know (and can agree on with a spouse) what's most important to you, you are in much better shape to tackle your financial future.

Organize Your Important Papers

Without your important papers and financial documents your calculations may be based on too much guesswork. See *Appendix I* for a form to list your important papers.

However, do not put off planning if you can't bring yourself to get all your papers together. Make necessary appointments, and the professionals you contact will let you know what documents to bring.

Examples of Important Papers

- Birth certificates, marriage certificates, divorce papers, child support orders
- Naturalization papers
- Legal agreements
- Stocks, bonds, CDs, IRAs, other investments
- Deeds
- Insurance policies
- Income tax returns
- Financial records
- Guardianship papers
- Letter of Intent for your child
- Advance Directives/Living Will
- Power of Attorney
- Wills
- Trust Agreement
- Names and addresses of people named in Power of Attorney, Trusts, Wills
- Burial Instructions

Figure Out How Much You Own and Owe

A financial statement tells at a glance what you own and how much you owe. This basic tool is often the starting point for future financial decisions. The process of compiling a financial statement may point out revealing things about the way you handle your money.

The financial statement tells your net worth by subtracting everything you owe (liabilities like credit card balances, mortgages, taxes, etc.) from what you own (assets you could sell or cash in). See *Appendix J* for sample forms.

Determine Where Your Money Goes

Collecting information on how much money you spend and for what may seem overwhelming but it may be one of the most important steps you take. To do this, you will need to collect receipts, check stubs, credit card statements, and other information for a period of time that is adequate to establish a picture of where your money goes.

Don't be surprised if you find you are spending more money than you thought in some categories. Most people have little idea where their money really goes — especially for miscellaneous items. Based on the information you gather, you may decide you need to develop a budget to track the money you have and to determine if some of your spending is unnecessary.

Once you know where your money is going, you are in a much better position to know what funds, if any, you have available for investment purposes. Then you can set long-term investment goals. See *Appendix K* for a sample cash flow statement.

What to Expect from a Financial Planner

If you decide to use a financial planner, a good one can assist you in the following ways:

- Assess your financial history, such as tax returns, investments, retirement and estate planning, wills and insurance policies.

- Review your financial statement, examine your debts, and determine if any should be consolidated, paid off or refinanced.

- Help you develop a financial plan, based on your personal and financial goals for you and your children, history, preferences, and attitude toward investment risk.

- Identify financial areas where you may need help, such as funding a trust, building up retirement income, improving your investment returns, buying or selling an insurance policy and tax saving suggestions.

- Write down and discuss an individualized financial plan and timetable that you understand.

- Help you implement your plan, including referring you to specialists, such as lawyers and accountants, if necessary.

- Review your situation and financial plan periodically and suggest changes when needed.

How to Choose a Financial Planner

Select a financial planner like you do other professionals — by considering credentials, experience, reputation, types of services, the manner in which services are provided, and fees.

There are several ways to look for a financial planner.

1. One place to start is to look for planners who are certified. Certification does not guarantee that a person will be a creative or effective planner. It does indicate, however, that he or she has studied important financial planning subjects. The major groups that represent financial planners who have taken courses and passed exams can be found in *Appendix B*.

2. Ask friends and colleagues for recommendations. Realize, though, that an investment advisor who impresses one client may not be suitable for someone else.

3. Planners often teach classes at local schools or offer free seminars. Going to these makes sense if you want to shop around before deciding what investments to make or which planner to work with. Keep in mind that these seminars are opportunities for professionals to promote themselves — go with a healthy dose of caution.

Always interview financial planners you are considering to determine if they have the knowledge, experience and business style that best fits your needs. Many will have an introductory meeting with you at no cost. Planners may specialize in a certain profession, income level, age group, or area of planning. You will find a list of questions to ask financial planners in *Appendix L.*

Ask for references and check them. Request a copy of the planner's Form ADV to understand more about his or her practice. In Maryland, this form is filed with the Securities Division of the Office of the Attorney General. You can also check with the Securities Division to see if complaints have been filed against the planner you are considering. Be aware, however, that it may take time for complaints to surface against someone because years may pass before investments are found to be worthless.

How are Financial Planners Compensated?

Financial planners are paid in several ways. Ask specifically how the fee is calculated and what it will be. No matter which fee structure you work with, make sure to get written estimates of what services will be provided at what price. Compare estimates and select the package of services that best meets your needs at a reasonable cost.

Fee-only: Fee-only planners base their charge on gathering your financial data, analyzing it, recommending a plan and helping you implement it. They do not earn income from financial products they suggest you buy or invest in. You may pay some fees to unaffiliated companies for investment and insurance products.

The planner's fees may be charged on an hourly or project basis, or on a percentage of assets under management. Your planner should be able to estimate these costs. Payment is required whether or not you implement the suggested plan.

Commission-only: Commission-only planners charge no fee for their advice and preparation of your plan. They receive commissions from the companies whose financial products they sell to you. Since commissions are often not disclosed, it is difficult to know how much you are paying toward the commission. Ask for a disclosure of this information. Commissions on mutual funds can average about five percent while on insurance they can be 50% or more of the first year's premium.

Exercise caution as some commission-only planners may be inclined to direct you toward products that provide them with the best commissions. Consider making a written agreement that the planner will disclose yearly total commissions earned on recommendations made to you.

Combined Fee and Commission: Some planners charge a fee for consultation and planning and earn sales commissions.

A note of caution: Please realize that not everyone offering financial or investment services has taken specialized courses in all aspects of financial planning. There is little regulation of the financial planning industry. Most financial planners earn all or part of their living from the commissions on the products they sell. If you visit a financial planner, you probably will be asked to consider purchasing some financial products as part of your overall financial plan. Be wary of planners who push particular financial products at the expense of your real needs or who promise quick riches or instant financial gain. Building a secure financial future is not accomplished overnight or with a single investment.

Also be wary of anyone who pressures you to make a purchase immediately, without adequate time to evaluate your options. Always take the time you need, outside your meeting with the planner, to make your decisions.

Services in Maryland

There are several state agencies that provide or fund services for people with developmental disabilities. Knowing what services exist, who is eligible, how to apply, and what to expect will help you and your son or daughter as you plan.

> *“You don’t just luck into things… you build step by step, whether it’s friendship or opportunities.”*
>
> *— Barbara Bush*

Services in Maryland

There are several state agencies in Maryland that provide support to people with disabilities. Some are available to anyone who qualifies, while others have waiting lists. Eligibility varies. The following is a brief overview to assist you in determining which programs might work for your child. Advocacy organizations and service provider agencies can often times help you identify and access resources. Call for more information.

Maryland State Department of Education (MSDE)

Maryland Infants and Toddlers Program

The Maryland Infants and Toddlers Program (MITP) coordinates early intervention services for children with developmental delays and disabilities from birth until age three, regardless of family income. Children and families are eligible if the child:

- has a delay of 25% or more in development, or
- is developing in a way that is considered atypical for most children his or her age, or
- has a condition that is likely to affect development.

Services are intended to enhance a child's potential for growth and development before he or she reaches school age.

MITP operates under authority of the Individuals with Disabilities Education Act, Part C. MSDE administers the program in collaboration with the Department of Health and Mental Hygiene, Department of Human Resources, and the Office for Children, Youth and Families.

MITP awards grants to local Infants and Toddlers Programs to support the coordination and provision of early intervention services in each county and Baltimore City. These local programs are composed of local departments of education, health, social services and other entities identified by each county. A multi-disciplinary team comprised of the family and involved professionals develops an Individualized Family Service Plan, which defines the team's recommendations for services.

Early intervention services may include such things as audiology, therapies (speech-language, occupational, physical), health services, transportation, service coordination, special instruction, and assistive technology.

The MITP also coordinates the Family Support Network (FSN). The FSN operates through a network of local coordinators in most areas of the state and provides information about available services, links families with similar experiences, and provides workshops and seminars.

For more information and referrals to local programs and staff, contact: Maryland Infants and Toddlers Program & Family Support Network, 800-535-0182.

Educational Services

The Maryland State Department of Education (MSDE) works in partnership with the 24 local school systems to ensure that a free and appropriate public education is provided to all students, ages 3 to 21, with disabilities. It is the responsibility of MSDE to ensure compliance with the federal Individuals with Disabilities Education Act in all school districts. This includes the right to be educated in the "least restrictive environment." This is usually defined as the student's neighborhood school, if appropriate, with the student's same age peers in a regular education classroom with needed supports.

The focus of special education is on the development and implementation of an Individualized Education Plan (IEP) for the student. A team consisting of the parents and involved professionals develop the IEP for the student. Services in the plan must be educationally related and may include curriculum modifications, speech-language, occupational and physical therapy, audiology, adapted physical education, and assistive technology for communicative disorders and physical impairments.

For more information, contact: Maryland State Department of Education/Division of Special Education, 410-767-0244. See "Education Advocacy" in *Appendix B* for assistance.

Partners for Success: Resource Centers for Families and Schools

(formerly Parent Information Training Centers — PITCs)

Partners for Success: Resource Centers for Families and Schools provide families, professionals, and the community with information, training, and support. The purpose is to enable families of children with disabilities, age 3 to 21, and professionals to function as equal partners in the educational decision making process and to assist families in accessing services for their children.

Services may include: special education resources, information and referral, assistance with IEPs, seminars and workshops, consultation, a lending library, and facilitation of parent support groups.

MSDE provides financial assistance to these centers and the local school systems support them financially and/or through in-kind services. A parent of a child with a disability and an educator work as a team to operate the center. All counties, the Maryland School for the Deaf, and the Maryland School for the Blind have a center.

For more information and referrals to a local center, contact: Maryland State Department of Education/Division of Special Education, 800-535-0182.

Developmental Disabilities Administration (DDA)

The Developmental Disabilities Administration is the principle state agency in Maryland that provides funding for supports and services to children and adults with developmental disabilities. To be eligible for most services, a person must have a severe, chronic disability that:

- is attributable to a physical and/or mental impairment, other than a sole diagnosis of mental illness;
- manifested before age 22;
- is likely to continue indefinitely;
- results in an inability to live independently without external support or continuing and regular assistance; and
- reflects the need for special, interdisciplinary or generic care, treatment or other services that are individually planned and coordinated.

What Types of Services Does DDA Fund?

Day and Vocational Services and Supported Employment:

These services teach skills for daily living and/or skills necessary to enter the workforce and provide supports to work in competitive employment.

Residential Supports in various settings:

Group Homes: Support provided to 4-6 people living in a house or apartment owned or rented by a service provider.
Alternative Living Units (ALU): Support provided to 1-3 people living in a house or apartment owned or rented by a service provider.
Community Supported Living: Support provided to a person in a house or apartment he or she rents or owns.

Residential supports range from drop-in support to 24-hour awake overnight staff in these various settings.

Individual Support Services (ISS):

These are lower cost, lower intensity services that assist adults to maximize independence, productivity and integration within the community. Examples include support with activities like grocery shopping and budgeting, purchase of services and equipment, and assistance accessing community services.

People with a severe, chronic disability who do not meet the definition of developmental disability listed above because they were not disabled before age 22, may be eligible for Individual Support Services.

Family Support Services (FSS):

These are supports and assistance provided to families with children under age 22 who have developmental disabilities. Services are flexible and uniquely tailored to each family's needs. Examples include information and referral, advocacy, parent support, respite care, and purchase of therapies, equipment and services.

Behavioral Support Services:

These are services designed to assist people with challenging behaviors acquire skills, gain social acceptance and adapt their behavior, as appropriate. Services include consultation, staff support, training, and respite services.

Service Coordination/Case Management/Resource Coordination:

This is professional staff who help individuals with developmental disabilities and their families plan, locate, coordinate and monitor community services. The DDA service system is moving toward having resource coordinators assist individuals and their families to coordinate the funding that is available to meet their needs.

How and When Do I Apply for DDA Services?

Contact DDA's regional offices for an application for services. The eligibility process can take many months so let regional office staff know if your situation requires more immediate attention. Don't wait until your child needs services to apply. There are differing opinions about how early to apply for DDA services that you foresee needing. We suggest applying at least several years ahead. There are usually waiting lists for services. If in doubt, ask for guidance from other parents and advocacy organizations and consult with DDA regional office staff. For specific information on DDA service providers, including mission and services offered, go to: www.dhmh.state.md.us/dda

When are Services Provided?

DDA services are not an entitlement. This means that not everyone who needs or wants services receives them. Whether your child waits for services, and for how long, depends on many factors. These may include the amount of new funding DDA receives each year; how critical your needs are; the needs of other people in your area; the types of services requested; and the area of the state you live in, among other factors. In 1998, DDA began a five year initiative to eliminate its waiting list. This will significantly affect who gets services and when. Contact your region's DDA office or advocacy organizations for updated information.

How are Services Provided?

DDA funds private, non-profit agencies to provide services and supports in communities throughout Maryland. As DDA funded services evolve and change over time to become more flexible and responsive to the unique needs of each individual served, the terms used to refer to services may change also. What services are called is not important. What is important is whether the services meet your child's individual needs and are provided in the way your child wants.

You may choose to talk with a few providers in your area who may help you envision the possibilities for your child. Which service providers do you and your child feel best about? Who can help you be more creative and bring your child more independence, while addressing health and safety issues? Even if you cannot access any, or all, desired services now you can start gathering information and planning. Service providers should be willing to help you do this now. If you meet resistance, this could tell you something about a provider.

For more information, to apply for services, and/or for a list of agencies providing community services, contact a DDA regional office:

Central Maryland	410-902-4500	Western Maryland	301-791-4670
Eastern Shore	410-334-6920	Southern Maryland	301-362-5100

The Division of Rehabilitation Services

The Maryland Division of Rehabilitation Services (DORS) is a federal-state funded program whose primary emphasis is on helping individuals with disabilities to become employed, within the Vocational Rehabilitation program. DORS also assists individuals with disabilities to become more independent, within the smaller Independent Living program. There are 22 DORS offices located throughout Maryland.

Eligibility for the Vocational Rehabilitation Program (VR)

To be eligible for vocational rehabilitation, an individual must 1) have a disability that results in difficulty getting or keeping a job; 2) be able to benefit from rehabilitation services; and 3) require services in order to get or keep employment.

Eligibility for the Independent Living Program (IL)

To be eligible for independent living services, 1) an individual must have a severe disability that limits independence at home or in the community; and 2) delivery of independent living services will improve the ability of the individual to function more independently at home or in the community. Eligible people can be served in the IL Program if they do not have an employment goal. Funds for this program are very limited.

Who Receives Services?

Individuals with severe disabilities are the highest priority for services and funding. If funding is not sufficient, individuals with less severe disabilities are placed on a waiting list. In general, a person is considered by DORS to have a "severe" disability if he or she has a physical or mental impairment which seriously limits one or more functional capacities relative to employment (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance or work skills). A person is considered to have a "most severe" disability if the disability seriously limits *three* or more of these areas.

Some conditions are automatically considered to be at least "severe". They include:

1. People receiving Supplemental Security Income or Social Security Disability Insurance;
2. People with "moderate" or "severe" mental retardation;
3. People who are blind or deaf; and
4. People with epilepsy, if not seizure-free for two years.

Individuals whose families are financially able to contribute to the cost of rehabilitation are required to do so based on a sliding fee scale. This only applies if the parents claim the child as a dependent on their federal income tax return. The individual or family is not required to pay for 1) assessment or evaluation services, 2) accommodations such as sign language interpretation and reader services, 3) vocational rehabilitation counseling, guidance and referral, or 4) placement services, including job coaching.

DORS Services

DORS works with individuals on a *time-limited basis*, until the rehabilitation goal is achieved or it is clear that progress is not being made toward the goal. Length of service varies from several months to several years depending on the individual's needs and types of services required.

Rehabilitation services are based on the needs, capabilities, interests, and choice of the individual. These may include:

Independent Living Services:

IL Services are focused on rehabilitation technology. A modification to a van, for example, may make it possible for a person to get out into the community. A ramp added to a home may make it possible for someone to increase independent activities. Other examples include counseling, advocacy, information and referral, and independent living skills training.

Vocational Rehabilitation Services:

- Vocational rehabilitation counseling and referral.
- Job search, placement assistance and job retention services. The counselor remains available for at least 90 days to assist with problem resolution as the individual begins employment.
- Physical and mental restoration services. These are time limited services such as short- term psychotherapy, special visual aids, occupational therapy, and prosthetics.
- Vocational and other training services. This includes personal and vocational training, books, tools, and other training materials.
- Supported employment services. This is assistance to work in integrated employment settings for competitive wages. The individual is provided a job coach who assists in teaching and reinforcing the job duties and relating appropriately to others on the job. DORS funds the initial intensive period of job coaching, after which continuing support is funded for the remainder of the individual's work life by an "extended service provider" such as the Developmental Disabilities Administration.
- Rehabilitation technology services. This includes architectural modifications like building a ramp into a home, vehicle modifications like installing hand controls or a lift into a vehicle, and modifications to computers for people with visual impairments or learning disabilities.
- Support services. In support of the services listed above, DORS may provide limited assistance to cover related costs such as transportation and personal assistance services.

For a referral to a local DORS office where you can apply for services and obtain more information, contact: DORS Headquarters, 888-554-0334 or 410-554-9411 (TTY)

Transition Planning for Students with Disabilities

(Inter-agency collaboration)

What is Transition Planning?

Transition planning is intended to assist students with disabilities as they prepare to leave school and move to employment, post-secondary education or training, independent living, adult services and community participation. Transition planning is designed so that the necessary services are in place and the student has developed the skills he or she needs to be successful upon leaving school. It involves collaboration between the student, family, school, adult service providers, various state agencies, and others as may be appropriate.

Upon leaving school, entitlement to services ends. In other words, a child moves from a system that assures educational services for ***all*** students with disabilities through the age of 21 to a system that serves only ***some*** people based on the availability of services. Students may want to access various services from adult service providers, all of which may have different application procedures, funding, and eligibility requirements. These applications should be completed well before necessary services are needed so that programs can make eligibility decisions about the child and families can make appropriate plans. Therefore, comprehensive and cooperative planning while the child is still in school is very important.

When Does Planning Occur?

The law requires that formal transition planning should begin in the calendar year the student turns 14. The individualized education plan (IEP) should identify the student's transition goals and service needs. A coordinated set of activities, based on these needs, should be developed — this is the transition plan. At this age, it focuses on a course of study in the school system.

By age 16, the IEP is required to expand to include linkages in the community to meet the employment, post-secondary education and independent living needs of the student. Each year after, the IEP must identify the student's current transition service needs and those anticipated to be needed after graduation. These may include, but are not limited to:

- job development and support
- public transportation
- living arrangements and support
- health services
- mental health treatment services
- independent living skills
- rehabilitation services
- recreation options
- career exploration and development
- self-advocacy and self-determination
- case management
- post-secondary education and supports

Governor's Initiative for Transitioning Youth

In support of the transitioning process, the Governor's Initiative for Transitioning Youth was created to coordinate the State's programs and services to students with developmental disabilities who are transitioning from local school systems at age 21 and who are likely to require supported employment services in order to maintain employment during the course of their working lives. Since its inception, the Initiative has expanded to include students who need day habilitation services.

Who is eligible?

To be eligible, students must:
1. meet DDA's eligibility criteria; and
2. be between the ages of 21 and 22 when leaving school.

If the student is likely to require supported employment services, he or she must also meet DORS eligibility criteria, be determined to be an individual with the "most severe" disability, and be determined through a comprehensive assessment as needing supported employment services.

Who is funded?

DDA funding for all students exiting school is not always assured because it is based on funding provided in the State's budget which can fluctuate year to year.

What services are students supposed to receive?

The Governor's Initiative for Transitioning Youth specifies that:

The Local School System (LSS) should:

- Provide educational services to transitioning youth that assist with job preparation and identify specific transition services as described above.
- Identify potential students for the Governor's initiative and refer them to DORS.

The LSS and DORS should:

- Place students in youth summer employment programs, as appropriate.

DORS should:

- Assist students to apply for SSI and other benefits for which the student is eligible.
- Fund supported employment services during the student's final school year.
- Assist students and parents in applying for DDA services.
- Refer students to supported employment providers when notified by DDA that the student is eligible for DDA supported employment services (the LSS shares this responsibility).

The DDA should:

- Provide ongoing funding for supported employment services as well as other follow-along services.

It is important for parents to note that the transition process (which can be anything from transition planning to application for adult services) does not typically happen as a matter of course. Parents and families must make it happen by initiating and participating in student meetings, networking with other parents, asking questions, and following up to ensure that all parties carry out their responsibilities.

For more information, contact:
The transition coordinator for your local school system and regional staff of the Developmental Disabilities Administration. Inquire at your school about the designated transition coordinator or call MSDE at 410-767-0231. DDA phone numbers are listed in *Appendix B.*

Planning Checklist

We have discussed a great deal of information that is critical to effective planning and have provided extensive lists of resources in the Appendix. The planning checklist serves as a “to do list” — summarizing important steps to take, with references to other parts of the guide. This guidance should prove helpful as you act to develop and implement your plan.

“All things are possible until they are proved impossible.”

—Pearl S. Buck

Planning Checklist

You should now have an understanding of critical issues involved in futures and estate planning and how to proceed. We've discussed the tools, processes, documents and resources you can use to establish and implement a plan for your son or daughter with disabilities. The information and worksheets in the appendix will support your planning and the resources can provide you with additional information and assistance on a variety of issues and topics.

The checklist in this section brings it all together. Use it to assure that you've considered everything as you plan, or when reviewing an old plan. For each item, we note where you can turn in this guide for more details and resources to assist you.

We recommend you begin with the first item to guide the rest of your planning. Beyond that, the order you approach each of these should be determined by your individual circumstances and interests. Each family is unique and your planning will reflect that. Please don't let an inability to complete all parts of the process stop you from contacting professionals or moving forward. These are suggestions.

☐ **Think about the future, discuss it with your child and other important people, and determine what your child wants and needs to live the life you all envision. This is the foundation of your plan. Involve your son or daughter as much as possible and appropriate for his or her age and abilities. Consult with other parents, advocates and service providers for ideas and guidance.**

Refer to:
- Introduction to Futures Planning and Estate Planning (p. 1)
- Common Principles & Trends (p. 9)
- Services in Maryland (p. 67)
- State and National Resources: Assistive Technology; Disability Information/Education/Advocacy; Disability Service Providers; Housing; Maryland State Agencies; Personal Assistance Services; Service Planning/Futures Planning (Appendix B)
- Pertinent Internet Sites (Appendix C)
- Other Reading: Information on Services; Homeownership for People with Disabilities; Miscellaneous Disability-Related Topics; Planning (Appendix D)
- Planning Questions (Appendix E)
- Person-Centered Planning Techniques (Appendix F)

☐ **Meet with an attorney knowledgeable about public benefits and estate planning for people with disabilities. Write a will, consider establishing and funding a special needs trust, and discuss tax implications. If you already have a will and/or trust but aren't certain they are drafted properly, have a knowledgeable attorney review them. Your will and trust should be written so that they do not result in your son or daughter losing vital public benefits.**

Refer to:
- Wills & Letters of Intent (p. 33)
- Trusts (p. 43)
- Other Planning Considerations (p. 53)
- State and National Resources: Pooled Trusts (Appendix B)
- How to Evaluate Your Supplemental Needs Trust (Appendix H)
- List of Attorneys (contact Service Coordination at 410-882-4710)

☐ **Write a letter of intent based on your planning that reflects your, and your child's, expectations and wishes for his or her life. Consider having your attorney review it to assure that it doesn't contradict your will or trust. Give copies to important people in your life.**

Refer to:
- Wills & Letters of Intent (p. 33)
- Planning Questions (Appendix E)

☐ **Estimate your child's needs and related costs to support his or her future plan. Determine what public benefits (e.g., SSI) and programs (e.g., DDA and Section 8 rental assistance) might cover. Consider what your child may be able to contribute from earnings and other sources.**

Refer to:
- Government Financial and Health Care Benefits (p. 15)
- State and National Resources: Disability Information/Education/Advocacy; Disability Service Providers; Maryland State Agencies; Personal Assistance Services; Public Benefits; Rental Assistance Programs; Service Planning/Futures Planning (Appendix B)
- Other Reading: Information on Services; Public Benefits (Appendix D)
- Income and Expenses worksheet (Appendix K)

☐ **With your attorney, review assets that are not covered by your will to assure that they won't make your child ineligible for needed public benefits upon your death. These include things like life insurance policies, joint bank accounts, and retirement plans. If your child directly inherits money, he or she could lose public benefits that are still needed. Instead, the proceeds could go into a supplemental needs trust for your child's benefit.**

Refer to:
- Government Financial and Health Care Benefits (p. 15)
- Wills and Letters of Intent (p. 33)

☐ **Determine what you can, and want, to contribute to supporting your child in the future. Consider meeting with a financial planner if you need guidance and assistance. Begin saving and/or investing to fund your plan.**

Refer to:
- Other Planning Considerations (p. 53)
- Financial Planning (p. 61)
- State and National Resources: Financial Planning (Appendix B)
- Other Reading: Financial Planning (Appendix D)
- Financial Statement worksheet (Appendix J)
- Income and Expenses worksheet (Appendix K)
- Questions to Ask a Financial Planner (Appendix L)

☐ **Assist your son or daughter to apply for public benefits he or she may be eligible for now, or determine when to apply in the future if your child will be eligible when he or she reaches adulthood.**

Refer to:
- Government Financial and Health Care Benefits (p. 15)
- State and National Resources: Legal; Public Benefits (Appendix B)
- Other Reading: Public Benefits (Appendix D)

- **Think about whether your son or daughter needs assistance with personal, health care, and/or financial decisions. Decide if things such as an advance directive for health care, durable power of attorney for legal and financial decisions, or guardianship are needed. Talk with your attorney and choose the least restrictive options that will work for your child and establish them.**

  Refer to:
  - Decision-Making (p. 23)
  - State and National Resources: Advance Directive Forms (Appendix B)
  - List of Attorneys (contact Service Coordination at 410-882-4710)

- **Complete "Important Documents and Information" (in the Appendix) and make sure important people, including the executor of your will, either have a copy or know where to find one.**

  Refer to:
  - Appendix I

- **Contact services your child will need (according to your plan) to determine when you should apply. Don't wait until your son or daughter needs a service to apply for it — there are usually waiting lists for publicly funded services. Talk to the state agency that funds the services (e.g., DDA and DORS) or speak directly with the agency providing the service. Also talk to other parents, people with disabilities, and advocacy organizations to get their perspective and advice.**

  Refer to:
  - Services in Maryland (p. 67)
  - State and National Resources: Disability Service Providers; Housing; Maryland State Agencies; Personal Assistance Services; Rental Assistance Programs; Service Planning/Futures Planning (Appendix B)

Ongoing:

- **Review your child's plan with him or her. Make changes as your child grows older and his or her needs, and those of your family, change. Your son's or daughter's wishes, interests, and changing life circumstances may also necessitate changes in your plan.**

- **Review your letter of intent — perhaps once every year or two (maybe around the time of your child's birthday, as a reminder). Make changes as needed.**

- **Review your will, trust, and other documents as advised by your attorney. Work with your attorney to make changes.**

- **Monitor your savings and investments to see if they are meeting your goals.**

- **Review and update "Important Documents and Information" when there are changes, additions or deletions.**

- **Keep abreast of significant changes in the service system through contacts with other families, advocacy organizations and service providers. This may affect what is available at any given time, who's eligible, and when to apply. For example, a significant increase in funding can make more services available, while a shift in policy could dramatically affect how services are provided.**

Appendix

OTHER RESOURCES, READINGS, FORMS, AND INFORMATION CAN HELP YOU EACH STEP OF THE WAY. PICK AND CHOOSE WHAT BEST MEETS YOUR NEEDS.

> *You can't stay in your corner of the Forest waiting for others to come to you. You have to go to them sometimes."*
>
> *— Winnie the Pooh*

Glossary

Advance Directive: A statement stipulating your wishes regarding your health care and medical treatment should you become unable to make these decisions for yourself. Used to name the person you want to make these decisions on your behalf. Also known as "health care power of attorney," "medical power of attorney," and "living will."

Applicable Exclusion Amount: Allows individuals to give away, during their lifetime or at death, up to $650,000 in assets without paying federal gift or estate taxes. This will increase to $1 million by 2006. Formerly known as the "unified credit."

Assets: Anything a person owns, including cash, bank accounts, personal property, real estate, stocks, bonds and promissory notes.

Assistive Technology: Equipment, aids and devices that assist a person to communicate, move about and perform other activities more independently. Examples include communication boards with pictures and devices that help people who can't stand up reach things in high places ("low-tech") and computerized communication devices ("high-tech").

Beneficiary: The person(s) named in a will, trust, life insurance policy, or other document to receive a financial benefit.

Developmental Disability (Maryland's definition): A severe, chronic disability that:
1) is attributable to a physical or mental impairment, other than a sole diagnosis of mental illness, or a combination of mental and physical impairments; 2) is manifested before age 22; 3) is likely to continue indefinitely; 4) results in the inability to live independently without external support or continuing and regular assistance; and 5) reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are planned and coordinated for that individual.

Discretionary Trust: A trust that gives the trustee full discretion over how assets in the trust are invested and distributed.

Durable Power of Attorney: A written directive appointing someone to act on your behalf to make legal and financial decisions. Remains in effect after you are incapable of making your own decisions.

Estate: All money, property and other personal belongings a person owns at the time of death. Also includes all remaining debts.

Estate Planning: Steps individuals or couples take to direct what will happen to their money, property and other assets after their death and steps to preserve their children's government benefits. Estate planning tools include letters of intent, wills, trusts, advance directives and durable powers of attorney. Estate planning is a part of futures planning.

Estate Tax: Tax imposed on the value of an estate upon a person's death. No tax is paid until a person's gifts (lifetime and at death) exceed the "applicable exclusion amount."

Futures Planning: Individualized planning with a person with a disability, his or her family, and other people important in his or her life. It involves envisioning a desired future and identifying the people, resources and services needed to carry out the plan.

Gift Tax: Tax imposed on assets given away during a person's lifetime. No tax is paid until a person gives away more than the applicable exclusion amount.

Grantor: The person(s) who creates a trust.

Guardian: Someone named by the court to make decisions on behalf of another person who is deemed incapable of certain personal decisions. Guardianship can be broad to cover all decisions or limited to certain kinds of decisions (e.g., about property or health care). Less restrictive options should be considered before guardianship.

Inheritance Taxes: A tax assessed upon death regardless of how much is in the estate.

In-Kind Support: Support with food, clothing and shelter received from other people that SSI and Medicaid consider when determining eligibility and the amount of benefits a person receives. Gifts of food or clothing; assistance paying for food or clothing; having someone pay all or part of your rent or mortgage; or living in someone else's house without paying full rent are considered "in-kind."

Intestate: When a person dies without leaving a will. The law stipulates who inherits the estate.

Irrevocable Trust: A trust that cannot be changed or terminated once established because the assets are no longer considered the grantor's.

Joint Tenancy: A type of co-ownership in which each person has equal interest and equal rights in the property. Upon the death of an owner, his or her share automatically passes to the other owner(s).

Letter of Intent: A personal letter written to people who may become responsible for a child, or an adult with a disability, in the future. The letter shares personal and helpful information, wishes, and expectations. It helps people better know and understand your child and work to support him or her in ways you, and your child, desire.

Living Trust/Inter vivos Trust: A trust that takes effect while the grantor is alive. Created by a trust agreement.

Means-tested benefits: Public financial and health care benefits that are based on financial need so they are only available to people with disabilities who have little income and few assets. Examples include Supplemental Security Income (SSI) and Medicaid.

Minor: A child under the age of 18.

Personal Representative/Executor: The person(s) named in a will to carry out the will's instructions.

Pooled Trust: A trust created and managed by a non-profit organization with individual accounts for each beneficiary. Each individual establishes his own account and the non-profit pools the money for investment purposes.

Probate: The court-supervised process of settling an estate following a person's death and distributing the assets according to the will. Some assets are distributed automatically, without going through this process. These are "non-probate assets" and include things such as joint bank accounts, life insurance and retirement plans.

Representative Payee: A relative, friend, support service agency or other interested party appointed by the Social Security Administration to receive, and be responsible for appropriately spending, an individual's SSI or SSDI benefits on their behalf.

Retainer Fee: An advance payment that some lawyers and financial planners may require. In some cases, the retainer is held in the attorney's escrow account and applied to the client's bill after services are provided. In other cases, the retainer fee is a pre-payment.

Revocable Trust: A trust that the grantor can change or terminate at any time before he or she dies. The assets in trust are still considered the grantor's.

Supplemental Needs Trust: A trust that stipulates that the trust funds cannot be spent on anything that is covered by the beneficiary's government benefits. Trust funds are to be spent on other needs that enhance the individual's quality of life.

Surrogate Decision-Maker: An individual who makes decisions about health care for a person who has been certified by physicians to be incapable of making an informed decision.

Tenancy by Entirety: A type of co-ownership of property available only to married couples that provides for ownership to automatically pass to the surviving spouse when one spouse dies.

Tenancy in Common: A type of co-ownership of property in which, upon the death of an owner, his share passes into his estate rather than to the other owner.

Testamentary Trust: A trust created by a will that becomes effective upon the death of the grantor.

Transition Planning: Collaborative planning with students with disabilities that is designed to prepare them to leave school and transition into adult life. Formal planning begins at age 14.

Trust: A legal document that provides a way for a person or institution to manage money and property for someone else.

Trust Agreement: A written document that establishes a trust to take effect while the grantor is alive.

Trustee: The person(s) or institution named to manage a trust. With a living trust, the grantor can also serve as the trustee.

Will: A legal document that stipulates a person's wishes and instructions regarding who will receive his or her money, property and other belongings. Also used to name guardians.

State and National Resources

Appendix B

TTY numbers are noted where there are dedicated lines. When there is no TTY number listed, use Maryland Relay at 711 or 800-735-2258.

Advance Directive Forms

MD Attorney General's Office	410-576-6300

Americans with Disabilities Act

ADA Information Center *(Mid-Atlantic Region)*	301-217-0124; 800-949-4232
ADA Information Line *(U.S. Dept. of Justice)*	800-514-0301; 800-514-0383 (TTY)
Disability Rights Education and Defense Fund	800-466-4232
Maryland Coalition for ADA Education	410-571-9320; 410-974-6139 888-272-3449

Assistive Technology

ABLEDATA *(database of a.t. & rehab. equipment)*	800-227-0216
Job Accommodation Network	800-526-7234
Learning Independence Through Computers *(LINC)*	410-659-5462
MD Technology Assistance Program	800-832-4827

Communication

Maryland Relay Service *Assists phone contact between TTY users and users of standard phones*	711 (within MD) 800-735-2258 (outside MD)
Speech to Speech Service *Assists with phone conversations for individuals with difficult to understand speech*	800-785-5630

Disability Information/Education/Advocacy

Alliance for the Mentally Ill of Maryland	800-467-0075
American Association on Mental Retardation	800-424-3688
American Council of the Blind	800-424-8666
American Foundation for the Blind	800-232-5463
Arc of Maryland *(formerly the Assoc. for Retarded Citizens)*	410-571-9320; 410-974-6139 888-272-3449
Autism Society of America	800-338-8476
Brain Injury Association of Maryland	800-221-6443
Centers for Independent Living:	
MCIL Making Choices for Independent Living *(Baltimore City, Anne Arundel, Baltimore, Carroll, Harford and Howard Counties)*	410-444-1400
Independence Now *(P.G. & Montgomery Counties)*	301-587-4162; 301-277-2839
Resources for Independence *(Garrett, Allegany, Washington, and Frederick Co.)*	301-784-1774; 800-371-1986

Center for L.I.F.E.	301-884-4498
(Charles, St. Mary's, Calvert Counties)	
Easter Seals Society	410-298-0991; 800-862-1377
Eastern Shore Center for Independent Living	410-221-7701; 800-705-7944
(Dorchester, Talbot, Caroline, Cecil, Kent,	410-221-5140 (TTY)
Queen Anne's, Somerset, Wicomico,	
Worcester Counties)	
Epilepsy Association of the Eastern Shore	800-776-5694
Epilepsy Foundation of the Chesapeake Region	800-492-2523
The Freedom Center	301-846-7811
(Carroll and Frederick Counties)	
Learning Disabilities Association of Maryland	301-549-2213
Maryland ADAPT	410/666-5484
Maryland Disability Forum	410-444-1400 (c/o MCIL Resources)
National Association for the Dually Diagnosed	800-331-5362
National Brain Injury Association	800-444-6443
National Down Syndrome Congress	800-232-6372
National Down Syndrome Society	800-221-4602
National Center for the Blind	410-659-9314
Nat'l Info Ctr for Children and Youth with Disabilities	800-695-0285
National Multiple Sclerosis Society/MD Chapter	410-527-1770; 800-344-4867
National Spinal Cord Injury Hotline	800-526-3456
Prader-Willi Syndrome Association	800-926-4797
Service Coordination	301-663-0909; 301-663-0936 (TTY)
	410-882-4710
Spina Bifida Association of Maryland	410-671-0047
Spinal Cord Injury Network	800-716-1393
TASH — Disability Advocacy Worldwide	410-828-8274; 800-482-8274
Telecommunications for the Deaf, Inc.	301-589-3786; 301-589-3006 (TTY)
(Publish a national TTY directory)	
United Cerebral Palsy Association	800-872-5827

Disability Service Providers

Many private agencies in Maryland that provide community services for people with disabilities belong to these professional associations. Contact them to learn about agencies near you. You can also contact the Developmental Disabilities Administration for a complete listing of community agencies it licenses and funds.

Maryland Association of Community Services for Persons with Developmental Disabilities *(MACS)*	410-518-9874
Maryland Association of Psychiatric Support Services *(MAPSS)*	410-788-1865

Education Advocacy

Maryland Coalition for Inclusive Education	410-859-5400; 800-899-8837
Maryland Disability Law Center	See listing under "Legal"
Parents Place of Maryland	410-859-5300; 800-394-5694

Financial Planning

For a list of certified planners in your area and information on selecting a planner:

Institute of Certified Financial Planners	800-282-7526
International Association for Financial Planning	800-945-4237
National Association of Personal Financial Advisors *(Fee-only planners not compensated by commissions)*	888-333-6659

For additional help and to check on a financial planner's disciplinary & complaint history:

MD Attorney General's Office/Securities Division	410-576-6360, 410-576-6372 (TTY)

Health Care

Complaints/Concerns for individuals with private insurance:

Consumer Protection Division of the Attorney General's Office	410-528-1840

Questions/Concerns/Complaints for individuals with HealthChoice (Medicaid):

Health Choice Enrollee Action Line	800-284-4510

Questions regarding the Maryland Children's Health Program:

(Health benefits for pregnant women, and children up to age 19 in families with low to moderate income)	800-456-8900

Housing

Baltimore Neighborhoods, Inc. *(Statewide fair housing advocacy)*	410-243-6007; 800-487-6007
Fair Housing Information Clearinghouse	800-343-3442; 800-483-2209 (TTY)
Maryland Center for Community Development/ Housing Counselor Hotline *(homeownership)*	410-752-6223; 800-949-6223
MD Department of Housing and Community Development operates the *Homeownership for People with Disabilities Program,* which offers low interest rate mortgages.	410-514-7530 http://www.dhcd.state.md.us (click on "Buying a Home")
MD Home of Your Own Coalition *(homeownership)* c/o the MD D.D. Council	410-333-3688; 800-305-6441

Legal

Bazelon Center for Mental Health Law	202-467-5730
Legal Aid Bureau of Maryland	410- 539-5340; 800-666-8330
Maryland Disability Law Center	410-727-6352; 800-233-7201
Maryland Volunteer Lawyer Service	410-547-6537
Service Coordination *(contact for a list of attorneys who have indicated an interest in estate planning with families with children with developmental disabilities. Note: the DD Council does not endorse any attorneys.)*	410-882-4710

Local Offices for Individuals with Disabilities

Anne Arundel County - ADA Office	410-222-4383; 410-222-4355 (TTY)
Baltimore City - Handicapped Services	410-396-1915
Baltimore City - Mayor's Commission on Disabilities	410-396-9944
Baltimore County - Commission on Disabilities	410-887-3580; 410-887-2799 (TTY)
Carroll County - ADA Coordinator	410-848-9707
Frederick County - Commission on Disabilities	301-694-1663; 301-694-1070 (TTY)
Harford County - Disabilities Coordinator	410-638-3373; 410-638-3086 (TTY)
Howard County - Commission on Disability Issues	410-313-6402; 410-313-6401 (TTY)
Montgomery County - Commission on People with Dis.	301-217-1256; 301-217-1236 (TTY)
Prince George' County - Disability Services	301-883-5160; 301-925-5167 (TTY)
St. Mary's County - Committee for the Disabled	301-475-4632
Talbot County - Department of Social Services	410-820-6699
Washington County - Disabilities Coordinator	301-791-3383

Maryland State Agencies

Developmental Disabilities Administration (DDA)	410-767-5600
Central MD Regional Office	410-902-4500
Western MD Regional Office	301-791-4670
Southern MD Regional Office	301-362-5100
Eastern Shore Regional Office	410-334-6920
Governor's Committee for Employment of People with Disabilities	410-333-2263; 800-637-4113
Governor's Office for Individuals with Disabilities	410-333-3098; 800-637-4113
Maryland Department of Aging	410-767-1100; 800-243-3425 410-767-1083 (TTY)
Maryland State Department of Education	
Division of Special Education	410-767-0244
Maryland Infants and Toddlers Program	800-535-0182
Resource Centers for Families and Schools	800-535-0182
Family Support Network	800-535-0182
Division of Rehabilitation Services (DORS)	888-554-0334; 410-554-9411 (TTY)
Anne Arundel, Calvert, Charles, Prince George's, & St. Mary's Counties	410-974-7604; 410-974-7742 (TTY)
Allegany, Carroll, Frederick, Garrett, Montgomery, & Washington Counties	301-791-4764; 301-791-4764 (TTY)
Baltimore City	410-333-6199; 410-333-6128 (TTY)
Baltimore, Harford, & Howard Counties	410-321-2395; 410-321-4035 (TTY)
Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, & Worcester Counties	410-543-6909; 410-546-9171 (TTY)
Mental Hygiene Administration (MHA)	410-767-6611

Miscellaneous

Maryland Trust for Retarded Citizens *Provides assistance and service monitoring upon the death or disability of a parent. Private pay.*	410-876-1836; 1-800-323-9407

Personal Assistance Services

Personal assistance services are tasks performed for a person with a disability by another person. They include things such as assistance with bathing, dressing, eating, getting in and out of bed, shopping, meal preparation, and house cleaning. Refer to ***"A Consumer's Guide to Personal Assistance Services in Maryland"*** *in Appendix D for more information. There are several sources for PAS in Maryland:*

Attendant Care Program: 410-767-7422

In-Home Aid Services Program:
Delivered through local Departments of Social Services (DSS). To learn where your local DSS office is, contact the MD Department of Human Resources:
410-767-7000; 800-332-6347
410-767-7025 (TTY)
800-732-7850 (Spanish)

Medical Assistance Personal Care Program:
Available through local Health Departments. To learn where your local health department is, check the phone book or contact the MD Department of Health and Mental Hygiene:
410-767-6860

Pooled Trusts (known at time of publication)

Penn-Mar Organization 410-343-1069; 888-273-4507
(A developmental disability service provider)

Public Benefits

For information, assistance, and training about SSI, SSDI, Medicaid, Medicare, work incentives, and Maryland Children's Health Care Program, contact:
Benefits INfoSource 800-704-7113 (daytime)
888-838-1776 (week nights/Sat.)
In addition to Benefits INFO Source, MCIL (Making Choices for Independent Living) can also assist with questions about public benefits. 410-444-1400

For information about SSI, SSDI, Medicare and other Social Security benefits and for information on local Social Security offices:
Social Security Administration 800-772-1213 (24 hours/day)
800-325-0778 (TTY: M-F, 7a-7p)

For information and publications about Medicare:
Medicare Hotline 800-638-6833; 800-820-1202 (TTY)

For information about Medicaid contact your local Department of Social Services (DSS). To learn where your local DSS office is, contact:
MD Department of Human Resources 410-767-7000; 800-332-6347
410-767-7025 (TTY), 800-732-7850 (Spanish)

Rental Assistance Programs (Section 8 certificates/vouchers)

Eligible low-income people can apply to receive rental assistance through the Section 8 program. Waiting lists vary by county and are often very long, so don't wait until you are ready to rent to apply. The following organizations administer the program. Some only cover certain areas of their counties. Call for more information.

Allegany County	301-777-2372; 301-759-2792
Anne Arundel County	410-222-6200
Baltimore City	410-396-4046
Baltimore County	410-887-4000
Calvert County	410-535-5010
Caroline County	410-479-3566
Carroll County	410-848-9707
Cecil County	410-996-5245
Charles County	410-934-9305
Dorchester County	800-445-4340
Frederick County	301-694-1061
Garrett County	301-334-9431
Harford County	410-638-3045
Howard County	410-313-6320
Kent County	410-479-3566
Montgomery County	301-929-6700
Prince George's County	301-883-5501
Queen Anne's County	410-758-3977
Somerset County	410-651-1818
St. Mary's County	410-475-4405
Talbot County	410-822-5015
Washington County	301-791-3168
Wicomico County	410-749-1383
Worcester County	800-445-4340
City of Annapolis	410-267-8000
Crisfield	410-968-0289
Cumberland	301-759-6450
Easton	410-822-8738
Elkton	410-398-5018
Frederick City	301- 662-8173
Hagerstown	301-797-6363
Havre de Grace	410-939-2097
Pocomoke City	410-957-1633
Princess Anne	410-651-1818
Snow Hill	410-632-2080
St. Michaels	410-745-5121

Service Planning/Futures Planning

Talk with families and professionals you know for ideas and assistance. Also, check with the following type organizations for direct assistance or a referral. The ability of individual organizations to assist you will depend on their staffing, funding, and geographic area of service.

Disability advocacy organizations	See “Disability Information/ Education/Advocacy” and “Local Offices for Individuals with Disabilities” above
Disability service providers	Contact DDA Regional Offices for list and see “Disability Service Providers” above
Service Coordination/ Case Management agencies	
County Health Departments in Southern MD and on the Eastern Shore	Contact DDA Regional Offices for information
Service Coordination *(this is the agency's name)* in Central and Western Maryland	301-663-0909 (Western MD) 410-882-4710 (Central MD)
Private consultants	Ask other families and organizations for recommendations

Transportation

Note: With demand-response services (also known as paratransit), eligible people schedule pick up times and designate where they are to be picked up and taken. Taxi-voucher programs allow eligible people to use taxis at a reduced fare. Call regarding the eligibility for these services and the geographic areas covered. Dept. of Aging programs listed also serve people with disabilities.

Mass Transit Administration (MTA)

Info. on buses, Light Rail, Metro & MARC train	410-539-5000; 800-543-9809 410-539-3497 (TTY)

Allegany County

AllTrans (demand-response)	301-724-1255

Anne Arundel County

Handy Cab (Taxi-voucher program)	410-222-4222
Annapolis Transit Mobility (demand-response)	410-263-7994, x110

Baltimore City

Dept. of Aging (Taxi-voucher program)	410-396-1578

Baltimore City and parts of Baltimore and A.A. Counties

Call-A-Lift (to arrange for a lift-equipped bus on any regular MTA bus route)	410-682-5438
Reduced Fare Certification	410-767-3441; 410-333-2051 (TTY)
Mobility (demand-response)	
Certification	410-767-3441; 410-333-2051 (TTY)
Ride Scheduling	410-727-3535

Baltimore County

CountyRide (demand-response)	410-887-2080; 410-887-3787 (TTY)

Calvert County

Calvert Co. Public Transportation (demand-response)	410-535-1600; 301-855-1243 410-535-0291 / 301-855-1862 (TTY)

Caroline County

Upper Shore Take-a-Ride (demand-response)	410-479-3867

Carroll County

Carroll County Transit (demand-response)	410-876-7433

Cecil County

Dept. of Aging Transportation (demand-response)	410-996-5295

Charles County

VAN GO (demand-response)	301-934-9305; 301-870-3388

Dorchester County

Delmarva Community Services (demand-response)	410-221-1900

Frederick County

TransIT Plus (demand-response)	301-694-2065

Garrett County

Community Action Committee (demand-response)	301-334-9431

Harford County

Harford Co. Transport. Services (demand-response)	410-612-1621; 410-838-2562 410-612-1643 (TTY)

Howard County

Howard Area Transit Service (HATS)	410-313-1919
Demand-response service	410-313-1921
Transportation subsidy program	410-313-6402; 410-313-6401 (TTY)

Kent County

Upper Shore Take-a-Ride (demand-response)	410-778-5187

Montgomery County

Ride-On (public bus system)	301-217-7433; 301-217-2222 (TTY)
Accessible Ride-On Service	301-217-2185; 301-217-2222 (TTY)
MetroAccess Paratransit Service	301-588-8181; 301-588-8186 (TTY)
MetroAccess Fare Subsidy Program	301-217-8500; 301-217-8177 (TTY)
Call 'N' Ride Program (taxi vouchers)	301-948-5409

Prince George's County

Call-A-Bus (demand-response)	301-499-8603
Call-A-Cab (taxi-vouchers)	301-883-5656

Queen Anne's County

County Ride (demand-response)	410-758-2357

Somerset County

Dial-A-Ride (demand-response)	410-651-1505
St. Mary's County	
St. Mary's Transit System (demand-response)	301-475-5100

Talbot County

Upper Shore Take-a-Ride (demand-response)	410-822-4155

Washington County

County Commuter	301-791-3047
(100% accessible fixed-route bus system; demand-response service & taxi vouchers)	

Wicomico County

Eastern Shore Human Services (demand-response)	410-742-0404

Worcester County

Commission on Aging (transport to medical appt.)	410-632-1277
Ocean City "The Bus" (demand-response)	410-524-7715

Pertinent Internet Sites

Appendix C

ABLEDATA http://www.abledata.com
Extensive database of assistive technology and rehabilitation equipment and products.

ADA Hot Links http://janweb.icdi.wvu.edu/links/adalinks.htm
ADA information, technical assistance, guidelines, and links to ADA web sites.

ADA Information Line http://www.usdoj.gov/crt/ada/
Information from the U.S. Dept. of Justice on the ADA, including questions & answers and myths & facts.

ADA Technical Assistance Program http://www.adata.org/
Information, training, technical assistance, and public awareness regarding the ADA.

American Association on Mental Retardation (AAMR) http://www.aamr.org
Publications, training opportunities, resources, internet links, and information on diverse topics related to mental retardation and other disabilities.

American Foundation for the Blind http://www.afb.org/afb
Resources and information related to blindness.

Arc of the United States http://TheArc.org
Legislative information, publications, conference material, and other extensive information and Internet links related to mental retardation.

Autism Society of America http://www.autism-society.org
Information and links to other resources related to autism.

Bazelon Center for Mental Health Law http://www.bazelon.org
Alerts, advocacy, resources, publications, and other information related to mental health.

Beach Center on Families and Disability http://www.lsi.ukans.edu/beach/beachhp.htm
Information, resources, and news on a variety of disability topics.

Brain Injury Association http://biausa.org
Information, treatment, publications, and other resources related to brain injury.

Brooke Publishing Company http://www.pbrookes.com
Disability related publications.

Boulevard http://www.blvd.com
Extensive information about products and services of interest to people with disabilities.

Centers for Medicine and Medicaid Services http://www.cms.gov
Medicare and Medicaid information.

Children and Adults with Attention Deficit Disorders http://www.chadd.org
Information, resources, and support group information related to attention deficit disorder.

DisAbility Information and Resources http://www.eskimo.com/~jlubin/disabled
Extensive information on resources, organizations and other disability related websites.

Disability Resources on the Internet http://www.disabilityresources.org
Extensive links to disability resources on the web, including national & international sites, databases and other information.

Disability Rights Education http://www.dredf.org
National law and policy center focused on disability civil rights. Information on legal cases, projects, and other activities.

Division of Rehabilitation Services (DORS) http://www.dors.state.md.us
Information on local offices and services through DORS — the state agency in Maryland providing rehabilitation and employment services.

Epilepsy Foundation of America http://www.efa.org
Research, information, resources, services, and advocacy related to epilepsy.

Family Village http://www.familyvillage.wisc.edu
Extensive information and resources for parents of individuals who have a disability. Includes very diverse topics covering most areas of life.

Family NET Works http://www.family-networks.org
Interactive website with excellent resources, discussion forums, list serve and information to empower and connect families. This site has extensive links to other sites.

IDEA's home page http://www.ed.gov/offices/OSERS/IDEA
Information from the federal gov't on the Individuals with Disabilities Education Act.

Job Accommodation Network (JAN) http://janweb.icdi.wvu.edu
Information on job accommodations and employability of people with disabilities.
Extensive links to other related sites.

Learning Disabilities Association of America http://ldanatl.org
Information, resources, and publications related to learning disabilities.

Learning Independence Through Computers (LINC) http://www.linc.org
Computer resource center in Maryland assisting children and adults to use computer technology to maximize independence and productivity.

MD Dept. of Health and Mental Hygiene http://www.dhmh.state.md.us
Information about state agencies and services within DHMH, including the Developmental Disabilities Administration, Mental Hygiene Administration, and HealthChoice.

MD Department of Housing and Community Development http://www.dhcd.state.md.us
DHCD news, events, and programs that address affordable homeownership and rental in Maryland, among other issues.

Maryland State Department of Education (MSDE) http://www.msde.state.md.us
News, legislation, programs, publications, and other information related to special education.

MD Technology Assistance Program (TAP) http://www.mdtap.org
Information on services, newsletter, and links to other disability and assistive technology web sites.

Medicare http://www.medicare.gov
Information on Medicare.

National Association of Personal Financial Advisors http://www.napfa.org
Referrals to financial planners who are "fee-only" (don't work for commissions).

National Down Syndrome Congress http://carol.net/~ndsc
News and information on Downs Syndrome.

National Federation of the Blind http://www.nfb.org
Information, research, services, technology, and publications related to blindness.

National Home of Your Own Alliance http://alliance.unh.edu
Information about people with disabilities becoming home owners, including publications, other state's activities, and funding sources.

National Information Center for Children and Youth with Disabilities (NICHCY) http://www.nichcy.org
Information on disabilities and related issues, referrals to other organizations, and a wide variety of publications.

National Organization on Disability (NOD) http://www.nod.org
Resources, information and descriptions of programs throughout the U.S.

National Parent Network on Disabilities http://www.npnd.org
Information, alerts, training opportunities, and other activities focused on parents of children with disabilities and special health care needs.

Prader-Willi Syndrome Association http://www.pwsusa.org
Facts, information, and updates about Prader-Willi Syndrome and links to local chapters.

President's Committee on Mental Retardation (PCMR) http://www.acf.dhhs.gov/programs/pcmr
Information about PCMR, publications, and state & national resources related to mental retardation.

Sibling Support Project http://www.chmc.org/departmt/sibsupp
Information for, and about, siblings of people with disabilities and special health care needs. Information on local sibling programs.

Social Security Administration http://www.ssa.gov
Information about services, benefits and publications from the Social Security Administration, including SSI, SSDI, work incentives, and other topics.

TASH: Disability Advocacy Worldwide http://www.tash.org
Information on national legislative issues & TASH's conference, and links to other disability web sites.

United Cerebral Palsy Associations (UCPA) http://www.ucpa.org
Research, resources, innovative projects, and other information related to cerebral palsy.

U.S. Dept. Of Housing and Urban Development *HUD news, information, and programs.*	http://www.hud.gov
West Virginia Rehabilitation Research and Training Center *Compilation of disability resources available on the internet, publications, disability data, and other information.*	http://www.icdi.wvu.edu

Financial Planning

Facts About Financial Planners. American Association of Retired Persons, AARP Fulfillment, 601 E Street, NW, Washington, D.C. 20049. (pub.# D14050)

Financial Planner Interview: How to Choose a Financial Planner/Tough Questions to Ask
Why select a 'fee-only' financial advisor?
The National Association of Personal Financial Advisors; 888-333-6659.

How to Choose a Financial Planner
Financial Advisor Interview Checklist
How the Maryland Securities Division Serves Investors
Maryland Office of the Attorney General/Securities Division; 410-576-6360.

Planning Today For A Secure Tomorrow
Selecting Your Financial Advisor
Seeking Professional Advise
International Association of Financial Planning; 800-945-4237.

Selecting a qualified financial planning professional: Twelve questions to consider.
Institute of Certified Financial Planners; 800-282-7526.

The Guardianship Handbook: A Guide to Adult Guardianship and Guardianship Alternatives in Maryland.
University of Maryland School of Law; Joan Sullivan, J.D.; 410-706-3838.

Homeownership for People with Disabilities

A Home of Your Own Guide. National Home of Your Own Alliance; 603-862-4320.

Homeownership and You: Helping individuals with disabilities become homeowners. Maryland Center for Community Development; 1-888-949-6677.

Threshold: Housekeeping Details on Renting or Owning a Home for People with Disabilities - A Set of Four Booklets. R. Froemming (1997). Wisconsin Developmental Disabilities Council; 608-267-3906.

Information on Laws

A Guide to Disability Rights Laws
The Americans with Disabilities Act: Questions and Answers
U.S. Department of Justice, Civil Rights Division, P.O. Box 66738, Washington, DC 20035-6738; 800-514-0301.

Special Education Rights and Wrongs
Maryland Disability Law Center. See Appendix B for local offices.

Information on Services

A Consumer's Guide to Personal Assistance Services in Maryland (1998). Independence Now, 818 Roeder Road, #202, Silver Spring, MD 20910; 301-587-4162.

Changes and Choices: A Directory of Aging Resources for Families and Service Providers Supporting People Who Are Aging and Have Developmental Disabilities (1998). Service Coordination; 301-663-0909 or 410-882-4710.

Guide To Services in Maryland. Developmental Disabilities Administration (see Appendix B for regional offices) or Service Coordination; 301-663-0909 or 410-882-4710.

I Didn't Know That Was Possible. The Maryland Self-Determination Project. The Arc of Frederick County; 301-663-0909 or 410-882-4710.

The Earlier the Better: A Guide to the Maryland Infants and Toddlers Program
Dreams and Challenges: A Family's Guide to the Maryland Infants and Toddlers Program
Mediation in the Early Intervention System
Maryland Infants and Toddlers Program; 800-535-0182

Transition Planning and Anticipated Services in the Individual Education Program (IEP) Process. Maryland Transition Initiative, Division of Rehabilitation Services; 888-554-0334 or 410-554-9411 (TTY).

Miscellaneous Disability-Related Topics

About Families
VISIONS of Equality
Best and Promising Practices
Maryland Developmental Disabilities Council; 410-333-3688 or 800-305-6441.

A Parent's Guide to Down Syndrome: Toward a Brighter Future. S. Pueschel (1990). Brookes Publishing Co.; 800-638-3775. Internet: www.pbrookes.com.

Couples with Intellectual Disabilities Talk about Living and Loving. K.M. Schwier (1994). Woodbine House, 6510 Bells Mill Rd., Bethesda, MD 20817; 800-843-7323.

Meeting the Needs of Youth with Disabilities: Handbook on Supplemental Security Income Work Incentives and Transition Students (1998). The National Transition Network, Institute on Community Integration; 612-627-4008.

Signs of Quality. People on the Go (1992). c/o The Arc of Maryland; 410-571-9320; 410-974-6139 (Baltimore); 888-272-3449.

The Special-Needs Reading List: An Annotated Guide to the Best Publications for Parents & Professionals. W. Sweeney (1998). Woodbine House; 800-843-7323.

Planning

A Family Handbook on Future Planning. R. Berkobien (1991). The Arc of the United States, 500 East Border Street, Suite 300, P.O. Box 1047, Arlington, TX, 76004; 800-433-5255.

"Estate Planning". News Digest, Volume 2, Number 1 (1992). National Information Center for Children and Youth with Disabilities; 800-695-0285.

Friendships and Community Connections between People with and without Developmental Disabilities. A. Amado, ed. (1993). Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285; 800-638-3775. Internet: www.pbrookes.com.

"Future Financial Planning". T.M. Varnet (Nov-Dec 1988). Exceptional Parent (check your local library).

"Getting Started". F.L. Brunetti (Dec. 1995). Exceptional Parent (check your local library).

Housing, Support, and Community: Choices and Strategies for Adults with Disabilities. J.A. Racino, P. Walker, S. O'Connor, & S. Taylor, eds. (1993). Brookes Publishing Co.; 800-638-3775. Internet: www.pbrookes.com.

It's Never Too Early - It's Never Too Late: A Booklet about Personal Futures Planning. B. Mount & K. Zwernik (1988). Minnesota's Bookstore, 117 University Ave., St. Paul, MN 55155; 616-297-3000.

Laying Community Foundations for Your Child with a Disability: How To Establish Relationships that will Support Your Child after You're Gone. L. Stengle (1996). Woodbine House, 6510 Bells Mills Rd., Bethesda, MD 20817; 800-843-7323.

Planning for the Future: Providing a Meaningful Life for a Child with a Disability after Your Death. L.M. Russell, A.E. Grant, S.M. Joseph, & R.W. Fee (1996). American Publishing Co., P.O. Box 988, Evanston, IL 60204-0988; 800-247-6553.

Self-Determination Across the Life Span: Independence and Choice for People with Disabilities. D. Sands & M. Wehmeyer,eds. (1996). Brookes Publishing; 800-638-3775.

The Road You Take Is Yours (video) (1997). James Brodie Productions, Inc., Brookes Publishing; 800-638-3775.

"Trusts for Children With Disabilities." F.L. Brunetti (Feb, 1996). Exceptional Parent (check local library).

Public Benefits: Financial, Health Care and Others

Available from the Social Security Administration:

SSA, Office of Public Affairs, Distribution Center, P.O. Box 17743, Baltimore, MD 21235
800-772-1213; Internet: www.ssa.gov

A New Definition Of Disability For Children (#5-11053)
A Special Examination is Needed for Your Disability Claim (#5-10087)
Basic Facts About Social Security (#5-10080)
Food Stamps and Other Nutritional Programs (#5-10100)
How Work Affects Your Benefits (#5-10069)
If You Are Blind — How We Can Help (#5-10052)
Red Book on Work Incentives — A Summary Guide to Social Security and Supplemental Security Income Work Incentives for People with Disabilities (# 64-030)
Social Security: A Guide For Representative Payees (#5-10076)
Social Security: Benefits For Children With Disabilities (#5-10026)
Social Security Disability Benefits (#05-10029)
Social Security: How We Can Help With Vocational Rehabilitation (#5-10050)
Social Security Supplemental Security Income (#05-11000)
Social Security: The Appeals Process (#5-10041)
Social Security: Understanding The Benefits (#5-10024)
Social Security: Working While Disabled — How We Can Help (#5-10095)
What You Need To Know When You Get Disability Benefits (#5-10153)
What You Need To Know When You Get SSI (#5-11011)
Working While Disabled: A guide to Plans For Achieving Self-Support (#5-11017)

Other publications regarding public benefits:

Medicare Handbook (#HCFA-10050). Health Care Financing Administration; 7500 Security Blvd, Baltimore, MD 21244-1850; 800-638-6833 or 800-820-1202 (TTY).

One Step Ahead: Resource Planning for People with Disabilities who Rely on Supplemental Security Income and Medical Assistance. R. Froemming (1998). Wisconsin Developmental Disabilities Council; 608-267-3906.

Working Families: Get the Health Insurance Your Children Need (re: Maryland Children's Health Program). Maryland Department of Health and Mental Hygiene; 800-456-8900.

Publications for Lawyers

Drafting and Using Trusts for Persons with Disabilities. The Maryland Institute for Continuing Professional Education of Lawyers, Inc. (MICPEL); 410-659-6730 or 800-787-0068.

Provisions: Sample Language for Supplemental Needs Trusts. R. Froemming (1998). Wisconsin Developmental Disabilities Council; 608-267-3906.

Planning Questions

This is a list of guiding questions covering an array of life issues. The appropriateness of each question will depend on things like your child's age, the impact of his or her disability on independence and decision-making, and other individual circumstances.

Considering these questions will help you and your child think about what he or she wants and needs in the future. From there you can plan how to maximize the likelihood that these wants and needs are met. Your answers to the questions, and the goals that result, should guide you as you write your will and letter of intent, establish a trust (if desired), plan your finances, apply for services and benefits, and assist your child in other ways.

The questions are a starting point to focus your thinking. Your answers are the foundation of your plan. And wills, trusts, and the other tools discussed in this guide are the means to an end — the establishment of the life you and your child want, with the supports that are needed.

You don't have to write down the answers to all of these questions. Use them to guide discussions with your child, family and other important people in your lives. Include what seems most important in your letter of intent. This information will also help you plan with an attorney, financial planner, and other professionals.

Consider:

1. What are my child's short and long term goals and dreams?

2. What are my, and my family's, wishes for my child (in the near and distant future)?

3. Can my child take care of himself/herself? What does he/she need assistance with? What kind of assistance and how much? What is the best way to provide the assistance? Can my child handle his/her own finances?

4. Does my child need assistance with decision-making? What types of decisions?

5. What do we want and need regarding the following things:
    a. A place to live: What kind of living arrangement? Roommates? If so, what kind of roommate is important? (e.g., shares interests or keeps to self; neat; active)
    b. Work or other meaningful, productive daytime activity: Are there interests and skills that my child has that should guide this decision? Training or education needed?
    c. Opportunities to develop friendships and relationships.
    d. Health care, dental care and therapies.
    e. Equipment and assistive technology: Consider future replacement and upgrading needs for things like communication devices, wheelchairs, lift equipment. If our insurance covers these things now, will it when my child becomes an adult and moves out? If my child is, or later becomes, eligible for Medicaid or Medicare, will they cover these costs?
    f. Other supports and services (e.g., behavioral support).
    g. Recreational and leisure activities; vacations.

    h. Social and religious activities; Other interests and activities my child would like to pursue.
    i. Transportation: In many areas of Maryland, public transportation cannot meet the needs of people with disabilities. Do we need to budget for transportation costs?

6. Will the impact of my child's disability change over time, necessitating additional or different services and supports? A degenerative physical disability, for example, could lead to a person who walks now and takes care of his personal needs requiring a wheelchair and personal assistance in the future, as well as accessibility modifications to his home.

7. What supports and services will be needed to make these things possible?

8. Who are the important people in my child's life? (e.g., family members, friends, neighbors, church/synagogue affiliations) What roles do they play now, and what support will they play in my child's life in the future? (e.g., advocacy, service monitoring, emotional support, assistance with activities like shopping or budgeting, or social activities).

9. What supports and services will be needed from service provider agencies? What type agency would best meet my child's needs and would provide services the way we want?

10. If our ideal plan can't be implemented for some reason, what are the most important things?

11. What public benefits is my child eligible for now or will likely be eligible for in the future? Which of my child's needs will these benefits assist with?

12. What estimated costs related to the wishes and goals we have identified will likely not be covered by government benefits like SSI or Medicaid, insurance, or state programs like the Developmental Disabilities Administration and Division of Rehabilitation Services?

13. What other assets does my child have to plan with (or might be expected in the future)? For example, inheritance, insurance proceeds, lawsuit settlement, SSDI benefits once parent retires.

14. What financial assets do I have to plan with for the benefit of my child?

15. What other information is important for us to consider?

Person-Centered Planning Techniques

Following are several types of planning techniques that fall under the general category of "person-centered planning." Brief information on each of these is provided to give you an idea of how they work. There are many other ways to plan, both formally and informally.

More information on planning may be found in Appendix D: Other Reading and on the internet at www:napanet.net/business/personal/ASA/resource.html

Each of these approaches has distinctive practices but share common foundations, such as:

- The person with a disability is the focus of all planning
- Planning is action oriented
- Respect for the person and his or her desires is paramount

Personal Futures Planning:

This ongoing planning process convenes a group of people most familiar with the person with a disability, known as a "circle of friends." They:

1. develop a comprehensive picture of the person;
2. develop a plan with the person based on information from the group; and
3. identify a smaller group of committed individuals to assist the person in carrying out their plan. PFP focuses on the person's capabilities and builds on them, rather than focusing on what the person cannot do.

Essential Lifestyle Planning:

This planning process focuses on gathering information about the person's core values and preferences — relying on the person, their parents, and others who know them best. This group of people helps the person identify and prioritize their likes and dislikes in three categories: non-negotiables, strong preferences, and highly desirables as they relate to the person's life and needed support. Then the group discusses several key things:

1. People who really know and care about the person say...
2. To be successful in supporting the person...
3. The person's reputation says...
4. If this is going to happen we must...

The resulting plan provides the basis for future supports and services.

New Hats:

This is an imaginative planning process (using specific decks of cards) designed especially for parents. It focuses on parents' feelings and perceptions of their sons and daughters and assists them to move forward in pursuit of independence. "Hats" is a synonym for roles. Each person wears different "hats" at various times in their lives. Trying on a "new hat" is like trying out a new role or responsibility. Identifying the person's dreams leads to goals and then plans for the future, no matter what the age of the child. The process is also used to assist adults to plan for themselves.

Applicable Laws

Several significant laws specifically affect people with disabilities and their families. A general understanding of these laws and where to go for more information will empower you and help you and your child advocate for his or her rights.

These are brief overviews. Please contact the organizations listed for more detailed information and assistance.

Americans with Disabilities Act (ADA)

The ADA is a comprehensive civil rights law that prohibits discrimination against people with disabilities in employment, transportation, state and local government services, telecommunications, and public accommodations. Public accommodations include things like restaurants, hotels, theaters, doctors' offices, stores, museums, libraries, parks, private schools, and day care centers. Private clubs and religious organizations are exempt.

The law was passed in 1990 and most provisions have taken effect. Some are being phased in more slowly.

A person is considered disabled if he or she:

1. has a physical or mental impairment that substantially limits one or more major activities (such as walking, seeing, hearing, learning, social interaction and self care);
2. has a record of such impairment; or
3. is regarded as having such an impairment.

Employment

An employer must make reasonable accommodations for a qualified individual with a disability. Reasonable accommodations include, but are not limited to:

- Making the workplace readily accessible to and usable by people with disabilities;
- Providing or modifying equipment or devices; adjusting or modifying examinations, training materials or policies; providing readers and interpreters; and
- Job restructuring or modifying work schedules

An employer is required to make an accommodation for a qualified applicant or employee with a disability unless the employer can show the accommodation would require significant difficulty or expense ("undue hardship").

Public Accommodations

Public accommodations must remove architectural barriers that limit access and must make "reasonable modifications" that are easily accomplishable and able to be carried out without much difficulty or expense to the business. This includes modifications in policies, practices and procedures. The ADA does not require modifications that would fundamentally alter the nature of the services provided.

State and Local Governments

State and local governments must eliminate any eligibility criteria for participation in programs, activities, and services that screen out people with disabilities and reasonably modify policies, practices and procedures to avoid discrimination. Some exceptions exist.

The ADA also prohibits state and local governments from discriminating in employment based on disability and requires them to make services, programs and activities readily accessible.

Transportation

Among other provisions, the ADA requires that all new fixed-route public buses and facilities be accessible and that supplementary paratransit services be provided for people with disabilities who cannot use fixed-route bus service.

Telecommunications

The ADA required the establishment of telephone relay services for people who use TTYs or similar devices. In Maryland it is "Maryland Relay."

For more information contact: the organizations listed under "Americans with Disabilities Act" in Appendix B.

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act is the federal law that mandates that a free, appropriate public education be provided to all children, regardless of the level or severity of their disability. This includes special education and related services. "Related services" are supportive services that are required to assist a child with a disability to benefit from special education. Related Services may include, but are not limited to:

- Audiology and speech therapy
- Physical and occupational therapy
- Psychological services
- Medical services for diagnosis or evaluation
- School health services
- Transportation
- Parent training

The IDEA governs early intervention services to infants and toddlers (age birth to three), as well as special educational services for children ages 3 through 21. Under the IDEA, states receive federal funds to assist in the education of infants and toddlers, preschoolers, and children in elementary and secondary schools who have disabilities. As a condition of receiving these funds states must ensure, among other things, that:

- A complete and individual assessment of the unique needs of each child is done;
- An Individualized Family Support Plan (for early intervention services) or an Individualized Education Plan (for educational services) is developed for every child determined eligible, stipulating the specific services needed;
- To the maximum extent possible, all children with disabilities are educated in the regular education environment with their non-disabled peers. They must be placed in the "least restrictive environment;"

- Children in special education receive related services that are necessary for them to benefit from their education; and
- Parents have the right to participate in every decision related to their child's educational services.

IDEA is an amended version of the Education of All Handicapped Children Act (P.L.94-142) which was originally enacted in 1975.

For more information contact:
Maryland Coalition for Inclusive Education, 410-712-4837 or 800-899-8837
Parents Place of Maryland, 410-712-0900 or 800-394-5694
National Information Center for Children and Youth with Disabilities, 800-695-0285

Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against individuals with disabilities by organizations that receive federal funds. The law states that no otherwise qualified individual with a disability shall, solely by reason of a disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance. Section 504 covers only people with disabilities who would otherwise qualify for the program or activity receiving federal funding.

A person is considered disabled if he or she:
1. has a physical or mental impairment that substantially limits one or more major activities (such as walking, seeing, hearing, learning, social interaction and self care);
2. has a record of such impairment; or
3. is regarded as having such an impairment.

For more information contact: organizations listed under "Education," "Housing," or "Disability Information/Education/Advocacy" in Appendix B.

Fair Housing Amendments Act (FHAA)

The Fair Housing Amendments Act of 1988 forbids housing discrimination against people with mental and physical disabilities. Its intent was to end the unnecessary exclusion of people with disabilities from the mainstream of society.

This federal law defines disability to mean a physical or mental impairment which substantially limits one or more of a person's major life activities (such as walking, seeing, hearing, learning, social interaction and self care). You are also protected if you have a record of having a mental or physical disability or if you are regarded as having such an impairment.

The Act makes it unlawful to discriminate in the sale or rental of housing because of a person's disability. Actions based on a person's disability that are illegal include:

- Refusing to rent or sell housing if otherwise qualified
- Refusing to negotiate for housing
- Making housing unavailable or denying that it is available
- Setting different terms, conditions, or privileges for sale or rental
- Advertising that housing is available only to people without disabilities

- Refusing to permit reasonable modification. Tenants with disabilities must be allowed to make reasonable modifications to their housing or common use areas at their own expense, if necessary for them to use and enjoy the housing. The landlord may require the dwelling be returned to its original condition at the end of the lease, but only if the modifications would interfere in future tenants' use and enjoyment of the dwelling.
- Refusing to make reasonable accommodations in rules, policies, practices, or services when the accommodations are necessary for the person with a disability to use the housing.
- Threatening, coercing or intimidating anyone exercising a fair housing right

Property owners, landlords, housing managers, real estate agents, brokers agencies and banks must comply with the Fair Housing Act. The FHA does not cover individual owners who sell their own homes without advertising and without a Realtor.

The Act also requires that buildings that are ready for first occupancy after March 13, 1991, and have an elevator and four or more units, must have public and common areas accessible to people with disabilities and doors and hallways wide enough for wheelchairs. In addition, all units must have:

- An accessible route into and through the unit
- Accessible light switches, electrical outlets, thermostats and other controls
- Reinforced bathroom walls to allow later installation of grab bars, and
- Kitchens and bathrooms that can be used by people in wheelchairs

For buildings without an elevator, these standards apply only to ground floor units.

For more information contact:
Baltimore Neighborhoods, 410-243-6007 or 800-487-6007
Fair Housing Information Clearinghouse, 800-343-3442 or 800-483-2209 (TTY)

How to Evaluate Your Supplemental Needs Trust

Appendix H

The following checklist is intended to give you some things to look for when preparing to sign a supplemental needs trust. In all cases, you should work with an attorney familiar with special needs planning and/or estate planning who has experience with supplemental needs trusts. If your family member with a disability currently receives government benefits, the government agency providing benefits may want to review the trust before it is signed. A knowledgeable attorney can tell you if this is required.

☑ Does your trust document state who will serve as trustee? Does it name the beneficiary, who is the person for whom the trust is created?

☑ Does the trust provide for a successor trustee, if the original trustee is unable or unwilling to continue as trustee?

☑ Are the purposes for the trust clearly stated in the trust document? That is, is it clear that you intend for the trust funds to be used to meet the beneficiary's needs, but only as a **supplement** to the beneficiary's government benefits? These requirements should be set out for the trustee, who will be making distributions on the beneficiary's behalf, so that he or she does not jeopardize the beneficiary's government benefits. The trust may be completely discretionary, meaning the trustee may have complete control over when to make distributions to the beneficiary. It may also limit trust distributions to supplemental items only. In either case, the trustee should be clear on how to use the trust fund for the beneficiary's supplemental needs.

☑ When will the trust be funded? If you are setting up a living trust, you may plan to fund it now by retitling assets in the name of the trust. You also may direct in your will that other assets will pass to the trust upon your death. If you are setting up a testamentary trust, which is created in your will, it will be funded when you die according to the directions in your will and/or your beneficiary designations on your life insurance policies and retirement benefits.

☑ If you are creating a living trust, do you have a will that directs some other assets into the trust upon your death?

☑ Is the trust revocable or irrevocable? Your attorney should consider your needs, as well as the beneficiary's needs in relation to the trust fund, and any tax consequences associated with the decision to make the trust revocable or irrevocable. Remember, you cannot change or terminate an irrevocable trust once it is established.

☑ Can the trust be amended? If so, are the provisions so broad that an irrevocable trust is actually considered a revocable trust? An irrevocable supplemental needs trust should have very limited amendment provisions to avoid this result.

☑ Does the trustee have the authority to defend any attacks to the trust by the state or other creditors?

☑ Does the trust name contingent beneficiaries, the individuals who will receive the trust funds when the trust terminates? Has your attorney discussed with you all conflicts of interest associated with your trustee and his or her relationship to contingent beneficiaries?

☑ Does the trust have a spendthrift provision, making it clear that the beneficiary is not the owner of the trust fund and that no creditors have a claim to the trust fund?

☑ Does the trust document list the trustee's powers, and are these powers broad so that they enable the trustee to make a variety of financial transactions and decisions as the beneficiary's circumstances change? Does the trust cover trustee liability, limitations on trustee powers and a provision for reasonable compensation for trustee services?

☑ Does the trust refer to a letter of intent, which outlines for the trustee your vision, expectations, and dreams for the beneficiary? The letter of intent is not a legal document, but is a way to outline for the trustee, attorney, guardian, or other advocate how you feel about these issues.

☑ If the trust is funded with the **beneficiary's** own funds, does it include "payback" provisions to the Department of Health and Mental Hygiene for all Medicaid paid on the beneficiary's behalf, and has it been approved by the Office of the Attorney General?

Important Documents and Information

Use this form to note where all important documents and personal information can be located. This information will make it much easier for your heirs to carry out your plans and wishes upon your death. Make sure important people in your life know where to find this list. Consider giving copies to at least one important person in your life who will assume responsibility for your estate.

Note: Don't place your will and life insurance policies in a safe deposit box. Your heirs may not have immediate access to it upon your death. Instead, put them in another safe place and consider giving a copy to a trusted friend or relative — possibly the executor of your will.

People	**Name and phone number**
ATTORNEY	____________________
EXECUTOR FOR YOUR WILL	____________________
FINANCIAL PLANNER	____________________
INSURANCE AGENT(s)	____________________
OTHER ____________________	____________________
____________________	____________________

Personal Information	**Location**
BIRTH CERTIFICATE	____________________
SOCIAL SECURITY CARD	____________________
MARRIAGE CERTIFICATE	____________________
DIVORCE PAPERS	____________________
LETTER OF INTENT	____________________
SAFE DEPOSIT BOX (location and key)	____________________
BURIAL INSTRUCTIONS	____________________
OTHER ____________________	____________________
____________________	____________________

Legal and Insurance Documents	**Location**
DURABLE POWER OF ATTORNEY	________________________
ADVANCE DIRECTIVES	________________________
WILL	________________________
TRUST AGREEMENT	________________________
GUARDIANSHIP PAPERS	________________________
INSURANCE POLICIES:	________________________
(Health, Disability, Life,	________________________
Homeowner’s, Automobile)	________________________
OTHER ____________________	________________________

Financial Documents and Information	**Location**
MORTGAGE(s)	________________________
INVESTMENTS	________________________
	________________________
RETIREMENT BENEFITS	________________________
BANK, CREDIT UNION, AND S&L ACCOUNTS	________________________
	________________________
	________________________
	________________________
OTHER ____________________	________________________

Deeds and Titles	**Location**
HOUSE	________________________
AUTOMOBILE	________________________
OTHER PROPERTY	________________________
CEMETERY PLOT	________________________
OTHER ____________________	________________________

Financial Statement Worksheet

Appendix J

		Current Value	
Assets (What You Own)	**Self**	**Spouse**	**Total**
CHECKING ACCOUNTS	$ ________	$ ________	$ ________
SAVINGS ACCOUNTS	$ ________	$ ________	$ ________
MONEY MARKET ACCOUNTS/FUNDS	$ ________	$ ________	$ ________
CERTIFICATES OF DEPOSIT	$ ________	$ ________	$ ________
IRA ACCOUNTS	$ ________	$ ________	$ ________
KEOUGH ACCOUNTS	$ ________	$ ________	$ ________
OTHER RETIREMENT ACCOUNTS	$ ________	$ ________	$ ________
PENSION/PROFIT SHARING	$ ________	$ ________	$ ________
LIFE INSURANCE CASH VALUES	$ ________	$ ________	$ ________
ANNUITIES	$ ________	$ ________	$ ________
BONDS	$ ________	$ ________	$ ________
MUTUAL FUNDS	$ ________	$ ________	$ ________
STOCKS	$ ________	$ ________	$ ________
OTHER SECURITIES	$ ________	$ ________	$ ________
HOME	$ ________	$ ________	$ ________
OTHER REAL ESTATE	$ ________	$ ________	$ ________
AUTOMOBILES	$ ________	$ ________	$ ________
OTHER PERSONAL PROPERTY:	$ ________	$ ________	$ ________
(Furnishings, jewelry, etc.)	$ ________	$ ________	$ ________
____________________________	$ ________	$ ________	$ ________
MONEY OWED TO YOU	$ ________	$ ________	$ ________
OTHER ASSETS:	$ ________	$ ________	$ ________
____________________________	$ ________	$ ________	$ ________
____________________________	$ ________	$ ________	$ ________
TOTAL ASSETS	**$** ________	**$** ________	**$** ________

		Current Value	
Liabilities (what you owe)	**Self**	**Spouse**	**Total**
HOME MORTGAGE	$ ________	$ ________	$ ________
OTHER MORTGAGES	$ ________	$ ________	$ ________
AUTOMOBILE LOANS	$ ________	$ ________	$ ________
CREDIT CARD BALANCES	$ ________	$ ________	$ ________
INSTALLMENT ACCOUNTS	$ ________	$ ________	$ ________
CONTRACTS/MONEY BORROWED	$ ________	$ ________	$ ________
INCOME TAXES	$ ________	$ ________	$ ________
OTHER: ____________________	$ ________	$ ________	$ ________
________________________	$ ________	$ ________	$ ________
________________________	$ ________	$ ________	$ ________
________________________	$ ________	$ ________	$ ________
TOTAL LIABILITIES	**$** ________	**$** ________	**$** ________

TOTAL ASSETS (from previous page)	$ ________	$ ________	$ ________
LESS LIABILITIES (from above)	- $ ________	- $ ________	- $ ________
NET WORTH (assets minus liabilities)	**$** ________	**$** ________	**$** ________

DATE: ________________________

Income and Expenses (Cash Flow) Worksheet

Appendix K

Calculate income and expenses for a typical month; estimate when necessary and divide annual and quarterly costs — like insurances — across all months. Use this form for yourself to determine how you spend your money and with your adult child to determine his or her cost of living. Not all items will apply.

Period: ______________________________
(month/year)

Income	**Amount**
EMPLOYMENT WAGES (amount after all deductions)	$ ________
SUPPLEMENTAL SECURITY INCOME (SSI)	$ ________
SOCIAL SECURITY DISABILITY INSURANCE (SSDI)	$ ________
OTHER SOCIAL SECURITY BENEFITS	$ ________
RETIREMENT/PENSION PLANS	$ ________
INTEREST FROM SAVINGS & CHECKING ACCOUNTS	$ ________
______________________________	$ ________
______________________________	$ ________
______________________________	$ ________
OTHER: ______________________________	$ ________
______________________________	$ ________
______________________________	$ ________
TOTAL INCOME	**$** ________

EXPENSES (How you spend your money)	**Amount**
MORTGAGE/RENT (include maintenance if own)	$ ______________
UTILITIES (heat, electricity, water, garbage, phone)	$ ______________
FOOD	$ ______________
PERSONAL (e.g., haircuts, miscellaneous items)	$ ______________
CLOTHING	$ ______________
TRANSPORTATION	$ ______________
RECREATION, ENTERTAINMENT, VACATIONS	$ ______________
EDUCATION	$ ______________
HEALTH CARE COSTS (not covered by insurance)	$ ______________
INSURANCE (health, disability, life, auto, home)	$ ______________
TAXES (e.g., property taxes)	$ ______________
GIFTS/HOLIDAY EXPENSES	$ ______________
INVESTMENTS	$ ______________
DEBT PAYMENTS	$ ______________
OTHER: ____	$ ______________
____	$ ______________
____	$ ______________
____	$ ______________
____	$ ______________
TOTAL EXPENSES	**$** ______________

Questions to Ask Financial Planners

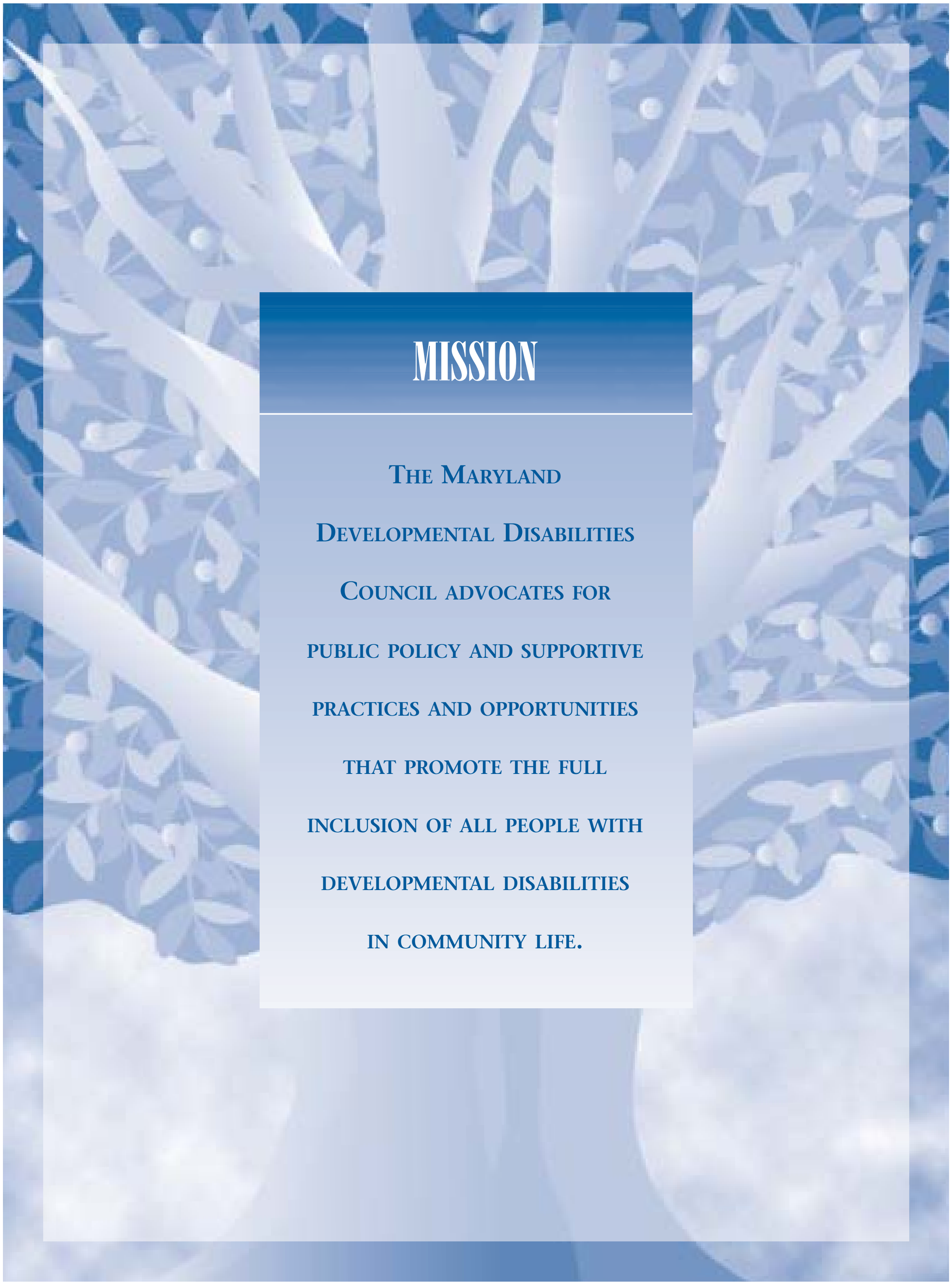
Contact the Securities Division of the Office of the Attorney General (410-576-6360) to obtain a "Financial Advisor Interview Checklist." You can use the checklist yourself during an interview or ask potential advisors to complete and return it to you as a way to screen them.

Some Questions to Consider:

(Make note of the rapport you initially develop in addition to the information you receive)

- ***What credentials do you have to practice financial planning?***
  Financial planners come from a variety of backgrounds so they hold a variety of degrees and licenses. Those that take specialized training earn specific credentials. Be certain that the planner you choose has ample knowledge of taxes, insurance, estate and retirement planning issues, as well as the basics of investments and family budgeting.
- ***Are you registered with the Securities Division of the Office of the Attorney General?***
  All financial planners must register. Ask for a copy of "Form ADV, Part II" which has information about the planner's background. Advisors are required to disclose information to you.
- ***What areas do you specialize in?***
- ***Have you worked with clients with similar financial situations as mine?***
- ***What knowledge and experience do you have with families who have a member with a disability?***
  Ideally, your planner would have knowledge and experience planning with families with children who have disabilities.
- ***How long have you been practicing financial planning? How do you keep up with the latest financial developments?***
  You may want to select a planner who enrolls in continuing education courses.
- ***Do you offer services that fit my income bracket and investment strategy?***
- ***How will you prepare my financial plan? How extensive is it? Do you provide a written analysis of my financial situation and recommendations? Are the recommendations for specific investment products?***
  Be sure to find an advisor who will give you personalized advise for your situation.
- ***Do you provide assistance with implementation?***
- ***Will you be involved in evaluating and updating the plan you suggest?***
  Some planners include provisions for updating your plan to adjust for changing circumstances. A financial planner can periodically review your plan to show you the progress being made toward your goals. Ask about the fee for this service.
- ***How are you compensated for various services?***
- ***Will you provide references?***
  Ask for references from clients with at least three years experience with the planner and call them. If possible, get references from clients that have similar situations, such as personal circumstances, income bracket, and/or investment philosophy.

Sources: American Association of Retired Persons and the Office of the Maryland Attorney General/Securities Division



MISSION

The Maryland Developmental Disabilities Council advocates for public policy and supportive practices and opportunities that promote the full inclusion of all people with developmental disabilities in community life.

Maryland Developmental Disabilities Council
300 W. Lexington Street, Box 10 / Baltimore, Maryland 21201
410-333-3688 / 800-305-6441
711 or 800/735-2258 (MD Relay)