

MARYLAND  
DEVELOPMENTAL  
DISABILITIES  
COUNCIL

# Planning Now



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



# Planning Now

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The Maryland Developmental Disabilities Council encourages you to share the information in *Planning Now: A Futures and Estate Planning Guide for Families of Children and Adults with Developmental Disabilities*

December 2011

- *Planning Now* can be downloaded at the Council's website
- While they last, copies can be requested by phone or email
- This publication is available in accessible formats upon request

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## A Message from the Maryland Developmental Disabilities Council

Raising any child to adulthood is full of challenges. For families of children with disabilities, concerns about their children's 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 can be difficult for families 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, the disability service system and others, your son or daughter can lead a meaningful, satisfying life. Failing to plan could leave your child in a situation with your hard-earned money not being used the way you intended.

In greater numbers than ever before, families 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. Include your child in the planning process to the greatest extent possible. Review your plan and change it as your child grows older and circumstances change. As your child grows older, it is important to include him and her even more. There are many things families can do to envision a desired future and to take steps to realize their vision.

Help your child develop his or her own vision for his or her future. You should also have a vision and plan for your child's future. It is very important to plan regardless of the type and severity of your child's disability, the makeup of your family, or the amount of money you may have. 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 your child desires and needs, and is what you want for him or her. 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, service providers, and others and direct any resources you may want to help. And you can picture your child, living a full and productive life 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 Families of Children and Adults with Developmental Disabilities* will help you along the way.

Tom Webb  
*Council Chairperson*

Brian Cox  
*Executive Director*

## Overview of the Guide

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*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.**

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

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

As you begin to plan, we encourage you to review this entire guide and the other resources provided in the appendices, and choose the pieces that apply to your family.

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 resource 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 “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.

All information is correct to the best of our knowledge as of December 2011. 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.

**For Important Updates to this guide, go to:  
[www.md-council.org/publications/pubs\\_and\\_reports.html](http://www.md-council.org/publications/pubs_and_reports.html)**

**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 contributions of many people.

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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 is 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 supports and services needed to make all, or part, of the plan a reality. When planning with your family member, the focus can be on the future while you are still living, as well as after your death.

“Estate planning” is one aspect of futures planning and generally refers to steps individuals or couples take to direct what will happen to their money and other assets after death. 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.

“Estate planning” is the process of planning how you want to transfer your money and other assets to others during your lifetime or at your death. This process includes thinking about your own needs and wishes, the needs of those for whom you want to provide in the future, the selection of the right people to carry out your plans, and choosing and executing the right documents.

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 your child and you 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 person’s needs change.

Parents who have a child with a disability may encounter special issues related to their child’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.

**“Estate planning” is the process of planning how you want to transfer your money and other assets to others during your lifetime or at your death.**

**A futures plan should be created for each particular individual and family situation and offer guidelines, but also be flexible enough to be used in the future.**

A futures plan should be created for each particular individual and family situation and offer guidelines, but also be 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 family member and to have planned accordingly.

Families should seek an attorney who understands not only estate planning issues but who is also 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 and 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 unable to continue 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 they have 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 families 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. These services typically cost tens of thousands of dollars a year for one person.

Some people 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 needs of your child, as well as his or her assets and government benefits. Families can leave assets to a trustee acting on behalf of an individual with a disability, while preserving their 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. 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 help 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, wishes 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.

Many families 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.

**It is important to include your child to the maximum extent possible during the process. Make sure what he or she wants is reflected in the plan.**

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. It is important to include your child to the maximum extent possible during the process. Make sure what he or she wants is reflected in the plan.

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.

The starting point for your estate plan is your own decisions regarding those you wish to leave assets to at your death. Next, you will need a thorough and up to date list of everything you own and any insurance policies covering your life. The documents that may help carry out your estate plan include a Will, beneficiary designation forms for insurance policies or retirement accounts, one or more trusts, and a letter of intent.

**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.**

### **One Plan Does Not Fit All**

Each individual and each family is unique. Therefore, each futures/estate plan will also be unique. Important questions to consider 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, inclusion in all facets of community life 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 supports and 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 families can no longer provide support. Planning with them will help direct how services should be provided when they do become available.

Make sure important people in your life know where all important documents and personal information is located. This information will make it much easier for your heirs to carry out your plans and wishes upon your death.

**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 public benefits he may need.

## Getting Your Plan on Paper

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

There are a variety of questions that might be useful in your planning. We included a list in *Appendix A* 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.

**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.

Make sure important people in your life know where all important documents and personal information is located. This information will make it much easier for your heirs to carry out your plans and wishes upon your death.

**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.**

## Finding Help with Planning

Sometimes families want assistance with planning, or just need ideas and guidance. Other families 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.

## 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** will help you plan and evaluate services by better understanding the most progressive ways people with developmental disabilities are supported in all facets of life.
- **Government Financial and Health Care Benefits** will make sense of Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare, all of which help many people with developmental disabilities with their daily living costs and medical care.
- **Decision-Making** will help you understand guardianship and less-restrictive alternatives so you can decide how to best assist your child if he or she needs assistance making important decisions.
- **Wills, Trusts and Letters of Intent** discusses these three types of documents in detail so you can use them effectively in planning for your family. It also explains how you can set aside money and other assets for your child’s benefit without jeopardizing vital government financial and health care benefits.
- **Tax Considerations** covers tax issues that may affect your planning.

- **Financial Planning** will help you determine if you need financial planning assistance, what to expect and how to select a financial planner.
- **Working with Professionals** discusses how to work effectively with professionals to assist you in reaching your planning goals.
- **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.
- **Appendices** include resources and information that can assist you through each step of your planning and implementation.

# Common Principles

Understanding common principles widely embraced as “best practices” by people with developmental disabilities, their families, advocates, and professionals can help you better plan with your son or daughter.

*“The future belongs to those who believe in the beauty of their dreams.”*

— *Eleanor Roosevelt*



# Common Principles

Guiding principles influence the way people with developmental disabilities are supported and included in all facets of community life. These are based on the belief that all people with disabilities should be supported to lead meaningful, rich lives. And that they should be encouraged and supported to direct their own lives to the maximum extent possible. Essentially this is what we want for ourselves and our children who don't have disabilities. These principles are inter-related and include:

**Inclusion and Integration:** People with disabilities should not be separated from people who do not have disabilities. People with disabilities can live, work and socialize in the community and workplaces when needed supports and services are made available. All people have the right to be included in, and contribute to, the community regardless of their abilities or disabilities. Quality services should assist people with disabilities to not just be present in the community but to be a part of the community by supporting the development of friendships, use of typical community services and participation 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 their own lives, including the services and supports they receive and how those services are provided. It means taking control of your life, trying out choices and having the power to exercise rights and responsibilities. It also means pursuing the things that are important to you, with support from family, friends, paid service providers, and others of your choosing.

**Person-centered planning:** Planning about people's lives must include them every step of the way and they should be empowered and supported to drive all decisions, to the fullest extent possible. We shouldn't plan for people, we should plan with them. Person-centered planning focuses on people's talents, skills and abilities.

**Self-directed supports:** Self-directed supports are part of the broader self-determination philosophy. A growing number of people with developmental disabilities and their families are choosing to actively direct the supports and services they receive. This means that people with disabilities, with support from their families and others if needed, take responsibility for managing their services, including hiring and supervising the people who provide their direct support.

**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 a unique individual — desires for his or her life. The focus is on whether supports and services result in the life the person wants for himself. An assessment of quality of life is determined by what is important to the person.

Quality services should assist people with disabilities to not just be present in the community but to be a part of the community by supporting the development of friendships, use of typical community services and participation in chosen activities.

People gain a sense of dignity from trying, even if we don't always succeed. People with disabilities should have these opportunities as well, even when risk is involved.

**Dignity of risk:** Taking risks is a natural way for people, disability or not, to learn and grow, and to fully experience many of life's opportunities. We learn from experience — both successes and mistakes. People gain a sense of dignity from trying, even if we don't always succeed. People with disabilities should have these opportunities as well, even when risk is involved.

**Natural supports:** These are supports provided by people who are naturally in the lives of a person with a disability as compared to supports provided by paid staff. This includes care and support provided by family, friends, neighbors, co-workers, and others in the person's life. Natural supports should be maximized and paid services should build on them.

**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. People with disabilities have the right to use the same services that everyone in the community uses and accommodations should be made as needed. As a result, 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.

## Effect on People's Lives

Guided by these principles, services that support people with developmental disabilities to live, work, play, and engage as members of 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.

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

### Where, and with whom, you live...

Services that are more flexible and individually designed 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 — adequate supports and services can be provided in the person's own home. This is happening for people regardless of the type or degree of disability they have.

People with developmental disabilities, including people with significant disabilities, are choosing to rent their own apartments and purchase their own homes more and more, instead of living at home with their families or in group homes...sometimes alone and sometimes with others to share costs. Families and housing programs help make this more affordable. This includes rental assistance programs, which help low-income people with the cost of rent.



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

In the past, 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 to be unable to work often attended segregated day programs where they learned "independent living skills" and engaged in other activities. Now services are focusing more on employment as the first option and providing support to people to obtain and keep regular jobs in the community. People are also supported to engage in activities that are meaningful to them like volunteering, learning new skills and participating in community activities.



# 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. Having a clear understanding of these benefits is vital to assuring that your family member receives them, if eligible, and retains them as needed.

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*“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 an important 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 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 earning more than a certain amount of money (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, burial plots, personal and household goods, and some 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 circumstances must be evaluated individually.

\* These amounts are current as of December 2011 and could change. Check [www.ssa.gov](http://www.ssa.gov) for updates.

**SSI is available to people who have disabilities, are elderly or blind and have very little income and assets.**

### Amount of Benefits

The amount of SSI a person receives is affected by how much income he or she has from other sources, including earnings. To find out the current maximum SSI benefit, go to [www.ssa.gov](http://www.ssa.gov).

If an eligible person has no income at all, he or she will receive the maximum amount. The amount will be reduced if the person has income or receives other types of support for food, clothing or shelter. This food, clothing or shelter provided at reduced or no cost is called “in-kind support.” 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 receive less SSI because the overall result, including the food, clothing and/or shelter, 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. How much the SSI is reduced 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 is considered living in the household of another. In this situation, the Social Security Administration will reduce his benefits by 1/3 of the maximum SSI payment, regardless of the actual value of the support he receives. For example, the maximum SSI benefit in 2011 was \$674; a 1/3 reduction would subtract \$225.\* This occurs even if the actual value is less than \$225. So, in-kind support is only really useful if it is worth more than the 1/3 reduction of SSI.

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 its actual value. The PMV is 1/3 of the maximum SSI payment plus \$20 (\$245 for an individual in 2011). However, if there is no other income than SSI, the reduction is only \$225. 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 \$800/month. You (or a trust) directly pay the landlord \$500, while your son pays \$300. You also give your son \$50 worth of groceries a month. The \$550 you provide is in-kind support, but SSI only counts \$245, which is the presumed maximum

\* These amounts are current as of December 2011. The full benefit amount went up to \$698 in January 2012. Check [www.ssa.gov](http://www.ssa.gov) for updates.

value. Your son's SSI check will be reduced by \$245. However, if you give your son money rather than paying the landlord and grocery store, SSI will consider the full \$550 as income.

- You, or a trust, make a \$15,000 down payment on a condominium your daughter is buying. 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 \$245 for 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 \$245 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 \$245. If you show that the actual benefit to your daughter is only \$100, SSI will reduce her check by that amount.

**When someone loses all their SSI, they also lose Medicaid. Many people with disabilities rely heavily on Medicaid as their health insurance.**

If a person on SSI only receives a small amount of SSI, it is important to make sure that the amount of in-kind support doesn't cause them to lose all of their SSI unless they don't need Medicaid for their health insurance. When someone loses all their SSI, they 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 or the in-kind support.

### **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 \$245. 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, if provided as in-kind support, they are subject to the above rules: 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:

- certain 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.

Consult with your local Social Security office or a knowledgeable advocate or attorney to assess how potential assistance given to your child will affect his or her benefits.



## 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. However, if a person does not receive SSI, there are several other ways to become eligible for Medicaid. If a person with a disability has very low income (less than \$350 per month for an individual in 2011) and very low assets (less than \$2000 for an individual) and the person meets certain other requirements, the person can qualify for Medicaid.\* Seek professional advice for more information related to your circumstances.

Another way to qualify for Medicaid is if a person has high medical bills. 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, the person can apply for Medicaid and submit their medical bills. Once the person reaches a certain level of medical bills, 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 services from the Developmental Disabilities Administration through one of DDA's Home and Community Based Waivers. We will not discuss the details of the waivers here, but DDA can provide you with more information. In addition to becoming eligible for Medicaid through one of DDA's Home and Community Based Waivers it is also possible for eligible people 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, through 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.

\* These amounts can change each year. Check [www.ssa.gov](http://www.ssa.gov) for updates.

**Medicaid covers the medical expenses of people with disabilities who have very low income and assets.**

**SSDI is a cash benefit paid to individuals with disabilities and their parents who have worked enough to be covered by the system.**

The amount a person receives in SSDI depends on how much he, or his parent, earned while working.

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 he or she will not meet the disability requirement 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 the set maximum. Earned income that is less than the set maximum does not affect the amount of SSDI benefits. However, whenever someone earns income, it could cause the Social Security Administration to examine whether they are still considered a person with a disability and therefore eligible for SSDI.

If a person receiving SSI begins receiving SSDI, he or she could lose their SSI. This would happen if the SSDI benefit is \$20 or more than the maximum 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. The biggest problem with going from SSI to SSDI is the loss of Medicaid. When someone receives SSDI, they may qualify for Medicare instead, as described below.

## Medicare

Medicare is the federal health insurance program for individuals receiving Social Security Disability Insurance or Social Security Retirement benefits. For more information, consult the Medicare website at [www.medicare.gov](http://www.medicare.gov).

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 being eligible for 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 of the cost of care or has different deductibles.

Medicare Part D covers prescription drugs and medications for people who receive Medicare. For more information, consult the Medicare website at [www.medicare.gov](http://www.medicare.gov).

Because Medicare does not cover the entire cost of a 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. If you qualify for both Medicare and Medicaid, Medicaid will pay for co-pays and deductibles not covered by Medicare.

If a person has Medicare, but has a low income and does not qualify for Medicaid, he or she may qualify for a Medicare Savings Program. These programs include the Qualified Medicare Beneficiary (QMB) or Specified Low Income Medicare Beneficiary (SLMB). QMB and SLMB help pay for premiums and/or co-pays for low income individuals. You can apply for QMB or SLMB through a local Department of Social Services.

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 more, of these benefits at the same time.

Consult with an informed advocate or professional, or with the Social Security Administration (through a local office or its national toll-free number 1-800-772-1213) if you have questions.

**If you qualify for both Medicare and Medicaid, Medicaid will pay for co-pays and deductibles not covered by Medicare.**



# 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.

*“Good decisions come from experience. Experience comes from making bad decisions.”*

— Mark Twain



# 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, including people with disabilities, 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 some cases, the parent’s or other family member’s authority is more formally stated through specific estate planning documents such as an advance directive, a trust or power of attorney.

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

**All adults, including people with disabilities, 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.**

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.

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 he or she 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, shelter, or health care or decisions related to his or her money or property because of a disability, and when guardianship of the person is sought, that no less restrictive method is possible. There does not have to be a less restrictive alternative available for "guardianship of the property."

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 be referred to as "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, or at a minimum who should make those health care decisions for them.

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. Some people who cannot make medical decisions might have the capacity to appoint a friend or family member to make those decisions.

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.



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 as certified by two physicians.

### Surrogate Decision-Making

If an individual is not competent to execute an advance directive (and did not sign one in the past), in certain circumstances, a surrogate can make health care decisions on that person's behalf. 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 what is in the best interest of the person as well as other 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)

**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.**

\* These forms can be found at <http://www.oag.state.md.us>.

### 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.

You should consult an estates and trusts attorney regarding power of attorneys, particularly in regard to any significant changes in Maryland law.

#### Trusts

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 can be created for different reasons. A trust can direct who will handle financial decisions, including how to invest and spend the trust money. A trust can also be set up to avoid probate, limit the use of assets for certain purposes, or protect assets for the use and benefit of a person with a disability while at the same time preserving that person’s eligibility for government benefits. This type of trust is called a “supplemental” or “special” needs trust. The chapter on *Wills, Trusts and Letters of Intent* has additional information and guidance on establishing a special needs trust.

A durable power of attorney can be broad or it can be limited so that the agent can only make certain types of decisions.

## Representative Payee

If a person who receives financial benefits from the federal government, such as SSI or SSDI, needs help with depositing 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.

## 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.

### Guardianship of Children under 18

All parents are automatically the guardians of their minor children, whether the child has a disability or not. 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 names 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 child 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 minor child. If the child is at least 14 years old, he or she may tell the court who he or she wants as guardian. The court will take the child’s opinion into consideration when making its decision. 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 and will serve as guardian until the child reaches age 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

If a guardian is needed,  
an individual may need  
a guardian of the person  
but not a guardian of  
property, or vice versa.

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.

### **Stand-by Guardians**

A parent can appoint a person to serve as a “stand-by guardian.” A stand-by guardian is an individual who takes care of the child in the event that the parent(s) is mentally or physically incapable of doing so.

A stand-by guardian can be accomplished by “parental designation.” Parents execute a document which announces their intention to appoint the stand-by guardian. The parent does not have to be incapacitated at the time that they create the document. The stand-by guardian petitions the court upon the parent(s)’ incapacitation to be appointed as stand-by guardian.

The court may also appoint a stand-by guardian in cases where a parent demonstrates that there is a significant risk of becoming incapacitated or dying within two years of the petition.

Regardless, if both parents of the minor child are living, both parents must consent to the stand-by guardian.

### **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 him 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. A person under guardianship may still make certain day-to-day decisions, such as what to wear and who to have as friends.

**A stand-by guardian is an individual who takes care of the child in the event that the parent(s) is mentally or physically incapable of doing so.**

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. There are some exceptions. A health care surrogate is not permitted to authorize treatment for a mental disorder or sterilization. A health care surrogate may not authorize treatment if the patient is actually refusing it.

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. A guardianship can be limited to a specific purpose, e.g. health care decisions or consenting to a specific treatment (limited in scope and time).

Under Maryland law, the true guardian of the person is the court. The court appoints the guardian and gives him or her authority to act on behalf of the person, yet may require the guardian to obtain permission before making certain decisions. For example, the court may require the guardian to get court approval to change the person's type of residence.

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.

### **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 the 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 the 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 funds to support people legally dependent on the person with a disability, such as a minor child or spouse. All expenses made on behalf of the person with a disability or an individual dependent on that person must be reasonable.

**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.**

Someone seeking guardianship 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.

### How to Become a Guardian

When 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, or one physician and one psychologist or clinical social worker, which describe the person’s disability. These physician certificates must be dated within 21 days prior to filing the petition for appointment of a guardian.

When the court receives the petition, it appoints an independent 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 any 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, 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, Trusts and Letters of Intent

Wills, Trusts and Letters of Intent are important documents that are a key part of effective planning for families. Creating these documents must be done properly to ensure your goals are met.

*“Only those who will risk going too far can possibly find out how far one can go.”*

— T.S. Eliot





# Wills, Trusts and Letters of Intent

## Wills

### What is a Will?

A Last Will and Testament is a legal document that stipulates your wishes and instructions regarding who will, at your death, receive your money, property and other assets that you own alone. It also states who will be responsible for carrying out the Will's instructions and any limits or restrictions. Wills can range from very simple to very complex documents depending on your circumstances. A Will is important even if you do not have a lot of money or other belongings.

In your Will you name your “legatees” or “beneficiaries” who will receive your probate assets, which make up your “estate,” and in what shares. Your Will names a “personal representative” (formerly called the “executor”) who will manage your probate estate and make sure it goes out to your named beneficiaries. It is always wise to name a back-up personal representative in case your first choice cannot serve. If no back-up is named, the court will appoint a personal representative. The court will consider the person's relationship to the deceased individual in making this appointment.

Your Will also serves other important functions, such as naming a guardian for children under the age of 18 or adult children with disabilities. If you have a minor child, you can state who you want to be the guardian after the death of both parents. If you have been named as the guardian of an adult with disabilities, you should state in your Will who you want to be appointed guardian at your death. The court will usually comply with the wishes expressed in your Will unless there are unusual circumstances. Even if you have not been appointed guardian, you should still name your choice of guardian so that a court has this guidance for any future appointment. It is always a good idea to name a back-up person as guardian in case your first choice cannot serve.

Your Will may also include a trust for your child or someone else, to take effect when you die. Your Will may direct that a share of your estate goes to a trust that already exists. These options are important if you are planning for a minor child or someone with disabilities, especially if he or she receives government benefits. A supplemental or special needs trust can receive that person's share of your estate so that his or her benefits will not be affected. Trusts are discussed in more detail later.

### How Do You Create a Will?

To make a valid Will you must understand what assets you own, how you want those assets distributed and to whom you want to leave your assets to. You must sign your Will in the presence of two witnesses, neither of whom will benefit from your death, and the witnesses must then sign the Will in your presence. You always have the right

Wills can range from very simple to very complex documents depending on your circumstances. A Will is important even if you do not have a lot of money or other belongings.

**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.**

to change your Will, as long as you have the understanding to do so. Only you can create or change your own Will.

While it is not a legal requirement to hire a lawyer to create a Will, there can be tax implications if the Will is not created in a manner that takes into consideration pertinent tax law. If you have a complicated family or you are in a domestic partnership, it is recommended that you hire an attorney to help you prepare or revise your Will. The attorney should meet with you and discuss your wishes about who will receive assets at your death and in what shares, the selection of your personal representative and guardians, and any other instructions or statements that are important to you. After your attorney drafts your Will, you should read it carefully and ask any questions that you have so that you understand fully what the Will says and why.

Some people who have few assets write their own Will, using forms 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 issues review it.

### **What Assets Does a Will Cover?**

Assets that are titled in your name alone, without a joint owner or a designated beneficiary, become part of your “probate estate” and are called “probate assets.” Your Will governs the distribution of your probate assets. For your probate estate, your personal representative will open the estate and file the necessary documents with the Register of Wills in your county. Your probate estate must remain open for a period of time after your death, 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 the 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 can be distributed to the people or trustees you have named in your Will.

Assets that are not subject to this process are called “non-probate assets.” These are assets you own while you are alive but are distributed to others automatically upon your death, rather than through the probate process. Examples of non-probate assets are joint bank accounts, life insurance, retirement accounts, annuities, and property owned in a trust.

If a jointly-owned asset is titled “joint tenants with right of survivorship” or “tenants by the entirety” (for married couples only), the asset will pass to the surviving owner or owners, without becoming part of your probate estate. By contrast, if you jointly

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 the joint owner.

If you own life insurance or retirement accounts, the beneficiary you have named will receive the asset upon your death. If you have a trust, the trust document should include instructions to the trustee about how to distribute the trust assets at 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 very careful to review all of your assets, check the beneficiary designations and titles, and terms of any trust you have to make sure that your estate plan covers all of your assets (probate and non-probate) and that the passing of your non-probate property is consistent with your overall estate plan.

### **Should You Avoid Probate?**

The probate process takes time, and it may be a year before all estate assets can be fully distributed. However, the personal representative may be able to make some distributions during this period, and many estate expenses can be paid during the probate process. Probate fees in Maryland are nominal and the process is relatively uncomplicated.

Avoiding probate may be simple and you may not have to give up much control over your assets while you are still able to make your own decisions. However, some steps required to avoid probate will limit your ability to control your assets. For example, if you name your daughter as a joint owner on a savings account, so that the account will pass to her automatically at your death, this asset will not go through probate. However, adding your daughter to the title of the account will also give her the right to withdraw all the money in the account while you are alive; it may also expose the account to her creditors. So to avoid probate in this example you will have given up your control and security over your finances.

An alternative would be to name your daughter as a payment on death or “POD” beneficiary on the account. This will allow the account to pass outside of probate at your death, but not give your daughter any control over it or access to funds during your lifetime.

In addition, if your daughter has a disability and receives government benefits, co-owning the bank account could jeopardize her eligibility for benefits. In this situation, if you have created a trust under your Will for your daughter’s benefit, it may be most useful for the account to go through probate so the funds go into the trust without ever being received directly by your daughter.

The pros and cons of probate are an important topic to discuss with your attorney.

**Review all of your assets, check the beneficiary designations and titles, and terms of any trust you have to make sure that your estate plan covers all of your assets (probate and non-probate) and that the passing of your non-probate property is consistent with your overall estate plan.**

Trusts are not just an option for wealthy families. Even small regular contributions can grow into a trust fund that can greatly enhance a person's quality of life.

Trusts can also be created to protect assets for the use and benefit of a person with a disability while at the same time preserving that person's eligibility for government benefits.

### What Happens 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 according to the laws of intestacy. This law lists, in order of priority, who in your family will receive your estate and in what shares.

For example, many married individuals want their estates to go to their spouse, and then to their children only if the spouse is no longer living. However, Maryland's intestacy law requires that if you are married and have children and 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 here regarding eligibility for benefits and coverage for 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 your child with a disability. It also gives you the opportunity to choose who will fill important roles related both to your estate and your child's well-being, such as your personal representative, trustee and guardian (if needed). Your Will should be consistent and prepared in conjunction with a letter of intent. Letters of intent are discussed below.

## 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. 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 are usually created by a Will or "trust agreement." Trusts created by Will are called "testamentary" trusts and become effective upon your death. Trusts that take effect while you are alive are called "inter vivo" trusts or "living trusts" and are created by a trust agreement.

Trusts can be created for 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 a trust to avoid probate. Some want to limit the use of assets for certain purposes, like future education costs, or to skip a generation and leave assets for the benefit of grandchildren.

Trusts can also be created to protect assets for the use and benefit of a person with a disability while at the same time preserving that person's eligibility for government benefits. This type of trust is called a "supplemental" or "special" needs trust. This type of trust is the focus of this section.

Certain types of government benefits are subject to “means testing;” that is, a person’s eligibility is based in part on his or her income or assets being below certain levels. The most common means-tested benefits are Supplemental Security Income, Medicaid, Food Stamps, and rental assistance programs. If a person who is eligible for such benefits directly receives money or other assets through a gift, inheritance or some other way, eligibility for these benefits may be lost. If this occurs, the person typically must spend down the assets until they are below the program limits, and then re-apply for benefits.

The loss of SSI or Medicaid health insurance can be extremely disruptive and costly for a person with disabilities. This is especially true for people who have high medical expenses or are dependent on regular medications. In addition, some services have long waiting lists, so if someone loses eligibility due to the receipt of funds over the program limits, it may take years to get assistance back. Such disruption can be avoided through careful planning and the use of a supplemental or special needs trust.

Public benefits cannot meet all the needs of a person with disabilities. Assets placed in a properly drafted trust can be used to supplement what these benefits provide and help enhance the beneficiary’s quality of life, and the trust will not affect the beneficiary’s ongoing eligibility for benefits.

### Terminology

Here are the terms commonly used in discussions about trusts.

**Grantor:** the person creating the trust.

**Trustee:** the person(s) or organization responsible for managing and using the trust assets for the beneficiary. With a living trust, the grantor can also serve as the trustee.

**Beneficiary:** the person for whose benefit the trust is created.

**Third party trust:** a trust created and funded by someone other than the beneficiary of the trust.

**Self-settled trust:** a trust funded with the assets belonging to the beneficiary.

**Testamentary trust:** a trust created by a Will that becomes effective after the death of the person who created the Will and is irrevocable as of that time.

**Inter-vivo trust:** a trust created and funded during the lifetime of the grantor.

**Irrevocable trust:** a trust that the grantor and beneficiary cannot change once it is executed or for a testamentary trust, once the person who created the Will has died; the grantor cannot take back any assets put into an irrevocable trust.

All of the types of trusts mentioned here require a written document, either a Will or a separate trust agreement. Such documents should be carefully drafted to accurately reflect the desires of the grantor and to thoughtfully provide for the needs of the beneficiary.

**Revocable trust:** a trust that the grantor may change or revoke during his or her lifetime, or before the grantor becomes incapacitated; the grantor may also take assets back from the trust.

**Supplemental or special needs trust:** a trust intended for a beneficiary with disabilities 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.

In practice, some of the different types of trusts are often combined. For example, a parent may set up a revocable trust during his or her lifetime to provide for the supplemental needs of a child with a disability. This would be a revocable supplemental needs trust. When the parent dies, the trust becomes an irrevocable supplemental needs trust, because the person who created it can no longer change or revoke it.

All of the types of trusts mentioned here require a written document, either a Will or a separate trust agreement. Such documents should be carefully drafted to accurately reflect the desires of the grantor and to thoughtfully provide for the needs of the beneficiary. Whether a revocable or irrevocable trust is appropriate for you will depend on your circumstances such as your health and capacity, your finances and the wishes of others who want to contribute to the trust.

There is no "one size fits all" for trusts. You should consult with an attorney who can advise you and consider such issues as tax planning, protection of assets, long-term care planning and probate issues, as well as your personal planning goals for all of your family members, including those with disabilities.

### **Important Distinctions between Types of Supplemental Needs Trusts**

#### ***Third Party Trusts***

A third party, such as a parent, grandparent or friend may wish to set up a trust for the benefit of someone who has a disability. It is best if the trustee is given complete discretion in making distributions for the beneficiary, so it is clear that the beneficiary has no control over the trust assets. This is important to include so that the trust does not affect the beneficiary's eligibility for government benefits. The trustee may be instructed to limit distributions to those things not covered by government benefits; that is, to *supplement* the beneficiary's benefits and not duplicate what the government already provides. With a third party trust, the grantor decides who gets the trust assets when the beneficiary dies.

#### ***Self-Funded Trusts for a Single Beneficiary***

In 1993, Congress passed legislation that established two types of trusts that an individual with disabilities could use to preserve his or her own assets and still qualify for SSI and Medicaid. The first is a trust for a single person under the age of 65 who has a disability. The trust may be established only by a parent, grandparent, guardian or a court. The beneficiary alone cannot set up this type of trust. The

trust agreement must provide that when the beneficiary dies, assets remaining in the trust must be repaid to the state Medicaid program up to the amount of benefits provided during the beneficiary's lifetime. Any funds remaining after that may go to the beneficiary's heirs, estate or, if the beneficiary is capable of making the decision at the time the trust is created, to whomever the beneficiary chooses. This type of trust is often referred to as a "payback trust" or "OBRA trust" or a "d4A trust." It may be necessary to obtain a court order to create or fund this type of trust. Also, the Maryland Office of the Attorney General must review and approve each trust.

### ***Pooled Asset Special Needs Trusts***

The second type of trust Congress authorized is a pooled asset special needs trust, which is operated by a non-profit organization and serves multiple beneficiaries. While each beneficiary has his or her own individual account, total assets are pooled for investment and management purposes. The non-profit organization selects the trustee. Beneficiaries get the services of a professional trustee and more investment options because there is more money overall to invest.

The beneficiary must have a disability and there is no age limit. If the beneficiary is over the age of 65 and receives SSI, he or she may be subject to a transfer penalty for putting assets into a pooled trust. Due to the inconsistencies in the law, Maryland currently allows transfers to pooled trusts by people of all ages without penalty.\*

An account in a pooled trust may be established by the beneficiary, a parent, grandparent, guardian, or court. This is in contrast to the individual trust discussed above, which does not allow the beneficiary to set up the trust for him or herself.

Unlike the payback trust, when the beneficiary dies, the pooled trust may keep the funds remaining in the beneficiary's account. If the trust does not do so, the assets in the account must be used to reimburse the state for the Medicaid benefits provided during the beneficiary's lifetime.

### **How Can a Special Needs Trust be Used?**

Although a properly drafted trust may be completely effective in protecting assets so that the beneficiary's eligibility for benefits is not affected, the trustee must be very careful when using the trust assets to avoid creating other eligibility problems. Trust distributions should generally be for the sole benefit of the beneficiary, and should not duplicate what public benefits already provide. For example, if the beneficiary receives SSI and Medicaid, the trustee should generally not use the trust assets to pay for food and shelter (which SSI is intended to provide for) or for medical care (which Medicaid covers). The trustee should be aware of all benefits that the beneficiary receives so that he or she can determine the effects of any distributions. The trust may be drafted to give the trustee permission to make distributions that would affect the beneficiary's benefits if the overall result is in the beneficiary's best interests. This flexibility allows the trustee to respond to changing circumstances in the beneficiary's life.

**Trust distributions should generally be for the sole benefit of the beneficiary, and should not duplicate what public benefits already provide.**

\* This is current as of 2011. Consult an attorney to learn about any possible changes.

A trust can own a home. Money and other assets in the trust can be used to maintain the home. This option offers a long-term living arrangement for the beneficiary.

There are housing costs that you or a trust can pay that will not affect SSI or Medicaid.

The trustee should avoid making any distributions directly to the beneficiary as this will usually be counted as income to the beneficiary, which will affect his or her benefits. Examples of the types of things generally allowed to be paid from a special needs trust include clothing, communications and assistive devices, education expenses like tuition, fees and books, computer equipment and services, vacations, transportation, memberships, subscriptions, cable and telephone equipment and services, hobbies, pets, a vehicle and necessary modifications, sporting goods and equipment, medical expenses not covered by government benefits or private insurance such as cosmetic surgery.

### Helping with Housing Costs

A trust can own a home. Money and other assets in the trust can be used to maintain the home. This option offers a long-term living arrangement for the beneficiary. When adequate supports are properly planned and provided for, 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 buy a home for your child. If you have sufficient assets, the trust may be able to buy the home outright. If not, the trust could be used for a down payment and closing costs, and/or to help pay the mortgage. The trust may also loan money to your child, if the trust terms permit this, for a down payment or rent. The trustee should be sure that he or she understands fully the beneficiary's government benefits and the effect that such payment may have on continuing eligibility for those benefits.

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 special needs trust should not be considered a resource to the individual and should not result in a reduction or loss of SSI. However, if the trust pays the mortgage or rent, property taxes, utilities and certain other shelter expenses for an SSI recipient, the SSI benefit is reduced every month these payments are made. As discussed in the *Government Financial and Health Care Benefits* section, it could be worth accepting the reduction in cash benefits in order to receive this assistance.

There are housing costs that you or a trust can pay that will not affect SSI or Medicaid. It may be easier to have the trust pay for these expenses and have the person with a disability pay the rent or mortgage. Examples include: telephone and cable service, home maintenance and repairs, furniture and appliances. All such payments should be made directly to vendors and not to the person with a disability. If he or she receives money outright, even if intended to be used to purchase something for his or her benefit, this is treated as income and will reduce the SSI payment and also affect other benefits.

Remember that different benefits programs have different rules, and these rules sometimes conflict. For example, SSI may allow a trust to pay a person's monthly



phone bill without any effect on eligibility. But, if the person with a disability is receiving government subsidized rental assistance, for example through the Housing Choice Voucher program (Section 8), the trustee must be very careful in making distributions. This program counts the regular payment of bills by a third party as income, unless the payments are for medical or dental care. This is the case even if the payment is made directly to a vendor. Because the payment will be counted as income and because the rental payment amount is based on income, the result is that the person's contribution to rent goes up.

Even a trust that is drafted properly can be used in ways that may harm the beneficiary. This is a good reminder that the trustee, or anyone else who may be helping with expenses, must be up to date on all of the beneficiary's benefits. Refer to the *Government Financial and Health Care 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 the first trustee is unable or unwilling to serve. At the very least you should pick someone who can select a new trustee when necessary.

The Will or trust agreement should instruct the trustee how and when to use trust assets. It may give the trustee guidelines but allow the trustee to use his or her judgment or discretion to make decisions on how to use the trust assets for the beneficiary. The trustee has other responsibilities too, such as managing and investing the trust assets, filing tax returns, keeping track of all transactions, and preparing any required accountings or reports.

A trustee should be capable of managing the trust investments or engaging an advisor to assist. It is helpful if the trustee is familiar with the beneficiary's needs and preferences, and takes the time to get to know the beneficiary personally if they don't already. It is essential that the trustee share your vision for the beneficiary, especially because the trustee will be making decisions after your death. A letter of intent is a useful way to help the trustee in this respect. The next section discusses letters of intent.

Maryland law requires that a trustee use the trust funds for the beneficiary's benefit alone, and not for the trustee. A properly drafted trust document will also include this requirement. Even with these legal protections, you should be very careful in selecting a trustee. It is not a good idea to give this responsibility to someone who cannot manage his or her own affairs effectively or who has financial difficulties. Having access to the trust assets may be too much of a temptation even to a trustee with the best of intentions.

Some grantors choose a family member or friend to be the trustee, or select an attorney or other professional. Some may name a bank or other financial institution, or may select a pooled asset special needs trust. Trustees are entitled to be paid for their services.

**It is essential that the trustee share your vision for the beneficiary, especially because the trustee will be making decisions after your death. A letter of intent is a useful way to help the trustee in this respect.**

Financial institutions may require a minimum balance, sometimes as high as \$1 million and charge fees for services that may be based on the trust assets or income. A pooled asset special needs trust will typically charge an enrollment fee and an annual fee. Friends or family members may be willing to serve as trustee for little or no cost. A trust can be written to allow the trustee to be paid for his or her time and services, even if you name a friend or family member. One exception is the self-funded special needs trust for a single beneficiary; Maryland regulation prohibits a family member from being paid trustee commissions with this type of trust. The cost of the trustee's services is an important part of the overall financial plan for the trust.

### Funding the Trust

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 may purchase life insurance and name the trustee of the trust as the beneficiary. This can be done with any type of trust — revocable or irrevocable, inter vivo, or testamentary. The trustee can also be named as the beneficiary of retirement accounts. You should consult with an attorney or tax advisor about any tax consequences of using retirement accounts for this purpose. Real estate can be deeded to a trust, either during your lifetime or at your death. Here again, you should seek professional advice regarding any tax consequences.

Perhaps there are other people who would like to contribute to a trust for the person with a disability. This is often true for a child with a disability, particularly in a large family. In this situation, you may want to consider setting up a trust during your lifetime, for the benefit of the child, and let family members know that they can send any contributions directly to the trustee. This can help to avoid the child accumulating gifts throughout childhood only to have too much money in his or her name to qualify for SSI at the age of 18. This scenario will require all the contributors to agree on where the trust funds go when the beneficiary dies. Often it is most effective to set up an irrevocable trust for this purpose, so everyone knows that no changes will be made to the terms or the future beneficiaries.

Other funding options to consider include:

- Start with a lump sum, whether a modest or large amount, that you are willing and able to contribute now.
- Direct subsequent gifts to the trust and invite others to do so, like grandparents.
- Inform others how to leave money to the trust through their own Wills.
- Make systematic investments each month or quarter; have an amount automatically transferred from your bank account.
- Name the trust as the beneficiary of your life insurance.

Different types of assets can be used to fund a trust such as cash, certificates of deposit, stocks, and life insurance.

## 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 family and friends and other appropriate people, such as a personal representative, trustee, guardian, or service provider to help them make important decisions with and 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. As with all planning about your child’s life, involve him or her to the maximum extent possible. Have your wishes and plans driven by what your child wants for his life. 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 is a good opportunity to describe your child now, explain the expectations and preferences that you and your child have for his or her future, and outline his or her wishes and plans in a variety of areas, such as:

- 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 and foods)
- Spiritual and religious affiliations, observances and practices
- 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)

**Have your wishes and plans driven by what your child wants for his life. The purpose is to provide guidance to others who may provide care, support or other assistance for your child.**

Revisit your plan whenever you or your family members have a significant change in health or financial circumstances.

See *Appendix A* 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 numbers 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.

You should periodically review and update your letter of intent when significant changes occur. Some families 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.

## Planning Options

In summary, there are many options and variables to consider when developing an estate plan that is best for you and your family and that suits your financial situation. This calls for an ongoing planning process that you revisit at least every three years, or whenever you or your family members have a significant change in health or financial circumstances.

**Example: Letter of Intent**

Dylan Joshua Smith  
SS #: 555-55-5555  
DOB: 5-17-99

April 20, 2011

Dear family and friends,

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

We hope that the information we have provided will help the people and organizations who assist Dylan to know him better and to support him to be as fulfilled, happy and independent as possible. Our wishes reflect what we have learned Dylan wants for his own life.

We envision Dylan 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. Dylan needs occasional reminders to thoroughly complete his personal self care and household chores. Dylan 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 Dylan with a bank account when he becomes an adult, with assistance to manage it.

We see Dylan 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 Dylan will choose, but he will require assistance to locate a job and ongoing support. Our hope is that the agency that supports him on the job will work to increase Dylan'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. Dylan 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. Dylan'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 Dylan can live close enough to his brothers, Ben and Danny, to visit regularly. We hope Ben and Danny remain involved as much as possible, even as their lives get busy. Other important people to maintain relationships with are Dylan's aunt Linda and uncle Lenny, cousin Abby, his friends Lisa and John Frederick, and Sam Warner who is a close family friend.

Dylan has an intellectual disability and epilepsy. His seizures are well controlled and he typically goes several weeks without a seizure...



# Tax Considerations

There are important tax issues to consider when planning how to leave money or other assets to your family. This may include gift and estate taxes, inheritance taxes, capital gains taxes, and other tax issues that may apply to your situation.

*“By failing to prepare, you are preparing to fail.”*

— Benjamin Franklin





# Tax Considerations

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 tax planning issues.

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

## Tax Issues

Tax laws continue to be in a state of flux. You should consult with an attorney or tax professional to make sure you understand all the tax implications and plan accordingly.

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 learn 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 generally high. For this reason, many individuals and couples seek ways to avoid gift and estate taxes. The Tax Relief Act of 2010 reinstated the federal estate tax through 2012, but at a lower tax rate and a higher “applicable exclusion amount.” This is the amount an individual can give away, during their lifetime or at death. For 2011 and 2012, the federal estate tax exemption is \$5 million and the federal estate tax rate is 35%. The lifetime gift tax exemption also increased to \$5 million (from \$1 million). But unless Congress acts before December 31, 2012, these exclusions for federal estate taxes and gift taxes revert to \$1 million dollars. Other additional options such as the annual exclusion, the medical exclusion, the education exclusion, and the exclusion for transfers to spouses, remain available.

It is important to note that even if a federal estate tax exclusion applies, a state estate tax may be applicable. In Maryland, taxable amounts exceeding \$1 million but less than \$5 million are subject to a Maryland estate tax.

**Federal gift and estate taxes get a lot of attention because the tax rates are generally high. For this reason, many individuals and couples seek ways to avoid gift and estate taxes.**

You can avoid gift taxes through the “annual exclusion.”

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 \$13,000 per individual and \$26,000 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 taxes do 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. Estate assets passing to spouses, parents, children, grandchildren, great grandchildren, etc. are exempt from taxation. Assets passed on to anyone else are subject to a ten percent tax.\*\* 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

You or your family member may qualify for tax exemptions for certain things such as medicine and medical supplies, and health and physical aids. Additionally, you or your family member may qualify for certain property tax exemptions and other tax credits. Consult with an attorney or other tax professional.

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 you should seek 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. All plans should be reviewed often, especially since federal, state and local tax laws are constantly changing.

\* These amounts are in effect as of December 2011 and are subject to change.

\*\* This tax rate was in effect as of December 2011 and could change. Consult with an attorney or other tax professional for updates.

## 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. Families 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 and Medicaid benefits until he does not need them anymore.

**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.



# Financial Planning

Effective 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 the 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 provides direction and meaning to your financial decisions. It allows you to understand how each decision you make affects other areas of your financial life. The information below is designed to help you better understand the financial planning process, to know what important questions to ask and, ultimately, to best determine the smartest path to take going forward.

## What is financial planning?

Financial planning is the long-term process of wisely managing your finances so you can achieve your goals and dreams, while at the same time negotiating the financial barriers that inevitably arise in every stage of life. Remember, financial planning is a process, not a product. The process involves gathering relevant financial information, setting life goals, examining your current financial status, and coming up with a strategy or plan for how you can meet your goals given your current situation and future plans.

According to the Certified Financial Planner Board of Standards, Inc., the financial planning process involves the following six steps:

1. Establishing and defining the client-planner relationship
2. Gathering client data, including goals
3. Analyzing and evaluating your financial status
4. Developing and presenting financial planning recommendations and/or alternatives
5. Implementing the financial planning recommendations
6. Monitoring the financial planning recommendations

## What are the potential benefits of financial planning?

If you're like most people, your daily life is focused on your immediate needs and those of your family. You may think about the future, but the thought may be just a passing one, as day-to-day activities take up most of your time. It is common for families to spend more time planning for their annual family vacation than they do planning for their financial future.

Developing a financial plan can help you strategize to accomplish the following:

1. Save for major expenses like funding a trust, paying for a child's education, buying a house or car, or developing a cash reserve for special occasions like weddings and vacations.

**Financial planning is the long-term process of wisely managing your finances so you can achieve your goals and dreams.**

**A financial plan can give you a clear picture of where you are currently, a strategy about where you are going and peace of mind about your future. It is never too early to start.**

2. Plan for your retirement by estimating your retirement income and expenses and the value of government programs. With this information, you can begin to determine the amount you need to save to meet your retirement goals.
3. Assess your risk tolerance and develop an asset allocation strategy.
4. Plan to reduce your taxes, project the effect of income taxes and develop a tax-deferred strategy.
5. Protect you and your family against financial crisis should you become disabled or die.
6. Plan your estate to ensure your assets are distributed the way you desire, fund estate taxes and minimize their effects where possible.

Finally, a financial plan can give you a clear picture of where you are currently, a strategy about where you are going and peace of mind about your future. It is never too early to start.

## Do I need a financial planner or should I do it on my own?

Many people don't have the time, interest or knowledge to create a solid financial plan. You may decide to seek help from a financial planner if:

- You need expertise you don't possess in certain areas of your finances. For example, a financial planner can help you evaluate the level of risk in your investment portfolio or adjust your retirement plan due to changing family circumstances.
- You want to get a professional opinion about the financial plan you developed yourself.
- You don't feel you have the time to spare to do your own financial planning.
- You have an immediate need or unexpected life event such as the birth of a child, inheritance or major illness.
- You feel that a financial planner could help you improve on how you are currently managing your finances. You know that you need to improve your current financial situation but don't know where to start.

## Who should be included in the financial planning process?

The right advisors take the time to understand your situation and help you define your vision. They should also help you understand what to expect during the course of your lifetime (and your heirs' lifetimes) and introduce you to resources. Your advisors may include an accountant, a financial planner, a life care planner (who can make recommendations to help address medical, physical, psychosocial, and environmental needs) and a trust and estate attorney (with knowledge of state-specific requirements and laws and how to obtain additional benefits). It may make



sense to have a friend or family member who you trust to be involved during the process as well.

## What are the best practices when approaching the financial planning process?

To achieve the best results during the financial planning process, here are the recommended best practices outlined by the Certified Financial Planner Board of Standards, Inc.:

- Set measurable goals.
- Understand the effect your financial decisions have on other financial issues.
- Re-evaluate your financial plan periodically.
- Start now — don't assume financial planning is for when you get older.
- Start with what you've got — don't assume financial planning is only for the wealthy.
- Take charge — you are in control of the financial planning engagement.
- Look at the big picture — financial planning is more than just retirement planning or tax planning.
- Don't confuse financial planning with investing.
- Don't expect unrealistic returns on investments.
- Don't wait until a money crisis to begin financial planning.

## How do I search for and choose a financial planner?

You should interview and evaluate several financial planners to find the one that is right for you. You should select a competent, qualified professional with whom you feel comfortable and one whose business style suits your financial planning needs. In addition to asking for a referral from a friend, family member, or trusted advisor, see *Appendix C* for resources to assist in locating a financial planner in your area. *Appendix C* also includes questions you can ask financial planners that will assist you in deciding who is right for you and resources for checking the disciplinary history of planners.

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. Please note that anyone can call themselves a financial planner without having any particular education, training or experience. However, most financial planners have one or more of these certifications:

- **Certified Financial Planner (CFP®)**  
Requires years of training and testing on financial subjects, continuing

Anyone can call themselves a financial planner without having any particular education, training or experience. However, most financial planners have one or more certifications.

education to update knowledge and adherence to a prescribed code of ethics.

- **Chartered Financial Consultant (ChFC®)**  
An insurance professional who has completed courses on financial subjects and continues to update knowledge through additional coursework and testing.
- **Chartered Financial Analyst (CFA®)**  
Must pass three rigorous exams, have at least three years of experience and commit to a code of ethics and professional standards of conduct. Continuing education is voluntary.
- **Registered Investment Adviser (RIA®)**  
Indicates that the adviser has registered with the SEC or with their state securities board (depending on the amount of money they manage).

There are numerous additional designations, indicating specialties in estate planning, divorce, personal financial planning, insurance, retirement, and others.

## How are financial planners compensated?

Financial planners can be paid in a variety of ways, and each has its merits. Choosing the appropriate method depends on your individual situation. However, before entering into a relationship with a planner, you should have a clear understanding of how he or she will be compensated.

Below is a list of financial planner compensation methods as outlined by the Financial Planning Association (FPA):

### ***Fee-only***

All of the financial planner's compensation comes exclusively from the clients in the form of fixed, flat, hourly, percentage or performance-based fees.

### ***Commission-only***

There is no charge for the planner's advice or preparation of a financial plan. Compensation is received solely from the sale of financial products you agree to purchase in order to implement financial planning recommendations.

### ***Combination Fee/Commission***

A fee is charged for consultation, advice and financial plan preparation on an hourly, project or percentage basis. In addition, the planner may receive commissions from the sale of recommended products used to implement your plan.

### ***Salary***

Some planners work on a salary and bonus basis for financial services firms.

**In all of the above categories of compensation, you should request information on any real or potential conflicts of interest. In addition to commissions received from any financial product sales, you should ask whether there are outside incentives or bonuses to be gained by the planner for certain recommendations.**

Financial planners can be paid in a variety of ways, and each has its merits. Choosing the appropriate method depends on your individual situation.

**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 will probably 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.

**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.**



# Working with Professionals

Working effectively with attorneys, financial planners and other professionals will help ensure that your planning accomplishes what you want it to and your money and other assets are used according to your wishes. Finding professionals with the right skills and knowledge is essential.

*“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



# 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 child with a disability, while considering your own needs and those of your other family members. It is important to start your search with attorneys who are knowledgeable about the capabilities and needs of people with disabilities as well as the numerous issues about estate planning for people with disabilities we have discussed here. 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.” Talking to other families who have already begun planning can give you a tremendous head start. Your child’s teachers, resource coordinators or advocates may also provide good referrals. Agencies serving individuals with disabilities may also know of attorneys familiar with benefits, estate planning and futures planning.

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/or 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 start your search with attorneys who are knowledgeable about the capabilities and needs of people with disabilities as well as the numerous issues about estate planning for people with disabilities we have discussed here.**

**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.**

It is important to think about your child's short-term and long-term goals, and to communicate those goals to your attorney. Then, he or she can help 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:**

- Understanding of the capabilities and needs of people with disabilities and their families
- 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 and Annuities)
- Guardianship and other alternatives
- Health insurance
- Life insurance

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 future's 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.



# Planning Checklist

We have discussed a great deal of information that is critical to effective planning. The planning checklist summarizes important steps to take, includes references to other parts of the guide and can help you develop and implement your plan.

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*“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 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 make sure 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 families, advocates and service providers for ideas and guidance.  
*Refer to:*
  - Introduction to Futures Planning and Estate Planning
  - Common Principles
  - Planning Questions (*Appendix A*)
  
- 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
  
- Meet with an attorney knowledgeable about public benefits and estate planning for people with disabilities. Write a Will, consider establishing and funding a 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

Please don't let an inability to complete all parts of the process stop you from contacting professionals or moving forward.

them. Your Will and trust should be written so that they do not result in your family member losing vital public benefits.

***Refer to:***

- Wills, Trusts and Letters of Intent
- Tax Considerations
- Working with Professionals
- How to Evaluate Your Supplemental Needs Trust (*Appendix B*)

- 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
- Wills, Trusts and Letters of Intent

- Write a letter of intent based on your planning that reflects your child's and your own 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, Trusts and Letters of Intent
- Planning Questions (*Appendix A*)

- Estimate your child's needs and related costs to support his or her future plan. Determine what public benefits and programs might cover. Consider what your child may be able to contribute from earnings and other sources.

***Refer to:***

- Government Financial and Health Care Benefits
- State and National Resources (*Appendix D*)

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

***Refer to:***

- Financial Planning
- Working with Professionals
- How to Choose a Financial Planner (*Appendix C*)

- 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

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

*Refer to:*

- State and National Resources (*Appendix D*)

## 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.
- 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 is 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.



# Appendices

Other resources and information can help you each step of the way. Pick and choose what best meets your needs.

*“A journey of a thousand miles must start with a single step.”*

— *Chinese proverb*





## 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. Think about ways to maximize your child's independence and the control she has over her own life, as well as inclusion in all facets of community life that are important to her.

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. The answers to the questions, and the goals that result, should be used as a guide to 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 your child wants and you want for him or her, 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. Keep your child at the center of, and in control of, the decisions to the maximum extent possible. Include what seems most important in your letter of intent. This information will also help you plan with an attorney, financial planner or 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. How 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 that 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 provide in my child's life in the future? (e.g., friendship, 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? How will these benefits assist with my child's needs?
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?

## How to Evaluate Your Supplemental Needs Trust

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, 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? This requirement 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 re-titling 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 make 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?

## How to Choose a Financial Planner

### Questions to Ask a Financial Planner

According to the Certified Financial Planner Board of Standards, Inc. here is a list of 10 questions to ask a financial planner during the interview process:

1. What experience do you have?
2. What are your qualifications?
3. What services do you offer?
4. What is your approach to financial planning?
5. Will you be the only person working with me?
6. How will I pay for your services?
7. How much do you typically charge?
8. Could anyone besides me benefit from your recommendations?
9. Have you ever been publicly disciplined for any unlawful or unethical actions in your professional career?
10. Can I have the above in writing?

### To Find a Financial Planner in Your Area

Certified Financial Planner Board of Standards, Inc.	<a href="http://www.cfp.net">www.cfp.net</a>
Financial Planning Association	<a href="http://www.fpanet.org">www.fpanet.org</a>
National Association of Personal Financial Advisors	<a href="http://www.napfa.org">www.napfa.org</a>
American Institute of Certified Public Accountants- Personal Financial Planning Division	<a href="http://www.aicpa.org">www.aicpa.org</a>
Society of Financial Service Professionals	<a href="http://www.financialpro.org">www.financialpro.org</a>

### To Check the Disciplinary History of a Financial Planner or Advisor

Certified Financial Planner Board of Standards, Inc.	<a href="http://www.cfp.net">www.cfp.net</a>
North American Securities Administrators Association	<a href="http://www.nasaa.org">www.nasaa.org</a>
National Association of Insurance Commissioners	<a href="http://www.naic.org">www.naic.org</a>
Financial Industry Regulatory Authority	<a href="http://www.finra.org">www.finra.org</a>
Securities and Exchange Commission	<a href="http://www.sec.gov">www.sec.gov</a>

# Appendix D

## State and National Resources

### Advance Directive Forms

**MD Attorney General's Office** [www.oag.state.md.us](http://www.oag.state.md.us)

### Americans with Disabilities Act

**ADA Information Center (*Mid-Atlantic Region*)** [www.adainfo.org](http://www.adainfo.org)

**Disability Rights Education and Defense Fund** [www.dredf.org](http://www.dredf.org)

**Job Accommodation Network** [www.askjan.org](http://www.askjan.org)

**U.S. Dept. of Justice ADA Information** [www.ada.gov](http://www.ada.gov)

### Public Benefits

**Centers for Medicare and Medicaid Services** [www.cms.gov](http://www.cms.gov)

The Centers for Medicare & Medicaid Services (CMS) is a branch of the U.S. Department of Health and Human Services and administers Medicare, Medicaid, and the Children's Health Insurance Program.

**Medicare.gov** [www.medicare.gov](http://www.medicare.gov)

The official U.S. government site for people with Medicare includes the latest information on Medicare enrollment, benefits, and other helpful tools.

**Social Security Administration** [www.socialsecurity.gov](http://www.socialsecurity.gov)

The Social Security Administration's website includes in depth information on a variety of topics, programs and services. You can also apply for benefits.

### Maryland State Agencies

**Developmental Disabilities Administration (DDA)** [www.ddamaryland.org](http://www.ddamaryland.org)

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.

**Maryland Department of Disabilities** [www.mdod.state.md.us](http://www.mdod.state.md.us)

The Maryland Department of Disabilities partners with other state agencies to improve services for people with disabilities. This website provides links to extensive resources on a variety of topics related to disability issues.

**Maryland Department of Human Resources** [www.dhr.state.md.us](http://www.dhr.state.md.us)

The Department of Human Resources offers many services that provide assistance and support to families and individuals, including Medicaid. More information as well as applications for Medicaid and other programs can be obtained through local departments of social services.

**Division of Rehabilitation Services** [www.dors.state.md.us](http://www.dors.state.md.us)

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 DORS offices located throughout Maryland.

**Maryland State Department of Education (MSDE)**

**[www.marylandpublicschools.org](http://www.marylandpublicschools.org)**

The Division of Special Education/Early Intervention Services works with children and youth with disabilities and their families as well as local early intervention systems and local school systems to ensure access to appropriate services and supports, a free and appropriate public education and other opportunities as required by federal and state laws. MSDE also administers Maryland's Medicaid Waiver for Children with Autism Spectrum Disorder (Autism Waiver).

## 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 \$5 million in assets without paying federal gift or estate taxes. 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 people 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.

\* This amount could change.



**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. The grantor cannot take back any assets put into an irrevocable trust.

**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 vivo Trust:** A trust created and funded during the lifetime of the grantor. 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 that 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 grantor may also take assets back from the trust.

**Stand-by Guardian:** A stand-by guardian is an individual who takes care of the child in the event that the parent(s) is mentally or physically incapable of doing so.

**Supplemental Needs Trust:** A trust intended for a beneficiary with disabilities 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.

**Trust:** A legal document that provides a way for someone to take care of assets, including money or 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 organization responsible for managing and using the trust assets for the beneficiary. 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, at his or her death, receive his or her money, property and other assets that they own alone. It is also used to name guardians.





**Maryland Developmental Disabilities Council**

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Baltimore, Maryland 21202

410-767-3670 / 800-305-6441

711 (MD Relay)

[info@md-council.org](mailto:info@md-council.org)

[www.md-council.org](http://www.md-council.org)

*The Maryland Developmental Disabilities Council is a public policy organization that advocates for the inclusion of people with developmental disabilities in all facets of community life.*