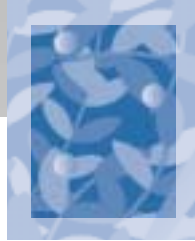


Introduction to Futures Planning and Estate Planning



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HAT ARE “FUTURES PLANNING” AND “ESTATE PLANNING” AND WHY MIGHT THEY APPLY TO YOU? WHY SHOULD YOU PLAN AND HOW DO YOU START? THESE AND MANY OTHER QUESTIONS ARE ANSWERED AS WE ADDRESS MYTHS ABOUT PLANNING FOR THE FUTURE AND HELP GUIDE YOU THROUGH THE PROCESS.

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

— Henry Ford

Introduction to Futures Planning and Estate Planning

What are Futures Planning and Estate Planning?

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

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

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

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

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

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

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

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

Why Plan for the Future?

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

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

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

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

Lack of Planning = Undesirable Outcomes

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

1. Your child will lose his benefits and have to use the inheritance for daily living costs and health care. Few inheritances are large enough to cover these costs for long. The needs you intended to meet with your money could go unmet.
2. If your child receives services funded by the Developmental Disabilities Administration (e.g., residential and day/employment services), the inheritance can be claimed by the state to cover the cost of these services until it is depleted. These services typically cost tens of thousands of dollars a year for one person.

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

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

When Should You Start Planning?

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

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

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

One Plan Does Not Fit All

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

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

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

Myths and Realities

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

Myth: *I have little money or assets so I don't need to plan.*

Reality: Planning involves much more than finances. It is important even when there is little or no money involved in order to increase the likelihood that your wishes are carried out.

Myth: *There is no guarantee that services will be available when we need them, and the service system keeps changing, so we shouldn't plan.*

Reality: If the exact support you specify isn't the same when it comes time to implement your plan, others can work with your child to change details within the framework you've built.

Myth: *I should disinherit my child so she does not lose her government benefits.*

Reality: You could set up a special needs trust in your will so that your child's inheritance is held by the trust and does not jeopardize her benefits.

Myth: *After I die, my child will receive government benefits, which will provide everything she needs.*

Reality: Government benefits cover basic necessities, such as food, clothing, shelter and medical care. Usually, other items that impact quality of life, such as vacations, special equipment, and personal and household items are not covered.

Myth: *I have left everything to my other children who will take care of my child with a disability.*

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

Myth: *If my child is not eligible or does not yet qualify to receive services from the Developmental Disabilities Administration, there's nothing I can do.*

Reality: Some families are able to help their children become more independent with little or no DDA services, particularly when support needs aren't very great. Some help their child by renting an apartment and assisting with the costs of supports. Others leave their house to their child when they die.

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

Myth: *I'm too old (too young) to start planning.*

Reality: Futures planning is an ongoing process. The earlier you start thinking about a futures plan, the better prepared you and your child with a disability will be for what the future may bring. However, it is never too late.

Myth: *I shouldn't establish a futures plan in case the laws change.*

Reality: It is true that laws change, but a good plan is flexible enough to adapt to any changes. Also, plans should be reviewed and revised periodically. If you die without a will, the state decides where your money will go and this distribution could affect your child's ability to collect important public benefits.

Getting Your Plan on Paper

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

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

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

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

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

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

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

Finding Help with Planning

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

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

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

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