

FUTURE PLANNING: LIFE, LEGAL AND FINANCIAL PLANNING

AN INTRODUCTION

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WHAT IS FUTURE PLANNING?

Future planning is thinking about the future for you, a family member, or a friend (*life planning*) and then identifying the people, resources and services needed to make all, or part, of the plan a reality (*legal and financial planning*). The focus can be on the future while you are still living, as well as after your death.

When you support a person with a disability, you will likely assist him/her in planning for the future. Just as it is important in your personal life, it is important to structure a legal and financial framework to support his or her needs, life plans and goals.

Those supporting a person with a disability may encounter special issues related to his or her care and support. Issues may range from obtaining communication devices, education, employment, housing, and transportation to ensuring access to favorite foods, recreation and visits with friends.



The most important part of a future plan is that it reflects your situation and that it is flexible enough to allow modifications in the future. It encourages the person with a disability to make decisions while providing guidance only as needed. No one knows what the future holds, but it is empowering and comforting to have thought about the possibilities for the future and to have planned accordingly.

Your plan will depend on whether you are planning for the near future or distant future. Some issues might be taken care of now while others are identified for future attention -- either during your lifetime or after your death. If the person with a disability is young, it may not be possible, or appropriate, to make specific plans about adult issues like employment and support services. However, as adulthood approaches, you may revise the plan to include the relevant issues.

KEY STEPS IN FUTURE PLANNING

1. Identify current and future needs;
2. Identify goals;
3. Identify current and future costs for needs and goals;
4. Identify resources;
5. Identify ways to maximize resources
6. Identify people that will help; and
7. Create a plan

Whenever you hire a professional, hire one who understands disability issues, including public benefit eligibility. Different professionals may help you to put the plan together. Seek an attorney who understands not only legal and financial planning issues but who is also knowledgeable about government benefits and understands and is sensitive to the needs of people with disabilities. The future plan may require the services of a financial planner, accountant, or life insurance broker to accomplish your goals. It may 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. Changes involving the important people in their lives can be especially disruptive. A future plan allows those currently providing support to set up alternatives in the event something happens that makes them unable to continue to provide support. Generally speaking, better and more comprehensive decisions are made when we plan rather than when we are reacting to a crisis.

Judy resides in Northern New Hampshire. She has cared for her daughter, Mary, at home since her birth. Judy is now in her late 70s and Mary is in her late 40s. Recently, Judy was admitted to the hospital with heart problems. When asked about her plans for Mary after she was no longer able to care for her, Judy responded that her plan was for Mary to go to a nursing home. Mary has no obvious medical needs that would require nursing home care and it is doubtful that such a setting would be approved by the State. With proper planning, Mary could remain in her community, enjoying the activities she engages in today. Judy's lack of understanding of the options available for Mary could result in a crisis for her and her daughter.

The purpose of any plan is to provide options and control over what will happen when a significant event occurs. While the future is unknown, we know some things will happen, such as the eventual death of a parent or other person providing support. Many other major life changes, however, come as a surprise. For example, if a mother who has supported her son his entire life suddenly becomes incapacitated or dies, someone else will need to support him. If his

mother has developed a future plan, she may have arranged for people he is familiar with to help ease the transition. She also may have lined up support services with people familiar with her son's needs and interests.

For those who are receiving government financial assistance or health care benefits, financial planning is imperative. A future plan can assure that a person with a disability keeps needed benefits and is able to use the additional assistance from others to purchase necessary items not covered by government programs.

The most important reason to do legal and financial planning is that it enables you and the person with a disability to get what you both want and need out of life. You know better than anyone what the needs and goals are. You are the best people to make this plan. If you do not create a legal and financial plan, a stranger may end up making many life-altering decisions for you.

A legal and financial plan should help to:

- Make sure that basic needs are always met;
- Support the achievement of goals;
- Minimize disruption from life changes;
- Keep the supports in place that you worked hard to put in place; and
- Give you peace of mind.

Planning is important whether you are rich or poor. Legal and financial planning is important for everyone .

Meeting Basic Needs — The basic needs of a person with a disability are more than food, clothing, shelter and health care. For many with a disability, there is another level of basic needs critical to quality of life. This other level may include communication devices, personal care attendants, or special transportation. Personal assets and public benefits may not cover all of these needs and a plan is important to make sure that these needs are met.

Supporting Goals — The person with a disability has goals. Goals may include recreation, travel, education and more. Goals may also include learning to ride the bus alone or to cook basic meals. Some goals may be fairly easy to fulfill and others will be challenging. A plan should help to develop and support all goals.

Minimizing Disruption From Life Changes — We know that life changes will occur, but often we do not know when. It is especially important to plan for life changes that we cannot time, such as sudden illness, incapacity or death. It is much easier to plan ahead, rather than to plan in the midst of a crisis. The person with a disability, for example, will have enough of a challenge dealing with your loss without also having to deal with a complete disruption of his or her life.

Joan is 76 years old and has always been very healthy. She has a 55 year old child, Alan, who has a developmental disability. Alan has lived with Joan all of his life. Alan has never worked and is dependent on Joan for his needs. Joan has made no plans for the future. She has always been able to care for Alan and preferred to provide his care. Joan had a stroke last week. She cannot walk, write or talk and will go to a nursing home. What happens to Alan?

Keeping Supports in Place — Many people have worked hard to support the person with a disability, making sure that the best supports are in place and continuing to watch for new supports and resources that may help make the person's life even better. Those who do not plan for the future, may cause the person to lose many of the supports that they worked hard to put in place.

Sarah is 23 years old and has a severe disability. Despite the disability, Sarah is expected to live well into her seventies. Sarah does not work, lives in a group home and is very happy. Before they died, Sarah's parents worked very hard to help Sarah gain as much independence as possible.

Sarah's parents were a middle-class couple who loved their daughter very much but were not able to meet the high cost of her care. Sarah depends on public benefits — SSI and Medicaid. Public benefits leave little extra spending money. Fortunately, Sarah's parents were able to provide the extras. For example, Sarah's parents purchased a television for her room and cable service. They took her on vacations to the beach with them in the summer. They purchased a new motorized attachment for Sarah's wheelchair that Medicaid would not cover.

In their will, Sarah's parents left her \$20,000 so that Sarah could continue to get the extras that they had always provided. The money went directly to Sarah. Sarah now has too much money to qualify for public assistance. Her public assistance has stopped and will not start again until she has only \$1,500 left which won't buy many extras over the next 50 years. If Sarah's parents had put the \$20,000 into a special needs trust, Sarah would have continued to qualify for public assistance and her parents would have continued to provide her extras for a long time.

Peace of Mind — A legal and financial plan will remove much of the emotional and economic strain of supporting a person with a disability. It is empowering and comforting to have such a plan in place.

Some people have disabilities that affect their capacity to manage money or make financial decisions. A future plan can name someone to manage assets on behalf of a person with a disability. The plan can be structured or somewhat flexible, but should be made keeping in mind the physical and emotional needs of the person. You can place assets in a trust to be managed by a trustee acting on behalf of the person. A trust can also own a house, cash and other income from savings or life insurance proceeds or other property.

Lack of planning = Undesirable outcomes

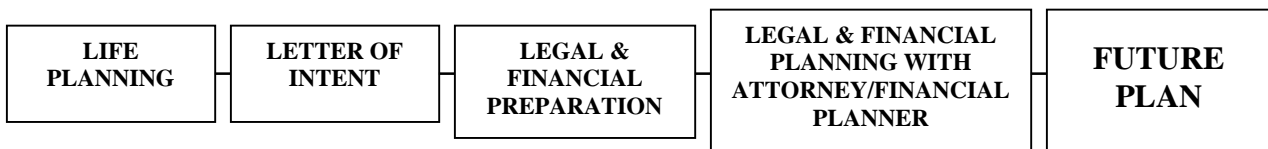
According to New Hampshire law, if you die without a will, your children will **directly** inherit money and other assets. If your son or daughter with a disability receives SSI and Medicaid (or could qualify for these benefits when he or she becomes an adult), the following is likely:

1. He or she will lose 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 he or she receives services funded by the Department of Health and Human 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.

A future 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 enables you and others who provide support to the person with a disability to make informed decisions together, taking into consideration all options, rather than having to act under pressure or having a court make those decisions for you. It also allows you to act before a key person dies or cannot participate due to illness or other unexpected changes.

WHAT ARE LIFE, FINANCIAL AND LEGAL PLANNING?

Future planning has two main parts: *life planning* and *the financial and legal plans* to support that life plan. Most people want to direct how money or assets will be distributed, minimize taxes, and choose who will care for their minor children. Those providing support may name people who will provide future support for a person with a disability who needs assistance. This is accomplished by creating a plan that includes a will, letter of intent, special needs trust and/or other pertinent documents.



Life planning is thinking about life today and what you would like it to be in the future. Planning should include: home, employment, learning/education, health & well-being, relationships/affiliations and lifestyle decisions. The same approach applies to planning for a person with a disability. Prior to considering your resources, you need to think about:

- What in the person's current lifestyle is important to maintain in the future,
- What is desired for the future, and
- What supports will likely be needed to make this happen.

Developing this *life plan* will help you to set priorities and will guide your legal and financial planning. Remember — it is natural and expected that plans will change over time.

To carry out the life plan, it is important to do the legal and financial planning to support the life plan. Legal and financial planning builds a legal and financial foundation to support lifetime needs.

Financial planning is the way people direct what will happen to money and other assets after their death. Financial planning can help people in all types of financial situations.

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 thought about a desired future. As a part of financial planning, you will identify costs of 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 having a general idea of what you want to do after retirement and what you will need.

A good future plan has a financial section that identifies 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 name who will help the person, if necessary, make other life decisions such as where he or she will live or what type of health care he or she will receive. It may name who will advocate for the person, make sure that appropriate supports are provided, and ensure that those supports are updated as the person's needs change.

Legal planning is the creation of mechanisms to assist the person with a disability with personal and financial decision-making. When planning for the future, evaluate the need for future decision-making assistance for the person, how much assistance is needed, and what method of assistance is best. Assistance includes, but is not limited to, an advocate, a durable power of attorney, living will, representative payee, and guardianship.

Planning may include exploring and applying for resources available to the person with a disability. He/she may be eligible for Medicare, Social Security benefits, or private benefits through an employer. If the person has limited self-support, he/she may apply for public assistance such as food stamps, Financial Assistance or Medicaid to support food, clothing, shelter and medical care needs. If you currently support him/her or supplement his/her public benefit, you may establish a trust to provide the same type of support that you provide today, even after your death. The person may also need to consider a will and mechanisms for assistance such as powers of attorney or guardianship.

WHEN SHOULD YOU START PLANNING?

It is never too early to start planning. And it is never too late either. The decisions that are part of future planning are not only legal and financial but also those that will determine what the life of the person with a disability will be like when you or other providers of support are no longer available. Planning helps that person live where and with whom he or she chooses.

Gregg has lived with his grandfather since a young age. Now in his early 80s, Gregg's grandfather realizes he must start to think about his grandson's future. Gregg has been relatively isolated from his community as his grandfather worries about his "outbursts" and has not wanted to worry that Gregg might scare someone. Originally he thought a neighbor would care for Gregg, however her health is failing and that is no longer an option. Gregg's grandfather realizes that he must begin to plan for Gregg's future, and that means helping Gregg re-enter community life while they are still together.

While this manual is about planning for an adult, it is never too early to plan. It is as important when someone is young as it is when he/she is an adult. Once established, the plan should be revisited and revised to meet life changes, changes in the law and changes in support programs.

It is wise to establish a plan early in the person's life, and to adapt it as needs and capabilities change. Parents of minor children who do not receive government benefits may believe that they do not need to establish a future plan until their child becomes an adult or becomes entitled to benefits. But future planning looks at more than finances.

A future plan has you consider the person's life now and think about what it should 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 this person so he or she can live the life you both want. If you have not already done so, evaluate where you are today and start planning for the future now.

Remember, a future plan may involve many parts that work together. Some parts of the plan may be informal such as talking with others about your ideas for the person with a disability 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. Many things that impact people with disabilities are governed by New Hampshire law so, it is essential to find an attorney familiar with those laws.

IS THERE ONLY ONE WAY TO DEVELOP A FUTURES PLAN?

No, one plan does not fit all. Each person and situation is unique so each future plan will be unique. When you are preparing a future plan consider:

- As you get older, what might your needs be? How does that impact planning?
- Who else do you need to think about and talk with as you develop a future plan?
- What assets do you want to leave to the person with a disability? To others?
- What types of support does the person with a disability need? What will he/she need in the future?

- How can you maximize his or her independence and ability to enjoy the highest quality of life possible?
- Who else in the person's life should be involved in the planning process? How will you include the person with a disability in the planning process?

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

Myths and Realities

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

Reality: Planning involves much more than finances. It is important to plan even when there is little or no money involved. Planning increases the likelihood that your wishes will be carried out.

Myth: *There is no guarantee that services will be available when we need them. 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 you've chosen can work with the person with a disability to change details within the plan you've developed.

Myth: *After I die, the person with a disability will receive government benefits which will provide everything he/she needs.*

Reality: Government benefits, if available, only 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 the person 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 the person with a disability, without a written plan you have no way to control how they actually spend the money.

Myth: *If the person with a disability is not eligible or does not yet qualify to receive services from the Department of Health and Human Services, there's nothing I can do.*

Reality: Some have been able to help the person with a disability become more independent with little or no formal services, particularly when support needs aren't very great. Some have helped by renting an apartment and assisting with the costs of supports. Some people may not be able to get formal supports now, but may when their caregivers are no longer able to provide support. Planning helps direct how services should be provided if and when they do become available.

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

Reality: Future planning is ongoing. The earlier you start thinking about a future plan, the better prepared you and the person with a disability will be for the future. However, it is never too late.

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

Reality: Laws do change, but a good plan is flexible enough to adapt to any changes. 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 the person's future.

HOW DO I GET MY PLAN ON PAPER?

Let's get started planning. Where do you begin?

- Think about your present life.
- Look at your family member's strengths and needs.
- Think about the future.

How can this manual help me?

This manual is divided into two main parts: **Part 1: Life Planning**; and **Part 2: Legal & Financial Planning**.

Part 1: Life Planning is divided into two major categories *life domains* (home, employment, learning/education, health & well-being, relationships/affiliations and lifestyle) and *critical concerns* (decision-making, communications, and beliefs).

There are a variety of planning tools for each section for you to choose from. Select the section and tools that work best for you and your situation.

Each section has a series of questions that you may use when preparing your plan. The appropriateness of each question will depend on things like the person's age, the impact of his or her disability on independence and decision-making and other individual circumstances. By addressing all the sections of that plan that are pertinent to the life of the person with a disability, a comprehensive picture of his or her life will emerge and your vision for the future will come together.

Once you have developed your future plan, you can insert it into a *Letter of Intent*. Whether or not you develop a detailed plan, and regardless of how young your family member is, you should write a *Letter of Intent*. This familiarizes others with the person with a disability and expresses your expectations and wishes for his or her life. While not a legal document, the letter of intent accompanies your legal documents and serves as a reference when legal questions arise. We have developed a framework for writing a letter that will make the process a bit easier.

Part 2: Legal and Financial Planning has important planning tools and facts to help you create a plan for your situation. A *legal and financial plan* should have three parts: a personal plan, a financial plan and an estate plan. The personal plan should address assistance in decision-making, assistance that may range from a power of attorney to a guardian. The financial plan should be a plan for how to meet the costs of the future and may include an investment or savings plan. The estate plan should be a plan for what will happen to assets and responsibilities after death.

This section provides information on: wills, cash assistance, health care coverage, public benefits, the Special Needs Trust, assistance in personal and financial decision-making. As with the life planning sections, there are tools at the end of the legal and financial planning section to assist you in your planning.

REMEMBER — Government benefits, laws and regulations are always changing. It is important to understand that many of the programs described here are subject to change. Please protect yourself by checking on the most recent changes before and while making plans for the person with a disability.

SOME FINAL THOUGHTS...

Planning for the future is critical to the quality of life of the person with a disability. A futures plan is unique to each person and situation; there is no cookie-cutter model. Look at your goals and your needs, as well as the goals and needs of the person. Take a thorough accounting of income and resources, as well as expenses. Figure out how to meet the goals and needs of the future and create a plan. Decide what you want to happen after your death and after the person's death. Seek knowledgeable professional advice and assistance in planning when necessary. Address your unique situation, stay flexible and stay in control.

We believe that the *Guide* will help you plan for the future of the person with a disability. This is a courageous undertaking and we trust the *Guide* makes the process just a bit easier.