

Legal Planning for Children and Young Adults with Special Needs

How to Put a Fortress of Protection Around Your Child Through All of Life's Transitions

 CAROLINA FAMILY ESTATE PLANNING
Protecting Your Family For Life



Introduction

Raising a child with physical or developmental disabilities can be challenging. Between running to and from specialist appointments, IEP meetings, occupational therapy, speech therapy, and caring for your child's basic needs, there is little time to take care of the tasks of today, ***let alone plan for tomorrow.***

But, as you likely know, **there are many legal and financial concerns that must be considered for the future, such as:**

- **Who would raise your child** if something unexpected happened to you and/or your spouse?
- **How can you ensure enough money is left behind** should your child require a lifetime of care?
- **What happens when your child turns 18?** How can you continue to make medical and financial decisions on his or her behalf? And,
- **How can you ensure your child is not taken advantage of** financially or emotionally if you are no longer there to protect him or her?

The answers to all of these questions are found in the pages of this guide. While each legal situation is as unique as your child, **we wrote this e-book as a basic overview for busy parents who simply need a roadmap for the future and simple action steps that tell them what to do and where to start.**

However, if you would like to talk to our attorneys about your individual situation and how to put a fortress of protection around your child through all of life's transitions, you can also skip ahead to the end of this book for a certificate to meet with us for a Vision Meeting at no charge.



Protecting Your Child Starts with Naming Legal Guardians

Naming legal guardians is one of the first and most important steps a parent can take to ensure their child is raised by the people they want in the event of their unexpected death or incapacity.

It is no secret that caring for a child with disabilities can be challenging. **That is why you want to** choose someone who will *love and care for your child* the way you would if you were not around for any reason.

When picking a legal guardian, we like to encourage parents to look beyond the obvious choices. Many times parents will choose a guardian simply because they have the most financial resources at their disposal.

However, as you will learn in this guide, there are many other ways to ensure your child has enough financial resources to last a lifetime. **Choosing a guardian based on financial** status should not be your primary concern.

Instead, consider the candidates whose values and outlook on life are similar to your own. You will also want to choose someone who will be committed to looking after your child for life, as many children with disabilities require supervision and support well into their adult years.

Here are some other questions to ask when choosing a legal guardian:

- Does the potential guardian have a similar parenting style to yours?
- Is your child already comfortable with this person?
- Is the potential guardian willing to take on the responsibility?
- Will they be emotionally able to care for your child(ren) after your death?

Once you have decided who to name as trusted guardians, **work with an estate planning lawyer to legally document your wishes.** You should leave a copy of your plan with your chosen caregivers, your child's school, babysitters, and any other concerned party in the event something happens to you and/or your spouse.

Don't Forget to Name Short-Term Guardians

Situations can arise where a parent is **temporarily and suddenly** unable to care for a child. A car accident or other emergency could require the need for a guardian on very short notice. Unfortunately, if the parent hasn't planned for this contingency, things can go from bad to worse pretty quickly.

That's because **emergency personnel can place your child with disabilities into the care of Child Protective Services** for the duration of the emergency, or until the long-term guardian can take custody. This can happen *even if* you have family members or friends who are willing and able to help!

The reason for this is simple: **the authorities can not leave your child in the custody of another adult without your explicit permission.** If you are incapacitated and can not give this permission, Child Protective Services will likely have to get involved until a judge can give a final "okay."

It's not hard to imagine the anxiety, terror, and pain this type of arrangement could cause for your child.

A better solution is to work with your attorney to designate **a temporary legal guardian.** This is someone who you are essentially "pre-authorizing" to help your child in a short-term situation so that Child Protective Services does not have to get involved.

Your temporary guardian should be someone who lives locally and can quickly be by your child's side for immediate care and emotional support in an emergency.

Temporary guardianships don't have to delegate full parental-type rights to the guardian. And, you should still name long-term guardians who are suited to care for your kids on a long-term basis. However, having short-term guardians in place allows parents to hand-pick someone who can care for their children in an immediate emergency in a manner that complies with state and local laws.

Starting The Process of Guardianship When Your Child Turns 18

Naming legal guardians is not to be confused with the process of adult guardianship that you will likely have to go through when your child turns 18.

Remember that **once your child becomes a legal adult, you can no longer make decisions for him or her.** This is true even if your child has disabilities and can not manage his or her own affairs.

In order to retain your decision-making rights to help your child, you will need to go through a separate process of setting up a guardianship with the local courts.

During this process, a judge must give someone (usually the parents) legal authority to continue to make medical and financial decisions for the young adult if it is determined that he or she is mentally or physically unable to carry out such responsibilities.

At this time, the parents can also name interested parties who can serve as co-guardians or successor guardians for the adult with disabilities should the parent pass away or become unable to serve.

Your attorney will walk you through the process of guardianship and help your family prepare for this necessary court procedure prior to your son or daughter's 18th birthday.



Pros and Cons of Guardianship for Young Adults with Special Needs

Again, guardianship is an important process that allows parents to have legal and financial authority over their child when their parental rights would otherwise be terminated.

However, before beginning a petition for legal guardianship, you should consider the following pros and cons of going through this court proceeding.

1. Your child loses a great deal of freedom.

If you gain guardianship, your child loses the freedoms he or she would have as an adult. The child will lose the right to handle his or her own finances, make healthcare decisions, choose residency, or make any other decision that the court has given the guardian power to decide. For young adults who are high-functioning and could possibly lead an independent life, this loss of freedom is a very real concern that families must consider.

2. You have a great deal of responsibility.

Your responsibility may be an extension of the things you did for your child when he or she was young. As a guardian, you have a responsibility to care for whatever the court has entrusted to you, and failing to do so could bring legal consequences. If you're responsible for your adult child's finances and you mishandle them or use his or her SSI fraudulently, you may not only lose guardianship but could be liable for civil damages or be criminally charged.

3. Your rights could be limited.

Unlike guardianship of a minor child, guardians only gain authority over the things the courts give them authority over, and nothing the petitioner doesn't ask for. Therefore, if a parent only has medical guardianship, for example, and not financial guardianship, that parent cannot make financial decisions on the child's behalf.

Likewise, your guardianship doesn't allow you to keep your child from engaging in adult behaviors you would prefer they didn't. They're free to do whatever

4. Your guardianship isn't transferrable and ends with you.

Guardianship either ends when you die or the court ends it. You can't pass on Guardianship of your child with special needs to a spouse or to a surviving adult child. They can petition the court and go through the same Guardianship process – and expense.

Alternatives to Guardianship

If your child is high-functioning, you may be able to utilize legal alternatives that will help you continue to make decisions for your now-adult without terminating his or her rights with the courts.

One strategy is to create a Special Needs Trust to handle financial affairs. You will learn how to do that in the pages to come. The trustee will use the Trust to pay for the child's expenses.

If your young adult has the legal capacity to sign documents, he or she can also name the parent as Healthcare Agent and Power of Attorney so the parent can help the child make financial and medical decisions whenever it's deemed necessary.

Many of these alternatives depend on the physical and mental needs of the child, and must be evaluated carefully by your legal and medical team.



Protect Your Child's Financial Future by Setting Up a Special Needs Trust

A Special Needs Trust (also called a Supplemental Needs Trust) is a legal tool that allows someone of the family's choosing to be in charge of managing money and making decisions on behalf of a child with disabilities.

The Special Needs Trust also helps to ensure there are enough financial resources available to meet the child's long-term care needs without jeopardizing eligibility for state or governmental aid.

This aspect is key, as benefits such as Social Security or Medicaid are *very limited* and cannot possibly cover all expenses your child may need to live out his or her life in a secure and comfortable way.

Unfortunately, many parents think that they can solve this problem by simply leaving a large inheritance to their child with special needs when they die. While an inheritance may give your child a "cushion" for the future, it could cause him or her to become ineligible for benefits—which, in the case of Medicaid, may be the only health care option available to your child!

Fortunately, there are ways to put aside money for your child's future care without disinheriting him or her or withholding necessary funds.

A Special Needs Trust is one such tool that will "hold" money and assets for your child without actually putting them in his or her name. The assets in the Trust are administered by a trustee of your choosing and according to the rules you set forth in your estate plan. This helps to keep Medicaid and Social Security benefits intact while providing your child with additional resources necessary for his or her care.

How the Special Needs Trust Works

Special Needs Trusts can be set up and funded in numerous ways. The Special Needs Trust can be either revocable or irrevocable and you can put assets into the Special Needs Trust during your life or have assets pass into the Special Needs Trust upon your death.

One of the biggest decisions you'll have to make is choosing a trustee. This is the person who will administer (or manage) the Trust that has been created to care for your loved one.

Careful thought needs to go into choosing this person, as he or she will have a significant impact on the life of the person cared for by the Trust. The trustee will also have access to funds and will make a lot of important decisions.

Your lawyer can help you to define the role of this person through your legal documents, but you still want to choose someone who is trustworthy and has your loved one's best interests at heart. He or she should also be very familiar with the specific needs of the person they will be responsible for, which could range from medical concerns to favorite foods and hobbies.

Additionally, you want to choose someone who has the ability to create and execute a reasonable budget. One option is to name both a family member and a professional as co-trustees.



Funding a Special Needs Trust

Knowing where the financial resources will come from to “fund” a Special Needs Trust can add an extra layer of concern. Medical concerns and housing options are certainly just the tip of the iceberg when it comes to planning for the rest of your child’s life. Chances are, you have been dealing with these expenses all along and are concerned that there will be nothing left to provide for your loved one.

Of course, if you have a valuable estate to leave behind, much of this can be used to fund the Trust. But for many parents, leaving such a sizeable estate behind to care for a child with disabilities is just not in the cards. So, what do you do in a situation like this?

One common solution is to purchase a life insurance policy that pays out directly to the Special Needs Trust. Perhaps surprisingly, there are policies that are set up to pay out only when the second parent passes away, and these can be quite inexpensive. They are often referred to as “second-to-die” policies.

Another option for funding the Trust is to ask others to contribute. Tax incentives allow for considerable breaks on money that is given in the form of gifts annually. For those looking for such an incentive, the Special Needs Trust can be a worthwhile recipient for an annual contribution.

In order to make it easy for others to contribute, the Trust should be created during your lifetime rather than upon your death.



How Can Our Family Spend Money in a Special Needs Trust?

Special Needs Trusts are designed to *supplement*, not replace, the kind of basic support provided by government programs such as Medicaid and Supplemental Security Income (SSI).

Special Needs Trusts can be used for comfort and luxuries that cannot be paid for by using government benefits. However, if Trust funds are used for housing and food, or if funds are distributed directly to the beneficiary, these payments will count as income to the beneficiary. **This will impact the individual's eligibility for Medicaid and SSI.**

Therefore, it is critical to also understand what you can—and can not—pay for using funds in your child's Special Needs Trust.

Generally, funds in a Special Needs Trust can be used for:

- medical and dental expenses
- eye glasses
- annual check-ups
- transportation (including vehicle purchase)
- medical equipment
- training programs
- maintenance
- education
- insurance (including payment of premiums)
- rehabilitation

In some cases, funds in a Special Needs Trust can pay for:

- entertainment such as movies
- electronic equipment
- trips and vacations
- computer equipment
- athletic training and competitions
- companion services/home health aid
- other items related to self-esteem such as haircuts

If the beneficiary receives government benefits, **the following list of expenses should NOT be paid through a Special Needs Trust** without talking to your special needs attorney:

- cash given directly to the beneficiary for any purpose
- food or groceries
- restaurant meals (except if given as an occasional gift)

- rent or mortgage payments
- property taxes
- homeowner's or condo association dues
- homeowner's insurance if the insurance is a mortgage requirement
- utilities such as electricity, gas, and water
- utility hookup or connection charges

Keep in mind that while many of these payments will cause a one-third reduction in SSI benefits, the trustee may determine that the benefit of the Trust making these payments far outweighs the loss of income. That's why it is important to talk to your lawyer when weighing the pros and cons of expenditures.

ABLE Accounts: An Additional Tool to Help Save For the Future

The Achieving a Better Life Experience (ABLE) Act was created by Congress in 2014 and allows people with disabilities and their families **to save up to \$100,000 in accounts for the benefit of a disabled person.**

The funds can be saved without jeopardizing the individual's eligibility for Medicaid, Supplemental Security Income (SSI), and other government benefits. **ABLE accounts may be opened by anyone with a disability as long as the disability began before the person turned 26.**

Currently, the amount of money that can be deposited in an ABLE account per year without jeopardizing public benefits is \$15,000. The amount that can be deposited in an ABLE account is tied to the federal gift tax exclusion.

However, **individuals with disabilities who are working** may have the ability to save even *more money* in their ABLE accounts. Rather than savings being capped at \$15,000 per year, recent changes to the law permit employed individuals to save their earnings up to the federal poverty level. Talk to your lawyer about this possibility if your loved one earns a paycheck.

Setting up an ABLE account is often a solid way to save money toward future expenses for an individual with disabilities. As with most federal or state programs, there are intricacies in the rules that should be understood prior to establishing an account.

Do I need a Special Needs Trust, ABLA Account... OR BOTH?

At this point, you may be wondering if you need a Special Needs Trust, ABLA account...or perhaps BOTH to get the most out of your special needs plan. It's really best to seek the advice of a qualified Special Needs Trust lawyer to discuss your unique circumstances. But, here's a quick comparison to help guide you.

Availability

ABLE accounts are approved at the federal level but continue to be rolled-out into states nationwide for implementation. If the ABLA program is not currently active in your state, your attorney can help you set an account up in a state where the program is available.

Age Restrictions

As previously stated, ABLA account beneficiaries must have become disabled before age 26. There are no age restrictions for Special Needs Trusts.

Qualified Expenses

ABLE accounts can be used to pay only specific types of expenses. Special Needs Trusts may be used to pay for "quality of life" expenses such as travel, recreation, entertainment, and hobbies.

Taxes

An ABLA account's earnings and qualified distributions are tax-free. A Special Needs Trust's earnings are taxable.

There are many other considerations to examine that may impact your choice, so it is best to work with an experienced Special Needs Trust lawyer who can help guide you based on you and your loved one's unique circumstances.



It Takes a Team: How to Build a Network of Support

As much as any parent hates to admit it, none of us are invincible. At some point, disability, illness, or even death may prevent you from giving your child the care he or she deserves.

That is why it's critical that you start building a team of caregivers and trusted advisors **now** who can immediately help your child if something happens to mom or dad. Pre-establishing these relationships while you have time to do your homework and interview candidates without pressure will give your entire family peace of mind that they are not being preyed upon or taken advantage of in a moment of crisis.

Ideal members of your team may include your chosen guardians, a trusted doctor or specialist, an estate planning attorney, a financial advisor, and dedicated family and friends. After creating your "support team," be sure to communicate regularly with everyone so they know exactly what to do and how to help if called upon in an emergency.

Another great way to help your team is by composing a *Letter of Intent* that would be included as part of your estate plan to help guide everyone in your absence.

The Letter of Intent is similar to a personal letter, and it's meant to *supplement* the special needs plan in order to provide additional information in the following ways:

- Parents often use it to address wishes that do not fall under the purview of legal requirements.
- This document is also useful for addressing information about your child that is subject to change. While various other special needs planning documents tend to be more static, the Letter of Intent can be changed out as the information in it needs to be updated.
- A Letter of Intent is used to discuss topics that are just too lengthy to include in the Special Needs Trust such as your child's preferences, dislikes, favorite activities, etc.

The letter is typically addressed to the people who will be caring for your child once you are unable to fulfill that role. When the time comes, your attorney will share the Letter of Intent with the child's caregivers, as well as with the trustee. They can use the letter to help interpret your desires and to help follow through on the wishes you have for your child.

Avoiding Mistakes in Special Needs Planning

Unfortunately, there are many misconceptions when it comes to special needs planning.

Even well-meaning caregivers and service organizations can misinterpret issues related to disability planning and give bad advice. Below are just a few mistakes we see families and caregivers make on a regular basis that you should be careful to avoid.

COSTLY MISTAKE #1: Disinheriting your child to preserve government benefits

As previously mentioned, many children and adults with disabilities rely on government benefits such as SSI and Medicaid for their basic needs (including health insurance). There are some well-meaning people and attorneys who would suggest that you disinherit your child to protect his or her benefits. But, government benefits provide only enough to secure food, clothing, and shelter. What happens if you become incapacitated or pass away? Will your child be able to maintain the life that you have so carefully crafted for him or her on these limited resources alone? *Probably not.*

If your child is likely to require government assistance to meet his or her basic needs, you should consider establishing a Special Needs Trust. Again, if done properly, a **Special Needs Trust** can protect your child's public benefits and help him or her maintain a secure lifestyle even after you are no longer able to provide support.

COSTLY MISTAKE #2: Procrastination.

It is critical for all parents of minor children to have an estate plan. You just never know when you might become incapacitated or pass away. But, it is even more important for parents of children with special needs to plan ahead. Your child is counting on you to have a safety net in place that will take him or her securely through all of life's transitions, including the time when mom or dad is no longer there to provide financial support or physical care. Don't procrastinate.

COSTLY MISTAKE #3: Creating a "Do-It-Yourself" or Online Special Needs Trust.

Special Needs Trusts should be created by a lawyer who focuses on this area of the law. That is because Special Needs Trusts are subject to both federal and state laws, and the laws of each state can vary. Furthermore, it's easy to make mistakes using online "Do-It-Yourself" Trusts that could jeopardize benefits or fail to account for your child's unique needs. One wrong answer on a "fill-in-the-blank" form could blow up your entire plan. Before you go this route, at least speak to an attorney to ensure you are covering all the right bases.

Finding the Right Special Needs Attorney

As you have learned in the pages of this guide, there are many decisions to be made regarding your child's future security and physical care. All parents want to protect their children, and those with kids who have disabilities sometimes find that they must take extra steps to achieve their goals. Working with a special needs lawyer who focuses on this area of the law and understands your family's unique needs can make all the difference.

Take the time to find an attorney or firm that you believe you can develop a long-term relationship with. Your attorney will likely be by your side as your family changes and grows—perhaps supporting you now with IEP issues, Special Needs Trusts, and benefit concerns, while assisting your family with guardianship filings when the child transitions into adulthood.

As you meet with qualified candidates, consider asking the following questions to narrow down the best fit for your family:

- How many years of experience do you have in special needs planning?
- What led you to this kind of work?
- What is your overall educational and professional background?
- How would you describe a Special Needs Trust and what it means for my family?
- What are your typical fees? Do you bill hourly, or will I have the benefit of flat fees?
- Do you recommend any specific products, and if so, are you affiliated with those companies?
- Can you provide references of other families similar to mine who have used your special needs planning services?

You will likely have other questions that are important to you. For example, are there specific considerations that come into play regarding your child's particular disability? Are there other family members or caregivers that need to be involved in the planning process? What government and other resources are available, and how does your special needs planning affect eligibility?

Of course, the overall goal is to find someone knowledgeable who can guide you as you put your plan together. In the end, you should feel confident that you have created a plan that will protect and care for your child when you are no longer able to do so yourself.

Conclusion

Planning for a child with disabilities is an extremely important and time-sensitive task. Your child is counting on you to create a plan that not only protects him or her now, but well after you are gone. Special needs planning makes that a possibility and gives you some level of control over the future.

By planning now, you can have the peace of mind knowing everything will be taken care of, no matter what happens. If you are ready to get started with your planning, we would be happy to meet with you to discuss your family's unique needs. By using the certificate on the following page, we invite you to come in and meet with us for a Vision Meeting at no charge.

Remember, you are your child's greatest advocate and lifeline for the future. Gathering information costs nothing, but failing to take action can cost your family *everything* if the unthinkable happens. Use the certificate below to make an appointment and learn the options available for your family. We look forward to meeting with you.



THIS CERTIFICATE

Grants you a Vision Meeting
at *no charge*.

Call us at **919-629-1817** to learn more.

About the Author



Jackie's estate planning and elder care practice, Carolina Family Estate Planning, is focused on guiding clients through the confusing, maze of balancing one's dignity, family protection, wealth preservation, and family values in the planning process.

Jackie is a member of WealthCounsel and ElderCounsel, the North Carolina Bar Association, and the Wake County Bar Association.

She has served as a board of director member of the North Carolina chapter of the National Academy of Elder Law Attorneys and on the board of directors of Guiding Lights Caregiver Support Center. Jackie has been named a Mover & Shaker by Cary Magazine and awarded in the Best Attorney category of Cary Magazine's Maggy Award competition. She has also been named a Super Lawyers Rising Star and has received a Superb 10.0 rating by Avvo, a legal rating system.

Jackie earned her Bachelor's of Science degree in Economics at MIT and graduated law school *magna cum laude* in the top 7% of her class at the University of Richmond School of Law.

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