



HAILEY-PETTY

— LAW FIRM, PLLC —
YOUR FUTURE IS OUR BUSINESS

PLANNING FOR CHILDREN & YOUNG ADULTS WITH SPECIAL NEEDS

Learn which legal tools you need to ensure your child is fully protected through every possible life transition.

✓ A GUIDE TO PROTECTING YOUR DISABLED LOVED ONES



WHAT IS SPECIAL NEEDS PLANNING?

Raising a child with physical or developmental disabilities is challenging. There are more specialist appointments than you can keep up with, IEP meetings, occupational and speech therapy, and caring for your child's basic needs...

There is barely enough time to take care of your to-do list today, let alone plan for tomorrow!

However—as you 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 be sure that enough money is left behind to provide your child with a lifetime of care?
- ✓ What happens when your child reaches the age of majority? How can you continue to make medical and financial decisions on their behalf?
- ✓ How can you be sure your child is not taken advantage of—financially or otherwise—if you are no longer there to protect them?

The answers to these questions (and more!) are found in the pages of this book. While every situation is as unique as your child, this guide provides a brush stroke overview for busy parents who simply need to know where to start, which steps to take, when to take them, and which direction to head in.

If you would like to talk to our attorneys about your individual situation and learn how to put a fortress of protection around your child through all of life's transitions, we encourage you to contact us for a free 30-minute consultation.

FIRST THINGS FIRST: NAMING LEGAL GUARDIANS

Naming a legal guardian who would raise your child(ren) in the event of your unexpected death or incapacitation is one of the first and most important steps you can take. This ensures your child will be raised by people you know and trust.

Caring for a child with disabilities is challenging. You'll want to choose a guardian who will love and care for your child the same way you would.

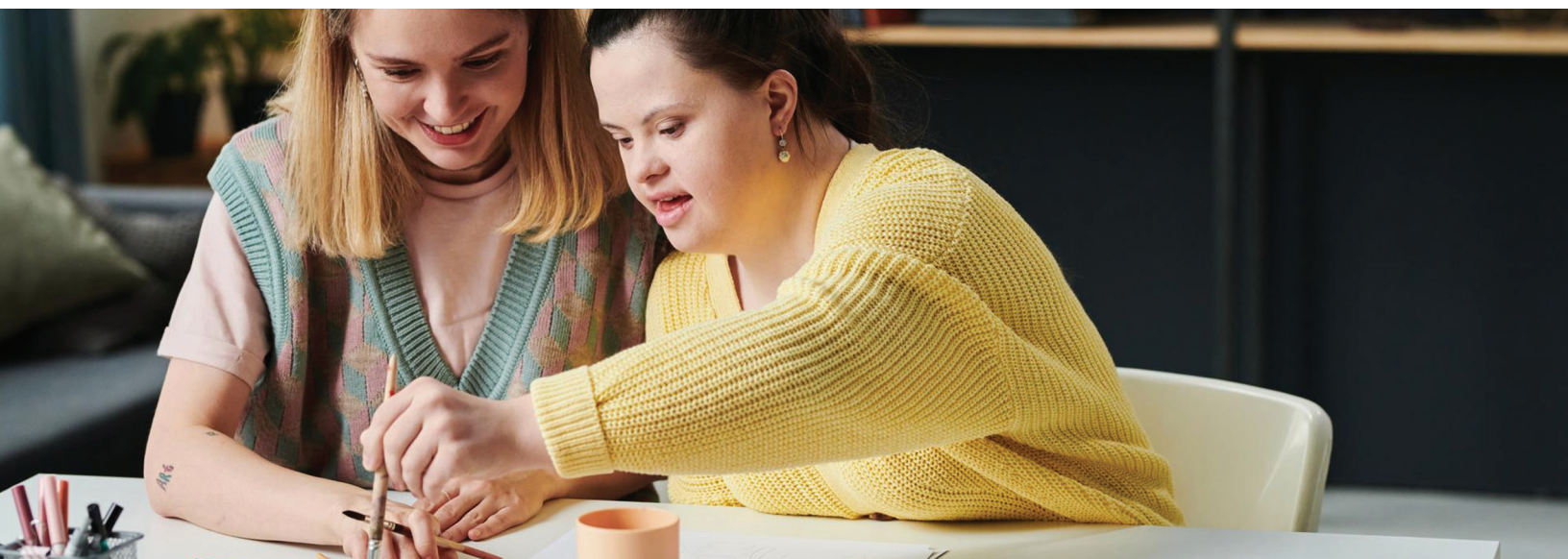
When choosing a legal guardian, we encourage parents to look beyond the obvious choices. Many times parents will choose a guardian simply because they have the most financial resources at their disposal. However, there are many other ways to ensure your child has enough financial resources to last a lifetime. Choosing a guardian based on financial status should not be your primary concern.

Instead, choose a guardian who embodies a set of values and an outlook on life 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 questions to ask yourself when choosing a legal guardian for your disabled child:

- ✓ 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 this responsibility?
- ✓ Will they be emotionally able to care for your child(ren) after your death?

Once you have decided who to name as your child's legal guardians, work with an estate planning attorney to document your wishes. Make sure the people who will need to access your estate plan in the event of your death or incapacitation know where to find it, so your wishes can be executed.





DON'T FORGET ABOUT THE SHORT TERM

Situations often arise where a parent suddenly becomes temporarily unable to care for their child(ren). A car accident or other emergency could create an immediate need for a guardian on very short notice. Unfortunately, if you haven't planned for this contingency, things can go from bad to worse—and fast!

Emergency personnel can place your disabled child 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 grant a friend or family member with temporary guardianship.

As you can imagine, being placed into the custody of a government agency would cause immense anxiety, terror, and emotional pain—especially for a disabled child.

A better solution is to work with your attorney to designate a temporary legal guardian. This is someone who would act as guardian to your child in a short-term situation, thus preventing the need for Child Protective Services to get involved.

Your temporary guardian should be someone who lives nearby, and who could quickly be at your child's side for immediate care and emotional support in the event of 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 select someone who can care for their children in an emergency situation, in a manner that complies with state and local laws.

PLANNING FOR ADULTHOOD

Naming a legal guardian is different than the process of adult guardianship/conservatorship that you may need to go through once your child reaches the age of majority—18 in the state of Texas.

Remember, once your child becomes a legal adult, you can no longer make decisions for them. This is true even if your child is disabled and unable to manage their own affairs.




In order to retain your decision-making rights as their parent, 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 they are mentally or physically unable to carry out such responsibilities.

During this process, you can also name co-guardians or successor guardians for your disabled child, should you pass away or become incapacitated.

Your attorney can explain the process of filing for guardianship, and help you prepare for this necessary court procedure prior to your child's 18th birthday.

CONSIDER THESE PROS AND CONS BEFORE PETITIONING FOR GUARDIANSHIP

-  **YOUR CHILD WILL LOSE A GREAT DEAL OF FREEDOM**
If you gain guardianship, your child will lose their freedom as an adult. They will not be able to manage their own finances, make medical decisions, choose residency, or make any other legal decision. If your child is high-functioning and could possibly lead an independent life, this loss of freedom is a very real concern.
-  **YOUR WILL ASSUME A GREAT DEAL OF RESPONSIBILITY**
As a guardian, you have the responsibility of caring 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 their SSI fraudulently, you may not only lose guardianship, but could be liable for civil damages or even be criminally charged.
-  **YOUR RIGHTS MAY BE LIMITED**
Unlike guardianship of minor children, guardians only gain authority over whatever the courts give them authority over. Therefore, if you only have medical guardianship, for example, and not financial guardianship, you cannot make financial decisions on your child's behalf.

Likewise, your guardianship doesn't allow you to keep your child from engaging in adult behaviors. They are free to drink, smoke, date, and engage in other adult behaviors—whether you want them to or not.
-  **YOUR GUARDIANSHIP IS NON-TRANSFERABLE**
Guardianship either ends when you die, or when the court ends it. You can't name a successor guardian, nor can you pass these roles on to a spouse or a surviving adult child. For someone else to gain guardianship over your disabled child, they would have to petition the court and go through the same legal proceedings.



ALTERNATIVES TO GUARDIANSHIP/CONSERVATORSHIP

If your child is high-functioning, you may be able to leverage legal alternatives that will help you continue to make decisions for your now-adult without terminating their 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 you as their **Healthcare Agent and Power of Attorney**, so you can help them make **financial and medical decisions** whenever it is deemed necessary.

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

SETTING UP A SPECIAL NEEDS TRUST

A Special Needs Trust—also called a Supplemental Needs Trust—is a legal tool that allows a third-party agent to be in charge of managing money and making decisions on behalf of a disabled child.

A Special Needs Trust can also help ensure there are enough financial resources available to meet the child's long-term care needs, without jeopardizing their eligibility for state or governmental aid. This aspect is crucial, as benefits like Social Security or Medicaid are very limited and cannot possibly cover all of the expenses your child may need to live out their 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 disabled child 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 the benefits they rely on—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 them 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 their name. The assets in the Trust will be managed and distributed by a trustee of your choosing, according to the rules you set forth in your estate plan. This helps to keep your child's Medicaid and Social Security benefits intact while providing your child with the additional resources they need to get by comfortably.

HOW A SPECIAL NEEDS TRUST WORKS



SPECIAL NEEDS TRUSTS CAN BE SET UP & FUNDED IN SEVERAL WAYS

The Special Needs Trust can be either revocable or irrevocable, and can take effect upon your passing, or be set up during your lifetime.



ONE OF THE BIGGEST DECISIONS YOU'LL 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 a trustee, as this person will have a significant impact on the life of your disabled child. The trustee will also have access to funds, and will make a lot of important decisions.

Your lawyer can help you define the role of your trustee through your legal documents, but you still want to choose someone who is trustworthy, and who 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 popular option is to name both a family member and a professional fiduciary as co-trustees.



Other things may CHANGE US, but we START & END with the family.

—Anthony Brandt



FUNDING A SPECIAL NEEDS TRUST

Setting up a Special Needs Trust is the first step, however, the Trust won't be very helpful to your child if it's not properly funded. Knowing where the financial resources will come from to fund the Trust is often an area 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 actually 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. However, for many parents, leaving a sizeable estate behind to care for a child with disabilities is just not in the cards. So, then, what are your options?

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. There are annual tax incentives for money that is given in the form of gifts. 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.

SPENDING MONEY IN A SPECIAL NEEDS TRUST

Special Needs Trusts are designed to supplement—not replace—the 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 for you to understand what you can and cannot pay for using the funds in your child's Special Needs Trust.

THE FUNDS IN A SPECIAL NEEDS TRUST MAY BE USED FOR:

- ✓ Medical & 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, the funds held in a Special Needs Trust can be used to pay for:

- ✓ Entertainment (such as movies)
- ✓ Electronic equipment
- ✓ Trips & vacations
- ✓ Computer equipment
- ✓ Athletic training & competitions
- ✓ Companion services/home health aid
- ✓ Other items related to self-esteem, such as haircuts

DO NOT USE YOUR SPECIAL NEEDS TRUST TO PAY FOR THE FOLLOWING EXPENSES

If the beneficiary receives government benefits, please discuss how to pay for these expenses with your estate planning attorney first:

- ✓ Cash given directly to the beneficiary (for any reason)
- ✓ Food or groceries
- ✓ Restaurant meals (except as given as a gift sporadically)
- ✓ Rent or mortgage payments
- ✓ Property taxes
- ✓ Homeowner's or condo association dues
- ✓ Homeowner's insurance (if required by the mortgage)
- ✓ Utilities, such as electric, gas, or water
- ✓ Utility hookup or connection charges

Keep in mind that while many of these payments will cause a 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.

WHAT IS AN ABLE ACCOUNT?

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

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

As of 2022, the amount of money that can be deposited in an ABLE account per year—without jeopardizing public benefits—is \$17,000*. The amount that can be deposited into an ABLE account is tied to the federal gift tax exclusion.

However, disabled individuals who are able to work may have the ability to save even more money in their ABLE accounts. Rather than their 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 estate planning attorney about this possibility if your disabled loved one earns a paycheck.

Setting up an ABLE account is often an excellent way to save money for your disabled loved one's future expenses. As with most federal or state programs, there are intricacies in the rules that should be understood prior to establishing an account.

**Total annual contribution limit as of 2023*





SPECIAL NEEDS TRUST, ABLE ACCOUNT, OR BOTH?

You may be wondering if you need a Special Needs Trust, an ABLE account...or perhaps BOTH to get the most out of your special needs plan. It's best to seek the advice of a qualified lawyer to discuss your unique circumstances. However, 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. Texas does have an ABLE account program.
- ✓ **AGE RESTRICTIONS**
As previously stated, ABLE account beneficiaries must have become disabled before age 26. There are no age restrictions for Special Needs Trusts.
- ✓ **QUALIFIED EXPENSES**
ABLE accounts can only be used to pay for specific types of expenses. Special Needs Trusts may be used to pay for "quality of life" expenses, including travel, recreation, entertainment, and hobbies.
- ✓ **TAXES**
An ABLE 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 estate planning attorney who can help guide you based on you and your loved one's unique circumstances.

IT TAKES A TEAM: BUILDING A SUPPORT NETWORK

As much as most parents hate to admit it, none of us are invincible. At some point, disability, illness, or death will prevent you from giving your child the care they deserve.

It's critical that you start building a team of caregivers and trusted advisors now, who can help your child immediately, if something were to happen to you. Pre-establishing these relationships without pressure to do your homework and interview candidates will give your entire family peace of mind that they are not being preyed upon or taken advantage of in a moment of crisis.

Members of your team may include your chosen guardians, a trusted doctor or medical specialist, an estate planning attorney, a financial advisor, and—of course—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, which would be included as part of your estate plan to help guide your support team in your absence. The Letter of Intent is similar to a personal letter. 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.

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Being a family means you a part of something **VERY WONDERFUL**. It means you will **LOVE & BE LOVED** for the rest of your life.

—Lisa Weed

3 COSTLY MISTAKES TO AVOID

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.

- 1 DISINHERITING YOUR CHILD TO PRESERVE GOVERNMENT BENEFITS**
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. However, 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 them on these limited resources alone? Probably not.
- 2 WAITING TOO LONG TO START PLANNING**
It is critical for all parents of minor children to have an estate plan. You never know when you might become incapacitated or pass away. However, it is even more important for parents of disabled children to plan ahead. Your child is relying on you to have a plan in place to protect them through all of life's transitions, including the time when you are no longer there to provide financial support or physical care. Don't procrastinate.
- 3 DIY-ING YOUR SPECIAL NEEDS TRUST**
Special Needs Trusts should be created by a lawyer who has experience in this area of the law. Special Needs Trusts are subject to both federal and state laws, and the laws vary from state to state. Furthermore, it's easy to make mistakes using an online "do-it-yourself" estate planning service that could jeopardize your child's benefits or fail to account for their unique needs. One wrong answer in a "fill-in-the-blank" form could cause your entire plan to fail. Before you take matters into your own hands, at least speak to an attorney to ensure you are covering all the right bases.

—CONTACT US TO START PLANNING TODAY—

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 them 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, the attorneys at the Hailey-Petty Law Firm would be happy to meet with you to discuss your family's unique needs. We offer a **free 30-minute consultation**, during which we can discuss your situation and determine the best plan moving forward.

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. **Contact us today!**

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