A Special Needs Plan™

The Family Advocate

A Guidebook to Special Needs Planning

Empowering families with the knowledge they need to ensure a safe and secure future for their loved ones.

INSPIRATION

Behind the Guidebook

Planning for the future can feel overwhelming—especially for families with special needs. Over the years, we've found that the biggest challenge many face is simply not knowing where to turn for guidance.

- 80% of individuals with an intellectual or developmental disability live with a caregiver who is a family member.
- 54% of those caregivers reported that they do not have a plan for the future.*
- 90% of special needs and disability caregivers and family members admit retirement planning isn't their main priority.**
- 93% of parents/caregivers have ***not*** spoken to a financial professional trained in special needs planning.***

**The Arc FINDS Survey, 2018*
***The American College of Financial Services, 2020*
****Easter Seals Study, 2010*

"Welcome, and thanks for downloading ***The Family Advocate***. We designed this ebook with a single purpose in mind — to educate families on what they need to do to secure their loved one's future. Our hope is that you find this information helpful."

Ryan Platt
MBA, ChFC®, ChSNC™, CFBS
Founder, A Special Needs Plan

What is Special Needs Planning?

Special needs planning is a process that identifies the financial, legal, and lifetime needs for you, your family and your loved one. For most families, this process will include discussion of:

- Defining your vision for your loved one's life
- Funding your loved one’s lifetime support needs
- Selection and Coordination of your loved one’s support team
- Wills
- Trusts
- Guardianship
- Education on Government Benefits
- ABLE Accounts
- and more...

Special needs planning does not end with the identification of these needs, but includes the necessary action steps that you need to take to ensure a bright future for everyone in your family during three distinct times of your life:

1. While you are alive and well.
2. While you are alive, but no longer able to be your loved one's primary caregiver.
3. When you pass away.

7 Common Misconceptions About Special Needs Planning

1 A Special Needs Trust *is* Special Needs Planning

Many families mistakenly believe that setting up a **special needs trust** means their planning is complete and their loved one's future is fully secured. However, this misconception can be especially risky, as it creates a false sense of security. While a special needs trust is an essential part of the planning process, it's just one piece of a much larger puzzle when it comes to preparing for your family's long-term needs. It is critical to understand the following items in conjunction with a special needs trust:

- How is the special needs trust tied to your financial plan?
- What type of special needs trust did you create?
- Can extended family, like grandparents, leave money to the special needs trust you created, or do they have to setup their own?
- Did you communicate with extended family regarding the details of the special needs trust?
- Does your trustee know the distribution rules of a special needs trust and how to ensure future government benefits are not interrupted?
- Do you know which assets are the most efficient to leave in the trust in terms of taxation and market strategies?

2 Government Benefits Will Provide Sufficient Support for my Child's Life.

Government benefits are essential resources that help reduce the financial burden of daily living expenses and long-term medical care. However, they rarely cover 100% of costs. These benefits come with complex rules, varying qualifications, and are often influenced by both your own circumstances and those of your loved one. That's why it's crucial to plan beyond what government programs offer. By understanding the gaps in coverage, you can create a more comprehensive strategy to support those who rely on you.

> ***"I wish someone would educate parents that government money does not pay for all their child's future needs, and they should, if possible, have additional resources available for their loved one's future."***
>
> — Residential Housing Provider Executive

3 I Can Always Make Decisions for My Loved One.

Many parents believe that, as parents, they are able to always assist with legal decisions in their child's life. This is simply not true. Once a child reaches the age of 18, they are seen as an adult by the legal system, and therefore competent to make all decisions (including financial and medical) on their own. A parent has no legal authority to continue to make decisions and guide their child at that time. If your loved one needs you to continue to make those decisions beyond age 18, you will need to be pro-active and become their legal guardian.

4 Guardianship is Irreversible.

Guardianship (conservatorship in some areas) is used by many families to protect their loved one, and to help them with decisions surrounding healthcare and their money. The guardianship process requires that your loved one is deemed incompetent to make decisions by the court. Considering your loved one incompetent can be difficult, especially if your child is "high functioning." Keep in mind that Guardianship can be reversed; although, the process can be difficult. Depending on your child's abilities, you may want to consider alternatives to guardianship .

5 I Need to Have All the Answers Before I Start Planning.

This is a common and deeply paralyzing misconception for many families. One of the biggest obstacles that often prevents families from starting the planning process is the daunting question: “Who will care for my loved one when I no longer can, or after I'm gone?” This decision can feel overwhelming and even frightening. However, working with a knowledgeable special needs planner can make all the difference. They have the experience and tools to guide you through these difficult questions as you build a comprehensive plan tailored to your family’s unique needs. The planning process not only provides answers and practical solutions, but it also brings to light important considerations you may not have thought of on your own.

6 My Child is Only 4-years-old. I Can Wait a While Before I Start Planning.

Whether your loved one is four or thirteen, it's often impossible to predict exactly how their development will unfold. In those early years, your focus is naturally on supporting their growth—maximizing their abilities and strengths in every way you can. That dedication is vital.

At the same time, life is unpredictable. While most of us will see tomorrow—and many tomorrows after that—there's always the chance that we won't be here to provide care, transportation to therapy or school, attend appointments, or offer financial support.

So, if you're not here... who will step in? How much will that care cost? Where will the funding come from?

These are the hard but necessary questions that a thoughtful and comprehensive planning process can help you answer. By the time your plan is complete, you'll have a clear set of action steps to help secure your loved one's future—no matter what tomorrow brings.

> ***"Waiting is a trap! There will always be reasons to wait... the truth is, there are only two things in life, reasons and results —and reasons simply don't count."***
>
> *—Robert Anthony*
> *Motivational Speaker*

7 I Don’t Have Enough Money to Even Worry About It.

You may have heard someone say, 'You don't know what you don't know." Special needs planning is different, because what you don't know can have a severe impact on your loved one's future. Government benefits are available for your loved one but only if they qualify. Some government benefits (SSI and Medicaid) are based on financial need, meaning your loved must remain below an income threshold, as well as an asset threshold. As of 2025 rules, your child must have **less than $2,000** in countable assets in their name to remain eligible for SSI and Medicaid benefits. (Certain exceptions to the $2,000 level exist). It is important to understand how much money is too much money.

An important new app:

A Special Needs Support is Here!

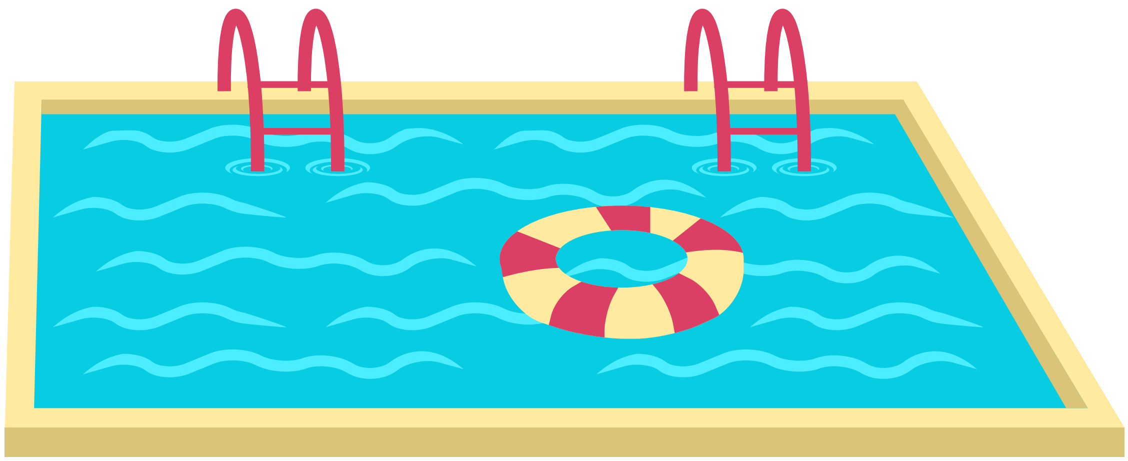
The **A Special Needs Support** app is giving families the answer they’ve been looking for — a single app where they can organize, coordinate, and share essential care and planning information about their loved one.

With intuitive, easy-to-use features, the app keeps vital details at the support team’s fingertips while giving you full control over access and permission levels. Learn more by clicking the link below:

ASpecialNeedsSupport.com

An Important Cautionary Tale

The grandparents of two siblings with autism passed away and left a generous gift — more than $250,000 — to provide for the children's future. The children's parents decided to set up a Special Needs Trust with the money and enlisted an attorney and financial planner to help and offer guidance. However, **neither had any training nor were experts in this specialized area.** Later, the parents decided to use some of the trust money to build a swimming pool.



They consulted with their attorney and financial planner to ensure they were following all the distribution rules and regulations and, because the pool was to be used for the children's therapy needs, the purchase qualified. They then asked their advisors if they could also build a pool house or cabana and the advisors said, "Yes!"

The government later audited their special needs trust and that's when everything fell apart. Unfortunately, the cabana was not considered a therapeutic necessity for the children and the trust was immediately disqualified as a special needs trust. The tragic result: in an instant the parents lost their children's government benefits. It gets worse. They also had to repay the government for all the benefits provided since the date the trust was first created. And that large inheritance from the grandparents?

Completely gone.

10 Common Mistakes You Need to Avoid

1 You Never Defined the Future Needs of Your Loved One

If you've ever used a GPS, you know that to get directions, you need to input both your current location and your destination. Without a destination, the GPS can't guide you. The same principle applies when planning for your loved one's future. First, you need to "program the GPS" by identifying their future needs—things like therapy, housing, caregiving support, monthly expenses, medical care, and employment. Then, you must set the "destination" by calculating the lifetime cost of meeting those needs. By taking these steps, you'll gain a clearer understanding of the financial resources required to support your loved one's future.

2 You Never Set Up a Will or Other Important Legal Documents

A Will serves three vital purposes for you, your family, and your loved one. It provides the court with clear instructions on:

1. How your property should be distributed
2. Who should care for your loved ones in the future
3. Who will manage and carry out your wishes (the Executor or Executrix)

Without a Will, these decisions are left entirely to the court. That means your loved one may not receive the assets you intended—or worse, they might receive assets that jeopardize their eligibility for essential government benefits. The court could also determine where your loved one lives, potentially placing them with someone you wouldn't have chosen. Creating a Will ensures your wishes are honored and that your loved one is protected and cared for according to your plan.

3 Using the "Disinheritance" Model

"Oh we'll just leave all of our assets to other children, or to a family friend, and they'll see to it that our loved one receives the care they need."

This approach has long been used in planning, but it comes with significant and unnecessary risks. When you leave money directly to another person with the intention that *they'll* use it to care for your loved one, that money legally becomes *their* asset. They can use it however they choose and there's no guarantee they'll prioritize your loved one's needs over their own. This method also exposes the funds to potential liabilities. For example, if the person you entrusted with the money goes through a divorce, up to half of those assets could end up with an ex-spouse. If they face financial trouble, such as bankruptcy or a lawsuit, the money meant to support your loved one could be completely lost. Fortunately, there is a much safer and more reliable way to protect those funds and ensure they are used as intended.

4 A Special Needs Trust is Not Set Up or the Existing Trust is Not Appropriate

A **Special Needs Trust** is a specially designed legal tool that allows you to set aside assets for your loved one's future care—without jeopardizing their eligibility for essential government benefits like Medicaid and SSI. By placing funds in a Special Needs Trust, you avoid the risks of leaving money directly to another person or to your loved one. This approach ensures the assets are used solely for your loved one's benefit, while safeguarding their access to critical support programs.

CAUTION

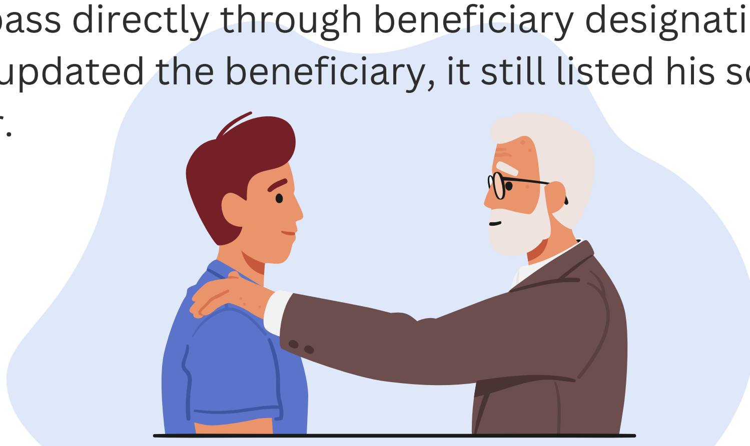
A Special Needs Trust is *not* a regular trust. You need to meet with a qualified special needs planner and qualified attorney to ensure you have the right type of trust.

5 You Never Changed Beneficiary Designations

Beneficiary designations are most notably found on life insurance and retirement plans such as a 401(k), IRA, Roth IRA, pension plan, etc. These are important because the beneficiary designation overrides the sentiments of your will. Make certain to designate the proper primary, secondary and tertiary beneficiaries to ensure your money goes where you intend.

Another Cautionary Tale

A father engaged an attorney to create a Special Needs Trust for his son. His goal was to protect his son's future and preserve his eligibility for government benefits. The attorney carefully crafted the trust with the proper language and all the necessary legal provisions. They named both a trusted family member and a professional corporate trustee to ensure the trust would be properly administered and remain compliant, even as government benefit rules evolved. The trust was thoughtfully designed, and the father felt confident that his son's future was secure. Then the father died and all of his assets were successfully transferred into the Special Needs Trust—with one exception. The existence of an old, overlooked IRA. Unlike other assets, IRAs do not transfer through a Will; they pass directly through beneficiary designations. As the father had never updated the beneficiary, it still listed his son as the sole benefactor.



As a result, the $85,000 IRA bypassed the trust and went straight to his son—instantly disqualifying him from all his government benefits. Everything the father had worked so hard to prevent happened because of a single overlooked detail: there was no coordination between the trust and his financial accounts.

6 You Don’t Understand the Tax System

Understanding the tax system can be challenging for any family—but it becomes even more complex when you're planning for a lifetime of care for a loved one with special needs, especially after you're gone.

Special Needs Trusts are a powerful tool to help ensure your loved one is supported long-term. However, as you build your plan, it’s essential to understand how different types of assets are taxed when placed in a Special Needs Trust.

Certain assets can create unnecessary tax burdens, while others can be more tax-efficient. That’s why it’s so important to work with a qualified professional who can guide you through the process—helping you fund the trust in a way that reduces taxes and increases the amount available to support your loved one.

Tax Rates: Individual Vs. Trust

For the tax year 2026:

- **Individuals**: The top marginal tax rate of 37% applies to single filers with taxable incomes over $634,900 and married couples filing jointly with incomes over $761,200.
- **Trusts**: Trusts reach the highest tax bracket much more quickly. The 37% rate kicks in for trust income exceeding $16,450.

This disparity means that income-generating assets, like traditional IRAs or 401(k)s, can be taxed at higher rates when distributed from a trust. It is **crucial** to know what types of assets should be put into a special needs trust.

**Based on 2026 rates. Subject to change.*

7 You Never Secured Your Own Future

Imagine your life as a truck traveling down the highway—and your child's life as the trailer hitched to the back. Wherever your truck goes, the trailer follows. Your child's future is directly connected to your own. If your truck breaks down, the trailer also comes to a full stop.

As parents, we naturally put our children's needs first and work tirelessly to give them a bright future. But it's important to remember: your child's future depends on your stability and well-being. Their path forward is only as strong as your own.

That's why, as you begin planning for your child's future, you must also plan for your retirement and future. By securing your future, you're laying a solid foundation for theirs.

8 You Never Named a Future Caregiver

Either you never chose a future care-giver, or you did choose one but never put it in a will. By placing those directions in your will, it provides the court system guidance regarding the future care-giver. This is usually one decision that is very difficult to make; however, a qualified planner should have the tools necessary to help you in making this decision.

9 Communication is Absent

Many parents and caregivers don't take the time to document key details about their child's life—medical history, routines, therapists, favorite things, behaviors, sensitivities, and most importantly, hopes for their future. You've gained valuable insight into how your child experiences the world, and passing that knowledge on gives future caregivers a strong head start.

It's also **essential** to share your plan with extended family. Planning in isolation can lead to costly mistakes—like a well-meaning grandparent leaving money directly to your child, unintentionally jeopardizing government benefits. With clear communication, you can avoid these risks and help secure your child's future.

10 You Didn't Invest in Your Plan

There are **three essential things** required to assemble a proper plan:

Time **Money** **Education**

Take the time to learn as much as you can about special needs planning, and invest in finding a professional that specializes in working with families that have special needs. *(Interview questions to help you find qualified professionals are provided on page 16.)*

Generally, there is a cost to designing, creating, and implementing your plan to ensure it will work from year to year. You can find additional resources online at [ASpecialNeedsPlan.com]() that will help you further your education and learn more about special needs planning. When you are ready to begin your plan, we are here to be of service to you and your family.

Interviewing Professionals

Finding a **qualified and trained** professional in special needs planning, including financial planners, attorneys, trust companies, and accountants, is vital in securing your plan. We've assembled a list of questions you can ask to aid in choosing the right one.

1. I know this is a highly specialized area that requires knowledge of government benefits, the legal system, tax code, distribution planning, and transfer of assets from one generation to the next, do you have expertise in these areas? How would I know that?
2. What professional training have you had in the area of special needs planning? What courses have you taken? Can you show me your most recent course manual? Can you share with me the books you have read on special needs planning?
3. Do you attend continuing education conferences on the topic of special needs planning? If so, how often? If not, how do you stay on top of the changes in the legal system, tax code, government benefits and their impact for special needs families?
4. When you're considering the distribution phase of our money and the transfer phase of our money, how do you ensure our money gets to our child after we are dead? What do you do to limit the erosion of these assets to taxation?
5. What is the maximum asset limit in order to qualify for Medicaid?
6. What is the difference between SSI and SSDI?
7. Can you explain the advantages, as well as the drawbacks, to an ABLE Account?
8. Can you clearly define the planning process you use to help me secure the future of my loved one with special needs? *(A qualified professional should be able to easily describe the steps they use in serving families.)*
9. Can you provide me three families that you have helped in the area of special needs planning, so that I may call them to discuss their experience?
10. Can you provide me the names of 2-3 professionals you work with in the area of special needs planning?

11. Who do you turn to when you have questions in the special needs area?

12. Are you involved in the special needs community? If so, how? (*This question will show you if the professional has his/her finger on the pulse of the special needs community by their involvement with organizations, societies or conferences. It will also show empathy and support for the community as a whole.)*

As you interview potential professionals, pay close attention to their confidence and demeanor. If they can clearly and confidently answer all 12 questions—and you receive strong recommendations from other families and professionals—you've likely found a highly qualified special needs planner. **Don't wait to engage their services.**

With their guidance, you'll begin a journey that brings clarity and security for you, your loved one, and your entire family. This planning process will help you answer one of the most important questions: "What happens to my child when I'm no longer able to care for them?"

Having that answer in place can lift a huge weight off your shoulders—and bring lasting peace of mind.

Understanding the ABLE Act

The **ABLE Act**, also known as Achieving a Better Life Experience Act of 2014, allows individuals who were deemed disabled before the age of 26 to save money in specific accounts and not jeopardize necessary government benefits. Before the ABLE Act was passed, an individual with a disability who relied on government benefits, like SSI and Medicaid, could not save more than $2,000 without losing all their benefits; therefore, impacting housing, employment, transportation and more.
The ABLE Act provides individuals with a disability the right to save money. The ability to work and save money provides a deep feeling of accomplishment, confidence and success. These feelings will help those with disabilities reach levels of independence not seen in the past.
Presently, the ABLE Act does include some drawbacks. For the majority of families, these accounts do not lend themselves to be the primary account for parents and relatives to save money for the future support of their loved one. For most families, these accounts will not replace other lifetime planning tools such as a Special Needs Trust because of the following drawbacks:

- Annual funding limitations based upon the annual gift tax exclusion amount (the 2026 limit is $19,000).
- Maximum account value of $100,000 before SSI is suspended (a monthly income used to fund housing and other necessary life-long supports).
- Payback Provision to Medicaid at the passing of the individual with the disability. This provision means that any remaining money in the ABLE Account, at death, will be susceptible to government payback
- The individual must be diagnosed with a disability, that meets SSI program standards, before the age of 26.

Remember: As with any planning tool, it is important to fully understand how to best use an **ABLE Account** for your family's specific situation before jumping in!

A Promising Plan

A family with two children—a son and a daughter—found themselves navigating the everyday challenges of raising kids while also managing the complex needs of their daughter, who had a lifelong disability. Like many families, their time was consumed with school schedules, therapy appointments, and the routines of daily life.

Their savings were primarily in a 401(k), with a small portion in an investment account. They had both employer-provided and privately purchased insurance, but they weren't sure if it was the right kind—or enough—to meet their children's future needs, especially the long-term care their daughter would require.

They had wills in place, including Testamentary Trusts for both children, and language to create a Special Needs Trust after their death. However, they had no clarity on how taxes would impact the inheritance or how to protect their daughter's eligibility for government benefits—something critical to her future well-being.

What's more, no one had advised them to create a Communication Plan. They had never spoken with extended family about gifts or accounts set up for the children. As a result, they had no idea if well-meaning relatives had made financial decisions that might unintentionally jeopardize their daughter's benefits.

That all changed when they connected with a team of **Chartered Special Needs Consultants™** at ***A Special Needs Plan***—experts in helping families like theirs. With the team's guidance, they were able to bring together all the financial, legal, government benefit, tax, and communication pieces into one cohesive plan that matched their vision for the future.
They calculated the resources their daughter would need across her lifetime and learned how to adjust their insurance to support those needs. They revised their wills and created an Inter Vivos Special Needs Trust, allowing them to control how assets were managed and distributed during their lifetime and after.

They also discovered that leaving certain assets in the trust—like retirement funds—would have triggered a 40% tax. With the team's help, they shifted assets strategically to reduce that burden.

Just as importantly, they created a Communication Plan. When they spoke with family, they learned that the grandparents had opened an account in the daughter's name, and the father's sister had named her as a beneficiary—acts of love that could have resulted in the loss of government benefits. The family provided clear instructions to redirect those gifts into the trust, preserving their daughter's support system.

In the end, this family walked away with a fully coordinated plan—one that secured their daughter's lifetime care, supported their son's needs, and gave them the peace of mind they had been missing. They no longer felt overwhelmed or uncertain. They had a clear roadmap from where they were to where they wanted to be.

A Special Needs Plan™

About Us

Since 2005, **A Special Needs Plan™** has been serving families with special needs, families who often struggle with the worry that comes with planning for the future care and financial well-being of their loved ones. As a nationwide planning advisory firm, we are here to put an end to all those frustrations and fears by providing an experienced team of professional experts.

We Offer

- Planning consultations for families.
- Educational workshops, seminars and webinars for families, organizations and financial professionals.
- Special needs planning educational resources.

Our Purpose

Everything we do is designed to accomplish one goal: Serving families by building **Lasting Independence for Everyone (LIFE)**. This includes a better life for those with speical needs, peace for parents and security for siblings.

Connect with Us

704-326-7910

info@aspecialneedsplan.com

www.ASpecialNeedsPlan.com

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Thank You

Thank you for downloading and reading ***The Family Advocate.***
It is our sincere hope that it is a useful and helpful tool for you and your family. All of us at A Special Needs Plan wish you, your family and your loved one, all the best. Please know we are here to help when you need us.

Check out our Free Resource Library at ASpecialNeedsPlan.com

Our free resource library is a tremendous asset for families with special needs. Our FAQ section quickly answers dozens of our most asked questions. Plus there are videos and articles you can view and download that address all of the import aspects of planning for your child's future.

For more information, please visit
www.ASpecialNeedsPlan.com
and click the "Resources" tab.

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