

Making Sense of Special Needs Finance

A Caregiver's Roadmap to Financial Stability

By Chris Ball, ChSNC™

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WHO THIS BOOK IS FOR

"Making Sense of Special Needs Finance: A Caregiver's Roadmap to Financial Stability" is written for caregivers, family members, and professionals who are directly involved with the financial planning and care of individuals with special needs.

If you are looking for a comprehensive guide that addresses the unique financial challenges and considerations surrounding special needs care, this book is for you.

This book is specifically designed for:

- Caregivers and family members who want to ensure the long-term financial stability and well-being of their loved ones with special needs
- Individuals who want to understand the intricacies of government benefits, such as Supplemental Security Income (SSI), Social Security Disability Income (SSDI), Medicaid, Medicare, and state-specific programs that can provide crucial support to those with special needs
- Anyone interested in estate planning, special needs trusts, ABLE accounts, and tax planning strategies tailored to the unique requirements of special needs families
 - People who seek guidance on guardianship, conservatorship, transition planning, and living arrangements for individuals with special needs

This book offers practical advice, real-life examples, and expert insights to help you navigate the complex world of special needs financial planning. This book will empower you to make informed decisions and create a solid financial foundation for your loved one's future. By understanding the various aspects of special needs finance, you can help ensure that your loved one is well-cared for and enjoys the highest possible quality of life.

By investing just one hour into reading *"Making Sense of Special Needs Finance: A Caregiver's Roadmap to Financial Stability"* cover to cover, you will be equipped with the tools, resources, and knowledge necessary to successfully plan and manage your loved one's financial future.

In this short time, you will learn how to:

- Develop a deeper understanding of the legal aspects of special needs financial planning, including estate planning, special needs trusts, and guardianship
- Learn about the various government programs available and how to maximize the benefits they offer to individuals with special needs
- Gain insight into the different types of living arrangements and transition planning for individuals with special needs, along with the resources available to support these options
- Discover tax planning strategies and tips specifically tailored to the unique requirements of special needs families
- Explore the intricacies of guardianship, conservatorship, and alternative arrangements to ensure the long-term well-being of your loved one

With *Making Sense of Special Needs Finance*, you will be better prepared to make the crucial decisions that impact the financial stability and well-being of your loved one with special needs.

But the benefits don't stop there. Our comprehensive roadmap will also help you build a

strong support network by connecting you with experienced professionals, such as attorneys and financial advisors, who specialize in special needs planning. This collaboration helps ensure that your loved one's financial plan is not only robust but also adaptable to the ever-changing landscape of special needs finance.

So, if all of this resonates with you and aligns with your goals, I invite you to continue reading ***Making Sense of Special Needs Finance: A Caregiver's Roadmap to Financial Stability*** and embark on this journey with me.

My Promise to You

Dear reader, let me tell you this: I committed to making a real difference in your life by guiding you through the intricate world of financial planning for families with special needs children. **It's essential that you understand that you are not alone on this journey.**

My promise to you is to provide you with a powerful, life-changing guide, crafted with empathy and understanding for the unique challenges you face.

I've brought together an exceptional team, with a wealth of professional expertise and personal connections to the special needs community. I've created this book to be your roadmap, your compass, guiding you towards a future where your family's financial wellbeing is secured.

Here's what you can expect from me:

- Straightforward, reliable advice on securing the long-term care and support your special needs child deserves.
- A game plan to fund the education of all your children, ensuring their bright futures.
- Guidance on planning for a comfortable and worry-free retirement for you and your spouse.
- Expert tips on maximizing tax benefits and savings designed specifically for families like yours.
- Comprehensive strategies for estate planning to safeguard your child's assets and wellbeing long after you're gone.

In this book, you'll find inspiration in real-life success stories and valuable resources to connect you with the special needs community. I'll address your concerns head-on, offering clarity in the face of uncertainty and empowering you to take control of your financial destiny.

Together we will build toward a future full of security, happiness, and financial freedom for your entire family.

Introduction

Navigating the financial landscape can be challenging for anyone, but when it comes to families with special needs children, the stakes are even higher. The emotional, physical, and financial demands of raising a child with special needs can be overwhelming, and parents often grapple with balancing their own financial well-being with the long-term care and support required for their loved ones. It is with this understanding and empathy that I have written this book, aiming to provide a roadmap to a more secure and fulfilling future for the entire family.

Through my years of experience, I have witnessed the struggles and triumphs that families with special needs children face. I have also recognized the critical importance of creating a comprehensive financial plan that accounts for the unique circumstances and requirements of these families. I believe that with the right guidance and support, parents can achieve both their financial goals and the peace of mind that comes with knowing they have provided for their special needs child in the best possible way.

In this book, I will share the insights, strategies, and tools that I have used through my work with special needs families. My goal is to help you navigate the complex financial landscape, focusing not only on your immediate needs but also on your long-term objectives, including retirement planning and the continued care of your loved ones.

One of the key concepts I introduce in this book is the idea of a life care plan, which goes beyond traditional financial planning. A life care plan encompasses all aspects of your loved one's well-being, from financial security to services, hobbies, and other factors that contribute to their quality of life. I believe that a comprehensive life care plan is essential for ensuring the best possible outcomes for your family, and I will guide you through the process of creating one tailored to your unique circumstances.

Throughout the book, I will also discuss the importance of open communication and collaboration with your financial planning team. I have found that a successful financial plan is built on a strong foundation of trust and understanding between families and their advisors. My approach is centered around listening to your needs, priorities, and concerns, and working together to develop a plan that reflects your family's unique situation.

As you read this book, I invite you to think about your own family's story, the dreams you have for your loved ones, and the legacy you wish to leave behind. My goal is to empower you with the knowledge and tools you need to confidently navigate the financial planning process and create a better future for your family.

I understand that the road ahead may seem daunting, but I am here to support and guide you every step of the way. Remember, you are not alone in this journey. By working together, we can overcome the challenges, celebrate the victories, and help secure the financial future that you and your special needs loved one deserve.

I am honored to be a part of your family's story, and I look forward to helping you create a life care plan that brings you peace of mind and the confidence that you have made the best possible choices for your loved one's future. With my guidance, expertise, and heartfelt commitment to your family's well-being, I am confident that together, we can build a brighter and

more secure future for you and your loved ones.

Welcome to this journey of empowerment, hope, and financial security. Let us begin.

Chapter One

Laying the Groundwork – Understanding Special Needs Financial Planning

As financial planners, we have the privilege of helping families build and secure their personal wealth. One of our main objectives in planning is to help secure the future of the people you love and care about. If you have a family member with special needs, you are the one who is looking out for their best interests.

We all wish for the best outcomes when planning. My wish is that you have a long and enjoyable life and achieve the goals that you have in mind. However, all of us must think about the future and consider the legacy we wish to leave behind. We also need to design a plan that can endure the unexpected events that happen in life. The question that most of our families wrestle with is this: What is going to happen to my loved one with special needs if I am no longer able to care for them?

This is a critical question to think about. None of us like to think about bad outcomes or the worst possible scenarios. With every client we work with, it's difficult to think about our own mortality and ask ourselves, "What if THIS happens?" However, this is exactly why we do financial planning. We want to build a plan that protects you and your loved ones. Our goal is to help eliminate failure as an option.

Our loved ones with special needs require that we have a strong plan in place. There are many important areas that we must discuss and plan for. We have additional legal and financial considerations we must consider. Governmental benefits, daily care, medical issues, social support, and quality of life are all critical areas of concern.

Important Legal Considerations

It's important to focus on the special legal considerations needed to protect your loved ones. One of the first questions we ask all our clients is about estate planning. Do you have a last will and testament? Do you have any trusts in place? The harsh reality is that there is a plan in place even though you haven't done any planning.

If you do not have an estate plan, it is likely that a judge will decide who gets your assets. More importantly, a judge will also decide who will raise your dependents. Think about your loved one with special needs. How would you and your family feel if a judge picked someone else to take care of them? Losing control of their care and well-being would be devastating.

Another important point to make is that your estate plan needs to be reviewed on a regular basis. Communication among well-intentioned friends and family is also part of this process. Unfortunately,

many families make critical mistakes when creating their estate plans. I will highlight some of the common errors we see later on.

I also get regular questions about the use of a Special Needs Trust in estate planning. The goal of a Special Needs Trust is to protect and preserve government benefit eligibility. It is likely your loved one is currently receiving benefits or will be eligible in the future. Because those federal and state programs are "means tested," there are strict limits on income and the amount of assets your loved one can have in their name.

A Special Needs Trust is a tool that protects the quality of life for your loved one. It is designed to supplement the benefits that they receive from state and federal programs. Everyone who is closely involved and wants to be of assistance needs to be aware of the trust once it is drafted. Anyone who makes a financial gift to assist with care and lifestyle enhancement should pay it into the trust. Assets cannot be given directly to the beneficiary. There are many ways to fund a Special Needs Trust, and we will examine those later.

One final point I cannot stress enough is the importance of working with a qualified attorney who has expertise in special needs planning. It is definitely not a "do-it-yourself" project and requires an attorney who has a specific focus in this area of planning. Think of a physician or a surgeon. While many doctors may be equipped to treat a variety of conditions, there are times when a specialist is needed. Even the most qualified heart doctor would likely not be your first choice if you needed foot surgery.

The legal profession works much the same way. There are many highly qualified attorneys who focus on very specific practice areas. Despite their qualifications, it's likely that you would not want a patent law attorney drafting your special needs trust. There are too many laws around things like government benefits, guardianship, and trust administration that could jeopardize the trust. I work with qualified attorneys all over the country who specialize in drafting special needs trusts that will stand the test of time.

Guardianship and Other Alternatives

In most states, the law presumes that individuals over the age of 18 are able to make decisions for themselves. They are deemed to be adults and can decide what is best for them in their daily lives. Since each circumstance is unique, many families consider guardianship to ensure the quality of life for their loved ones with special needs.

Guardianship is a deeply personal decision. It is also one that must be appointed, approved, and monitored by a probate court. Another reason to engage a proper attorney is that laws vary from state to state. It's important for an attorney to be familiar with the legal process where you live. A qualified attorney will also know the alternatives to guardianship that might be a better fit for your family's circumstances.

Many families are comforted knowing that guardianship is not an "all-or-nothing" situation. There may be other avenues available that help your loved one feel more independent and do not require as much legal involvement. Again, each state is different, so it's important that you and your attorney discuss the options in your area. You can also implement a plan that allows for any change in circumstance or condition that may require reevaluation at that time.

The Letter of Intent

It's likely that you've given a lot of thought about a care provider for your loved one with special needs. You would want that person to honor your wishes and provide the best care possible. One of the best tools to ensure that happens is by putting together a Letter of Intent.

Although the Letter of Intent is not a legally binding document, it is a very important tool. The purpose of the Letter of Intent is to convey your thoughts, feelings, concerns, and your wishes for your loved one. It is designed to be a detailed story about them and what you consider to be important to provide them with the best quality of life.

The Letter of Intent doesn't necessarily have to be a written letter. I have seen all types – some in written form, others in audio or video format. You can describe a day in the life of your loved one. What are their likes and dislikes? What is their favorite food? Are there things that they really love that make them happy and calmer? These are all really important things for others to know about them.

No detail is too small or unimportant. You can list their medications and doctors that you have had good experiences with. There may be services that you would never use again. Talk about your loved one's hobbies. What are your thoughts on religion and the communities you may currently be a part of? Once again, your circumstances and situation are unique. So, it's helpful if others know those details and can honor you and your loved one.

Endeavoring to Bring Peace of Mind

I love working with our clients because one of the major purposes of financial planning is to provide peace of mind. There are so many fears and uncertainties that come with money. My goal is to help build a plan that helps you and your loved ones enjoy the lifestyle you envision. We want everyone in the family to reach their full potential and have the resources available to make that happen.

We'll focus on estate planning mistakes later, but I can tell you right now the biggest mistake I see on a regular basis is doing nothing. Not planning at all is a recipe for disappointment and hardship if something happens. With a special-needs loved one, you cannot afford to make this mistake. As we acknowledged, none of us like to think about the worst-case scenarios or think about our own mortality. However, procrastination and inaction impact families of all circumstances. I am way too familiar with horror stories of what can happen when there is no plan in place for the future.

With that in mind, I am here to make that process as smooth as possible. One of the most gratifying things I hear is when a client says, "That was easier than I thought. I really wish I would have done this much sooner!" I am here to help you implement all aspects of a plan that will protect your loved one and also honor your hopes and dreams for the future.

Chapter Two – The Importance of a Life Care Plan

Now that I've demonstrated the importance of planning, let's discuss the elements that go into making it a success. With a special needs family member, there are many people and professionals that are involved with their care. The financial element is critical, but so are many other aspects of the plan. Because of that, we want to develop a total life care plan that provides for the needs of the entire family.

I understand the unique challenges that our families face when it comes to putting a comprehensive plan together. Each day may present distinct issues that you have to address. You may feel that your life is so reactive, that it's difficult to be proactive for all the things you ultimately need to address. My goal is to make this task less overwhelming and assemble a team of trusted advisors who are there to support you every step of the way.

Integrated Planning

One of the ways my method of planning differs from many advisors is by taking a coordinated approach. That means that not only am I aware of the other members of your support team, but I also communicate and integrate with them. I have learned through experience that most people take an "a la carte" approach to planning. While this may address individual needs as they arrive, it often does not end up providing optimum outcomes.

A sound life-care plan not only requires careful planning in every aspect, but it also requires coordination. As an example, what happens if we as the special needs financial planning team do not speak with your accountant or CPA? Is that person aware of special needs tax planning and what deductions might be available? Can we be sure that we are maximizing all the tax advantages available to you and your family?

I already emphasized the important relationship between our team and a competent special needs planning attorney. It is important that the financial plan and goals are clear to legal professionals. A Special Needs Trust might be required. If that is the case, that means it also needs to be funded properly. Since we want the entire family to benefit from our plan, we would want to make sure we determine the best way to fund the trust. That would have to be coordinated into the plan and be a part of a regular review.

Setting a Planning Timeline

It is common in the financial industry to have the delivery of a financial plan be a one-time event. While that approach is a good starting point, I strongly believe that planning needs to be dynamic and ongoing. This is particularly true when planning for a loved one with special needs. Because life is constantly changing, it's important that a life care plan is adjusted accordingly.

With a life care plan, there are milestones that we need to be aware of. Prior to age 18, it may start with early intervention services right at birth. As your child grows up, we have to take into account individual education plans, a legal structure, and start transition planning. Many families apply for Medicaid Waivers and Social Security benefits, depending on their circumstances.

After age 18, those issues change due to the child legally becoming an adult. We talked about guardianship and other alternatives to help ensure a quality of life and level of independence if appropriate. Supplemental Security Income, Social Security Disability Income, Medicaid/Medicare, and other benefits take on critical importance for the life care plan.

Part of our planning process is anticipating all these milestones. Most transition planning starts around age 14 to ensure benefits are available as the child enters adulthood. The timeline helps keep things on track and allows for full integration of the legal, tax, and financial support team. We all want the transition to be as smooth as possible for you and your loved one. For that to happen, we must be proactive.

Family Assets and Planning

As discussed, our planning is done with a focus on the entire family. This requires us to have a balanced approach as we take into consideration the needs of all family members. A loved one with special needs requires that we give extra care to the coordination of financial resources.

Caring for a special needs loved one is a family affair. It only makes sense that this labor of love is shared by others who have a vested interest in the care plan. Communication among family friends is a critical but sometimes overlooked step in setting things up for success. Although there are many deeply personal aspects to the planning process, I see so much benefit when other loved ones are involved.

Sharing information about the vision of the future for your loved one helps address any concerns and clears up misunderstandings. Sometimes difficult conversations are necessary to ensure that the right person oversees future care and responsibilities. For example, it's common to have a sibling be appointed as the caretaker and trustee once the parents are no longer able to provide care. However, this may not always be the best arrangement for all involved.

Make sure that those involved are clear on future medical, educational, and housing needs. We talked earlier about the Letter of Intent. Although it's not legally binding, it is often considered by the court when they are reviewing the care plan. Have your family and friends assist with the Letter of Intent. Do not be afraid to go above and beyond when it comes to providing details about your loved one.

It's common for others to want to contribute financially to help in some way. This also requires communication. Some well-meaning family and friends have caused harm to many care plans in the past. For example, if assets are left directly to a loved one with special needs, it could disqualify them from their government benefits. That could potentially have devastating consequences. Good communication ensures proper planning that helps mitigate these risks and protect everyone involved.

Taking Inventory

Accurate data helps us design and implement the best possible plan. As we gather an accurate inventory of your assets and benefits, it allows us to build a sound strategy. Not only do we want to get a current snapshot of your financial position, but we also want to make sure you are taking advantage of what is available to you. This may involve state and federal government resources, additional workplace benefits through your employer, and other strategies that provide needed protection and funding.

Once we get a clear understanding of what you have in place, we can start to build on recommendations. The current and future care of your special needs loved ones will always be at the center of our planning, but your well-being is just as important. For example, what happens to your plan if you were to become disabled and could not work anymore? Do we have protection in place to guard against that? How much of a benefit would your employer provide, and what is the cost?

I can speak from experience and say that short-term and long-term disability protection tends to be woefully inadequate for most people. If you are someone with a family and a special-needs loved one, this type of protection is part of the first line of defense. The odds of a person becoming disabled before age 67 are much greater than those of a person dying prematurely.

One recent article from the Social Security Administration “Faces and Facts of Disability” page said that 25 percent of today’s 20-year-olds will become disabled before reaching the age of 67. That is a very sobering statistic.

Employer benefits are not always the best available, but they are an important place to start. We find that employer benefits are often overlooked. Many times, this is simply because it is a time-consuming and often confusing process to review employer benefits. If your employer doesn’t clearly communicate to you how to find all the programs that are available, it is hard to take advantage of everything. We make sure that we review these options along with other viable strategies to help construct a cost-effective and sound protection plan.

One Step at a Time

I know that there are a lot of moving parts to these discussions. Once again, that is why I am here to support you on your journey and help construct a life plan that protects against the unforeseen. We can address the most important items first and implement them one step at a time. Not only that, but I’ve also stressed that this is an ongoing process. Things change and we need to be ready to adjust as needed.

I especially love it when changes happen because of good news. While we must plan for the worst-case scenarios, sometimes new developments occur with your loved one. For example, I know many families who never envisioned that their loved one would be able to live independently or find a soul mate. However, years later they saw them get their own apartment, find roommates, or even get married. Those are wonderful things that can happen, and we want to be able to accommodate those possible outcomes in our life plan.

Chapter 3: Estate Planning – Preserving Your Legacy

Now that we have stressed the importance of planning, let’s discuss some common mistakes and misconceptions. Because planning for a loved one with special needs can get complicated, it’s a challenge to always get accurate information for every important topic. Well-meaning family, friends, and professionals may offer advice that doesn’t meet your planning objectives.

Not Having a Plan

We are going to stress this point again. The biggest mistake we see on a regular basis is not having a plan. This applies to every family I encounter, not just our special-needs families. Having a 401K plan and investing regularly is a start, but it is not a financial plan. One of the biggest misconceptions we address

with our clients is that financial planning is mainly focused on investing and growing assets.

That is certainly a critical component of building wealth. However, there are so many other areas that must be addressed in order to have a sound plan in place. If there is one word that we want to highlight, it would be the word “risk”. We encounter risk every day in our lives. How we manage it is very important to our success.

Think of a sports analogy for a moment. What does it take to win a championship in a team sport? First, you need to have a good offense. You need to outscore your opponent to win. However, you also need a strong defense in order to make sure the other team doesn’t outscore you. There’s an old phrase that applies, and that is “defense wins championships”. Teams that have a great defense have an excellent chance to win.

That also applies to your finances. A strong offense would involve earning a good living, saving a portion of your money, and growing your assets over a lifetime. A strong defense involves protecting your ability to make a living, ensuring that you have protection in place if you die prematurely, and having a rock-solid estate plan to ensure that your legacy takes care of everyone you love and care about. I am here to guide you on that journey and help you address everything that could potentially cause your plan to derail.

Special Needs Planning and Asset Management

There are several mistakes that I want to highlight in this section in regard to asset management. Thankfully, we see fewer of these mistakes due to advocacy and the rise of Special Needs Trusts. However, I do still see them on occasion and we want to make sure these are avoided.

It used to be very common to disinherit a loved one with special needs. To protect the government benefits, the family would avoid leaving assets to that family member. Since those benefits are designed to only provide the very basics of necessities, they are not nearly enough to enhance the person’s quality of life. A properly designed Special Needs Trust can make it possible to leave assets, protect government benefits, and make sure there are assets to benefit your loved one.

On the opposite end of the spectrum, the other mistakes involve having assets in the name of your loved one with special needs. There are so many problems that arise when assets are titled this way. First off, if your loved one has assets directly in their name, they may have to be “spent down” in order to qualify for critical government benefits. This includes accounts that may have been started at a young age, like a Uniform Transfers to Minors Account (UTMA) or savings bonds.

The other reason it’s critical to address this is that there are predators out there who prey on those with special needs. It could also open issues with creditors. Another point to consider is that of liability. If there is a large pool of assets in their name, they are at risk for lawsuits, bankruptcy, and other situations that would derail the care plan. We must ensure that the proper protections are in place to eliminate these risks to the best of our ability.

Leaving Money to Others to Support Your Loved One

One issue that I do encounter is a plan that involves leaving money to a loved one to take care of a family member with special needs. The most common situation I see is the intention of leaving money directly to a sibling who will be responsible for the care of their special-needs brother or sister.

I know that most families have nothing but the best intentions when it comes to the care of their loved ones. Some families have misinformation about Special Needs Trusts or have been informed by others to not use them as a mechanism to protect assets. While this ultimately is a very personal decision, this strategy introduces many risks to the care plan.

What happens if the sibling receives a large amount of money in their name and they die? Where would those assets go? What happens if the assumed caregiver gets divorced, gets sued, becomes disabled, or goes bankrupt? Those funds could be lost forever and leave everyone in much worse shape.

Another huge problem is that of accounting. What if the money is used for other purposes? Whether intentionally or unintentionally, not everyone makes good financial decisions. An additional risk to consider is this: What if the caretaker becomes sick or disabled and they need a large amount of money for their health care? What if they need to be put into a long-term care facility and cannot take care of their loved one?

Beneficiary Review and Update

Another area of planning that we focus on is making sure your beneficiaries are up to date on all your accounts. This is something we often catch right away as we begin to work with a new client. It's a part of planning that many planners fail to address, to the great detriment of everyone involved.

I can tell you many horror stories about beneficiaries that were not updated. It's just human nature that people set up an account and do not give beneficiary designations any thought going forward. Some of the common mistakes I've seen are beneficiaries still designated for an ex-spouse, a dead loved one, a minor child, or a friend that the person no longer has a relationship with. When I got into this industry, I studied many actual cases where people left huge sums of money to people they would have never wanted to include in their estate. Mistakes might lead to a judge deciding who gets what.

Thankfully, we catch these proactively as part of our review process. Unfortunately, many people come to us after the fact when the damage is done. One common circumstance is a life insurance policy left to an ex-spouse. That might be the desired outcome if the couple had children together. However, if that is not included in the divorce decree, state law may prohibit the assets from going to the ex-spouse. Instead, it might go to the oldest child and can't be accessed until the age of 18.

With your special-needs loved one, perhaps you set them up as a beneficiary on an account. Since that could disqualify them from their future benefits, that would need to be addressed immediately. This simple mistake could cause even the best plans to fail. We cannot allow that to happen.

Making Assumptions for Future Care

There is another mistake that requires strong communication and frank and honest dialogue. Many times, a sibling is automatically assumed to be the one responsible for future care. While there are times when the brother or sister is absolutely the right person to handle the responsibility, it's not right for every family circumstance.

The sibling may feel a moral obligation to become the future caregiver. This is natural since they love and

are likely very involved in the life of their brother or sister with special needs. However, it can also cause resentment if they are thrust into a role that they may not feel equipped for.

What about the family arrangement of the sibling? What happens if they are married or decide to get married? Would they be able to fully take care of the individual with special needs? What if they start a family and raise children of their own? Would their spouse understand and be supportive or could that cause divisions? These are very real issues that come up and need to be addressed.

There is an expert in the field that made a very powerful point to me on this subject. He was talking about his brother with special needs. Although he is very involved in his brother's life, being the trustee and main caretaker for his brother would change the dynamic of their relationship. Instead of simply being his brother, he would have responsibilities that could cause both of them to have resentments.

When the dynamic changes from that of a sibling to more of a parental role, it's very hard on everyone. Caregiver burden is also a very real phenomenon, whether that involves aging parents or a loved one with special needs. Families need to make sure this is discussed and acknowledge that there may be better alternative arrangements.

Care Options and Counting the Costs

Cost is always a consideration when it comes to a third party providing care assistance. This is often the main driver when it comes to having a family member provide care. However, a properly designed trust along with a legal arrangement that fits your loved one's capability and needs might provide options that best fit the circumstances of the entire family.

Remember, guardianship is not an all-or-nothing situation. There are options out there that might fit your circumstances and preserve a level of independence for your loved one. Again, I know that this is a very personal decision. I am here to help you review all of the options based on financial considerations, work closely with legal representation, count the cost, and weigh the pros and cons. Then, you make the ultimate decision and work with the attorney to implement the solution.

Plan for Peace of Mind

Planning helps to eliminate mistakes and identify issues that need to be addressed. Many well-meaning individuals have implemented strategies that they thought were solid, only to be exposed to risks that they had never imagined. I cannot stress enough the need for planning strategies that suit your personal goals and desires and honor the dignity of your loved ones. There is a need for strong communication and sometimes difficult conversations. We work together as a team to make sure this happens and that the right people are involved. This can help provide peace of mind for you and your family, especially knowing the best interests of your loved one with special needs are being protected.

Chapter 4- The Power of Government Benefits

The details and rules around government programs could fill an entire book on their own. The original 1935 Social Security Act was 29 pages long. As of 2015, the current law with all of its expansion and amendments was said to run over 2,600 printed pages alone. With those laws constantly changing and being updated, it makes it difficult even for legal experts to keep up.

I am going to touch on the very basics of government programs in this chapter. This is another area that we assist our clients with since these benefits are critical to a successful life plan. We engage and communicate with experts in the field to make sure you understand what benefits your loved one with special needs qualifies for and how we protect them moving forward.

Most people we work with have already been down the path of applying for or receiving some form of government benefit. As your loved one approaches adulthood, these programs become critical to their care and well-being.

The major programs we will discuss are the following: Supplemental Security Income (SSI), Social Security Disability Income (SSDI), Medicaid, Medicare, and State-specific programs.

SSI and SSDI

SSI is a non-medical federal income supplement program funded by general tax revenues. This program is not funded by Social Security taxes. It's designed to help people over 65, the blind, and people with disabilities who have little or no income.

The standard definition for a disability is one that is expected to last more than 12 months OR result in death. Like most government programs, these programs are designed to provide cash to meet a person's basic needs for food and shelter. When a child reaches the age of majority (the age when they are no longer considered a minor), eligibility is based on the child's income, not the parents.

SSDI pays benefits to children who have a disability that began before age 22. The reason this is referred to as a "child's" benefit is that it is paid on a parent's Social Security earnings record. For an adult person with a disability to become entitled to this "child" benefit, one of his parents must be receiving Social Security or have disabilities OR have died with enough Social Security credits to qualify.

Medicaid and Medicare: They Are Not the Same

It is very easy to confuse Medicaid and Medicare. Since they are very different programs with different qualifications, it's important to determine which one is appropriate for your circumstances.

Medicare is a program that everyone in the United States can qualify for. It's likely you know friends and family who qualified for Medicare and began using it when they turned age 65. Medicare is not a program based on income. It will provide benefits regardless of the financial status of the recipient.

If a person is under age 65, there are other ways to qualify for Medicare. If you are under 65, have a disability, and have had Social Security for 2 years, you can qualify. This is where it becomes important to those with loved ones with a special need. The other 2 major conditions that qualify those under 65 are kidney failure and Lou Gehrig's disease.

Medicaid on the other hand is a needs-based program. Medicaid is designed to help those who can't afford medical care. The program is implemented by each state individually with reimbursement by the federal government. Medicaid is common in the special needs community since typically it also applies as governmental health insurance for children with disabilities.

Those eligible for Medicaid are low-income families with "medically needy" children under age 21, SSI recipients, infants born to Medicaid-eligible women, children under 6, and pregnant women with

income below 133% of the federal poverty level.

Because Medicaid is a joint federal-state program, rules and regulations vary by state. Some states have “waiver programs” which may qualify a person who might not automatically meet the criteria. Some states have additional programs that provide financial and medical assistance to children and those with special needs. Since the laws are different in every state, it’s often necessary to contact an attorney that specializes in Medicaid where you live.

Use Medicaid to Open Doors

If there is one benefit that could be identified as the most critical, I would say that it is most likely Medicaid. Medicaid is a program that opens doors to a variety of services. There are so many programs for our special needs population that are directly tied to Medicaid.

We are going to talk about them throughout the book, but these services go beyond just providing healthcare coverage for your loved one. Many housing and community programs are also funded by Medicaid. These are the waiver programs that fund things like residential placements and other support programs for those with disabilities.

You might be familiar with some of these programs, but there is much more beyond the standard Medicaid program. There is also “buy-in” Medicaid, which consists of healthcare benefits for the working disabled. Many of the families we work with have a loved one with special needs who works at least part-time.

There are other home-based programs that have special eligibility through the Department of Human Services. They might have different names in your locale, but many of them offer similar services from state to state.

Can My Loved One Hold a Job?

Some families have fears about their loved one holding a job because they think they would get disqualified from their benefits. These Medicaid programs allow them to earn some income and still maintain critical benefits. Part of our life care plan includes calculating the cost of working and seeing how it fits into the overall budget.

I have heard so many success stories from friends, families, and clients when their loved ones with special needs began working. The increase in quality of life, social skills, and self-determination are hard to even quantify. There is a local grocery store that I visit frequently. There are two adults with special needs that work there, and they made such an impression on me.

Both warmly welcomed me immediately when I walked into the store. They struck up a conversation and I was so impressed with their kind demeanor and enthusiasm. Not only did I have two new instant friends, but I also spoke to the store manager about them. The manager quickly acknowledged how valuable they were to the team. I was not the first customer who had approached her and expressed such compliments.

Proactive Planning to Preserve Benefits

This chapter highlights why planning is always an ongoing process. So much of our strategy is done with the goal of ensuring that benefits such as SSI and Medicaid will not be unintentionally jeopardized. Since

those programs are “means-tested”, you can understand why our planning requires that your loved one with special needs not have assets in their name or be the beneficiary of an account.

We want to maximize resources to provide the best quality of life possible for the entire family. I’ve worked with some well-meaning families who were hesitant to take advantage of some or all of these benefits. They had many misconceptions about the programs, so it was necessary to have a conversation about those topics. My overwhelming feeling is that these programs provide protection for you and your family.

These benefits protect you in the sense that they provide valuable health and income support to your loved one. That is very important for your assets and how you use them in the future. It might be the difference between being able to enjoy retirement or feeling like you must work the rest of your life. These benefits also help your loved one with special needs. They open doors that improve their quality of life and protect them if something happens to you. This is another area where it is a deeply personal choice, but I want to make sure you carefully weigh all of your options and protect yourself and your loved one in the best way possible.

Chapter 5 Creating a Safe Haven – SNT and ABLE

I’ve already mentioned Special Needs Trusts and how they are a common tool to protect and preserve benefits. Let’s dig a little deeper into the types of Special Needs Trusts, how they are commonly funded, and how they are administered.

Special Needs Trusts allow caregivers to have a way to provide for their loved one with special needs and improve their quality of life. These funds can be used without disqualifying them from federal and state assistance programs.

Trusts can be set up funded or unfunded and must be overseen by a trustee. It is common for a caregiver and/or a third party to be designated as trustees. The funds can be contributed to over the years, or the trust can be funded after the death of a loved one. This is usually done through an inheritance or a life insurance policy. These funds are then used to supplement, not supplant standard services and benefits received from the government.

Types of Special Needs Trust

There are several types of special needs trusts you need to be aware of. I will highlight the three main types we typically encounter. They are First Party Special Needs Trusts, Third Party Special Needs Trusts, and Pooled Special Needs Trusts.

A First Party Special Needs Trust is formed when the person with special needs has their own assets. The two most common funding for these comes from a settlement from an accident or a direct inheritance that was given.

Previously, people with special needs were not allowed to set up their own trusts. A third party such as a parent or grandparent had to set up the trust and a trustee controlled the funds. Thankfully, the laws changed in 2016, and these are now permitted. They are referred to as Self-Settled Special Needs Trusts.

These are especially useful to move assets out of a person's name so they can either qualify for or maintain government benefits.

One thing to remember with these trusts is that they have stricter distribution rules and have a state payback requirement. That means that when the person with special needs dies, any money left in the trust will be used to pay back the state for the amount of money it spent on Medicaid after the trust was established. Any funds left over would go to whoever was listed as a beneficiary.

A Third-Party Special Needs Trust is created by someone other than a person with special needs. It is usually created by the family to provide direction for resources and protect assets. A properly constructed Third Party Special Needs Trust will also protect the loved one's access to government benefits.

A Pooled Special Needs Trust is typically organized by a non-profit organization. The assets are "pooled" together from all of the families who participate, and still can be used for the benefit of the loved one with special needs. In most cases, once the beneficiary dies, any remaining assets would go to the non-profit. These types of trusts are generally less expensive for people who do not have complex estate needs.

Funding the Trust

There is no right answer when it comes to determining how much to fund the trust. There are a variety of factors that we must consider. The main driver is based on your loved one's needs. That includes their ability to be independent, their ability to work, their medical needs, living arrangements, social and entertainment needs, and quality of life scenarios.

We also need to consider unexpected events and plan for the future. What happens when one or both parents are not around? What would it cost to replace caregiving, income support, and quality-of-life items? We typically try to quantify lifestyle needs to a monthly or annual amount for your loved one, then plan around that dollar figure.

The most common planning scenario I see is a Third Party Special Needs Trust established by the parents. There are often other family members who want to help fund the trust. Grandparents will often contribute during their lifetime if they are able, then also provide additional funds with life insurance or other assets upon their death.

For parents, the most common funding source is life insurance. Life insurance gives the family the ability to leverage dollars and the flexibility to protect in a variety of ways. Permanent life insurance provides living benefits and also future funding opportunities with the death benefit. Life insurance proceeds can be paid free of taxation to a Special Needs Trust.

One form of life insurance I often utilize for many of our clients is called Survivorship, or "Second-To Die" policies. This insurance covers two lives instead of one and pays a benefit upon the second death. It can be structured in many different ways and allows for funding of the trust when both parents are no longer around. Each family has unique circumstances, but this is a common tool used specifically for a Third Party Special Needs Trust.

Trust Administration

The final area to address is the administration of the trust. There are different ways of administering your trust upon your passing. You have many factors to consider: what type of trust, the complexity, and the amount of assets. It's common for a parent to appoint a sibling as the trustee, but that isn't always the optimal solution.

Trust administration requires following rules and meeting government reporting requirements in addition to the main purpose of supporting the person with special needs. Some families have decided to have a professional fiduciary administer the trust. Others have decided to have a family member or friend administer it in conjunction with a neutral third-party professional. There are many options, so it's important to do your research and ask a special needs attorney for their direction.

ABLE Accounts

Now let's discuss another relatively new tool available to help support those with special needs. The ABLE account is a tax-advantaged savings account for individuals with disabilities. The account is designed to fund disability-related expenses.

The ABLE Act was signed into law in 2014. The ABLE account is modeled after 529 college plans, which you may already be familiar with. Funds in an ABLE account will not affect eligibility for federal benefits. Each state has its own requirements around the ABLE account, so it's important to understand the program where you or your loved one lives.

For people receiving government benefits, they are a good spending account. It also can be used as an accumulation vehicle for future planning and usage. ABLE accounts work very well with Special Needs Trusts, so they can be a valuable part of a life care plan.

ABLE Eligibility

To be eligible for an ABLE account, the beneficiary must be blind or have a disability that occurred before their 26th birthday. The person can be over 26 to open the account, as long as the disability occurred prior to that age. If the age criteria is met and the person is already receiving SSI and/or SSDI benefits, they are automatically eligible. If the person is not yet receiving benefits, they must meet the Social Security definition and criteria for disabilities and have a letter of certification from a licensed physician.

As of this writing, Congress recently announced that they intend to raise the eligibility age from 26 to 46. That is not scheduled to go into effect until 2026, and there will be a long waiting period before more people will be able to take advantage of the program. Our team makes sure to stay up to date on any changes to the ABLE program.

ABLE Account Limits

The maximum amount of annual contributions is limited to the annual IRS gift tax exclusion. In 2023, that amount was \$17,000, per the Social Security Administration's "SSI Spotlight" page. Some states allow additional contributions from the earnings of the beneficiary. Only one ABLE account is allowed per person, but contributions can be made by anyone. Contributions must be in cash.

The maximum amount allowed in an ABLE account is currently set at \$100,000 when it comes to eligibility for SSI, per the Social Security Administration's "SSI Spotlight" page. If the account exceeds

that amount, the beneficiary could lose their monthly SSI cash payment but would continue to receive Medicaid benefits. In most states, the maximum total amount allowed in the account is tied to the 529 plan limit. That is usually in the \$500,000 range.

ABLE accounts can typically be opened under any state program, as long as the state is accepting new enrollees and accepts out-of-state residents. Enrollment and maintenance are primarily done through the individual state ABLE program website. Some do allow initial enrollment via mail.

Using ABLE Funds

I get a lot of questions about ABLE accounts and how they should be utilized. Disbursements must be made for what are called "Qualified Disability Expenses" or QDE. The list of QDEs is quite generous and is connected to a variety of expenses designed to enhance the quality of life for the beneficiary. Education, housing, transportation, employment support, and personal support services are just a few of the categories.

Another issue I encounter is when a child is the beneficiary of a 529 plan. Families that have a 529 college plan in place can transfer the money into an ABLE account without penalty. Both accounts must have the same named beneficiary or be a qualified member of the beneficiaries' family. Contributions can also be transferred from a Special Needs Trust, subject to the annual contribution limit.

ABLE accounts aren't right for every situation. There are some disadvantages that need to be considered. Between the contribution limits and the asset cap, there are limitations. There is also a Medicaid payback rule, which means the remaining funds in the account must be paid to Medicaid upon the death of the beneficiary. Because of those disadvantages, some families may not choose to utilize them. However, for many families, they are a valuable planning tool and can be used to strategically enhance the quality of life for a loved one with special needs.

Chapter 6 – Tax Planning

We think Albert Einstein may have had it right when he reportedly said, "the hardest thing to understand is income taxes". It can make us all feel better that one of the greatest minds in human history found our tax system confusing and intimidating. Not only is the tax system complicated, but it also changes every year. Just when you think you understand the rules of the game, they end up changing.

For that reason, we are only going to discuss some high-level tax planning when it comes to your loved one with special needs. One of the main points I want you to understand from this chapter is that you need to be aware of all of the possible tax benefits available to you. Many people overlook potential deductions and credits that they could take advantage of based on their family circumstances. Let's look at a few things that you will want to keep in mind when you are tracking your annual expenses.

Since I am not a tax professional, I want to make sure to stress the importance of working with a qualified tax expert. However, I will say that in the area of special needs planning, we often communicate

with tax planners and CPAs to make sure they clearly understand current tax law. Because it is such a specialized area of expertise, not all of them are aware of the full benefits available to families who have a loved one with special needs.

I do understand the appeal of doing it yourself or using a software platform. If you enjoy it and do a good job capturing everything properly, then that is your prerogative to do your taxes if you want. However, I uncover mistakes all the time when reviewing returns. For most of our clients, I strongly recommend having a professional do it. If you save a few dollars by doing it yourself but do not record all the deductions available, this could end up costing you a lot more in the long run. Plus, they can be your representative to the IRS if issues arise. That can save you a lot of aggravation and stress.

Medical Expenses

I encourage you to make a careful accounting of every medical expense you incur. By definition, these include any amount paid for the diagnosis, cure, mitigation, treatment, or prevention of disease. This is for the purpose of affecting any structure or function of the body and transportation primarily for and essential to the above medical care. If that sounds legalistic, that's because it's paraphrased right from the tax code.

When it comes to medical expenses, there are several items that are often overlooked. These are capital expenditures for medical care, special schools and education institutions, and medical conferences and seminars. There is an annual standard deduction that applies for everyone, so there may be years that your total deductible expenses do not exceed that amount. However, if they do, it's worth taking the time to itemize and maximize your tax savings.

A capital expenditure usually involves equipment or upgrades for a residence or office. For example, we have friends, family, and clients who have made upgrades to their homes to accommodate a loved one with special needs. When it came to tax time, it did not occur to them that those could be considered medical expenses.

Here are just a few of the expenses I've seen that could have allowed for deductions: installing central air conditioning at the recommendation of a doctor to help a child with respiratory issues, constructing entrance ramps to the home to accommodate wheelchair access, altering bathroom facilities, adding railing in the home, and adjusting the height of cabinets. Those are just a small sampling, so make sure you carefully track expenses for anything you do to enhance the quality of life for your loved one.

Special Schools and Education

All educational expenses for your loved one with special needs also need to be tracked. This area of tax planning has caused confusion for families and tax planners alike. For most families, there are very few tax credits and deductions available. A big exception is when education qualifies as a medical expense.

Standard education curriculum may be offered in these types of schools. However, the education must be incidental to enabling the student to compensate for or overcome a handicap. The nature of the service determines the medical expense eligibility. The IRS considers medical and therapeutic orientation as a critical factor for deductions.

A few examples include schools for teaching Braille or lip reading and training physically and

intellectually disabled individuals, which would include children with learning disabilities. As you can see, it's a broad definition, so it's worth seeing if it applies to your situation.

I was on a call recently with a group of advisors who specialize in special needs planning, and one of them mentioned that their client has sent their son to a school geared specifically for children with Autism. The cost of the educational program was approximately \$30,000, a significant annual expense. The family had been told by their CPA that this expense was not deductible. After the advisor recommended the family get a second opinion, they were able to provide references to help their CPA see that this qualified as a medical expense and could be deducted.

I mention this example not to be critical of the CPA, only to again highlight the point that this is a highly specialized area of tax planning. Even the best tax preparers and CPA's miss items despite continuing education and extra effort to stay up to date on regulations and serve their clients. I just want to again highlight how important it is to communicate as a team and make sure everyone is up to date on special needs planning. Our goal is to do everything we can to capture tax advantages for your family and use those funds in other areas of the life care plan.

Medical Conferences and Seminars

Here's one last area of tax planning I want you to be aware of. If you travel to medical conferences and seminars, the IRS allows for some medical deductions. If the seminar is directly related to a dependent's illness and recommended by a physician, there is some tax benefit available. Meals and lodging are not deductible, but you likely have the opportunity to deduct transportation and the cost of the seminar.

I meet so many families who are very active in organizations that serve the special needs community they are a part of. These events are really important to them since it helps them build a support network of friends and professionals. It also helps them keep up to date on the best treatments and support for their loved one. Some were unaware of the tax benefits, so I was happy to relay that information.

Take Advantage of Tax Benefits

These are just a few of the main tax benefits I see overlooked. As mentioned, make sure you track everything carefully and evaluate what might qualify as a tax deduction. We work closely with our clients and a knowledgeable tax professional to see how it fits into the annual budget.

Good communication and annual planning allow for our families to take advantage of any deductions available. This often opens doors for families who may have felt that some expenses were out of reach, only to find out that are indeed feasible. This enhances the quality of life for the entire family and gives their loved one with special needs access to the level of services and care they deserve.

Chapter 7 - Guardianship and Conservatorship

One of the key decision points for a family with a loved one with special needs is that of guardianship. Most state law presumes that an individual over 18 can make their own decisions about what is best for them. However, what if that is not the case? What if your loved one needs assistance to protect their personal and financial decisions?

We briefly touched on this topic earlier in the book. Guardianship comes in a variety of forms and options. It is a deeply personal decision, and each situation is unique. However, guardianship is not a mandatory arrangement. There are several alternatives to guardianship that may be appropriate for your family.

Guardianship is also not an all-or-nothing proposition and can be either temporary or permanent. This depends on the needs of the individual with special needs. Temporary guardianship can be appointed by the court in emergency situations.

Terms and Definitions

Let's highlight some of the legal definitions you might encounter. The first is that of a "protected person". That refers to the individual for whom the guardianship is requested. The person appointed by a court of law to handle the protected person's affairs is called the "guardian". A guardian typically has control over the healthcare, well-being, and finances.

There are different types of guardianship. Some families request full guardianship, which is full authority for decision-making on someone else's behalf relating to their legal, financial, and healthcare matters. The protected person is deemed by the court as unable to communicate or make the decisions themselves.

Limited guardianship is where limited authority is granted to a guardian. For many families, it may make more sense to only limit decision-making to specific areas the dependent needs help with. They want their loved one to maintain a level of independence and decision-making. Limited guardianship usually involves areas such as residential, educational, medical, legal, vocational, or financial issues.

Sometimes you will see the term "conservator". In a conservatorship, the conservator is generally responsible only for the management of the person's finances. Depending on the state and local law, that arrangement might be put in place instead of a limited guardianship.

Finally, I know some families that have joint guardianship. That simply means they are more than individuals sharing guardianship authority. This is more common for divorced parents who both have an active role in their child's life. I know a divorced couple that live in different states and they have this type of arrangement. It takes coordination and involvement from competent attorneys in both locations to make sure everything is properly arranged.

Guardianship Procedures

For a guardianship request, the court must receive proof that the protected person is not able to take care of themselves. Depending on the state, other state agencies may be involved in the proceedings. A licensed physician's certificate is usually required. Also, all "interested parties" must be notified.

The court will also appoint someone to represent the protected person during the hearings. This person

is referred to as the “guardian ad litem” (GAL). The GAL is there to validate that the guardianship appointment is in the best interest of the person.

As you can imagine, the guardian has a great deal of responsibility. Their activity is carefully restricted by law when it comes to the person’s property. A guardian has to use reasonable care and caution when making decisions and doing things on behalf of the protected person. They could be held liable if their actions are deemed to be careless when it comes to the protected person’s property.

Guardianship Removal or Termination

Some families have requested that a guardian be removed from the care of a loved one. If a court determines that a guardian is not doing their job, a successor guardian can be appointed. This is also the case if the guardian resigns from their role or dies.

There are also situations where a guardianship is terminated due to an incident or event. In some cases, the protected person is no longer incapacitated. Sometimes a guardian is appointed over an estate. Once the resources of the estate are exhausted, the appointment is terminated. Another example is when a loved one moves to another state. A new guardian would be appointed in that area, and the guardianship would terminate in the original location.

Alternatives to Guardianship

Many families seek alternatives to guardianship. Their loved one with special needs often desires a level of independence and self-determination. In some families, there may be strong opinions on guardianship and an inability to come to an agreement. When appropriate, other arrangements can be put in place to provide support and meet the needs of those involved.

A “representative payee” is a person that is authorized by the Social Security office. They are allowed to manage the funds of a person who is unable to do it on their own. The only source of income must come from SSI or Social Security. Completely separate records must be maintained, and the representative payee cannot commingle funds with their own. Periodic accounting updates may be required, so it is very important to keep accurate records.

A “healthcare representative” may be appointed by a person who is not confident in their ability to manage decisions regarding their healthcare. This appointment must be made when the individual is deemed competent. Due to the nature of the person’s capacity, this may not always be a viable option.

Durable Power of Attorney

A “durable power of attorney” allows a person to maintain a level of independence but also grants authority to someone else to make decisions on their behalf. The person appointed is referred to as the “attorney-in-fact”. The appointment can be immediate, or it can become effective only if the person is incapacitated.

The powers can be limited or broad in scope, depending on the nature of the agreement. It can include handling financial affairs, buying and selling real estate, and making health care decisions. It is considered “durable” because it remains in effect during incompetency or disability.

Some locales also have what is called a “limited power of attorney”. Those are usually designed to manage a specific asset – usually an account or deposit at a bank or a credit union. This is preferable to a joint account, which would create ownership interest for the individual being asked to manage the funds.

Finding the Right Arrangement

When a loved one with special needs approaches adulthood, there are many decisions that need to be made. I know that there is a great deal of emotion and concern given to these important milestones. The goal of guardianship or other alternatives is to make sure that their best interests are protected and cared for.

Each family circumstance is unique, and situations change. Our team is here to provide support through these transitions and make sure the goals of the life care plan are accomplished. Having an attorney that has expertise in special needs planning is an invaluable asset in making these critical legal decisions. When the team works together and has good communication, it can make a very difficult process easier and help bring your family peace of mind for the future.

Chapter 8 Transition Planning and Living Arrangements

An important part of the life care plan is to assist your loved one with special needs to live independently. I understand that this may not be possible with everyone we work with. This is another deeply personal decision and also relies on the circumstances and desires of the family. However, in many of the families we work with, this is the optimal outcome they envision.

Another challenge for those in the special needs community is being aware of the various housing options and in-home support available. The goal of this chapter is to help you see the possibilities that exist and see if they fit your circumstances. Many of our loved ones with special needs have the ultimate goal of independent living in some form.

It's Never Too Early to Plan

Even if you have a young child, it's likely you've given this some thought. Many of our family, friends, and clients have talked about this topic with us. It may be too early to make any determination, but it's human nature to envision the future for those we love. You may feel like you have time before you have to implement a transition plan for your loved one. However, we can start laying the groundwork for it early on in the planning process.

When your loved one approaches their early teens, transition planning begins to take on importance. This is often initiated in school, where a determination must be made in regard to secondary education. By high school, most families have a much clearer picture of the types of services their loved one might need in adulthood. This is also the time when you and your child will get a feeling for your desires when it comes to independent living and what their home life might look like.

Transition planning also requires flexibility and openness to change. We can think of several examples where the family did not see a path to independent living for their loved one. However, as they grew up, developed skills, and blossomed into adulthood, their loved one with special needs expressed a desire to live independently. This was a welcome blessing for all involved since the families saw how much growth it provided. Their loved one obtained greater happiness and quality of life.

Where Do We Start?

The best way to get started is to become familiar with all of the programs that offer support and services in regard to independent living. With all of the options out there, the challenge can be putting them all together and seeing what is the best fit. I help families with that in our area, and am happy to say there has been an increase in these types of organizations. Many of them were started by parents searching for options for their loved ones with special needs. Having someone who has been through it before and knows how to make it fit within a life care plan is so valuable.

Of course, the preferences of your family and your loved one will drive this entire process. This is another area where open and frank conversation must take place. It can be challenging to try to meet everyone's desires and find a happy medium. As mentioned, we also want to be open and flexible with our planning to accommodate a change of circumstances.

Another driver is the issue of guardianship or other alternatives. We have seen a variety of circumstances in this area. Some families have legal guardianship, but their loved one with special needs lives in a group home nearby. Others utilize alternatives such as power of attorney or conservatorship.

If a measure of independent living is desired, that's when we calculate the resources available and see if a combination of private and public means is required. An attorney knowledgeable in special needs law is also a critical member of the team at this point. We want to make sure everything is in place legally to make sure your family is protected and can be represented in court to make this process as smooth as possible.

Sliding Scale Fee Benefits

We've talked about government benefits like SSI and SSDI, and how instrumental they are to your loved ones with special needs. Once your child reaches adulthood, there are other benefits that might be available. These are often referred to as sliding scale benefits. These are fees for services adjusted depending on an individual's income. This helps make the services more affordable.

Each program has its own criteria, but the common element is that these programs are for low-income families or those with special needs. Some of the more common programs are the Supplemental Nutrition Assistance Program (SNAP), heating assistance, Section 8 vouchers, public housing, and other healthcare benefits. Depending on local law, you can see which programs your loved one qualifies for.

The Importance of Medicaid

When it comes to living arrangements, Medicaid is the most critical governmental benefit. Medicaid is the benefit that opens doors to services. The most critical service in this space is the Home and Community Based Services (HCBS). These provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than just in an institution or another isolated setting.

Although you might think of health care as being the primary service of Medicaid, a majority of the budget goes to help support HCBS programs. As recent as 2014, the Medicaid.gov web page reported that 53% of all long-term care spending was on home and community-based services. Since Medicaid is a joint federal and state program, you need to be familiar with what is offered in your area. Sometimes,

I see a situation where a loved one with special needs lives out of state, so it's important to engage support in the area where they live.

As you can imagine, these programs are always in high demand. There are long waiting lists in most states for HCBS programs. We recommend that you apply early – that might mean as early as age 18 in some locations. HCBS regulations do get updated regularly, usually with an emphasis on community integration and providing support in natural settings. Educating yourself about HCBS programs is very beneficial. I recommend the website hcbsadvocacy.org, which is a phenomenal resource.

Residential Options

I see a variety of residential arrangements among friends, family, and clients. From independent living, shared living, adult foster care, and group residences, there are a lot of options to choose from. Advocacy in this space has been on the rise, so it's really helpful to know all of the resources available in your area.

Some families have gotten very creative to provide the right arrangement for their loved one. Many of them have partnered with other families who were also seeking the right fit for their child. Several of the success stories include people who grew up together and had similar needs. This is just another example of the benefit of having a strong support community and making sure to talk with others who are going through a similar situation.

Putting it Together Financially

The economic and political climate have an enormous impact on critical Medicaid and HCBS programs. It can be challenging to navigate these services for that reason. There have been attempts to limit certain groups for benefits, which could result in those deemed to have “less severe” disabilities to fall through the cracks. There is also the issue of an aging population that can no longer care for their loved one with special needs.

For the financial plan, it's important that we work together and weigh the cost for all options. If funds are available in a Special Needs Trust or an ABLE account, we might find that we can fit them into the budget. Those accounts can be used to supplement government benefits and open up more options for your loved one.

Chapter 9: WHY I'M UNIQUELY QUALIFIED TO HELP YOU

I firmly believe that there's a unique connection between professionals and their clients - a connection that flourishes when clients resonate with the values and mission of the business they choose to work with. My commitment to the special needs community stems from personal experiences and understanding of the distinct challenges families face. In order to help you determine if we are the right team to support you, I'd like to share more about myself and my background. To facilitate this, my book publisher, Paul McManus, conducted an interview with me, providing an opportunity for you to get to know me better and decide if our team could be the perfect fit for your financial planning journey.

IMAGE

<https://www.dropbox.com/s/kk4bkizsv6asc06/Chris%20Ball%20Author%20Interview%20-%20edited.mp4?dl=0>

QR CODE

Chapter 10: THE NEXT STEP

"The future belongs to those who believe in the beauty of their dreams." - **Eleanor Roosevelt**

Congratulations! You are one step closer to achieving the peace of mind that comes from knowing you're on the right financial path, one that ensures a life filled with happiness, adventure, and opportunity for your family, especially if you have a child with special needs.

I wrote this book for two primary reasons:

1. To inform and inspire parents like you to think seriously about both your short and long-term financial goals, particularly in the context of special needs planning.
2. To extend an invitation for a conversation to explore the possibility of us working together.

You may have a great relationship with your financial advisor. However, most parents (even successful ones) have never taken the time to develop a comprehensive financial plan that addresses the unique needs of their special needs children. Without a plan, it's difficult – if not impossible – to make informed, strategic decisions about your family's financial future. If you appreciate what you've read so far, consider these three questions:

1. Have you established specific short and long-term financial objectives to secure the future of your family, including the well-being of your child with special needs?
2. Do you have a written plan that outlines how you will achieve those goals?
3. Do you have a team that you trust to act as a sounding board to give you advice and help you implement your goals?

If you've answered no to any of those three questions, then you have two pathways in front of you:

You can close this book and do nothing with the information I've shared. (If you have gotten this far, I hope this is not an option.)

You can schedule a 15-minute introductory phone call with me to begin the conversation and see how our team might be able to help you reach your goals for you and your family..

We understand your goals are uniquely yours, which is why we need to talk. This call is all about helping you decide if working together is a good fit for both of us. Maybe we are meant to work together. Maybe not. But we won't know unless we have this first, critical conversation.

Note: This is NOT a Sales Call

It's a two-way interview to make sure we agree this is a good match. I'll ask you some questions, and you can ask me some questions (in fact, as many questions as you want). And then, we can go from there. This is typically a 15-minute phone call; however, I will stay on until you and we have decided if it's a good fit or not. That's it. There is no obligation.

TODAY Is the Day. NOW Is the Time.

Schedule your initial Strategy Session with me right now. There's absolutely no fee, no obligation, no risk, and nothing to lose.

How to Schedule Our Call:

Go to: [LINK](#)

Pick a day and time that works best for you. That's it! Or, if you have any questions, you can email our team directly at: office@staltfinancial.com You can also call our office directly to set an appointment at (248) 733-4344. I look forward to hearing from you and, more importantly, working together to help you create a secure financial future for you and your family, addressing the unique needs of your special needs child for years to come!

SERVICES

- Special Needs Planning
- Investment Management
- Insurance Planning
- Retirement Income Planning
- Business Succession Planning
- Estate Planning*
- Tax Strategy*

**Estate Planning and Tax Strategy services are provided working in conjunction with your Estate Planning Attorney, Tax Attorney and/or CPA. Consult them for specific advice on legal and tax matters.*

RESOURCES AND SOCIAL MEDIA

Website: <https://www.staltfinancial.com/>

Author's LinkedIn Profiles:

Chris Ball: <https://www.linkedin.com/in/chrisballfinancial/>

ABOUT THE AUTHOR

Chris Ball, ChSNC™

Chris Ball is an experienced author, speaker, trainer and co-founder of Stalt Financial. Chris holds the Chartered Special Needs Consultant (**ChSNC™**) designation and has a special passion for servicing families that have dependents with special needs.

Chris also has many family members and close friends that have special needs, so that inspired him to get educated on how to better serve his loved ones and his clients. Chris strongly believes in a team approach to help ensure proper life care planning and to prepare for the unexpected life events we all face.

Chris obtained his BA in Business from Charter Oak College and has his Series 7 and 66 licenses as well as his Health and Life License. Chris lives in Royal Oak, MI with his wife Isabella. He enjoys working out, golfing, and is an avid reader. Chris loves all things Detroit sports and is a very passionate Bayern Munchen Fan.