



FAMILYVEST

SPECIAL NEEDS FINANCIAL PLANNING



A PRIMER
FOR CREATING
AN OPTIMAL
LIFE FOR
YOUR CHILD

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For My Family

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Prologue

"Sometimes the most scenic roads in life are the detours you didn't mean to take."

— *Angela M. Blount, Once Upon an Ever After*

Having struggled with money as a young college student, I set out to learn as much as I could about saving and investing. I took a long hard look at what money meant to me. What did I want from it? I came to the conclusion that what I really wanted from money was *a feeling*. Not flashy cars or homes, but the feeling that it gave me knowing that I was okay. I certainly realized quickly that life made no promises. I couldn't control so many things that happen to myself and my family, but I could do my absolute best to control what I could *do about it*. I don't mean to sound as if money solves every problem. It doesn't. We all know that. But it is important. We need it to sustain ourselves and to provide for our loved ones. Money seems to have a way of working its way into every aspect of our lives. Decisions seemingly void of financial need can often find themselves the central player in our lives and decisions. So when we think of a Life Plan for ourselves and our family, it undoubtedly becomes a financial plan as well.

As the father of two boys on the Autism spectrum, I learned early that the road would not be easy and that the margin for error would be small. While planning for our children's future, I realized the lack of transparent advice for families with special needs. My wife, Crissie, and I struggled to deal with not only the emotional aspects of 2 newly diagnosed children (adjusting to our "new normal") but the realization that this was going to be a financial maze as well. Having trained in the technical side of finance for the last 20 years, I decided to leave the world of institutional portfolio management and dedicate the second act of my career to helping guide families like ours on a path where we tackle these obstacles together. Small decisions we make every day have a compounding impact on our financial lives and seemingly straightforward decisions turn out to be more complex than we could have ever imagined.

That's why I'm here.

My goal is to help you stay away from the tricks and traps that are laid before you and to help bring clarity and peace to the overwhelming process of building wealth for your family.

You are here reading this, which means you are already mindful that getting your financial ducks in a row, so to speak, is important and you have the desire to prepare. Reading this primer is a valuable start to the process of creating a financial life plan for your family and you will no doubt succeed through tenacity and dedication.

Making decisions for the care of your special needs child, be it short term or long term, can be very emotionally grueling. We cannot predict the future, but we can create a process to think through the many variables that will inevitably arise and craft a bright future for you and your loved ones.

My intention with this book is not to come at you with absolutes, but rather to help you start the process of systematically breaking down the problem and devising the solution that is right for you and your children and the vision of what their life can become.

Life has a funny way of not turning out exactly the way we plan, doesn't it? And that's okay. That's more than okay. The twists and turns are what make us who we are. Everyone has challenges and struggles, of course, but there is also immense joy and love.

That is what life is.

And it's beautiful.

Introduction

The purpose of this e-book is to help parents answer some of the tough questions that come along with having a child with special needs. Questions such as, "who will care for our child when we are gone?", "where will our child live?", "will he have a job." The purpose of this book is to serve as an overview of the construction of a life plan for your child. For our purposes here, when we use the term "child" in our discussions, we are referring to adult children as well as minor children. While we move through these topics, we don't necessarily move chronologically with the age of your child, because these areas of discussion apply to any age. Certainly, there are ages that mark important milestones, such as turning 18 years of age and demand certain specific consideration in the life plan at that time, but many of the other topics covered while discussing a life plan for your child can apply to many age points. That said, time is on your side when it comes to planning and the earlier you begin to plan and solidify these decisions, the chances are higher that your child will be able to have the kind of care and lifestyle that your family envisions.

Chapter 1

Letter of Intent (LOI)

What is a Letter of Intent?

A letter of intent is a document that serves as a guide to individuals who may care for your child in the future. In many cases, it contains pertinent information that only a parent would know about their child's history and personal preferences. This includes things like your child's eating habits and aspects of their daily routine.

When creating a letter of intent, it's important to remember that you need to view the document through the lens of your child's life today as well as in the future—as they grow and as their needs may change. Equally important to keep in mind is that this document needs to be updated annually to account for those changes that may have taken place as they grow older.

Historically, a letter of intent has been a physical document that's held in paper form, either in the home of the person who created it or with the future responsible party. That, in itself, immediately presents a few challenges. For example, what happens if either party misplaces the document? Or worse, what would happen if the future responsible party didn't realize that the letter of intent was misplaced until it was too late?

Thankfully, we live in a digital age where we no longer need to store important documents in a physical location where they run the risk of being lost or stolen. Now we have options to save important information in electronic form where all parties have access and where updates can be made and shared by a few clicks of a mouse. One company that I have found to be leading the way in simplifying the process for creating a letter of intent is [Specialvest.com](https://www.specialvest.com).

What to Include in Your Letter of Intent

Although a letter of intent is generally viewed as an important step in ensuring continuity in quality of life for your child should you pass away, this document also serves an important function while you are still alive. As a financial planner, I take a holistic approach to addressing my clients' needs. For my clients who are parents of children with special needs, the letter of intent can assist a great deal in ensuring that not only are long-term financial needs being met but that we are also adequately prepared to achieve their vision for their children down the line.

One question that I hear quite a bit is "What information should I include in my letter of intent?" My general answer is "As much as you feel that someone who doesn't know your child on a day-in, day-out basis would need to know."

For practical purposes, here are a few things that should absolutely be included:

The role of the future responsible party

The letter of intent should have a specific section on how much care your child currently requires and how much you expect them to require in the future. It's important to be very specific about the role that the caregiver (and others—siblings, etc.) will play in your child's life and the level of care they can expect to provide.

While it's understandable that these roles may change over time, and their level of involvement may increase or decrease depending on the need, at a minimum you want to set the baseline so the responsible party can have an idea of what to expect.

Medical history

Additionally, the letter of intent should address any medical, health or wellness issues. You will want to provide your child's medical history for the future responsible party to have an idea of your child's medical past and know important facts for helping plan for their future.

These are considerations such as medications that they are taking, and therapy or treatment plans that are in place. You should also include contact information for physicians, therapists and any other professionals who preside over the care of your child.

Lifestyle and living arrangements

Finally, it should be stated how your child wants to live and where they wish to live in the future. Since this is your child's well-being that we're talking about, if possible, this is a perfect time to involve them in the process.

For example, if your child is active socially or physically, and you want this to remain the case, you should articulate this inside your letter of intent. In addition, you want to mention lifestyle issues like your child's favorite foods, activities that they enjoy and how they prefer to spend their leisure time. You will also want to include any further education or career choices that you think would be helpful for the responsible party to know.

The Key to Your Letter of Intent

By now you're probably thinking that this all sounds like a lot, and you're right—well, partially. It's true that creating the letter of intent takes time and probably won't be accomplished in one sitting. The key is to develop it over time, and this process is made considerably easier with the power of the internet and companies like SpecialVest that walk you step-by-step through the process.

Chapter 2

Social Security Supplemental Insurance (SSI) & Disability Insurance (SSDI)

The SSI program pays a monthly stipend to people with few assets and low incomes. Recipients must be at least 65 years of age, blind or disabled. Blind or disabled children whose parents have limited income and few financial resources may qualify for SSI benefits. Applicants must be American citizens living in the U.S., although in certain cases, noncitizen residents could qualify. The program is managed by the Social Security Administration (SSA); however, SSI is paid for by general taxes and not Social Security taxes (this is unlike the SSDI program, which I cover below). As a federal program, the basic amount paid out is the same nationwide and is known as the federal benefit rate (FBR); however, states are at liberty to add to this minimum benefit, and many actually do. The FBR is subject to annual increases to adjust for changes in the cost of living. For couples, the monthly SSI payout amount is 1.5 times that of an individual beneficiary.

Income calculation

When calculating income to determine eligibility, the Social Security Administration considers wages, pensions, Social Security benefits, and shelter and food that may be paid for them. It also includes part of the spouse's income for married applicants and part of the parents' income for applicants under 18 years of age. For applicants who are blind or disabled, wages used to pay for goods and services that facilitate work (a wheelchair, for instance) are excluded from the income calculation.

Once a child reaches age 18, they qualify for SSI based on his or her own income and assets. In order to receive benefits, the child must meet the government's disability standard, have less than \$2,000 in assets, and receive minimal income. Each dollar of unearned income (including resources such as direct payments of cash to your child and reductions for in-kind payment for food and shelter) and every two dollars of earned income reduces a beneficiary's base SSI award by one dollar. If the SSI benefit reaches zero because of this reduction, SSI coverage ends. Despite these restrictions, an SSI beneficiary needs only a \$1 award in order to retain their Medicaid benefits, so careful planning in this realm carries great rewards.

The income cutoff that qualifies you for SSI may vary from state to state. Certain incomes are excluded from this calculation, including the Supplemental Nutrition Assistance Program (SNAP), home energy assistance (there are exceptions), and shelter supplied by private not-for-profit organizations.

Asset calculation

Assets looked at during the resource calculation of SSI eligibility include bonds, stocks, cash, bank accounts, and real estate. The maximum total assets valuation to qualify for SSI is \$2,000 for individuals and \$3,000 for couples. Certain items are excluded from the resource calculation, including your primary residence and one personal automobile.

Social Security Disability Insurance (SSDI)

The SSDI program provides a monthly payment to people who are unable to work because of a medical condition expected to last for one year or more, or lead to death. Family members of the disabled person may also qualify for SSDI in certain instances. As with the SSI program, SSDI is managed by the Social Security Administration. SSDI is, however, funded by Social Security taxes.

About 11 million Americans (9 million workers and 2 million dependent spouses and children) receive SSDI benefits. The amount you receive will depend on your past earnings, and there is a ceiling.

Most special needs planning begins with a look into whether a child needs and qualifies for Supplemental Security Income (SSI) for support. SSI is a means-based program for people with disabilities and provides a limited monthly cash benefit of about \$733 a month, the exact amount depending on the state and whether the beneficiary receives housing or income from other sources. In and of itself, this payment may or may not mean much for a child's financial future (although for poorer families or individuals it may), but SSI eligibility also comes with a much more important benefit — access to Medicaid. For this reason, many families, especially those with children who have major medical expenses, pursue SSI benefits despite the program's severe income and asset limits. SSI can also be the ticket into vocational training and group housing services.

A child who became disabled before reaching 22 years of age can also collect Social Security Disability Insurance (SSDI) based on a parent's work record if either of his parents has worked enough quarters to collect Social Security and is already receiving Social Security benefits or has died. Under SSDI, the "adult disabled child" of the Social Security beneficiary receives a monthly benefit check, as long as he doesn't perform substantial work, defined as earning more than \$1,090 a month. After receiving SSDI for two years, the adult disabled child also begins to receive Medicare, a substantial benefit.

Often, adults who became disabled as children receive SSI benefits until their parents retire, at which point they transition to SSDI, which is usually preferred both because it may offer a higher monthly benefit and because the beneficiary no longer needs to be concerned about SSI's strict rules on other sources of income and savings. On the other hand, the switch to SSDI can be problematic if it means that the adult child loses eligibility for Medicaid or other programs.

Work tests

Applicants for SSDI must meet a recent-work test and a duration-of-work test. The recent-work test measures how many years you worked in the immediate period preceding your disability. Requirements vary depending on an applicant's age. For those 24 years and younger, it's 1.5 years of work in the preceding three-year period. For 24- to

30-year-olds, it's three years in the preceding six. For applicants 31 years and older, you must have worked for at least five years in the preceding 10.

The duration-of-work test is also based on age. It has **age brackets, each with its own requirement for years worked**. Note that if you are disabled but still working and earning above a certain minimum each month, you will not qualify for SSDI.

Application

If you have a disability that you believe makes you eligible for SSDI, submit an application at the earliest opportunity. Processing and approval of your application can take months or, if the application is initially denied, even years. The longer you wait, the more likely you will experience significant financial pressure since the disability prevents you from making a satisfactory income. Even if you do not have all the required information, it's better to file the application and submit the information as you go along. If the application is denied, you have the right to appeal the decision. Recent research shows that nearly 60 percent of applicants denied at the first stage by the state disability examiner file an appeal, with about half eventually accepted into the SSDI program.

Retirement

The days of fully vested lifetime pensions are long gone, Social Security is under threat from budget cutters and the stock market is a volatile place that has recently offered more downs than ups. Add to this unstable mix a variety of confusing retirement planning options with opaque names like 401(k)s, 403(b)s and SEIRAs and it's no wonder that most people are worried about how they will finance their retirements. But let's throw one more factor into the mix: Instead of just worrying about yourself, let's say that you have a child with special needs who relies on you for support. What happens to your child when you retire?

First, the good news. Under our current Social Security system, when a parent of an adult child retires and begins collecting Social Security retirement benefits, this child may be eligible for Social Security Disability Insurance (SSDI). The criteria for collecting benefits is complicated, but if your child suffers from a permanent disability that manifested itself prior to her turning 22, then there is a chance that your child could receive SSDI upon your retirement.

SSDI is a great benefit, but it may not be nearly enough to provide for your child when you retire. The obvious reason is that retirees often end up living on reduced incomes that come nowhere near their previous salaries. In other words, while you work there may be plenty of money to assist your child, but once the money gets tight in retirement it may be impossible to provide the benefits that he or she needs.

In an age dominated by private retirement plans and benefits, it should come as no surprise that the best strategy for helping a child with special needs when you retire is essentially the same strategy that you should follow for yourself, namely saving additional funds in your retirement account now for use when the time comes. This involves a detailed calculation of your needs and your loved one's needs, both now and into the future.

Knowing how much money you'll need for retirement is one thing, but selecting the appropriate financial vehicle to hold

that money for you and your loved one with special needs is an equally pressing concern. Many financial professionals are great at making money, but they may not have any idea how that money affects the benefits of a person with special needs. Retirement options that work for one family may not be suitable for another. This is where your special needs financial planner comes into the picture to help your family with a plan that will generate enough income for retirement and protect that income for the benefit of your child.

Retirement should be a time to relax and enjoy your well-earned time off. It shouldn't be one long period of stress, especially when it comes to your child's special needs. Consult early and often with your retirement planner and your special needs planner and you should be able to rest assured that you will still be able to provide for your child with special needs throughout your retirement.

Retirement accounts like 401(k)s and IRAs make up the majority of most people's savings. While these plans encourage saving by offering significant tax rewards, they were certainly not set up to help families with special needs, who are typically trying to provide a protected source of liquid funds for a child long into the future. The biggest problem with retirement benefits when it comes to special needs planning is that most retirement plans require some form of distribution from the account once an account owner dies, especially if the account names someone other than the account owner's spouse as a beneficiary. In these cases, naming a child with special needs as a direct beneficiary of a retirement account can affect the child's ability to access government benefits. This is so because the income received from the retirement account is counted when it comes time to determine the child's eligibility for Supplemental Security Income (SSI), Medicaid, housing benefits and a host of other programs. In general, if a child is receiving or expects to receive benefits from any of these programs, or if he is simply not good with money, then he shouldn't be named as the direct beneficiary of a retirement account. In order to avoid this problem, many people seek to name a special needs trust that benefits the child as the beneficiary of a retirement plan. When properly constructed, the special needs trust can hold the distributions from the retirement plan for the child's benefit without endangering his eligibility for government services. However, this strategy has three main drawbacks.

First, if the trust for a child with special needs names a charity as the ultimate beneficiary when the child passes away, then the entire retirement account must pay out into the trust within five years from the account owner's death. This could create an income tax penalty because distributions from the retirement plan are taxed as income in the year they are taken. These distributions, if retained in the trust, will be taxed at the trust tax rate, which is usually much higher than the individual tax rate.

Second, if the trust names other people as the so-called remainder beneficiaries (those who receive what remains in the trust after the original beneficiary's death), and any of those beneficiaries is older than the child, then the retirement account must make payments into the trust based on the age of the oldest beneficiary. This, too could increase the income tax penalty.

Finally, because in most cases the trust income tax rate is significantly higher than the individual tax rate, income held by the trust and not used for the benefit of the child with special needs will be further reduced by excessive income taxes. In many cases, the benefits of using a special needs trust to hold retirement benefits outweigh the alternatives. However, some families who have other assets available, like cash, investment accounts or life insurance, may want to use those to fund the special needs trust while leaving the retirement benefits to other children. Also, some retirement plans, such as Roth IRAs, do not generate taxable income when they are cashed out, making them a better choice to fund a special needs trust. In any case, consultation with a special needs planner is a must before naming or changing beneficiaries of any retirement account.

Chapter 3

Tax Deductions and Credits for People with Disabilities and Their Families

If you or your spouse have a disability, or if you care for a dependent with a disability, you may be able to qualify for one or more tax credits and deductions. Here is a description of some of the more common ones.

Medical Expenses

If you, a spouse or a dependent incur medical or dental expenses over the course of a year, you may be able to deduct them. In general, if you are under age 65, you can deduct your medical or dental expenses that exceed 10 percent of your adjusted gross income. People who are 65 and over can deduct expenses that exceed 7.5 percent of adjusted gross income. For example, if your adjusted gross income is \$50,000 and you have \$10,000 of medical expenses, you can deduct \$5,000. (10 percent of \$50,000 is \$5,000, subtracted from \$10,000 of total medical expenses to arrive at a \$5,000 deduction). There are many types of services that qualify as medical expenses, including Braille books, telephone equipment for the hearing impaired, guide dogs, some long-term care insurance premiums and hearing aids, just to name a few.

Impairment-Related Work Expenses

If you have impairment-related work expenses due to the purchase of goods or services that allow you to do your job, you can include these expenses as a business deduction on your tax return instead of deducting them as regular medical expenses. In this case, you don't have to wait until your expenses exceed 10 percent of your adjusted gross income; you can deduct all qualifying impairment-related work expenses from dollar one.

Child and Dependent Care Tax Credit

You may be entitled to a **tax credit for up to 35 percent of your expenses** if, in order for you to work or look for work, you must pay for care for a dependent child under the age of 13, a spouse who can't care for themselves, or any other person living with you defined as a dependent.

Elderly or Disabled Tax Credit

If you are 65 or older, or if you have retired on permanent or total disability, you are entitled to a small tax credit.

Earned Income Tax Credit

If your adjusted gross income from working is low, you can qualify **for this tax credit**. In order to qualify in 2017, you must make less than \$15,010 if you are single with no children, \$20,600 if you are married and filing jointly with no children, and between \$39,617 and \$53,930 depending on your marital status and number of children. In order to qualify, your children must either be under the age of 19, a full-time student under the age of 24 or permanently and totally disabled. In some cases, a person with disabilities or his or her family could qualify for these credits and deductions. If you file an income tax return, or if you think you might need to in the future, talk to your special needs planner about how these credits and deductions may apply to you.

Chapter 4

Guardianship & Alternatives

Once a person reaches the age of 18, they are guaranteed certain civil rights under state and federal law. These rights cannot be taken away by parents, support coordinators or social workers. It's an exciting time for some people with a disability as they gain the opportunity to explore their independence.

However, not every person who reaches the age of majority will have the mental capabilities to make decisions that are in their best interests. While many parents of children with special needs will consider guardianship first to take care of their child, there are alternatives worth exploring before taking such a major leap.

Guardianship has far-reaching implications. Therefore, the court considers it a measure of last resort when no alternative means of intervention is feasible. The following are some of the options to guardianship that parents can consider.

A strong circle of support is ideal when the disability is not severe and the person can make most choices on their own. It is an informal decision-making assistance mechanism that relies on family and close friends. If the person is open to the opinions of their support circle and can be convinced to make prudent decisions, there is little need to pursue a more formal process. This avenue is, however, not practical for those living with a significant developmental disability.

A **power of attorney (POA)** is a legal mechanism through which a third party (referred to as an attorney-in-fact) is granted authority to make decisions on behalf of another person (the principal). A POA is considered durable if it remains in force even after the principal is incapacitated. A durable POA (DPOA) can vary in scope. It's important to note that the DPOA *does not* take away the principal's power to continue making their own decisions. The principal can revoke a DPOA in writing anytime they choose. A DPOA is automatically revoked on the death of the principal. A DPOA can also be specific—e.g., a health care DPOA, an education DPOA or a financial DPOA. We will go into DOA's and DPOA's a bit further in the upcoming chapter on legal considerations.

A **representative payee (RP)** is an agency or individual authorized to receive and manage government benefits on behalf of the payee/recipient. To authorize an RP, you must complete the requisite paperwork and notify the Social Security Administration (SSA). The government agency oversees an RP in much the same way that the court supervises a guardian. The RP receives the beneficiary's monthly SSA payment and must document how the funds are used for the recipient's benefit.

An **advance health care directive** is usually applied to the elderly or those afflicted by a condition that leads to a steadily deteriorating ability to make choices. The advance directive details who and how your medical rights will be exercised when you can no longer make the decisions. A **living will** is an example of an advance directive and comes into force in

the event of terminal illness, a perpetual vegetative state or the terminal phase of a health condition. A *health surrogate* is another example of an advance directive. The designation must be signed in the presence of at least two witnesses. The surrogate can make medical decisions, access health records and apply for the individual's benefits. The surrogate designation only comes into effect when the treating doctor decides the individual is incapacitated.

A *trust* is a legal arrangement in which a person(s) or institution is charged with managing an asset for the benefit of another party. The three parties to a trust are the settlor (the person who sets up and funds the trust), the trustee (the person(s) or institution managing the assets) and the beneficiary (the person(s) for whose benefit the trust has been established). Trusts can be revocable or irrevocable.

A *Revocable trust* (or living trust) is revocable as long as the settlor is alive. The settlor is free to move assets into and out of the trust. They can also alter the terms as they relate to trustees and benefit distribution. However, a living trust becomes irrevocable once the settlor dies. The advantage of a revocable trust is flexibility. Its major drawback is that it limits the beneficiary's access to government benefits such as Supplemental Security Income (SSI), Medicaid, public housing and the [Supplemental Nutrition Assistance Program \(SNAP\)](#).

An *irrevocable trust* cannot be altered once it is established (though some states such as Florida provide for exceptional circumstances under which the trust can be modified). Irrevocable trusts are favored when the settlor wants to provide for the long-term care of an elderly person or a disabled child. For individuals with disabilities, a special type of irrevocable trust known as a *special needs trust* is set up to protect the person's eligibility for government benefits. We will delve further into the specifications of a special needs trust in the upcoming chapter on legal concerns.

Choosing Guardianship

Guardianship is the process by which the court determines an individual ("the ward") has questionable ability to make decisions and therefore assigns some of the individual's rights to a third party. Guardianship seeks to protect the person's property, welfare and health. The process leads to the selection of either a guardian or a guardian advocate.

Guardian

People who are eligible for guardianship include those with dementia, severe developmental disability and any condition that prevents them from normal function. Unlike guardian advocacy, the process for establishing guardianship is rigorous and hinges on determining the ward's incapacitation based on expert opinion.

Guardian Advocate

Guardian advocacy is an option available to Florida residents. It is limited to people with specific developmental disabilities—that is, autism, retardation, cerebral palsy, spina bifida and Prader-Willi syndrome. The individual must lack the capacity to make only some but not all decisions necessary for them to care for themselves and their assets. As a less intrusive form of guardianship, the court does not need to make a determination of the ward's incapacity.

Depending on the court's evaluation of the individual and their circumstances, the court may appoint a guardian of the property (responsible for delegated property rights), a guardian of the person (responsible for delegated personal rights) or a guardian of both (responsible for delegated property and personal rights). The person appointed by the

court may be a family guardian (a relative or close friend of the ward), a professional guardian (paid by the ward's assets) or a public guardian (if available).

A guardianship is terminated when the ward's rights are restored, the ward cannot be traced, the ward's assets have been exhausted (applies to guardian of property only) or upon the death of the ward.

Chapter 5

What to Do When Your Child Turns 18

Education & Employment

At some point in a child's early adolescence, most families suddenly realize that the services and programs that they rely on to care for the child will soon disappear and be replaced by radically different benefits. Most of these new benefits abruptly come into play once their son or daughter leaves the public education system, which often provides the bulk of the child's care and daily structure. This may happen at any time between age 18 and 23, depending on the state and the child's needs. One of the most important aspects of this transition is securing additional educational and employment services for the child. According to the National Collaborative on Workforce and Disability, *one-quarter of all adults with disabilities work at either a full- or part-time job*. Some of the remaining three-quarters are unable to work at all due to their disability, but many disabled adults who aren't employed don't have a job because they lack the skills necessary for gainful employment. Several federal laws address this situation with the goal of providing vocational education to a wider segment of the population with disabilities.

The **Individuals with Disabilities Education Act (IDEA)** mandates that special education plans begin transition planning when a child turns 14. At this point, a written transition plan must be incorporated into a child's Individual Education Plan, outlining the steps a school will take to help a child with special needs acquire skills necessary for an eventual move into the workforce. By the time the child turns 16, the special education team must steer the child towards development programs keyed towards the child's individual vocational preferences. The law also mandates periodic measurement of the child's progress to ensure that he receives attention from the proper vocational advocates. Once a child reaches 18 and receives either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) payments, the Social Security Administration (SSA) offers several programs to encourage him to work.

The best-known program, **Ticket to Work**, is a somewhat complicated program designed to offer beneficiaries a way to begin a career without having to worry about losing their SSI or SSDI benefits. Under the program, any month that a beneficiary earns more than \$780 counts as a month of "trial work." If during any 60-month period a beneficiary has nine months where he earns more than this \$780 limit, the trial period ends. After the end of the trial period, a beneficiary does not receive an SSDI payment in any month where he makes "substantial earnings" of more than \$1,090. For three years after the end of the trial period a beneficiary can immediately regain benefits if he falls below the substantial earning level and still has a disability. Also, a beneficiary receiving Medicare because of participation in SSDI can continue to receive free Medicare Part A services for up to four and a half years following the end of the trial period. While complicated, these rules make an SSDI beneficiary's transition into the workforce slightly less burdensome than if benefits immediately ended. SSI beneficiaries, on the other hand, must conform to very strict income and asset limits. Often, beneficiaries who could hold a job do not pursue one because they are worried that they will lose their SSI benefits once they earn too much. While this is certainly a concern, the benefits of employment may outweigh the loss of SSI. Furthermore, the government provides specific incentives for SSI beneficiaries to work. For instance, if a person with disabilities is under 22 and at school or in a vocational training program, \$1,780 of his monthly income does not count against his SSI benefit, up to a yearly limit of \$7,180.

The Social Security Administration also offers the **PASS (Plan for Achieving Self Support)** program for SSI beneficiaries who would like to work. Under this program, a beneficiary presents the SSA with a detailed plan for obtaining a specific type of employment. Once the SSA approves the plan, a beneficiary sets aside income and assets towards achieving her goal without having those funds count against her benefit. Funds can be used for things like child care, transportation, books and supplies, and additional education and training. Many programs are available for people with special needs to seek employment if they would like to do so. Unfortunately, the rules for most of these programs are complicated. Parental attention and planning well before a child turns 18, usually with the assistance of local vocational agencies and qualified special needs planners, offers the best chance for successfully navigating the maze of educational and employment opportunities.

Medical Coverage

Medical care is one of the most important services, if not the most important service, that a person with special needs may need over the course of his or her life. The transition from a parent's health insurance to an individual plan can begin at age 18 and stretch until the child turns 26 or, in some cases, even longer. Since proper medical care is literally a life-or-death matter, it makes sense to begin planning for this transition as early as possible. Depending on your child's specific special needs, turning 18 could require significant health care or need no immediate coverage. Some parents have health insurance that covers their child with special needs if the child is still living at home due to significant disability. However, each health insurance company's definition of a disability may or may not match the Social Security Administration's definition, making it possible to receive federal disability benefits without qualifying for private insurance. The insurer may not offer coverage for the specific drugs or services the child requires, or it may not offer coverage for adult children with disabilities at all, making it all the more important to review the family insurance policy to determine what further coverage a child's condition requires.

The Affordable Care Act has made some of these issues a little less complicated than they used to be because the Act requires all insurers to allow children to qualify for benefits under their parents' plans until the child turns 26. This significantly delays some of the headaches parents used to face when their children turned 18, but it does not remove the ultimate concern. Rather, it pushes it out a few years and allows some additional time for proper planning. If a parent's private insurance is not going to provide the coverage their child needs and the child will not receive coverage through employment, then he must seek Medicare or Medicaid coverage. The "easy" way to obtain access to these programs is to qualify for Supplemental Security Income (SSI), which automatically qualifies a beneficiary for Medicaid, or Social Security Disability Insurance (SSDI), which allows a beneficiary to receive Medicare two years later.

These are not the only ways to obtain government-funded health care. Many individual states may offer Medicaid to adults with disabilities who meet different income or asset requirements, and some states have taken advantage of the Affordable Care Act to dramatically expand access to Medicaid. Furthermore, some states offer working adults with disabilities discounted health insurance or access to supplemental insurance that may improve upon the benefits provided by an employer.

Housing

Although medical care is probably more fundamentally important for a person with special needs, housing is right behind it on the list of necessities. One of the most difficult hurdles for families of children with special needs is the question of where the child will live. Will your child stay with you, go to college, live independently, or move to a group

home? Will he or she be able to be self-sufficient, need support from parents, or require subsidized housing? Families may grapple with these tough decisions at the time a child reaches adulthood or at a later time when living at home with parents is no longer appropriate or possible. Whenever this transition occurs, it requires careful planning and extensive research about the options available in your particular community. Planning is important so that this vital transition does not occur under the sudden pressure of a parent's illness or death.

Section 8 housing vouchers are the main government program for people with low incomes who need housing assistance. Once an individual has obtained a voucher from his local housing agency, he or she is qualified to move into a subsidized housing unit in his community. The resident will pay approximately 35 percent of his income towards his rent and the government will pay the landlord the balance, up to a certain amount. Section 8's income and asset rules are reminiscent of SSI's rules, but they differ in fundamental ways, especially when it comes to the treatment of assets and how the housing agencies count income. Obtaining Section 8 benefits can be a very long haul so it is important for parents of children turning 18 to think about applying for a voucher as early as possible, even though the child may not be ready to move out of the family home.

Applying **early** will start the waiting game and make it more likely that a voucher is available when the time comes to use one.

Chapter 6

Legal considerations: Securing your Plan

Why do I need an Estate Plan?

What is an estate? An estate is essentially everything someone owns. This includes business holdings, personal possessions, financial assets, real estate, insurance policies, and more. The reason we need an estate plan is so we can protect and maneuver our assets and successfully transfer these assets to others as we wish during our lifetime and after our death.

It's important to begin an estate plan with a holistic family point of view. This estate plan reflects what is important to your family; where your values lie. So, the discussion will begin with figuring out what you want exactly to happen for your child, and then how to create that outcome. Using your child's support system of friends and family will be important during estate planning since many of these people could assist in executing the wishes that have been expressed for your child after you are no longer there. Items such as the **Letter of Intent**, wills, medical directives, and trusts can be reviewed with this group so they are all aware of what has been discussed and decided upon to help plan for a supportive and caring environment for your child.

How can I use a Special Needs Trust in my Estate Plan?

One very useful tool used for planning for a child with special needs is a **Special Needs Trust (SNT)**. This trust begins with a trust creator or a "trustor" or "grantor", with provisions for the management of the property or money by a legal entity or individual called a "trustee". The person for whom the trust is drafted for is called the "beneficiary". This type of trust is an excellent tool because it allows parents to allocate money to care for their child **while preserving SSI, Medicaid, and other state services** since trust assets *are not* put toward the \$2,000 asset limit that these programs require for eligibility. It is intended to supplement, not take the place of, government assistance. The purpose of SSI is to assist with housing expenses and Medicaid to pay for healthcare. Consequently, funds allocated from a SNT are intended to enhance the quality of life of the beneficiary and not duplicate these government programs.

It is important to have this document drafted by an attorney that has specific expertise in laws pertaining to Medicaid and Social Security and most preferably have a designation as an elder law or a trust and estate attorney. This is important because for a SNT to be valid, the language must be in accordance with articles in the Social Security Act. The SNT must clearly convey that the beneficiary has no access or control of the assets in the trust.

It also makes sense to make family decisions regarding how the family would like for the trust to be carried out before meeting with an attorney so the attorney knows what direction to go in from the beginning of the process. The attorney will need to know if you intend on initiating a *revocable* or *irrevocable* trust. The attorney can listen to your desires for

the trust and help direct you on which is best suited for your family. A revocable trust gives the creator of the trust more flexibility and control. A revocable trust is often called a “grantor trust”. Any income from a revocable trust is deemed income of the grantor and is reported on his or her tax return as such. On the other hand, an irrevocable trust has its own tax ID number and is considered its own taxable entity that is required to file a Form 1041 annually to report trust income taxes. You would not want to keep earnings in an irrevocable trust as the taxes could be quite high for these earnings. Again, it’s a good idea to consult with your attorney, and possibly a CPA or tax attorney if you are a high net worth individual, about which type of trust to utilize based on your individual circumstances.

Who will act as a trustee? This can get tricky. First, let’s take a look at what some of the responsibilities are of a trustee:

- To act as a **fiduciary** for the trust beneficiary. This means that any and all decisions must be made with the best interest of the beneficiary in mind with a relationship based on good faith, honesty, and trust.
- To make payments or distributions of funds to the trust beneficiary
- To manage the preparation of tax filings and attempt to minimize trust taxes
- To submit annual reports to whomever is required to receive one based on state statutes or per the trust agreement
- To stay abreast of eligibility requirements for SSI and Medicaid programs, directing the trust as to maintain these benefits.
- To deliver all other responsibilities outlined in the trust agreement

It’s understandable as parents to believe that a business or corporate entity would not be able to make the best decisions for their child’s well-being. Surely a family member or close family friend would be the best choice to oversee these decisions, right? Maybe. Then again, perhaps not. Managing an operating trust can be a great deal of work. Learning and implementing all of the tasks related to, for example, taxes and investments, is no small endeavor. Family members and/or family friends may not have the base of knowledge to work from like a corporate trustee would.

Corporate trustees, such as banks and trust companies can be great options given they are external and objective entities, have specific expertise in the managing of trusts, and are strictly monitored and audited. Parents or another family member who is experienced in managing investments or has the skills and know how to monitor other professionals, such as accountants or investment managers, could be a viable choice to serve as a trustee. A family member who is a trustee can hire other professionals for assistance, but those other professionals cannot be assigned *fiduciary* responsibilities. These remain with the trustee only. Additionally, it can be beneficial to have a trust protector, or trust advisor. A trust protector has the authority to appoint or replace a trustee. There can be many reasons why a trustee would need to be changed, be it deficient performance or simply the trustee’s desire to no longer perform the duty. Your attorney would need to include the trust protector’s responsibilities in the trust.

Whatever direction you choose as far as selecting a trustee for your child’s trust, make sure to weigh out the positives and negatives or assigning a professional versus a family member. Either can work if the pieces fit.

What is a Power of Attorney (DPOA) and do I need one?

As we briefly covered in a previous chapter, **A Power of Attorney (POA)** is a legal form used to designate someone to take care of your affairs when you are not able to. The individual that you decide to designate is called an attorney-in-fact or an agent. You have the ability to construct the limits of your agent’s authority as you choose. A **“durable” POA** is one drafted with the provisions that it remains effective even if you become disabled or you are not able to communicate. A POA essentially dissolves upon your death.

So, what does this have to do with you? Well, if you are caring for a special needs child, it is important that you have someone designated to take over for you if you are temporarily unable to fulfill your duties as a caretaker. If it appears that you will be disabled on a permanent basis, the court will need to delegate a successor for you. If you are using this POA to assign power for personal affairs, you will most likely want to have your spouse or a family member perform this duty. Keep in mind that unless you include medical provisions in your POA, your agent will not have the authority to make any of these decisions. A separate medical POA would be required.

A durable POA can have its advantages for an individual with a mental illness who does not have a guardian. This document would allow for someone to intercede if necessary if, for example, an individual had a psychotic episode and hence were temporarily unable to make decisions for themselves. There can be an issue with this, however. This principal has the power to revoke a POA at any time, so when this individual may need this sort of help the most, for example, when he or she might be in a manic episode, it can be removed. With this in mind, there is something called a **Psychiatric Advance Directive (PAD)** which cannot be revoked by the individual in need of psychiatric attendance. An "instructive" PAD can be initiated by someone with a mental illness, while displaying competency, who wishes to outline his or her preference for treatments in the event they become incapacitated. It is also possible to appoint someone to make these decisions if it is a "proxy" PAD. As this is being written, 25 states have specific PAD statutes in place and most states have some form of accepted legal advances (AD) for healthcare.

You need a Will. You just do.

A will elects someone to handle your estate and finalize your affairs after you are deceased. It also makes sure that you transfer what assets and to whom after you die. A very important purpose for our discussion here is that of appointing a guardian for a child who is unable to care for him or herself. Both parents should have a will in place. Typically, one spouse assigns guardianship to the other in the event of their death. A parent should also have a succession plan several layers deep to accommodate the possibility that one of your designees either passes away or resigns as a guardian. Special attention should be paid to what is called a **residual property clause**, which transfers remaining property or cash not specifically mentioned in the will. You will want to make sure that assets don't inadvertently get passed to a special needs child disqualifying him or her from their government benefits.

Review your will periodically with your trust or estate attorney. You can amend your will as needed throughout your life as circumstances change, but you may consider replacing your will if major changes are needed to avoid any misinterpretation or confusion.

Can I just go online and print these things out myself? Do I really need a professional?

Some people have a limited amount of possessions and do not have children. In this case, sure. There are online will templates and forms that can be downloaded and filled out without the aid of an attorney. Parents of children with special needs shouldn't take the risk of preparing documents that are not valid due to incorrect preparation. For example, if a will is not witnessed correctly, it may not be valid. Also, if a will is partially printed and partially handwritten, this can also make the intentions ambiguous and difficult to honor. Also, medical directives that are not written clearly and/or are handwritten may not be accepted by medical professionals.

In other words, this is not the time to take short cuts. It's very important to find a good elder law or trust and estate

attorney to help you with the drafting of these documents to ensure that they are drafted correctly and include the necessary components to protect your loved ones.

Chapter 7

Funding a Special Needs Trust with Life Insurance

Life Insurance Offers a Way to Fund a Special Needs Trust Without Financial Strain

Many families are justly concerned about the long-term financial security of their loved ones with special needs, especially if parents who have been providing support pass away. This concern is one reason to create a special needs trust. But not every family can afford to fund a special needs trust with enough money to properly care for a person with special needs over the course of his lifetime. Life insurance provides a unique opportunity for many families to guarantee the financial security of their loved ones with special needs without placing a significant financial strain on other family members.

There are many different types of life insurance that can be used to fund a special needs trust, but whichever type of insurance is purchased, the death benefit is directed to a special needs trust created for the individual with special needs to provide financial security after the parents are gone.

Term life insurance is the easiest to understand. Under a term policy, the insurance company agrees to pay a fixed amount of money if the insured person dies during a set period of time. If the insured person survives the policy's term, the insurance lapses and there is no benefit.

Whole life insurance is a little different. A whole policy typically lasts for the insured person's lifetime and the policy accrues value over time. The accrued funds generate interest and the policy typically pays dividends, adding to the value of the payout. Universal life insurance accumulates value like a whole life insurance policy, but the policy owner can typically adjust the premium payments and death benefits over the life of the policy. With both whole life insurance and universal life insurance, the policy owners can contribute enough money to the policy to guarantee a future death benefit, regardless of how long they live. This is called a "paid up" policy, and it provides the emotional security of knowing that the life insurance will be there to fund the trust even if a family's financial circumstances change in the future.

One of the most important types of life insurance for families of people with special needs is called "second to die" or survivorship insurance. These are policies taken out on the lives of two people that only pay out when the second person passes away. Because of this, the premiums are typically lower than individual policies, allowing families to provide greater sums for the beneficiaries after the death of the second parent. However, there is no guarantee that the second insured person will continue to pay for the policy, potentially leaving the special needs trust in the lurch. Once a family has decided to fund a trust with life insurance, the follow up question becomes "how much life insurance should we buy?"

You should always consult with your special needs planner before purchasing any life insurance destined for a special needs trust.

Chapter 8

Hiring a Financial Advisor for Special Needs Planning

Trustees of special needs trusts have a duty to properly manage the funds in their care. However, most trustees, especially non-professional ones, are not sophisticated investors and they should not be directly managing the investment of large sums of money. This does not mean that the trustee of a special needs trust should simply toss the trust funds into a savings account and be done with it. On the contrary, a trustee needs to grow the trust principal as best he can, keeping in mind the current and future needs of the trust's beneficiary. In many cases, this means that the trustee should hire a professional investment advisor.

There are countless investment professionals out there to choose from — so many, in fact, that the choice of an investment advisor can quickly become overwhelming. The Web site of the *Securities and Exchange Commission (SEC)* offers [several tips for beginning investors](#) who are seeking to hire an investment professional. According to the SEC, investors should know exactly what services they are looking for prior to interviewing advisors, and they should find out what services their potential investment advisor provides, how much those services cost, and how and when the advisor gets paid. These threshold questions are important, but the SEC also recommends asking each potential advisor a battery of specific questions, including questions about their experience, education and employment history, whether the advisor is limited to recommending a certain set of products and whether the advisor is registered with the SEC or with a state licensing agency.

Trustees should also understand the various types of fee structures utilized by investment advisors, including a percentage fee based on the total assets under management, an hourly system, a fixed fee or a commission based on the products sold. Trustees of special needs trusts have slightly different needs than typical investors, and, if possible, they should work with advisers who are flexible and who already have experience investing the funds of special needs trusts. Trustees should also be aware that hiring a poor financial advisor could lead to a breach-of-fiduciary-duty claim against the trustee, so more detailed background checks and due diligence are required than if the trustee were an individual investor. Asking friends, relatives, and other professionals — including especially estate planning attorneys — to recommend an advisor is a good option

To learn more from the SEC about selecting an investment advisor, [click here](#). To review the standards for [Certified Financial Planners](#), a subset of advisors who have chosen to pursue accreditation, [click here](#).