



Basic Estate Planning FOR PARENTS WITH SPECIAL NEEDS CHILDREN

Tips to protect assets for your
special needs child

CHRISTINE L. MATUS, ESQ.

Basic Estate Planning for Parents with Special Needs Children

First Edition

By Christine L. Matus, Esq

For help getting started planning for your special needs child, reach out to The Matus Law Group at (732) 281-0060, or visit us online at www.NewJerseySpecialNeeds.com to schedule a free consultation.

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First Edition

By

Christine L. Matus, Esq.

The Matus Law Group, LLC

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Introduction

Whether a doctor recently diagnosed your young child with autism or Asperger's; or your baby endured a traumatic brain injury or another medical or developmental crisis, you're feeling confused, scared and overwhelmed.

You love your child dearly, and you want to provide compassionate, strategic care. But you also don't know where to start or how to get a grip on what the future might hold. Every parent faces a welter of challenges and surprises. Raising a child in modern America can be a lonely and bewildering experience, even if your child has no developmental issues. But you and your co-parent (if you have one) need knowledge and support that go beyond the ordinary.

This eBook is designed to help you to navigate this parenting journey easier by tackling a critical challenge: *how to plan, financially, for your special needs child.*

This book is a work of passion, and it reflects the intersection of attorney Christine Matus' personal sphere and professional work. When she learned that her youngest daughter had Downs Syndrome, she and her husband confronted many challenges. Despite her deep knowledge of New Jersey estate planning law, she had to do a lot of research and talk to dozens of advisors to develop a game plan. This experience sparked her desire to create a guide for other parents in similar situations – to help them avoid common mistakes and obtain actionable insights.

This guide obviously does not constitute legal or financial advice, but it can hopefully at least stimulate you (and your co-parent, if you have one) to meet the diverse challenges of special needs parenting with love, energy and strategic focus.

Here's what we'll be covering:

Section 1: Financial Planning for Special Needs Parents 101

Whether your physician just diagnosed your child with a learning disability, or you've been wrestling with how to care for a child with a birth defect, this section will define common terms and concepts, so you can navigate the system wisely and sidestep bureaucratic obstacles. This section will address wide-ranging questions. For instance: what should you do if you have two children: one who's not developmentally impaired and one who is? How should you nimbly address pointed questions from relatives, teachers, and acquaintances? How can you be a positive advocate for your child in the medical system? Etc.

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Section 2: Addressing the Diverse Life Challenges of Raising a Special Needs Child

Parenting involves financial, emotional, logistic, and career-related components. How can you meet these challenges in a mindful fashion? We'll go over surprising insights and point you to resources to kickstart more effective thinking and more productive behaviors and habits.

Section 3: Additional Resources

We've compiled powerful resources (including links to websites and articles) that can help you navigate different parts of the special needs parenting journey.

By the end of this guide, hopefully you will have a clearer understanding about how to manage your finances, challenges and opportunities. You'll also feel calmer, more in control, and more optimistic about what lies ahead. So with all that said, let's begin!

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Section 1: Financial Planning for Special Needs Parents 101

The greatest glory in living lies not in never falling, but in rising every time we fall. - Nelson Mandela

This section will orient you regarding the basic needs and challenges of estate planning for special needs children. Before we dive into the technical aspects of what to do and how to do it, let's first start with the "why" question. What's the *purpose* of doing this kind of planning? Why bother with the complications?

Here are five reasons to get started right now.

1. Maximize potential benefits you can obtain from the government and other sources.

The United States may lack a comprehensive social safety net, but the federal and state government -- as well as other groups -- can provide benefits to help you and your family. Plus, when you make your money work more effectively, you can avoid taxes and other negative financial consequences and penalties.

2. Planning can free up your mental and emotional resources to deal with other challenges.

Whether you need to track a complex medical diagnosis or help your child work through issues at school, you must minimize distractions. Eliminating worries about your finances can help you bring your most compassionate, attentive self to bear on the issues.

3. With sound guidance, you can make progress surprisingly quickly.

It's probably not going to take you months (or even weeks) to get a handle on the big picture issues and start to make serious progress on them.

4. Proper planning can help you avoid common mistakes and errors of omission.

Deferring planning because you're "too busy" or life is "too hectic" is penny-wise, pound-foolish. Yes, you may have a lot to do. But when you prioritize planning, your future should get easier and easier, not harder or more complicated.

5. Planning will help you deal with financial surprises, setbacks, and serendipities.

President Dwight Eisenhower once wisely observed: "In preparing for battle, I've always found that plans are useless, but planning is indispensable." That aphorism applies equally to the battlefield and to the financial arena. Your career, your finances, and your parenting will all

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evolve over time. It's difficult to predict what will happen five years from now, let alone 20 to 30 years from now. However, the purpose of planning is not to set your life on a locked-in, sclerotic trajectory but rather to give you guy wires and structure, so that you can adapt your plans as need be to meet future contingencies.

For instance, let's say your child suffers a medical setback three years from now that forces you to restructure your estate, take on a second job or divest an important asset. If you have your documents and plan in place, you'll be much more nimble when it comes to adapting that plan.

Introduction to Special Needs Planning

Per recent census data, nearly three million children between ages of 5 and 15 have some sort of disability. Broadly speaking, roughly 15% of the entire American population – more than 41 million people! – struggles with a mental or physical disability of some sort.

Collectively, we may not be ready to have a grown up, national, action-oriented conversation about how to acknowledge these people and help them. That said, enterprising parents can take advantage of a variety of processes and financial instruments to ensure bright, healthy, comfortable futures for their special needs children.

A **trust** is a financial instrument that allows a third party to hold and manage assets on behalf of a **beneficiary**. Many diverse kinds of trusts can be established. You appoint someone known as a **trustee** to manage and administer the funds to ensure your child's lifestyle and care.

A **Supplemental Needs Trust** (also known as a "Special Needs Trust" or SNT) is a type of type of trust designed to help disabled individuals access assets, over time, to meet life needs. We're going to talk in depth about SNTs, since they often play key roles in planning. The money in the trust is meant to supplement – not replace! – benefits that the individual might obtain through government benefits programs like Medicaid or Supplemental Security Income (SSI).

Is going through the hassle of setting up an SNT worth it?

Some parents might worry that the process of setting up a trust **might be too expensive and time consuming**. You do need to invest some time and money, but the investment is almost always worth it because of the peace of mind and long term security it provides. The document can protect your child (and your entire family) against unlikely but plausible contingencies.

Think of it this way. We buy things like car insurance all the time. If you never get into a crash, you will, technically, have "wasted" money on coverage you didn't need. But you obviously still want this coverage, because it can protect against unlikely but horrific events. What if, for whatever reason, your luck runs out and you crash? Likewise, when you invest in a Special Needs Trust – and in planning in general – you can mitigate against catastrophic risks.

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Parents also sometimes believe that **siblings or other family members will “take care” of the special needs child**. For instance, let’s say you have three children -- two without disabilities and one younger boy who has severe autism. You might contemplate leaving all your money to the nondisabled children, under the assumption that they will take care of their younger brother. This is a dangerous assumption! First of all, your children may love their little brother now, but you cannot guarantee family harmony forever. Secondly, your children may not be in a position to be ethical, knowledgeable fiduciaries. Finally, in some ways, this strategy “kicks the can.” The advantage of planning, as we’ve discussed, is it gives you flexibility in the face of the unpredictable. When your plan is “well, my kids will figure it out at some point,” you don’t have much of a plan!

Yet another misconception involves **the mystique of trusts**. You may have only heard the term *trust* used in the context of fusty, fancy “moneyed folk” who use trusts to keep large fortunes contained within their families. News flash: *Trusts are not just for the wealthy*. Many families who establish SNTs struggle with credit card debt, second mortgages and a lack of savings. You don’t need to be a millionaire (or even a hundred-thousandaire) to start a trust.

Other families defer planning because they **figure that they have plenty of time**. This impulse to do nothing makes sense. After all, if a doctor only recently diagnosed your child as disabled, you have a lot on your plate. However, the earlier that you organize, the more mental and financial resources you will free up, and the easier it will be to avoid worst case scenarios.

Understanding the Profound Benefits of Starting a Trust

In New Jersey, your disabled child’s ability to collect money from Medicaid or the Supplemental Security Income (SSI) program is limited. He or she can only have \$2,000 in assets. If the child receives more money (as a result of a verdict in a personal injury case or an inheritance, e.g.) those extra assets can knock him or her out of eligibility... unless a trust has been established.

A trust can give you some control over your child’s financial destiny. Also, plaintiffs in a personal injury lawsuit, creditors and other financial predators cannot touch funds in the trust. The trustee can also limit the disabled child’s ability to access funds, which can be a really good thing! For instance, let’s say your child develops impulse control problems. You wouldn’t want him or her to take the money that you have carefully set aside, for instance, and gamble it away during a weekend at Vegas or invest in some dubious pyramid scheme. Funds that you set aside are also tax deductible, and they can be used to pay for diverse expenses, such as furniture, vacation, personal aids, rehab, education, and medical and dental expenses.

How Restrictive Should the Trust Be?

Can a trust be too strict? Potentially. To protect funds from predators, a trustee’s bad judgment and other contingencies, you might think that you should make the instrument rigid. But remember 38 Special’s classic song, “Hold on Loosely”? The lyrics go: “Just hold on loosely, but don’t let go... If you cling too tightly, you’re gonna lose control.” In terms of special needs

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planning (and parenting in general), this is sage advice. You really need to be flexible, and your instruments need to be flexible. An overly restrictive trust might prevent a sibling trustee from accessing money from the trust to finance an addition to his home that he planned to use as a spare bedroom for the beneficiary. Or that same sibling might not be allowed to access funds to buy a plane ticket to fly out to help the beneficiary after a natural disaster. The point is that there's an art to setting up a trust as well as a science. It should offer structure without rigidity.

Choosing an Appropriate Trustee

Select a trustee who has strong managerial and technical skills as well as a good ability to communicate clearly.

Should you opt for a relative, like your brother or sister? After all, ideally, the trustee should feel a deep connection with your child and a heartfelt fiduciary obligation to him or her. Or should you choose a professional co-trustee, like an institution that has lots of experiencing managing money? Or should you opt for both? Ultimately, the decision is a highly personal one. We typically recommend that our clients double up – that they choose a family member who has a close relationship with the beneficiary *as well as* a professional co-trustee. This way, you get the best of both worlds. No matter whom you select as trustee, take time to have open hearted, strategic conversations about your fears, hopes and dreams for your child with the trustee.

Groups That Can Help

Several organizations can help you plan and handle aspects of raising your special needs child. This list is by no means comprehensive:

The Special Needs Alliance (www.specialneedsalliance.org). This nonprofit can connect you with numerous third party resources to meet your parenting and planning challenges.

The Academy of Special Needs Planners (www.specialneedsanswers.com). This professional group can provide insight into government benefits, estate planning and other logistical concerns.

Insurance Companies. Some insurance companies offer excellent free tools and resources. For instance, MetLife has a “Division of Estate Planning for Special Kids” (available at www.metlife.com/desk). It provides insurance products, financial insights and a cost of care calculator for parents. MassMutual’s “Special Care” program (www.massmutual.com/specialcare) offers advice and insurance products for families with special needs kids. Be aware, however, that insurance companies are ultimately in the business of selling products and services; they’re not providing free information solely to be charitable.

Is a Special Needs Trust considered an “asset” of the disabled child?

No. As long as an independent trustee oversees and manages the trust, the funds are legally not considered “assets.”

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What happens if the trustee pays money directly to the disabled person?

This can lead to problems. The trustee must be extremely mindful about how and when distributions are made from the trust to avoid breaking the rules or the law. For instance, a clumsy distribution could accidentally disqualify the disabled person from SSI or Medicaid.

What if a grandparent or another relative wants to leave money to the disabled child? Should that money be given as an inheritance or distributed in some other way?

Money from life insurance policy proceeds and inheritance should be given to the trust, *not* to the beneficiary directly. Direct gifts could disqualify the child from government assistance. This means that you may need to coordinate your estate planning with your parents' estate planning, for instance, so that they and their financial advisors understand what to do.

What are “pooled trusts”? How are they different from individual SNTs? Are they a potentially good option?

A pooled trust is a trust that pools resources from multiple sources. For instance, you might bundle your funds together with funds from several other special needs families and then allow a nonprofit to manage and administer it. You might opt for this type of instrument if you don't have much money to put in trust (and hence might benefit by leveraging the investing power of other people's money) or if you can't find a bank or family member to serve as a trustee. Ideally, to maximize control and peace of mind, try to establish an independently managed fund.

How might the Affordable Care Act (ACA) (also known as “ObamaCare”) impact Special Needs Trust planning?

The ACA prevents insurance companies from denying coverage to people because of preexisting conditions, such as mental or physical disabilities. If you just want to make sure that your child maintains Medicaid and Supplemental Security Income (SSI) benefits, then, strictly speaking, you might not need a trust. However, as this book is being written, the Supreme Court is considering taking up a case, which could dismantle key provisions of the ACA. The law is in flux. Speak with a qualified estate planning attorney to understand your options.

Beyond Trusts – Other Types of Documents and Strategies to Use

In addition to taking care of the financial planning, you might also seek to establish **power of attorney** or a **guardianship** over your child. Such a strategy might sound somewhat aggressive at this point in the game. After all, your child is probably still quite young. By default, you're still allowed to make critical decisions for him or her regarding healthcare, investing and education, etc. However, when your child turns 18, unless you have established power of attorney or guardianship, you will be blocked from obtaining important records or making decisions regarding your child's healthcare, education, or financial planning.

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In addition to establishing power of attorney, you might also want to compose a “**letter of guidance.**” This formal document provides insight and guidance for any caregiver who might be wind up temporarily in charge of your child. It can include discussions of medications that you child might need, his or her likes and dislikes, medical history, food allergies, and so forth.

The Four Stages Of Special Needs Estate Planning

Here’s the basic process for organizing and executing a financial vision for your child:

Stage One: Planning

The more detailed your plans, the more control you can have over the process.

You can use a variety of tools and get help from many experts, including financial planners, care coordinators, accountants, and technicians who specialize in public benefits. Be prepared to “dive deep” into your current financial situation and spend time constructing an idealized future. For instance, you might want a professional financial assessment as well as insight into long term housing, medical care and employment options.

Before you create your blueprint -- ideally in conjunction with a qualified, knowledgeable New Jersey special needs estate planning attorney -- consider going through the following exercise.

First, **write down the purpose** of your plan. You need to understand the “why” to make sure the “what” and the “how” of your plan go in the right directly. You need to have clear answer to the question “*how will I know if the planning process has gone off purpose?*”

Next, **define the principles** by which you want the process to unfold. We all have subtle, often unstated guidelines for how we want to accomplish things. For instance, you might want to “get this all done” within three months. Or preserving your family’s privacy might be hugely important. Or you may want to make sure to revisit the plan at regular intervals to keep it fresh.

One easy (and actually kind of fun) way to do this is to imagine how the process *might go wrong*. Then simply define your principles in terms of the *opposite* of those things. For instance:

- **You worry:** *What if I get so distracted by setting up the trust that I drop the ball on a big work project?*
 - **This translates to the following principle:** *Make sure the planning process leaves me plenty of time and energy to focus on critical work tasks.*
- **You worry:** *What if my wife and I make it three quarters of the way through the planning process only to abandon it because we’re too confused or overwhelmed?*

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- **This translates to the following principle:** *The process must ensure that my wife and I complete what we need to complete and avoid getting overwhelmed.*
- **You worry:** *What if I put too much money in the trust and wind up having to raid it two or three years from now in order to pay the grocery bills and keep the lights on?*
 - **This translates to the following principle:** *The plan must respect our family's cash flow concerns and be integrated in a reasonable, careful way with our other overall financial goals.*

Come up with as many of these caveats as you want, and share them with your financial planner and attorney. They can constrain your planning and give you a reference point for success.

The next step involves **envisioning positive outcomes**. Learning that your child might need help for decades or for the rest of his or her life can be depressing at first – or at least jolting. However, the best planners engage with their futures optimistically. There's a time and a place for your "internal critic." But during this stage in the process, give yourself free reign to brainstorm. Imagine the plan has been finished, and your perspective is "wow, this was a really awesome plan!" Spend time working with your spouse (if you have one) to brainstorm this vision. It doesn't have to be fully formed. Capture features, ideas, and other elements of your vision on paper. For instance, your list might start out something like this:

- We have \$50,000 a year set aside for the child for life;
- Our retirement and special needs trust are both fully funded;
- Our parents have changed their wills to redirect money that would be given to our child as inheritance into the SNT itself.
- Our child, at 50, lives in a comfortable assisted living community, leads an independent life and has great, meaningful relationships.

You also might want to talk with your financial planner or attorney for inspiration and insights.

Next, spend time away from your desk, so you can refresh your perspective. Then come back and reassess your brainstorming from a more practical, critical eye. During this stage, prioritize, sort the "good" ideas from the "bad" ones, and sequence any projects you need to do. Lastly, determine the next steps for each of the individual components of the plan.

The plan's degree of detail will depend on your current financial state and the amount of time and energy you can invest. But here's the point: *write out your values and your vision, and then work through some of the details*. Don't worry about getting it perfect! Just getting starting with this process will help you feel more relaxed and in control. You will probably have to think about the plan more than you've done... but less than you fear that you might!

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Stage Two: Drafting the Plan

Turning your rudimentary plans into solid legal documents is both an art and science. While you technically can research and deal with this process yourself, you are far better served to hire an attorney to formalize the paperwork. Just like you would be ill-advised to conduct surgery on yourself or dismantle and rebuild your car by yourself; so, too, should you avoid handling the legal paperwork associated with special needs planning by yourself. Find a trustworthy, qualified lawyer, and let him or her walk you through this process.

Stage Three: Funding

What are your current resources? What are your income streams? What's your anticipated career trajectory? What are your other critical financial and life goals? You may have the best plan in the world, but if you can't fund it appropriately, it's not going to do you or your child much good. You need to create and maintain the funding strategically.

Stage Four: Administration

Once you have set up the "rules of the game" and figured out a way to fund the trust, you then need to monitor and manage the situation over time. For instance, you may need to manage your trustee (and/or co-trustee). In Hollywood, writers and actors often talk about "agent-ing their agents." What they mean is that you need to oversee the people who oversee what's important to you. Likewise, you need to set up rules and systems for your trustee, so that you can feel comfortable that your child will be in good hands, even if you're not there.

Getting Started

First, take stock of the key stakeholders: the caregivers, the beneficiary and the trustee. You'll want to answer a litany of key questions about each.

In terms of the beneficiary (your child):

- What's the nature of the disability? How severe is it? Do doctors anticipate that the disability could get worse overtime or possibly improve?
- How are you currently paying for the child's needs?
- What kind of medical and social support network do you have, if any?
- What current plans, if any, do you have to support the beneficiary and other children or dependents? How satisfied are you with these plans?

Next, you need to assess your situation:

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- How old are you? Are you in relatively good health?
- What financial resources do you have at your disposal?
- What are your anticipated income streams, career trajectory and retirement needs?
- Have you put together any estate planning documents?
- Do you and the other parent (if there is one) see eye-to-eye about what needs to be done and what your ideal financial future might be?
- If you have other children or other dependents, how do you want to include them in your financial and legal planning?

Avoid overwhelming yourself with a battery of questions. Just remember this general principle: the clearer you understand your situation, the easier it will be to avoid dithering or infighting. For instance, let's say you and your spouse both have very different visions about retirement, but you never discuss the situation. Five or ten years from now, this disconnect about retirement could derail your plans for your special needs child. *Get everything out on the table now* -- to the best of your ability -- so that you can make smart decisions.

Lastly, think about the trustee. Should you choose a brother or sister? Do you want to opt for a corporate trustee or co-trustee? As we mentioned above, our office generally recommends a combination – e.g., name your brother *and* a corporate co-trustee to administer the trust.

Terms to Know

The vocabulary of financial planning can seem complex and formal. Here are some key terms that you will want to understand and remember:

- **Grantor:** The person or entity who sets up or funds the trust. Only four entities can do this for your child: the court, a parent, a grandparent, or a legal guardian.
- **Beneficiary:** A person or entity positioned to receive funds from the trust.
- **Self-settled trusts:** Congress passed a statute in 1993 to create a category of trusts known as “self-settled trusts.” Among other things, this statute allowed grantors to establish trusts for special needs dependents without risking their eligibility for Medicaid or Supplemental Security Income. Per this law, the beneficiary must be a “disabled” individual who is younger than 65.
- **Payback:** Some trusts include what's known as a payback provision. When the disabled individual dies, the trust must repay Medicaid for services incurred during the beneficiary's life. Not all trusts include this requirement. For instance, third party trusts

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set up for special needs individuals do not have this requirement. Your attorney can help you figure out whether this could affect you and, if so, what you can do to mitigate its affects on your and your child's financial legacy.

Information You Will Need to Assemble

As you work through this long list, take a breath and remember that you don't need to assemble all these documents at once; this list is merely meant to give you a sense of the scope of what might be required.

- Collect critical information about the beneficiary (your child), including his or her birthday, social security number, medical diagnosis, surgical and medical history, allergies, and prescription drug regimen (if any).
- Document any special dietary needs, types of care, or medical or prosthetic equipment that your child needs.
- Write out the names and contact information of all healthcare providers, rehab specialists and all relevant insurance companies.
- Document all of your child's current assets as well as the monetary values of those assets. Likewise, document any benefits that your child is receiving from the state or federal government, including the type of benefits and the dollar amounts.
- Document key information for all family members and other advocates of the beneficiary, such as godparents.
- Document the child's housing needs (present and future) as well as social, emotional, educational and play-related needs.
- Finally, document what financial resources you can use to fund the plan and help your family generally plan for college, retirement and other future needs.

Special Financial Challenges for Special Needs Kids

Disabled individuals face many unique expenses. For instance, ongoing medical and surgical bills, rehabilitation bills, prosthetics, and home care can all add up. Plus, disabled individuals are often limited in terms of what they can do to generate income. The disability may make it impossible, for instance, for your child to work more than 20 hours a week or engage in certain types of lucrative work. The child may need a special taxi service to leave home and go to work or go out on errands. Most importantly, Medicaid and Supplemental Security Income will generally not provide enough money to ensure the overall quality of life for your child -- to

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purchase computer equipment, vacations, housing, rehabilitation, and other essentials that will allow your child to live in comfort and ease.

Finding a Qualified Attorney

Writing key documents, managing the trust, and integrating all the “moving parts” of your planning into your daily life can be complicated, to say the least! A qualified attorney can keep you organized as well as provide moral support, resources and ongoing guidance.

As you vet prospective attorneys, examine each candidate’s education, background and professional references. All things being equal, work with a lawyer who has handled lots of special needs planning cases like yours. Such an attorney will be more likely to have developed in-house systems and processes to deal with you concerns. You also want to look for someone with whom you have a personal connection -- someone who is empathetic and who shares your values.

Attorney Christine Matus’s youngest child has Down Syndrome, and she and her family have had to go through the same complex planning issues and hard decision making that we’ve been discussing. Her experience helps her connect with her clients, understand their needs and anticipate how to help them better.

When you meet with a prospective attorney for the first time during your free consultation, come prepared with a lot of questions. Ask about the attorney’s background and processes as well as your particular situation. What are your big concerns? What are your hopes and fears? The more “pre-thinking” that you do before your meeting, the easier it will be to make progress and get a sense for whether the attorney is a good fit.

When evaluating prospects, use both rational analysis and your intuition. Our instincts are often able to pick up on information that our conscious minds miss or ignore.

Once you’ve chosen your attorney, learn his or her systems and protocols, and don’t be afraid to voice concerns or ask questions. Your attorney should be an advocate in the true sense of the word and should be accessible. Your end goal, after all, isn’t just to get the nuts and bolts of planning in place but also to obtain peace of mind and clarity about your next steps.

Choosing a Trustee

Your special needs trustee can have wide-ranging, diverse powers over the trust. A corporate co-trustee might be good at managing and investing the assets of the trust and also dealing with any critical accounting. A close relative acting as a trustee, meanwhile, can protect your child’s emotional and spiritual needs and ensure the trust truly serves him or her.

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Here are some questions to ask:

- Will the trustee attend to your child's needs?
- Can you foresee any potential conflicts of interest?
- Is the trustee a good communicator and financial manager?
- Do you want the funds to be managed professionally? If so, what constraints do you want to put on that management? How much do you want to pay for the service?
- What could happen if a major life event impacts the trustee – e.g. a divorce or a move to another country compromises his or her ability to act as a fiduciary?

Along those lines, you also might want to establish **successor trustees** -- people who could “pinch hit” for the trustee, if he or she cannot serve, for whatever reason.

In addition, consider establishing **trust protectors** -- people who can look over shoulder the trustee and intervene if and when needed.

You might also want to include a provision to **pay the trustee something from the fund**, since the management can take quite a bit of work.

Basic Documents to Prepare

1. A Last Will and Testament

If you have any dependents -- whether they have special needs or not -- you want to establish a will, which is a legal document that provides instructions for how you want your estate to be distributed after you die. In addition, your will could call for the establishment of a special needs trust. Along with your will, consider including a *letter of intent*, which we discussed earlier. A special needs trust established after death is known as a *testamentary trust*; whereas, one established while you are alive is known as an *inter-vivos trust*.

2. Power of Attorney (POA)

A POA gives you financial and medical powers to manage the welfare of your disabled child. As we mentioned earlier, a POA allows you to retain some control of your child's medical and healthcare processes after your child turns 18.

3. Medical Directives

These directives allow you to ensure that certain medical treatments are given (or withheld) in the event that you're not conscious or of sound mind.

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Other Critical Features of a Smartly Conceived Plan

- When you write the trust, be very clear that you want to *supplement* any public benefits (Medicaid, SSI, etc.) and not *replace* them.
- Likewise, make it clear that the *beneficiary cannot extract distributions* from the trust in a way that contradicts your intentions. You want to avoid a scenario, for instance, in which the disabled child gets involved in a dubious business partnership, and the partner convinces your child to raid the trust for investment money.
- Likewise, the trust should be defined as a *spendthrift trust*, which means that creditors cannot tap the trust for funds owed to them.
- You might also want to ask for an *annual care report*, a yearly analysis compiled by a therapist or other professional like a social worker that will make recommendations about how to improve the trust and tweak its terms. For instance, maybe this analysis will suggest that the distribution plan in place is too inflexible, and it's causing unneeded stress for the beneficiary or for family members taking care of him or her.
- The trust might also support *housing options*. For instance, the trust could own a home or apartment where your child lives, or the trust can articulate a living arrangement for your child.
- You also want to document *who will receive the trust's funds if your child dies*. For instance, the money can be passed to other family members or go to a charity.

New Jersey Specific Information about Special Needs Planning

Federal and state estate planning laws are supposed to work harmoniously. However, in reality, the situation is often far from tidy. State and federal laws sometimes contradict each other. Or a regulation established by a state agency might conflict with state law. In the worst cases scenarios, navigating these paradoxical instructions may seem downright Kafkaesque.

Your attorney should watchdog these issues for you. This is another reason why you want to choose a lawyer who handles special needs planning frequently, since he or she will be more likely to spot conflicts and deal with them proactively.

- **New Jersey statute N.J.S.A. §3B:11-37** outlines how special needs trusts work in the state and discusses their limitations, strengths and constraints.
- **New Jersey's Medicaid Manual** describes what needs to be included in special needs trusts to preserve eligibility for Medicaid funds.

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- **The state also operates a pooled trust**, called Pooled NJ.
- **Social Security rules** follow New Jersey Medicaid requirements, in general, as long as the beneficiary lives in New Jersey.

A Word on “Being Overwhelmed”

We’ve just walked through a detailed discussion of the instruments and strategies that you can use to help your child. Even if you understand the gist, you may be overwhelmed by the size and complexity of the process. Don’t lose heart! This feeling is natural.

First of all, appreciate *you don’t have to take all of these steps at once*. If all you do today, for instance, is just read through this guidebook and process it, then you have taken a tremendous first step. Give yourself some credit.

Second of all, as you move through the process, *you will become more and more familiar with these concepts and terms*. Whenever you start something new in life -- a new sport, a new job, a new relationship -- it takes time to acclimate. The same is true with special needs planning. But you’ll get there.

Third, remember the old joke: *how do you eat an elephant? One bite at a time*. Taking small action steps, over time, will lead to big results for your planning.

Here’s an analogy that should be helpful. When you heat up water ice, it eventually melts and becomes a liquid. However, a lot of heat is needed just to break the bonds holding the ice together. This heat (the “heat of enthalpy”) turns frozen ice to liquid water at 32 degrees Fahrenheit. But only after this melting can the temperature of the water go up. The moral? In all sorts of systems in life, it takes a lot of energy just to get started; but once you *do* start, things get easier. So persevere!

In our next chapter, we’ll talk more broadly about how to get a grip on the diverse challenges of raising a special needs child that go beyond the nuts and bolts of financial planning.

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Section 2: Addressing the Diverse Life Challenges of Raising a Special Needs Child

“You’ve developed the strength of a draft horse while holding onto the delicacy of a daffodil... you are the mother, advocate and protector of a child with a disability.”

– Lori Bergman

You probably don’t need to be told that having a child with special needs (or any child, for that matter) can change your life profoundly. Whereas you and your partner (if you have one) once might have thought nothing about partying until 2 AM and then sleeping in and enjoying breakfast in bed while reading *The New York Times*; now, your schedule is dictated for you.

Evenings might consist of racing to get your children fed, washed, read to, and tucked in... following by a manic session of writing work emails while mindlessly eating the children’s leftovers for dinner. Mornings, meanwhile, might start at 6 AM sharp and consist of screaming, cajoling and frantic preparations. It’s easy to get into these kinds of family routines but much harder to amend or reengineer them so that you and your partner can thrive.

Special needs parenting comes with its only special challenges... as well as special joys.

In addition to establishing your financial plan – envisioning and putting into place the instruments and strategies you need to prepare for the future – you also need an integrated approach to your life. After all, becoming a parent does not mean abandoning your own needs for organization, rest, health, social engagement, support, happiness, and spirituality and financial effectiveness. In fact, the better you can meet these needs, the calmer and more effective you’ll be as a parent. As flight attendants always warn parents prior to takeoff: put your own oxygen mask on first before attending to your children.

In this chapter, we’re going to sequentially unpack common special needs parenting challenges and introduce concepts and strategies to help you tackle them. Let’s begin with logistics.

Getting Organized While Raising and Caring for a Special Needs Child

Your life was busy enough before your child came along (or before an injury disabled your once healthy child). Most New Jersey parents are overworked, under-slept and perennially scrambling to pay the bills and meet work obligations. Having a special needs child can mean injecting more commitments into this already overfilled schedule. For instance, you might now have to:

- Shuttle your child to and from doctors and therapy appointments regularly;

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- Spend more time than the average parent preparing meals, dealing with bedtime, and handling “behavior issues.”
- Recalibrate your life, career and daily schedule to deal with certain responsibilities indefinitely. While other parents you know may, over time, enjoy more freedom as their kids grow up, talk, walk, learn to play quietly by themselves, etc. -- you may face ongoing obligations to dress your child, cut his or her food, and etc.

Unless you belong to a support group for parents of special needs children -- which you might strongly consider doing -- you probably also struggle to relate to other moms and dads. You may find it hard to summon sympathy when a friend moans to you about how her child won't eat his spinach or won't play nicely at school, if you're scrambling to provide round the clock medical care for your own child and wondering whether he or she will ever walk or talk. This disconnect can lead some moms and dads to retreat into isolation, depression and anxiety.

So what can be done about these problems?

To get useful answers, let's first talk about the likely root cause of much of the stress. The sheer weight of your obligations – *in and of themselves* -- can be downright oppressive. You might feel like you will literally never get to the bottom of your to-do list. That's not a pleasant feeling. Understanding *why* it's not pleasant can help us identify solutions.

Research scientists have recently discovered that the brain has fundamental limits in terms of the amount of information it can store in conscious memory, in much the same way that a computer has only limited amounts of Random Access Memory (RAM).

If you exceed this amount of “RAM” in your mind -- if you try to store more commitments in your head than your head can hold -- the brain's “operating system” (so to speak) slows down and doesn't function as well. Consciously, you may forget to-do items like “buy cat litter” or “set appointment with the pediatric pulmonologist,” because you've got so much going on. Unconsciously, though, your brain will still remember that you have committed to do something. Thus, you will be left with a vague kind of background noise of fatigue and irritation.

Stop Holding onto Everything in Your Head

One way to get around this overtaxed-RAM problem is to get out of the habit of storing your commitments in your memory. You need to a system that's external to you that's robust enough to store and process your commitments – a system that you can trust and review frequently enough, so that you can stop worrying about what's undone and what needs to be done. You probably already have fragments of such a system, such as grocery lists, to-do lists on your computer and an appointment calendar. But odds are that you're not using these tools

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consistently and in an integrated-enough fashion to achieve true peace of mind. You want to free up your mind's RAM, so you can think *about* your commitments instead of just *of* them.

To that end, here's an activity to try. Rope off four hours. You can do this activity in chunks, but it's better if you can do it all at once. The process is simple. Just write down on a piece of paper (or on a computer Word document) *every single commitment that's on your mind about anything in your life*. This list should be wide ranging. Examples might include:

- “Find a babysitter for the weekend of the 29th”
- “Climb Mount Fuji one day”
- “Figure out what to do about dad's diabetes”
- “Deal with the tree in the front yard”
- “Get a handle on what to do about daughter's asthma”
- “Make amends with my brother for Christmas fight over plane tickets”
- Etc.

The point is to articulate everything that you've been storing in your head, so you can assess things in a methodical way. You will undoubtedly find that just this act of writing your commitments out on paper should give you a sense of renewal and perspective. You'll probably only generate a list that's a few hundred items long. This list will not be infinite; seeing that it's not should give you palpable relief.

Next, go through each item on the list and ask yourself:

1. What am I trying to accomplish with respect to this item?
2. If I wanted to work on this right now, what's the very next *physical* action I would take?

As productivity author David Allen notes in his book, [*Getting Things Done*](#), to get commitments off your mind, you don't necessarily need to *finish* them. You just need to *finish your thinking about them*. Here are some examples of how to process this list:

- “Deal with fight with brother” might be processed as follows: “Project: Make amends with brother.” Next physical action: “Call dad to talk about what happened at Christmas.”
- “Climb Mount Fuji” might be processed as follows: “Project: Plan Fuji trip.” Next physical action: “Call Brooke (travel agent) at 212-555-4372 about Japan package trip.”

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- “Get a handle on what to do about daughter’s asthma” might be processed as follows:
Project: “Finalize plan to treat daughter’s asthma.” Next physical action: “Call Dr. Thomas at 646-555-3946 to make an appointment.”

Do you see the methodology here?

Lastly, you want to organize this huge list of projects and actions in a way that makes sense to you and review it once a week to make sure it’s fresh and complete. That may sound like a lot of work! However, you don’t have to follow every piece of this methodology. You should, however, strive to write down your commitments and finish your thinking about them.

Take Care of Your (and Your Family’s) Health and Wellness

Getting organized and clearheaded can feel fantastic. However, you also need to protect your health, wellness and sanity, so that you can be sharper and more capable as a parent and as a person. Of course, while intellectually you may understand that you need to “take care of yourself” and “eat healthy” and “feed your family good food,” applying these ideals in the crucible of the real world is a very different exercise.

For one thing, debate rages about what exactly constitutes the best kind of diet and exercise. For instance, most New Jersey parents grew up eating according to the USDA Food Guide Pyramid, which recommends breads, sugar, rice and other carbohydrates as the base of a healthy diet and urges the consumption of fats and oils only sparingly.

However, a variety of respected scientific analyses have questioned the Food Pyramid way of eating, suggesting that these recommendations were [based on flimsy science](#) and that they may have actually contributed to our current epidemics of obesity, diabetes and other diseases.

In fact, many research trials have attempted to compare a standard low fat diet and a lower carbohydrate higher fat diet that flips the Food Pyramid on its head, and the low carb version has won every time in [23 head to head trials](#).

This isn’t to say that diet science is conclusive either way, but rather that more ambiguity may exist about what people should and should not be eating than conventional wisdom suggests.

So where does that leave you? Well, one idea that has gained a lot of institutional support recently is the idea to *eat real food* and to cut back on added sugars and refined flour.

Another idea that’s emerged is the concept of *individual nutrition*.

Current research suggest some people (e.g. [diabetics](#)) may be best served by watching their carbs closely; while other people might tolerate carbs more or do exceptionally well on them. One

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takeaway message is that you really want to work with your doctor (and a respected nutritionist) to track what you do and to find something that works for you.

The same concept holds for your child. If your child is sensitive to gluten or corn or dairy or some other element in the diet, find out and revise the diet as needed. Buying real food can be more expensive; it can put additional financial strain on your family. At the same time, eating right can have profound, positive effects on wellness, mental sharpness and behavior. As advocates of healthy eating will say: “you pay your grocer or you pay your doctor.”

Here are some other concepts that you might want to research and discuss with your doctor:

- **Find an exercise program that works for you (and for your children, if they’re old enough.)** [Safe resistance training](#), in some trials, seems to be excellent at improving insulin sensitivity and bone density and preventing onset of conditions like osteoporosis.
- **Get a safe amount of sun exposure.** You obviously don’t want to fry yourself in the sun or exposure your child to [too much sun](#) and burn. However, dermatologists now believe that a safe amount of sun exposure can help [boost vitamin D levels](#), and vitamin D is a hormone that’s linked to immune function and overall health.
- **Get proper sleep; it can have profound benefits.** Many researchers believe that Americans -- and parents of young children in particular -- are chronically “under-slept.” [Not sleeping enough](#) can lead to poor decision-making and reaction time. One study in Australia found that a person who stays up for 24 hours in a row becomes so bad at driving a car that he or she drives as well as someone [over the legal limit for DUI!](#) Prioritize sleep. If your child is keeping you up at night, find a way to take a nap during the day, or just move bedtime up. Cut out non-essential activities, like watching TV, to get an extra half an hour shut eye. Along those lines, if you’re going to use computer or iPad or cell phone at night, consider wearing “[blue blockers](#)” to prevent the light from the screens from interfering with your sensitive circadian rhythms and melatonin levels. Doing this can ensure a better night’s rest and improve mood and concentration.
- **Carve out time to meditate, pray, or just generally introspect.** A lot of [new science](#) suggests that spending 15 to 20 minutes a day meditating can reduce stress, improve concentration, boost empathy, and inspire a sense of loving kindness for other people and for yourself. Depending on your child’s age and medical situation, he or she might also benefit from and enjoy meditation in the context of a regimen that includes better sleep, good exercise, time outdoors, etc. Excitingly, studies suggest that regular meditators

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actually may improve their general level of happiness -- what researchers have called the [“hedonic set point.”](#)

- **Give gratitude.** Another way to feel happier and more comfortable about what’s going on in your life is to spend time every day reflecting in gratitude about things that are going well in your life. Even if you’ve had a “terrible” day, odds are that you can think of at least three things that happened that made you feel grateful. For instance, maybe you “just got through it.” Or maybe you managed to have an awkward but important conversation with a school administrator or doctor. Don’t just shrug off these accomplishments; take time to savor them and focus on them. Science suggests that this simple habit can offer [profound benefits](#). Likewise, you may want to include your child in this activity; have him or her reflect on a few things every night that went well during the day. This can be great practice to share at night right before you turn off the lights.
- **Journal.** Journaling can also be quite healing. “Free write” about what’s happening in your life and what concerns, hopes and dreams you have. Or do focused exercises ([here are several to try](#)) to understand the patterns that are governing your choices and habits and retraining how you operate, think and react.
- **Play!** You have serious concerns, and you are taking your obligation to your child and to your family seriously. That’s wonderful. That’s responsible. The very fact that you’re reading this book means that you are committed to becoming a mindful, strategic parent. But being a parent is not just about fielding challenges; it’s also about cherishing small joys that emerge, often spontaneously, in the course of day-to-day life. It's about watching your child smiling, getting silly, putting scotch tape over everything in the room, sneaking up on you for a tickle fight, and so on. So what if the house gets a little messy or if furniture gets dinged up? Try to let things go and play more.
- **Cut yourself some slack.** Along those lines, as you strive to meet these diverse needs for health, financial clarity on logistical control, go easy on yourself. You are only human. You’ve got a tough job -- tougher, probably, than most parents have. Do what you can, with what you have, and appreciate yourself for what you’re doing for your child and for your family.

Setting Up Safety Systems and Protocols

Whether you have a one-and-a-half year old who is committed to tasting every single item on your floor, under the fridge, and hiding in your utilities closet; or you have an older child who

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has impulse control problems who has a scary tendency to spontaneously run out into the street and say dangerous things to strangers, you need to minimize risks around the house and beyond.

Here's an excellent article on this topic, [20 Tips For Keeping Your Child With Special Needs Safe In Your Home](#)." The author wisely notes: "we, as parents of kids with special needs, often need to be extra vigilant when it comes to household safety, remembering that "child-proofing" our homes is sometimes necessary for our adult offspring as well as our young children."

Here are some more tips:

- If you have a young child (who has special needs or not) call a professional home safety company to locate and "defuse" hazards around your house. For instance, you might want to put rubber or felt tips on the edges of tables, cover outlets with special child-proof cases, add locks to cabinets that contain medicines and household cleaners, etc.
- If you live with a dog or other pet that has a tendency to be aggressive, strongly consider giving the pet up for adoption or investing in professional training for the animal. Most animal attacks happen with animals within the home.
- Be observant. If a teacher voices a concern, or if your child gets into an accident or "near accident," pay attention. You might even want to document and reflect on the accident or near accident, so that you can take action to prevent crises in the future. For instance, let's say your child is constantly running ahead of you, whenever you walk near traffic. Be sure to bring a stroller with you on errands. Or let's say your child demonstrates an impulse to pull dogs' tails. Make sure to warn friends or neighbors with dogs that your child might do this, so that they can take appropriate measures.

Don't Go It Alone: The Importance of Obtaining Strong Social and Emotional Support

You are only human, and you have your own limitations, needs and fears. You don't have to go through this journey by yourself. Strongly consider getting involved with local support groups, so that you can swap notes and strategies and just bond over the experience. We are social beings, and sometimes we just need to have other people listen to us and reflect what's going on inside of us. Along those lines, if you're really struggling with depression or anxiety (having to do with your child or not), strongly consider obtaining therapy or counseling.

Reclaim Integrated Financial Control

We've spent the bulk of this book talking about special types of strategies and instruments you can use to plan for your special needs child's future. However, this planning process should be just one component of a fully integrated vision for your family's financial future. Obviously, a general discussion of "best practices" for money management and financial planning could fill

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10 books this size (or more). Here are several powerful articles that can help you tackle diverse challenges (and opportunities) and regain a sense of control over your financial destiny.

- [25 Ways to Get Smarter About Money Right Now](#)
- [6 Tips For Financial Planning In Your 40s](#)
- [6 Financial Planners Spill: 14 Tips We Tell Our Friends](#)

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Section 3: Resources

Here are some more resources to help you plan and cope, financially and otherwise, for the special needs parenting journey.

- [20 Quotes to Encourage Special Needs Moms \(and Dads\)](#)
- [7 Things You Don't Know About A Special Needs Parent](#)
- [15 Reasons Why Its Hard To Get Along With Special Needs Parents](#)
- [Understanding the 13 Categories of Special Education](#)
- [20 Things Every Parent of Kids with Special Needs Should Hear](#)
- [Detailed report on Special Needs Trusts from the American Bar Association](#)
- [Parenting Special Needs Magazine](#)
- [Editor's Picks from the U.S. Department of Education: Resources for Special Needs Parents](#)
- [Special Needs in Child Care – New Jersey Specific Resources](#)
- [Resources for Including Children with Special Needs in Child Care \(New Jersey\)](#)

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Conclusion

Being a parent is one of the most awesome and exciting experiences you can have as a human being. It's also abjectly terrifying and overwhelming. The expression "you can't understand until you're a parent" may be trite, but it is also so, so true. And you and your family have a unique extra set of challenges (and blessings), since one of your children has special needs.

In this book, we've laid out a foundation for how to plan, financially and otherwise, to protect and ensure the wellbeing of your child not just over the next few months and years, but for the rest of his or her life. We discussed critical instruments and documents like special needs trusts, power of attorney and wills as well as general estate planning principles. We also reviewed best practices for how to do things like select a trustee, organize appropriate documents to begin planning, and work effectively with service professionals, like attorneys, financial advisors, doctors and therapists.

Hopefully, you now feel a lot clearer about the work and projects that you need to handle. However, you may still have more questions than answers. We're here to help. If you'd like customized, personalized assistance with your special needs planning, call the team at The Matus Law Group at (732) 281-0060, or explore more about us at www.NewJerseySpecialNeeds.com. We wish you much joy and grace on your parenting journey!

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