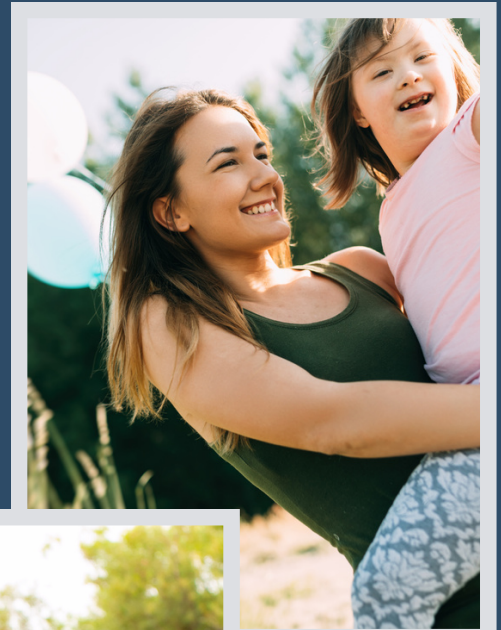


Planning with Purpose

A Guide to Special Needs Planning
for Parents & Guardians



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PLANNING WITH PURPOSE



Being a special needs parent or guardian is challenging; finding helpful advice even more so. In a world of ever-changing regulation, shifting eligibility requirements, and evolving personal circumstances, many families find it difficult to identify their immediate needs, let alone plan years or decades in advance.

The statistics support this: 52% of special needs caregivers don't have a plan for supporting their special needs family member when they can no longer do so. This is despite nearly all caregivers (96%) desiring a residential solution, level of community involvement, and general quality of life beyond what government assistance will reasonably provide.*

That's why we created this guide - to stress the necessity of a plan that takes care of your loved one with special needs and your family as a whole.

Chances are you've seen some of this material before; you even may have started the special needs planning process in some way. No matter where you are in the journey, our goal is to provide guidance so you can build a plan and make the right decisions for your family.

While helpful, this guide is no replacement for a conversation with a financial professional trained in Special Needs Planning. If you haven't already, we encourage you to reach out and find someone appropriately credentialed with the necessary experience to help you. If you don't know where to start please let us know - we'll be happy to point you in the right direction.

*Source: ARC Family & Individual Needs for Disability Supports Survey Report 2023

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WHAT IS **SPECIAL NEEDS PLANNING?**

While there is no universally accepted definition of Special Needs Planning, we prefer the definition provided by Hal Wright, CFP(R), in his book [The Complete Guide to Creating a Special Needs Life Plan](#):

Special Needs Planning is “a process to assure an adult with a physical, cognitive, or mental impairment a place in the community appropriate to his or her needs, capabilities, financial resources, and wishes for the nature and quality of their own life.”

The ultimate result of the Special Needs Planning process will look different for every individual and family. Everyone approaches planning with differing circumstances and possesses unique interests & desires for their long-term future.



WHAT IS **SPECIAL NEEDS PLANNING?**

What is consistent across every planning engagement, however, is the desire for success - more explicitly defined as things accomplished and things avoided.

Trying to Accomplish:

- Ensuring a quality of life above the bare minimum standard set by government agencies
- Provide security, independence, dignity, and sense of purpose

Trying to Avoid:

- Living a lower than desired quality of life
- Disqualification for government benefits
- Exhausting financial resources
- Failing to accomplish broader family goals



THE PURPOSE OF PLANNING

Special Needs Planning requires a lot of things: time, money, patience, and trust. But it also requires confronting hard truths. For parents & caregivers one truth is most difficult: we will not always be capable of caring for our children.

With the increase in life expectancies among those with a disability diagnosis, the harsh reality is many individuals will outlive their primary caregivers. An even greater percentage of caregivers will become incapable of providing support due to age, cognitive decline, or disability. Despite best intentions it is beyond the abilities and desires of many individuals 65+ to care for an adult with special needs.

Reliable support from extended family is also eroding. The combination of older first-time parents, smaller households, and geographically separated families results in fewer caregiving successors. In cases when the primary caregiver becomes unable to assist, the question arises: **“what will happen when I’m gone?”**

The purpose of planning is to answer that question and the answer is simple: **your loved one will live the life you’ve planned for them.** Good or bad, their existence becomes the outcome of your preparation.



THE PURPOSE OF PLANNING

Families that plan create a massive advantage; they build a future based on THEIR intentions. They arrange residential solutions, select future guardians, outline required activities & provide the financial resources to support their choices. They can also balance the needs of their special needs child with other familial needs such as retirement, education, etc. Individuals are well cared for, and family members enjoy the relief that comes with responsible preparation.

Families without a plan find themselves without answers when change happens. Surviving relatives are likely under-resourced and ill-prepared because funds and awareness weren't provided. In some cases the assumed caregivers might refuse their responsibilities, and the individual with special needs is left to the mercy of state assigned conservators. Where they live, who takes care of them, what their day looks like - these choices are then made by strangers.

Our goal isn't to frighten; we know that this subject is difficult. From our perspective it is better to confront this hard truth up front and directly. We need to acknowledge that inaction is unacceptable and the only way to assure a worthwhile quality of life is to create a special needs plan. When in doubt ask this question: **"do I trust a stranger to care for my child?"**



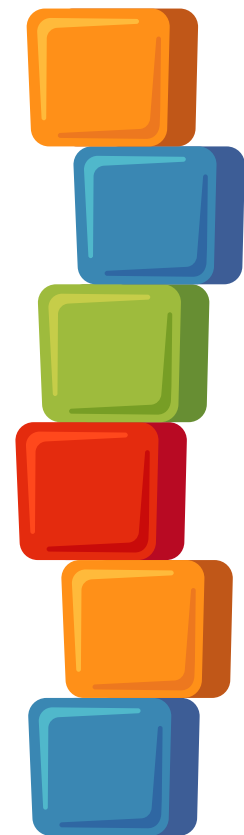
WHY PROFESSIONAL PLANNING IS NECESSARY

Of all the financial challenges that we assist clients with - running small businesses, creating a remarkable retirement, managing professional careers - special needs planning might be the most demanding. It is complicated in every case by a confluence of personal, familial, governmental, and environmental factors that require strict attention to detail and subject matter expertise. Success for the special needs community requires being proactive about these factors, not reactive. When it comes to special needs the axiom is true: failing to plan means planning to fail.

Below are just some examples of why going without a plan or attempting the “do-it-yourself” approach is inadvisable:

Complexity of Issues

Each special needs situation involves making assumptions about a litany of inter-related factors beyond the individual's or the family's control. These assumptions are the building blocks of your plan, and they require knowing each issue to address, question to ask, and calculation to perform to get to a viable solution. Asking the wrong questions - or worse omitting critical details - can lead the whole endeavor to collapse.

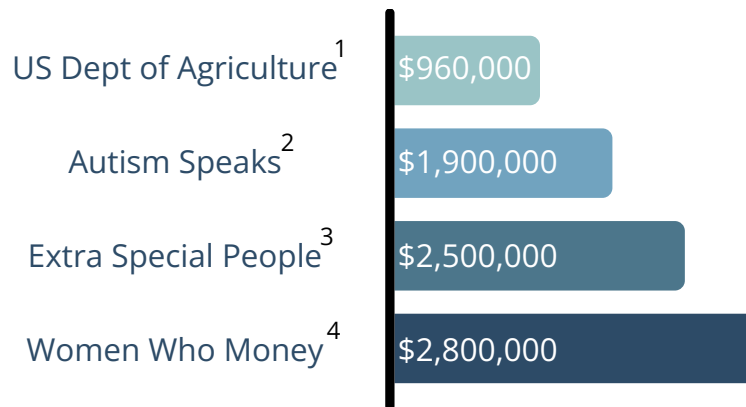


WHY PROFESSIONAL PLANNING IS NECESSARY

Lack of Community Consensus

One of the reasons it remains hard for families to plan alone is the disparate view of what lifetime care costs; there is no “holy grail” amount of savings that is guaranteed to provide for an individual with special needs. Some organizations, like the ones listed below, use a broad brush to create cost estimates. In our opinion all this does is muddy the waters and create additional confusion.

Cost of Raising Special Needs Child



Absence of “Rules of Thumb”

While less effective than a purpose-built plan, “rules of thumb” have become ubiquitous in the investment industry for their simplicity and ability to serve clients at scale. You have probably heard some of these before:

- “Save 10-15% of your pre-tax income for retirement”
- “Maintain debt to income ratio of 35% or less”
- “Limit annual retirement withdrawals to 4% of your account”

Whether you believe in these principles or not, the fact remains they don’t exist for special needs planning due to the highly specific needs and circumstances of each individual and their family.

1 Dehner, C. (2021, December 15). The Cost of Raising a Special Needs Child. Intuit MintLife.

2 Horvath, H. (2021, December 20). How to afford raising a child with disabilities. PolicyGenius.

3 Wilkes, L. (2016, October 26). The Surprising Costs of Raising a Special Needs Child. University of Georgia.

4 Lorz, Kari. (2022, July 30). Raising a Special Needs Child: The financial impact. Women Who Money.

WHY PROFESSIONAL PLANNING IS NECESSARY

Whole Family Focus

In many cases when a family tries create a Do-It-Yourself (DIY) special needs plan, the needs of the individual overwhelm broader family considerations. This is understandable, especially if the individual is expected to lack the capacity for independence when they reach adulthood.

However, having a child with special needs doesn't mean the broader family aspirations become unattainable. More common planning considerations - retirement, education, estate planning - are just as important and need to be prioritized.

The 800lb Government Gorilla

Government benefits are simultaneously the greatest source of funding and the greatest source of frustration for special needs families. Attaining eligibility is a long, cumbersome process complicated by bureaucracy and opacity. Being approved in many cases requires herculean effort and immeasurable patience. Once granted, these programs require an equally diligent management effort: controlling the individual's income, assets, and activities to stay compliant with program eligibility.

While some families manage the quagmire of government benefit eligibility alone, most lean on experienced professionals to help them attain and maintain these essential services, as well as fund the lifestyle requirements that government benefits don't support.

WHY PROFESSIONAL PLANNING IS NECESSARY

Do-It-Yourself (DIY) Is Often Unsuccessful

Special Needs Planning is a complex undertaking requiring specific knowledge and expertise. Each step of planning builds upon the one before it and the process is linear - it's critical that the steps be performed in the correct order. Failure to do so usually results in revisiting certain steps at the cost of time and financial expense.

Often we are approached by families who attempt to DIY a special needs plan, but can't complete it without professional help. While the reasons for this vary, typical themes of incomplete DIY plans are:

- Attempting to do too much at once
- Forgetting or omitting critical steps
- Incorrect calculations and assumptions
- Following incomplete guides/advice
- Overwhelmed by amount of material and requirements



PLANNING

ROLES & RESPONSIBILITIES

Special needs planning takes a village; in this case a village of financial, legal, and advocacy professionals. There is no one-stop-shop for special needs planning; it requires assembling a team of allies for your family based on knowledge, experience, and personality. What follows is a brief description of the most common roles in special needs planning, organized by the tenure of relationship.

Temporary/Transactional Relationships

- Benefit Specialist: handles application for government benefits
- Estate Attorney: creates estate vehicles & documents (trusts, wills, powers of attorney, etc.)

Long-Term Advisory Relationships

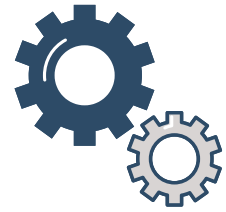
- Financial Planner: builds, monitors, & maintains the special needs plan
- Investment Advisor: manages and invests accounts to achieve plan goals
- Accountant: handles trust accounting and tax filings

Day-to-Day Relationships

- Trustee/Trust Administrator: approves distributions from accounts & supervises other team members
- Guardian: makes decisions regarding the person and/or property of the individual



SPECIAL NEEDS PLANNING TOOLS & RESOURCES



This list highlights some of the different tools & resources we utilize as special needs planners. To learn more about the items listed here, please visit the Resources section of our website.

Letter of Intent: Document that outlines (as parent/caregiver) your instructions, arrangements you have made, and what needs to be done in the event of your death or incapacity to ensure your child's quality of life.

Special Needs Trust: An estate planning tool and distinct legal entity capable of holding title to financial resources for the benefit of the individual with special needs. Assets held by a properly structured special needs trust do not disqualify an individual from government benefit eligibility.

529 ABLE Account: A savings and investment account for individuals with disabilities. Can hold up to \$100,000 worth of investable assets that are not counted for government benefit eligibility. Funds inside the account grow and can be withdrawn tax-free if used for Qualified Disability Expenses (QDE).

Guardianship: The process by which an individual loses or gives up some of their civil rights to another individual to carry out on their behalf. Typically a result of an individual deemed to have a developmental disability or prior poor decision-making skills.



SPECIAL NEEDS PLANNING PROCESS



Our Special Needs Planning process is comprised of nine steps, each one critical to a successful outcome.

Step 1: Build a Family Financial Plan

The family financial plan is the foundation of all other planning, addressing issues such as retirement, education, legacy, etc. Each detail of the special needs will impact, and also be impacted by, the family financial plan.

Step 2: Write a Life Plan & Letter of Intent

These documents provide the guiding vision for the special needs plan. They dictate residential preference, social life, vocation, quality of care, and other issues. These documents also describe the capabilities and limitations of the individual as well as emergency instructions for their care in the event the primary caretaker is incapacitated.

Step 3: Calculate Lifetime Cost of Care

Using the details of the LP and LOI, identify the cost of the individual's anticipated lifestyle from current age to anticipated mortality.

Step 4: Determine Government Benefit Eligibility

Assess which programs - entitlement, financial need, or other - the individual could qualify for, as well as the amount and timing of anticipated assistance.

SPECIAL NEEDS PLANNING PROCESS



Step 5: Calculate the Funding Gap

Once we calculate how much lifetime care will cost, and how much we can expect the government to contribute, the next task is to calculate the difference, or “funding gap”. This represents the amount the individual and their support system are required to contribute for their care.

Step 6: Assess Resources Available to Individual

Perform an accounting of all assets that the individual owns, as well as assets the individual’s family can dedicate to their care.

Step 7: Estate Planning

Establish the proper planning structures to make sure that money flows to the correct locations and, more importantly, doesn’t flow to places it shouldn’t.

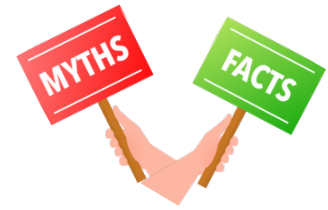
Step 8: Create Funding Plan(s)

Build pathways to close the funding gap by saving, investing, and transferring risk. Plans should be based on a base case (standard life expectancies) and worst case (untimely death or disability of caretakers).

Step 9: Manage, Monitor, & Adjust

Plans are dynamic and an individual’s situation can change frequently - monitoring & adjusting the investment mix, altering savings levels, and shifting timelines are usually required.

COMMON MISCONCEPTIONS



We've been helping families for years, and have heard a lot of assumptions, expectations, and excuses related to special needs planning. This list is by no means exhaustive, but represents some of the more widely held and perilous statements that we wish to debunk right upfront...

“The government is going to provide for my child once they become an adult...”

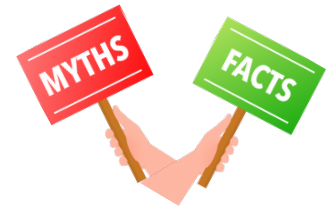
While the government MAY provide SOME support for your child with special needs, this support very rarely covers all the essential costs of daily living. In most cases government support becomes a piece of the overall support plan. For example, SSI payments for a single individual in 2023 are \$941/month; but the average 1BR rent in Florida is \$1,404.* Government support won't cover even average housing costs.

“My child with special needs is still in elementary school, we don't need to start planning for years...”

We can't stress this enough: the earlier you begin planning, the more effective and resilient your plan will be. Time is one thing you can't create in planning and delaying represents lost opportunity. Wait lists for government benefits are typically measured in years; investments can take decades to grow and compound; and no one knows if they will be around tomorrow. If you don't put a plan together now and something happens to you - what happens to your loved-one?

*Source: Social Security Redbook. Nd. <https://www.ssa.gov/redbook/newfor2023.htm>

COMMON MISCONCEPTIONS



“We don’t have the financial resources for a plan...”

You don’t need liquid wealth to build a plan. Only 37% of special needs households report income at or above \$100,000. There are other ways (savings, investment, insurance) to fund your child’s future.*

“We created a Special Needs Trust/529 ABLÉ account and purchased life insurance, so our planning is done...”

Trusts, ABLÉ accounts, and insurance are critical tools in special needs planning...but they aren’t a plan themselves! A proper plan is much more complicated, factoring lifetime cost of care, benefit eligibility, available resources, and multiple funding strategies. Planning is an evolving process - a good plan must be continuously monitored, managed, and maintained.

If you have done some component of Special Needs Planning previously but aren’t actively engaged with a planner, ask yourself these questions:

- When did I last calculate my loved-ones lifetime cost of care?
- Have the funds (investments, insurance, etc.) I earmarked for care kept up with the cost?
- What changes need to be made to “bridge the gap?”

If you don’t know the answer, you need to speak with a planner.

“I have a special needs child, so I’ll never be able to retire...”

In most cases, getting ahead of the situation early and developing a special needs plan can provide for both the individual with special needs’ desired future and the desired future of their family members.

*Source: ARC Family & Individual Needs for Disability Supports Survey Report 2023

SPECIAL NEEDS PLANNING

THINGS TO AVOID



We believe there is a right way to do special needs planning - the corollary to that is there must a wrong way to do special needs planning as well. While not all practitioners do the job in identical fashion, there are some things we suggest you avoid at all costs:

Choosing the Wrong Team of Professionals

Choosing the right financial advisor, attorney, benefits advocate, and accountant are critical to special needs planning. Credentialing and experience matter - make sure you are engaging someone who has done this work before and is committed to the rapidly evolving landscape of special needs planning. Ask how involved practitioners are in the broader community, if they have references they can provide, and what other professionals are part of their network.

Seeking the Fast & Easy Solution

Silver Bullet. One-Stop Shop. Quick Fix. It doesn't matter what you call it, it's an incredibly alluring idea - doing one thing to address all the issues in special needs planning. Some organizations, especially those without real experience or knowledge of the issues, advertise "solutions" like this. Examples include the disinheritance model of estate planning or insurance only financial solutions. Our opinion - what's good isn't fast, and what's fast isn't good. Avoid at all costs.

Disregarding Typical Family Aspirations

Its easy to be overwhelmed with the complexities of special needs planning and overlook the needs of the rest of the family. In most cases the family is not only providing financial support but also serving as primary caregiver - so your personal & financial well-being are equally as important to plan for.

SPECIAL NEEDS PLANNING

THINGS TO AVOID



Not Funding Your Plan

Many times we hear “something is better than nothing” - with special needs planning that is not true. Families that set up only part of their plan give themselves a false sense of security for their future. Creating a special needs trust is a good start, but it doesn’t provide value without a corresponding funding plan. What good is an empty trust when the time comes to utilize it?

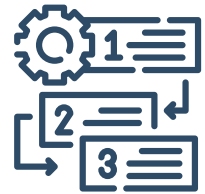
Making Assumptions About Guardianship

In many cases an individual with special needs has neuro-typical siblings in their immediate family. As parents we understand the desire for our children to be there for each other when we are gone. But as planners we know that sibling guardianship arrangements work best when they are discussed and agreed to in advance. Assuming your neuro-typical adult children will have the personal, financial, and familial capacity to take care of their sibling without condition can lead to a disastrous outcome.

Using Quantitative Instead of Qualitative Goals

Lots of clients will start a consultation by telling us how much money they need to set aside for their child, not the quality of life they envision for them. In many cases the assumptions made about dollar figures are wildly incorrect; remember that “rules of thumb” don’t exist for special needs plans. A million dollars isn’t always the answer - sometimes more (or less!) is required to give an individual the life they deserve.

UNDERSTANDING WHY WE PLAN



It's one thing to talk about what Special Needs Planning is, but we also need to address why we do it. It's a weighty conversation so we prefer to break it into three categories: the impact it has on the individual, the impact it has on caretakers, and the impact it has on us as practitioners.

Impact on the Individual

The first and most important reason we plan is also the most obvious - it positively impacts the quality of life for the individual with special needs. In many cases Special Needs Planning is the key to multiple lifestyle enhancements, especially as an individual ages: better residential arrangements, more societal integration, increased sense of purpose. All of these things require the resources and structure that Special Needs Planning provides. Without them, quality of life is severely diminished.

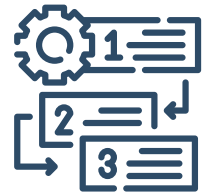
Impact on the Caregiver

The secondary but no less important reason we plan is the impact on the caregiver. This impact is significant, sometimes more significant than the impact on the individual.

It is very common for families to put the member with special needs at the center of their focus and devote everything they have to their success. But many times that level of sacrifice detracts unnecessarily from other members of the family.

Assuring the desired quality of life for the broader family - whether through retirement, education, or estate planning - is a distinct benefit of creating a plan. The only thing better than securing your child's future is doing so while also securing your own.

UNDERSTANDING WHY WE PLAN



Impact on Practitioners

Ask anyone who has spent considerable time working with the special needs community and you will hear the same thing regarding their motives: “it isn’t about the money.” It’s about helping take care of people who can’t always take care of themselves.

Individuals with special needs have been historically underserved by the financial industry. Advisors who are uncomfortable interacting with or don’t understand the nuances of the community, combined with the stereotypical rigidity of most banks & brokerages has created a vacuum of services.

We are dedicated to changing that paradigm and partner with attorneys, accountants, trustees, and advocates who feel similarly. At the end of the day this is a calling for us. Making money is great in our business; positively affecting lives is better.



ABOUT OUR PRACTICE

The Johnson Cotroneo Group (JCG) of Moors & Cabot is a full-service wealth management practice. In addition to our work with Special Needs Families we also work with Small Business Owners, Career Professionals, and those seeking a Remarkable Retirement.



SMALL BUSINESS OWNERS

For most small business owners, their largest and most important investment is their business. We have a unique perspective as professionals who have valued closely held businesses, established retirement programs, and built viable succession plans. That's why we offer strategies designed to protect, grow, and eventually maximize the value of your business for sale or transfer.



CAREER PROFESSIONALS

A life dedicated to a particular field - medicine, law, military service, business - and the perfection of its practice. Career professionals face significant demands on their time and increasingly complicated environments in which to operate. Let us provide the process to increase your financial efficiency and free up time valuable time.



REMARKABLE RETIREMENT

Engaging in one's enthusiasms shouldn't be a luxury; it should be the outcome of every successful plan and the reward of a life well-lived. Whether simple activities like golf & fishing or once in a lifetime experiences, the things you dream of should be the core of your retirement planning.

ABOUT OUR PRACTICE

Both our partners, Matthew Johnson and Brian Cotroneo, possess extensive credentials and over 40 years combined experience in financial planning. Before founding JCG, they worked at multi-national brokerages Merrill Lynch, Citi, and Bank of America as well as boutique firms in Florida. Matt & Brian possess a shared vision for JCG where clients are given what they need, how they need, when they need it.



Matthew Johnson

Co-Founder, Johnson Cotroneo Group

Certified Financial Planner (CFP)
Chartered Financial Consultant (ChFC)
Accredited Estate Planner (AEP)

Brian Cotroneo

Co-Founder, Johnson Cotroneo Group

Chartered Special Needs Consultant (ChSNC)
Chartered Financial Analyst (CFA)
Certified Financial Planner (CFP)



Matt and Brian are also active contributors to the broader Special Needs community - presenting at Florida's Family Cafe symposium, participating in regional conferences, members of the Academy of Special Needs Planners, and supporting special needs related organizations such as Special Olympics, National Down Syndrome Society, Autism Society of Florida, and the Arc.

TAKE THE FIRST STEP

Special Needs Planning is complicated - but it starts with a simple conversation. Contact us today to schedule an introductory meeting with one of our partners.

We will walk you through the planning process and discuss the issues unique to your individual scenario. Appointments can be scheduled via phone, virtual meeting, or in-person at a location convenient to you.

If you have specific questions or are interested in more resources, please visit our website below.



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