



Autism Speaks Special Needs

Financial Planning Tool Kit

 **AUTISM SPEAKS**[®] FAMILY SERVICES



It's time to listen.

A tool kit to provide you with essential information
and guidance you need to develop a plan for
your child's financial future.

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this tool kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.

Table of Contents

Introduction	1
Accessing Funding Through State and Federal Programs	2
Planning for the Future: “We All Share the Same Sleepless Nights”	9
Special Needs Trusts	10
Financial Products & Instruments Used in Planning	14
ABLE Accounts: A Savings Tool for Individuals with Disabilities	16
Guardianship and Conservatorship	20
Finding the Strength to Plan for the Future	24
Finding the Right Professional	25
The Basics of Budgeting: A Step in the Right Direction	28
Tips on Applying for Financial Aid for your Family Member with Autism	33
Financial Assistance	34
Conclusion	38

Acknowledgments

Autism Speaks would like to thank The SunTrust Foundation for their generous contribution to fund the development of the Special Needs Financial Planning Tool Kit.



A Note from The SunTrust Foundation

The SunTrust Foundation was established in 2008 to support not-for-profit organizations with the sole focus of helping their constituents achieve a Life Well Spent through financial education and financial well-being programs. SunTrust Foundation grants are in the areas of education, health and human services, civic and cultural activities. In addition, the SunTrust Foundation proudly supports disaster relief organizations to help heal and rebuild a community after tragedy strikes. Since 2008, the SunTrust Foundation has given more than \$100 million throughout the Southeast and Mid-Atlantic states. These grants have been guided by our founding principle of “build your community, build your bank”.

The SunTrust Foundation is proud to partner with Autism Speaks and sponsor this comprehensive toolkit to serve as a guide for financial and legal resources available for parents of children with special needs. You’ve taken the first step to learn more about these resources. For more resources and support as you plan for the future, Autism Speaks is here to help. Contact the Autism Response Team at 888-288-4762 (en Español 888-772-9050) or familyservices@autismspeaks.org.

Contributors

Autism Speaks would like to extend special thanks to those who contributed to the Special Needs Financial Planning Tool Kit for their time and effort:

Shirley Blaier-Stein
Ginny Duhon
Michael Giangregorio
J-Jaye Hurley
Reilly Morrison
Ryan Platt
Katrena Shipp
Anne St. Clair
Karen L. Starbowski
Evan Whittle

Introduction

All parents worry about their children's futures – some call it part of the job. But for parents of children with special needs, the worry can be even bigger. Some of the biggest concerns special needs parents have are financial. How can I afford the added costs of raising a child on the spectrum? How will my son or daughter be supported financially when I am gone? What can I do now to be as certain as possible that all of my child's needs will be met when he or she becomes an adult? An elderly person? These questions can be very overwhelming and unfortunately, the answers can be complicated.

As the parent of a child with autism, you likely have a variety of expenses today that you have had to budget for more so than other parents, like therapy sessions and assistive technology. And in addition to these current costs, the future costs of supporting your child will likely be higher as well. While some individuals with autism are able to attend college and/or go on to full time employment that will allow them to be financially independent, many will require other forms of financial support throughout their lives, both from government benefits and from private sources like family income.

Mapping out your child's financial future can seem like a daunting task, but having a plan in place can help ease your fears. The Autism Speaks Special Needs Financial Planning Tool Kit was created to provide you with all the information that you need to develop that plan. The kit covers technical topics like Medicaid and ABLE Accounts, and also provides guidance on managing your budget and finding the right professional to assist with your planning process. The information comes from top experts in the field with many years of both personal and professional experience with special needs financial planning. We have also included some personal stories from other parents or caregivers like you.

My son just turned 19. We planned ahead to make sure he had no financial resources in his name over \$2,000 when he turned 18 so that he qualified for SSI and Medicaid.

He started a work program in school to learn necessary job skills and we are working on a plan to make sure his needs continue to be met after he turns 21 and ages out of the school system. Planning is key!

As always, if you have any questions or are looking for additional resources, please feel free to contact our Autism Response Team at 888-288-4762 (en Español 888-772-9050) or by email at FamilyServices@AutismSpeaks.org.

Happy reading and best of luck planning!

The Autism Speaks Family Services Team

Autism Speaks would like to thank the SunTrust Foundation for their generous contribution to fund the development of the Special Needs Financial Planning Tool Kit.

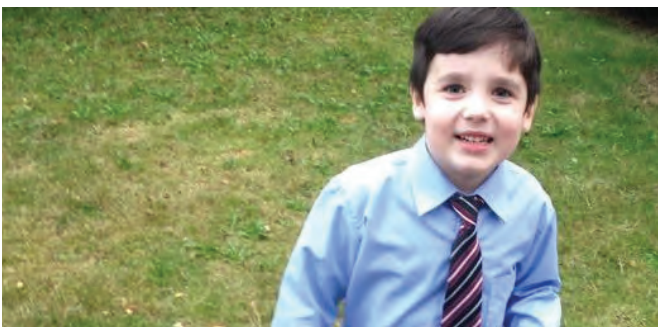


Accessing Funding Through State and Federal Programs

Caring for children with autism can be overwhelming. There are so many needs and life is often chaotic, especially when severe behaviors are involved. I have met many parents who were desperate for help and support, yet were too overwhelmed with day-to-day life to be able to figure out their child's rights and their right for support.

There are roughly three avenues of support for our children, and it is our role as parents to advocate these three avenues tirelessly in order for our children to receive the maximum help.

The first avenue is the school program. Different states and different towns and school districts offer different services, but under federal law, services should be based on a student's individualized needs. Unfortunately, the services offered are often dictated by the town's budget rather than the child's needs. That's when we parents come in and advocate. The difference that getting involved and advocating can do in getting your child the right program is vast. Do not hesitate to ask around in your community, talk to other parents, collect the most information, and use a professional when needed. It is usually worth the initial investment because your child has many years in school. You may need more help along the road, yet the initial creation of a good program is very important.



This section was prepared by Shirley Blaier-Stein, the author of *Autism Mom: New Ways of Thinking*, an attorney and an autism advocate. Shirley's son has autism. He attends a behavior-focused school in CT and is doing well. Shirley lives and writes autism and is passionate about helping autism parents reach their potential in order to become empowered, exercise their children's rights, achieve the best program and treatment for their children, and help their children thrive.

The second avenue for services is health-related therapies covered by health insurance. Services such as speech therapy and occupational therapy are typically covered. In recent years, some states have adopted laws that mandate covering behavioral therapy for children with autism. Such therapy is need-based and must be assessed by a medical professional. Once your child gets approved, he/she will receive hours of therapy that typically help tremendously.

The third avenue and the one I will focus on here is government entitlements like Medicaid.

Medicaid Funding

What is Medicaid?

Medicaid is a program that is funded in part by both the federal and state government. Medicaid pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports. An individual can qualify for Medicaid based on both income and disability. Eligibility rules vary across states.

Determining Eligibility and Application Process

To be eligible for Medicaid, an individual must meet financial eligibility criteria which looks at the individual's (or in the case of a child, their parents') income and resources. Income and resource limits vary within and across states. Eligibility is also determined based on an individual's functional level-of-need, i.e. the healthcare and support needs created by the individual's disability. Functional eligibility also varies within and across states both in terms of the criteria and levels set as well as the processes by which states determine eligibility. Eligibility criteria vary widely and states have many optional rules that they can use in determining eligibility.

As a result, parents and individuals should consult experts in their state's Medicaid program, such as the state protection and advocacy system for individuals with developmental disabilities, to learn more about the specific rules in their state. That being said, in all but 10 states, if an individual is eligible for Supplemental Security Income (covered later in this section), he or she automatically qualifies for Medicaid.

To obtain Medicaid, you must apply through the relevant agency in your state (such as Department of Health or Department of Developmental Services, depending on where you reside). Such requests need to be supported by medical documentation showing a child's current medical status needs. An academic evaluation and diagnosis would not do for that purpose.



Home and Community Based Services (“the Waiver”)

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of **Medicaid Home and Community-Based Services (HCBS) Waivers**, people with autism and other disabilities can use these funds more flexibly. The program enables states to serve people who wouldn't normally be eligible for Medicaid or provide services that aren't offered as part of the regular Medicaid benefit package in that state.

The purpose of HCBS waivers is to provide services that offer an alternative to Medicaid institutional services such as intermediate care facilities, in-patient psychiatric facilities or nursing facilities. HCBS waiver services may, for example, provide support to families and individuals to help them remain in the home and community. In many cases, HCBS programs enable state Medicaid programs to achieve greater cost effectiveness within their long-term care programs.

States have considerable flexibility in designing their HCBS waiver programs. Eligibility levels (both financial and functional), services and benefits available (in terms of type, amount, duration and scope) and populations served vary across HCBS programs within and across states.

State Department of Developmental Disabilities

Another source of funding is your state's agency supporting individuals with **developmental disabilities (DD)**. (The names vary across states – in some states it's a department, others a division, etc.)

There is wide variation across states in terms of the services available through the state's DD agency. In some states, the services received through Medicaid and HCBS waivers will actually be provided by your state's DD agency. (In these cases, the Medicaid agency provides the funding for the programs that serve individuals with developmental disabilities, but contracts the DD agency to actually provide the services.) Some DD agencies might also provide services beyond what is available through Medicaid, including respite care and supported employment services, among others. Be sure to check with your state to see what services are offered by the DD agency and which supports your family is eligible for.

The pathway to eligibility and to access those services isn't always straight or clear. In fact, it is often quite messy. So it is important to do your homework! Make sure that you are contacting both Medicaid and the DD agency in your state to be certain that your child is getting everything to which he or she is entitled. And don't be afraid to be persistent! Many of these available services can be very helpful to your entire family.

You can learn about and find the contact information for the agency in your state on the [National Association of State Directors of Developmental Disabilities Services \(NASDDDS\)](#) website.



Services Covered

Services covered under the waiver include support in the home and in the community. There are many different services available in HCBS waivers and the exact type, amount, duration and scope of services available is determined by the state.

Therefore, you should contact the state agency that operates the waiver to find out which services are available. Waiver services can include things like in-home behavioral support, in-home support staff, care coordinator (case manager), respite, and others. Such services are different from the typical Medicaid services provided outside of the waiver.

States also allow Medicaid participants to self-direct their care, meaning the participant gets a budget and can hire and manage staff independently. This allows more flexibility and control of who is working with the participant. Insurance services are often not self-directed and follow the medical model, meaning an agency or medical professional is hired to run the program, and brings their own staff to support the individual. Typically this leads to better supervision of staff and therefore more accountability.

The level of support varies from state to state and depends on the level of care and necessity for the individual.

I always associated Medicaid with health insurance coverage for the financially disadvantaged and assumed that was it. Now I know there is so much more to it. And I'm so glad I do!

Funding from the Social Security Agency

A very important funding channel for your child's future is through the U.S. Social Security Administration (SSA). This funding can come in two different ways: Supplemental Security Income and Social Security Disability Insurance.

Below is a brief overview of these two benefits and some information on how you can access them for your family if not eligible.

Supplemental Security Income

Supplemental Security Income (SSI) is a Social Security program that makes monthly payments to adults and children who have limited income and resources and meet Social Security's definition of disability. For low income families, monthly SSI payments can be very helpful to cover expenses.

Definition of Disability

To be considered disabled and eligible for SSI, your child must meet all of the following requirements:

The child must not be working and earning more than \$1,090 a month in 2015. (This earnings amount usually changes every year.)

The child must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.

The child's condition(s) must have been disabling, or be expected to be disabling, for at least 12 months or the condition(s) must be expected to result in death.



Limited Income and Resources

To determine whether your child is eligible to receive these monthly payments, the SSA will consider the income and resources of all family members living in the child's household, including the child if he or she is working. The minimum earnings amount usually changes every year. The test for eligibility takes into account an individual's income as well as resources. Income means money earned from work; money received from other sources, such as Social Security benefits, or even friends or relatives; AND free food and shelter. For example, when the child lives with his family, the shelter and food he receives from his family counts towards "income."

Resources means cash, bank accounts, stocks, U.S. savings bonds, land, vehicles, personal property, life insurance and anything else you own that could be converted to cash and used for food or shelter. Liquid resources must be under \$2,000.

The SSA will look at the household income and assets and the parental living allowance to determine how much a child will receive in SSI benefits.



Applying for Disability Benefits

There are two ways that one can apply for disability benefits:

1. Apply online at [SocialSecurity.Gov](https://www.socialsecurity.gov); or

2. Call 1-800-772-1213, to make an appointment to file a disability claim at the local Social Security office or to set up an appointment for someone to take the claim over the telephone.

When you apply for SSI payments, you will also need to fill out a [Child Disability Report](#) on behalf of your child. In addition to requesting your financial documents, the SSA will ask you for lots of detailed medical information about your child's condition and how it affects his or her functioning level. You may need to give permission to his or her doctors, teachers, therapists and other professionals to share information with the SSA. The more information you provide, the easier the process will be. They may require your child to take additional tests or assessments, all at their own expense. It can take 3 to 5 months to decide a child's SSI disability claim.

Based on the information you provide, the SSA will determine a dollar amount for monthly benefits. Once your child starts receiving SSI, the SSA will review his or her condition from time to time to be sure that he or she still meets the criteria for eligibility. The review happens at least every three years.

When Your Child Turns 18

When a child becomes an adult at age 18, the SSA uses different rules to determine if he or she is eligible for SSI disability payments and as a result, you will need to go through a redetermination process to maintain his or her benefits as an adult. At age 18, only the individual's income and resources are counted when determining eligibility for SSI. As a result, there are many individuals with disabilities from higher income families who do not qualify for SSI until they turn 18.

There are also different rules when deciding whether an adult is disabled. The SSA will review your child's condition when he or she turns 18. As an adult, "disability" under Social Security is based on an individual's inability to work.

If your child is 18 or over and working or interested in working, his or her Social Security benefits do not have to be disrupted. The SSA offers some work incentives in order to allow individuals receiving SSI to work and keep their benefits. These include a **Plan for Achieving Self Support (PASS)**, **Impairment-Related Work Expense (IRWE)** and the **Ticket to Work** program.

You can learn more about these rights in the [Autism Speaks Employment Tool Kit](#). Call the [Ticket to Work Help Line](#) to speak to an expert about your child's specific situation at [866-968-7842](tel:866-968-7842) or visit [ChooseWork.net](https://www.choosework.net).

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance provides income supplements to people who are restricted in their ability to be employed because of a disability. The SSDI program pays benefits to adults who have a disability that began before they became adults. SSDI is payable to adult “children” of parents who are receiving Social Security retirement or disability benefits; or who have died and worked enough prior to their deaths to qualify for Social Security benefits. The SSA considers this a “child’s” benefit because it is paid on a parent’s Social Security earnings record. These benefits continue as long as your child meets the definition of disabled.

One important difference between the two programs is that SSDI payments are uniform in all states. SSI is different in each state, as sometimes the state supplements the federal payments.

Summary of Social Security Benefits

In summary, if your child is considered disabled by the SSA’s definition (which is different for children and adults), SSI payments are an option if:

Your child is under the age of 18 and your household meets a limited income and resource requirement; or

Your child is age 18 and over and his or her income meets a limited income requirement (your income and resources are not counted when determining eligibility)

In addition, SSDI payments are an option if:

You or your spouse receive Social Security benefits; or

You or your spouse pass on after paying Social Security taxes



SSI and Medicaid benefits for my son have been even more helpful than I thought they could be. Because of SSI, he was able to start working using the PASS work incentive program. Through Medicaid, he has been able to keep up with regular doctor appointments and transportation has been provided to and from the appointments. It took some serious advocating to make sure he got those benefits he deserves, but it was certainly worth every ounce of hard work!

Other Entitlements

Once you or your child are eligible for payments through SSI, you may also be able to access additional supports. In all but 10 states, if you are eligible for SSI, you are automatically eligible for Medicaid. In many cases, eligibility for SSI also automatically qualifies you for other low-income assistance programs in your state. These can include, but are not limited to:

[Supplemental Nutrition Assistance Program](#) (SNAP), also known as food stamps

Energy cost savings through the [Low Income Home Energy Assistance Program](#) (LIHEAP)

[Childcare subsidies](#)

[Temporary Assistance for Needy Families](#) (TANF)

[Head Start](#) (school readiness programs for young children)

Housing assistance (Contact your [local public housing authority](#) - often low-income housing will prioritize services for individuals who are disabled or are receiving SSI.)

Transit subsidies (Contact your [local public transit authority](#) - transit authorities will discount or offer special fares to people who are disabled.)

[Work Incentives Planning and Assistance](#) (service to help you plan benefits in way that enables you to work)

Keep in mind that many of these entitlements are state-specific so you will have to reach out directly to your specific state office.

The most important thing when securing these benefits is to be persistent. Oftentimes the SSA might exclude people with autism with higher functioning levels from the definition of “disabled.” You may need to appeal the SSA’s decision if your family is denied benefits to which you are entitled based on your child’s diagnosis or if you feel your benefit amount should be higher. There are four levels of appeal: reconsideration, administrative law judge hearing, appeals council review and federal court. Benefits from the Social Security Administration can be very helpful for families in the autism community. Don’t give up!





Planning for the Future:

“We All Share the Same Sleepless Nights”

This blog was written by autism dad Michael Giangregorio, Vice President at JP Morgan Chase and Autism Speak Programs and Services Chair, Long Island Chapter

Planning for a child’s future is an exciting time in a family’s life. It is a time to dream about the wonderful “what ifs.” For families that have a child challenged with a developmental disability, however, it is very different.

When your child is young, the “what ifs” are still so far away. You still have time on your side. You daydream that the hours of therapy will make him indistinguishable from his peers, and while some get to enjoy the leap, many of us do not. Then what? What do we do when the school bus no longer comes?

These are the thoughts that keep me awake at night.

I must prepare for the future, whatever that future may be. When it comes to financially planning for the future of a person with a developmental delay, we must ensure that all needs will be met. Many individuals with a developmental delay will receive Medicaid and Supplemental Security Income (SSI) benefits. While these programs are meant to meet an individual’s basic needs, they are not enough. There are many additional expenses which will not be covered by these plans - ranging from medical care, housing and clothing to education and technology, and maybe a vacation or two.

Though I’m not planning for the expense of college for my son, I am providing financial support so he will have

a meaningful future. The challenge comes in terms of the regulations limiting the assets that a person with a disability is allowed to hold before being disqualified for SSI benefits: just \$2,000. For this reason, my family will establish a Special Needs - or Supplemental - Trust for my son. This trust will authorize supplemental payments, allowing me to provide future financial stability for my son without jeopardizing government assistance.

Most recently, President Obama signed the ABLE Act (Achieving a Better Life Experience). While not perfect, when finally fully implemented this law will allow me to save for my son’s future without jeopardizing his government entitlements.

Another challenge I face is the question of who will speak for my son. Although my wife and I decide what is best for him now, all bets are off when he turns 18. The law will view him as an adult. Guardianship is the only way I can make sure that his mom or I will be able to advocate for what is necessary so he will be safe and happy. To secure this, I must prove to a court that my son is incapable of making decisions on his own. My wife and I must also choose someone to accept this responsibility when we are no longer alive - and who we can trust to carry out our wishes.

It’s not something I would have imagined 14 years ago when I looked at that beautiful face in the nursery, when I wondered and dreamed of all the wonderful things waiting for him to enjoy. While these challenges were not what we had planned for, we’re not alone: they are faced each day by many parents. We all share the same sleepless nights.

But it’s the smiles of our children and their gentle hugs that give us strength and serve as a poignant reminder of why we take on these tough responsibilities. At the end of the day, I’m a parent – and working for the bright future of my children is what a parent does.

Special Needs Trusts

Special needs planning involves comprehensive financial planning for the special needs person including income, tax, insurance and retirement planning, as well as estate planning. One of the cornerstones of special needs planning is the creation of a “third party” supplemental or Special Needs Trust.

The primary objectives of a special needs trust include:

Protect the assets left to a special needs beneficiary from predators and creditors.

Provide additional income to facilitate a better quality of life.

Prevent the loss of government benefits, including Supplemental Social Security (SSI) and Medicaid.

Plan for the ultimate future avoiding a burden on siblings once the primary caregivers are no longer able to take care of the person with autism.

State and federal benefits may help cover the basics – food, shelter, and routine medical care – but not specialized treatments. “Extras” like educational programs, therapy equipment or home-modifications are not usually covered.

Expenses to plan for:

Medical, dental, or surgical expenses not covered by government benefits

Enrichment programs for educational or recreational experiences

Psychological or behavioral counseling and support



This section was prepared by Anne St. Clair, a Senior Private Banker for The Private Bank at Wells Fargo with 17 years of experience in the financial sector. Anne services a national clientele of high net worth families, entrepreneurs and closely held businesses.

As a Board member of Community Hope, The Overlook Medical Center Auxiliary and Chairwoman of The Autism Speaks Fall Classic at Baltusrol, Anne is actively involved in her community.

Personal caregivers

Transportation for medical and recreational purposes

Entertainment such as magazines, movies, classes and gym memberships

Physical therapy not covered by insurance or benefits

Supplemental Special Needs Trust

A special needs trust helps plan for individualized care over your child's lifetime while protecting his or her eligibility for public benefits.

To qualify for benefits, there is a limit to the assets your child can own, usually less than \$2,000. A gift from a well-meaning relative may jeopardize your child's eligibility for benefits, even if the gift is not cash.

This is where a special needs trust (SNT) comes in. A SNT is a legal arrangement that is set up for the benefit of the child, but is not owned by the child. You then can set aside money, property – even life insurance benefits – to help prepare for current and future expenses.

The assets in a SNT will likely not be enough to fund your child's long-term financial needs. But, combined with any benefit programs, these funds can be stretched to enrich his or her quality of life.

What You Need to Get Started:

Choose an experienced attorney to prepare the Special Needs trust document.



Once I hired an attorney to set up my special needs trust, I felt a lot better about my son's financial future. I had somewhere to place my son's monetary gifts. Also, my mother wanted to leave my son a big inheritance because she knew he was going to have difficulty living on his own in the future. I feel a lot less anxious because I know the gifts will be used to my son's benefit in the future and he wouldn't lose his eligibility for government benefits.

Select a Trustee to manage the investments of the trust, administration, monitor benefits and to receive and monitor distribution requests from the trust.

Complete a Letter of Intent. This is a vehicle through which parents communicate their instructions regarding their disabled beneficiary's future.

Where Do I Get the Money to Fund the Special Needs Trust?

Assets you already own (you may choose to leverage with life insurance).

Life insurance can be the most cost effective way to leverage your assets. Your death benefit will be income and estate tax free directing the entire sum to the trust.

Your estate. Revise your will to include the Special Needs Trust as a beneficiary instead of gifting direct to that child.

Trust Document Explained:

Contains a special provision stating that assets of the trust are to be used to supplement, not replace, any benefits your child is receiving

Can be simple or complex depending on the kind of assets in the trust

Avoids family conflicts by detailing when and how assets can be withdrawn

Can protect the child's inheritance from creditors

Should be prepared by an attorney familiar with special needs documents

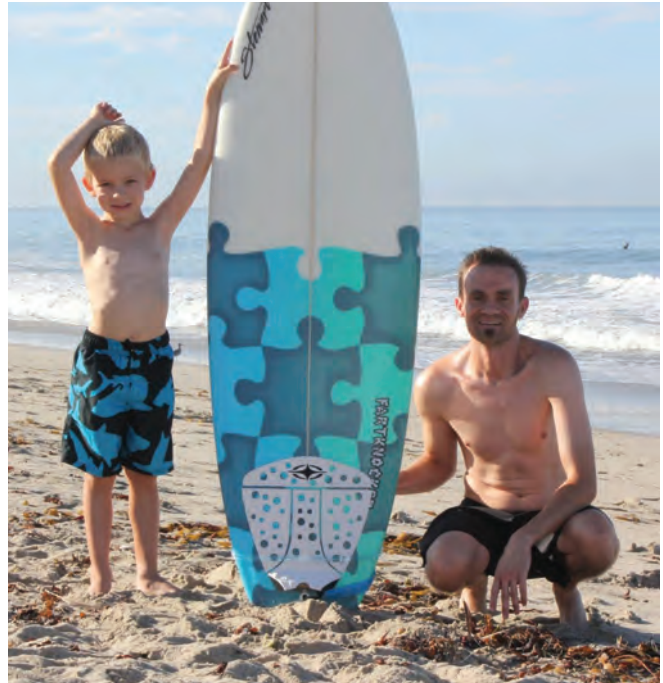
Letter of Intent Explained

You know your child best. The Letter of Intent is not a legal document, but it will help ensure that the courts and others involved in the process will know more about him or her in order to make decisions.

The Letter should **describe your son or daughter's history**, current status and your hopes for his or her future.

You might want to **start the letter now** and add to it as years go by, updating it when information about your child changes.

It is also a good idea to **involve your child** to the best of his or her ability when writing the letter, so that the letter truly "presents" and represents your child. The letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter.



Other things to consider:

Even **unearned income** – such as interest on a savings account – may cause your son or daughter to lose some, or all, of their public benefits.

Expenditures from the SNT need to be made for the sole benefit of the child.

Trustees should make any **payments directly to a third party** vendor or service provider – not to the child.

The trust, not the child, should be named as the beneficiary on your life insurance, retirement funds, annuities, deeds, etc. Take some time to review and revise all your financial beneficiaries and documents carefully.

Having a letter of intent written up about my daughter made me feel better in a lot of ways. I was able to relax, a little, knowing that all of my daughter routines, likes and dislikes, medical information, and family history are documented in case something happens.

Planning Note: Many financial planners recommend survivorship life insurance or a second-to-die life insurance policy for funding of the SNT. Due to the lower cost of the policy, the funds become available upon the death of the second insured when they are most likely to be needed because all caregivers are deceased. Underwriting of a second to die policy is less strict since two lives are being insured. These types of policies are available as either whole or universal life and estate taxes can be delayed until both parties/caregivers pass away.

Helpful Links

[Special Needs Alliance](#)

(nonprofit organization helping those with special needs)

[Writing a Memorandum of Intent for Your Child with Special Needs](#)

(from [SpecialNeedsAnswers.com](#))

[Social Security's Supplemental Security Income](#) information

[Social Security's Disability Information](#)



Financial Products & Instruments Used in Planning

When you are a family who has a child/children with special needs, you will find there are many considerations available to help you complete your vision for the benefit of the child/children. The process can seem overwhelming, but it's all about giving a "quality of life". It is important to remember all families and their situations are different and you will build the plan which works best for your family's needs and budget.

Funding a Special Needs Trust

Life Insurance

The simplest way to fund your Special Needs Trust (SNT) is to purchase life insurance. Life insurance uses the leverage of your premium payment to provide a much larger benefit for your child/children (through the SNT) when you pass away. In many cases a child/children will outlive their parent by many decades, so the need is a permanent need. A permanent life insurance policy should be used versus a term insurance policy. Depending on the family's budget, the life insurance policy could be a whole life policy or a universal life policy on one of the parent's lives or it could be a single policy on both parent's lives (sometimes called a survivorship policy or second to die policy where the benefits are received at the second death). Insurance policies can be specifically designed to create assets, supplement income, be minimally funded, self complete or add cash for retirement. Term is not recommended for funding a special needs trust as a term policy is issued for a specific period of time which you may outlive.



This section was prepared by Karen L. Starbowski who is a Chartered Special Needs Consultant (ChSNC) and SpecialCare Team Leader for MassMutual Arizona. The MassMutual Arizona SpecialCare Planning Team's mission is to help make a positive difference in the lives of individuals with special needs, their caregivers and other family members. The SpecialCare Planning Team has developed a unique network of professionals within the Special Needs community. This devoted network assists families, not only with their financial planning, but also provides a wide range of expertise to fit the diverse concerns of Special Needs families.

It is also important to ensure the ownership of the policy will never revert to the child/children with special needs. This too would interfere with government benefits because it would be deemed an asset. Beneficiary designations can specify which portion goes to your child/children with special needs and your typical child/children.

It is important to remember to make your Special Needs Trust the beneficiary of your life insurance policy. Benefits going directly to a child/children with special needs would conflict with their government provided benefits.

Retirement/401k plans

If you are still working, it's important to add contingent beneficiaries to your plan. Typically, an employee has their spouse as their beneficiary. Should something happen to the two of you, your retirement plan would go to your next surviving family members. If this is a child/children with special needs, it will conflict with their government provided benefits. The share of your retirement plan you wish to be left to your child/children with special needs should be assigned to your Special Needs Trust. Using retirement and 401k investments allow for tax favored accumulation which could benefit your child/children with special needs or your retirement.

Other Instruments Used in Planning

Disability Insurance

Disability Insurance is used to protect a person's income and could play a role in your family's planning. What would happen if you or your spouse were unable to work because of health or injury? Disability insurance would allow you to maintain your lifestyle and not disrupt the planning put in place for your child/children with special needs. Disability insurance can be provided by an employer and the benefit would be taxable. A personally owned disability insurance plan could supplement an employer plan or be standalone and its benefits are non-taxable.

Long Term Care Insurance

Long Term care insurance protects your assets by paying for some or all of your care should you need it (at any age if the policy is in place). Long Term care insurance protects your retirement income and could play a role in protecting the plans you have put in place for the benefit of your child/children too. Depending on the severity of the disability, it may be possible to obtain a policy on the child/children as well.

Annuities

Annuities can be used to provide a guaranteed income stream for the child/children. Like life insurance, it's very important to make sure it's titled properly as to not interfere with government benefits. (Titling: who is the owner and the beneficiary)

Government Benefits

When planning, it is also important to take the government benefits (SSI/CDB) your child/children qualifies for into consideration. These benefits could reduce the ultimate lifetime dollar amount needed for your child/children.



There are many financial products and instruments for you to use when planning for your child/children with special needs. It's important to work with your advisors (financial planners and attorneys) to understand what is available and what will work best to complete your planning goals.

ABLE Accounts: A Savings Tool for Individuals with Disabilities

A new type of savings option was made available for families of individuals with disabilities through the Achieving a Better Life Experience (ABLE) Act of 2014 that was signed into law as part of the tax extenders bill in December of that year. The ABLE Act authorized the establishment of private tax-advantaged savings accounts that can help you save for long-term expenses without sacrificing eligibility for public benefits such as Medicaid and Supplemental Security Income (SSI). These accounts are modeled after the current 529 education savings plans that help families save for future college costs.

The following information is an overview of ABLE accounts. These accounts will be governed under Internal Revenue Code Section 529A and will be established and operated by states under federal guidelines. Although the IRS and the Treasury Department still have to finalize regulations, states are establishing programs and will soon begin accepting account applications. Here are answers to some questions you may have about this new savings tool.

What is an ABLE account?

An ABLE account is a tax-advantaged savings vehicle that can be used to save for future needs without sacrificing an individual's eligibility for public benefits such as SSI and Medicaid. To receive public benefits, individuals with disabilities must meet a means or resource test. Because individuals who have more than \$2,000 in assets may lose their eligibility for these much needed public benefits, they may not be able to save for retirement, education, or even general living expenses.



This section was prepared by Evan Whittle, Senior Vice President, Investments with Raymond James & Associates, a CERTIFIED FINANCIAL PLANNER™ professional with over 20 years experience in the financial market who helps families and individuals create Legacy Plans. He is also the very proud dad of Tyler- a 15 year old all-around great kid, a photographer who has had numerous showings, and a book “Through Tyler’s Eye’s – Vision’s into the World of Tyler Whittle”. Along with many other traits, Tyler is on the autism spectrum.

Disclaimer: Opinions expressed are not necessarily those of Raymond James & Associates, Inc. Member New York Stock Exchange/SIPC. Information was provided by Broadridge, an independent third party. It is general in nature, is not a complete statement of all information necessary for making an investment decision, and is not a recommendation or a solicitation to buy or sell any security. Investments and strategies mentioned may not be suitable for all investors. Certified Financial Planner Board of Standards Inc. owns the certification marks CFP®, CERTIFIED FINANCIAL PLANNERTM, and federally registered CFP (with flame logo) in the U.S., which is awards to individuals who successfully complete CFP Board's initial and ongoing certification requirements.

Note: Evan Whittle's branch of Raymond James & Associates is located at One Progress Plaza, Suite 165, St. Petersburg, FL 33701 (727) 896-0848

But with the passage of the ABLE Act, saving for the future may now be easier. The stated purpose of the legislation is to:

1. encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and
2. provide secure funding for disability-related expenses of beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, title XVI (Supplemental Security Income) and title XIX (Medicaid) of the Social Security Act, the beneficiary's employment, and other sources.

ABLE accounts are modeled after 529 college savings accounts and have many similar features and benefits. Once an account is established for a beneficiary, account contributions will accumulate tax deferred and any earnings will be tax free at the federal level if the money is used for qualified expenses. If any funds are withdrawn and not used for qualified expenses, then the earnings portion of the withdrawal will be taxed at the recipient's rate and subject to a 10% federal penalty. There are no federal tax incentives for contributions, but states may offer their own income tax incentives to residents such as a tax deduction for contributions.

One feature unique to ABLE accounts is a Medicaid payback provision. Any funds remaining in an ABLE account upon the beneficiary's death may be claimed by the state as repayment for assistance the state has provided under the state's Medicaid plan before any remaining assets are passed on to heirs. This is a potential drawback of establishing an ABLE account that will need to be weighed against the potential benefits.

I am so glad the ABLE Act was passed. Now I am able to save money for my son's future like I have been doing for years for my daughter's college education. College may not be in the cards for my son, but his ABLE account will allow me to save money for things that he will need to live as independently as he can, like housing and utility bills that his Special Needs trust won't cover.

When Will ABLE Accounts Become Available?

Each state is responsible for establishing and operating an ABLE program. As of April 2016, over 40 states have enacted ABLE laws. To learn more about the implementation of ABLE in the states, visit AutismSpeaks.org/Advocacy/Federal/Able.

What Are the Criteria for Opening an ABLE Account?

The account beneficiary must meet the definition of an "eligible individual." The beneficiary can be any age, but his or her disability must have begun before age 26. In addition, to be eligible, the beneficiary must be entitled to Social Security Disability Insurance (SSDI) benefits or SSI benefits, or obtain a disability certification that meets IRS rules.

Only one ABLE account can be opened for each beneficiary.



How Much Can Be Contributed to An ABLE Account?

Contributions to an ABLE account may be made by the beneficiary, parents, grandparents, friends, or others, but the total annual contribution limit from all sources is \$14,000 (the annual gift tax limit). This limit may increase from year to year since it is indexed for inflation. The lifetime contribution limit will be tied to each state's 529 contribution limit, which in most states is \$300,000 or more. However, if an individual with a disability is eligible for SSI, only \$100,000 is exempted from the state's individual resource limit. That means that if the ABLE account balance exceeds \$100,000, the individual's monthly SSI benefit will be suspended until the account balance falls below \$100,000. Eligibility for Medicaid will not be affected.

What investment options will be offered?

States may offer various investment options for ABLE account funds. Of course, it will be up to account owners to select investment options that match their

financial need and tolerance for risk. Investment allocations can be changed twice per year.

All investing involves risk, including the possible loss of principal, and there can be no guarantee that any investing strategy will be successful.

What Can Account Funds Be Used For?

Funds may be used for disability-related expenses. These qualified expenses may include the following:

Education

Housing (but a distribution for housing expenses is not disregarded for purposes of the SSI program)

Transportation

Employment training and support

Assistive technology and personal support services

Health and prevention and wellness expenses

Financial management and administrative services, legal fees, and expenses for oversight and monitoring

Funeral and burial expenses



Will ABLE Accounts Replace Other Planning Tools Such as Special Needs Trusts?

No. ABLE accounts give individuals with disabilities and their families an additional tool to address financial challenges. Which tool or tools work best will depend on individual needs and circumstances, and each individual or family will need to determine how an ABLE account might fit into a comprehensive special needs plan.

For up-to-date information on ABLE accounts, visit [AutismSpeaks.org/Advocacy/Federal/Able](https://www.autismspeaks.org/advocacy/federal/able).

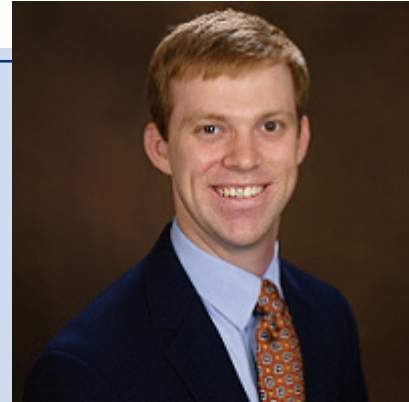
Guardianship and Conservatorship

Introduction

When an individual turns 18, he or she is presumed competent to make decisions about his or her person and property unless a court determines otherwise. Up until age 18, parents are the “natural guardians” of their minor child and have legal authority to make decisions about their child’s health, education, safety and support. If you feel that at 18, your child is not or will not be able to make important legal decisions on his or her own behalf, you may want to consider pursuing guardianship so that you can retain your ability to make such decisions for him or her. Guardianship and conservatorship are legal relationships between the guardian/conservator and the ward that are created by court Order.

Each state has established formal court procedures to appoint a guardian and/or conservator for an adult or child in need of a legal decision maker (the “ward”), and each state has its own terms. In some states, the term “guardian” refers to the person appointed by the court to make decisions of a personal nature – such as medical treatment, place of residence and general health and safety concerns – and the term “conservator” refers to the person appointed to make decisions concerning financial matters. Other states use the terms “guardian of person” and “guardian of property” to distinguish the two roles. Terminology, legal procedure, and court oversight varies from state-to-state; it is important to seek legal advice to determine how best to proceed in your state.

When seeking guardianship for an adult, the court must determine that the ward lacks the capacity to make or communicate significant responsible decisions regarding his or her health and safety or management of his or her property. For a minor, state law



This section was prepared by Reilly Morrison and Ginny Duhon. Reilly is a Trust Advisor in the Special Needs Trust Group at SunTrust Bank and is admitted to practice law in the state of Georgia.



Ginny is a Trust Advisor with SunTrust Bank’s Special Needs Trust Group and is an experienced attorney who has practiced in the specialized fields of elder law and special needs law. She is the proud sister of a special needs brother who perseveres in spite of his challenges.

determines when it is appropriate to appoint a guardian in place of the natural guardian or a conservator to manage property of the minor. Parents may designate in their Will their choice of a guardian for their minor child.

An individual may serve as both guardian and conservator, and courts generally favor those who are most involved in the ward's life and who understand the ward's needs. Parents, siblings, relatives, friends, professional guardians, and non-profit agencies are all potential candidates to serve as guardians and conservators. The court may choose to appoint co-guardians if two individuals wish to serve together.

Ultimately, an Order of guardianship or conservatorship terminates or severely limits the ward's rights and freedoms. State laws require that less restrictive alternatives are explored before guardianship or conservatorship is ordered. Some alternatives include **Power of Attorney** - a grant of shared authority by one person (the principal) to another (the agent or attorney-in-fact) to make decisions regarding finances or health care – and **Representative or Protective Payee** – a person appointed to manage benefits like Social Security.

Minor Guardianships

In the absence of parental authority, it may be necessary for a court to appoint a guardian for the child. Minor guardianship is a court proceeding to grant custody of a minor to someone other than the minor's parent or to appoint an individual to manage and administer the minor's property. Similar to adult guardianship, an individual can be appointed to make decisions regarding the minor's person or property – or both.

A guardianship of the person of a minor is most frequent when the child's parents pass away or are currently unable to care for him or her. In this circumstance, the guardian of the minor is granted the same power and authority as the minor's parent to make decisions regarding the child's health, education, safety and support. A guardianship of the person of a minor does not terminate the parental relationship and is not necessary if you are the child's parent. As a child's parent, you are considered the child's "natural guardian" and have the authority without court intervention to make most decisions regarding the minor's residence, medical treatment, confidential information and other decisions regarding the child's personal well-being.

We weren't sure about pursuing guardianship for our adult son, Sam, but after a recent experience, we are so grateful that we did. He has been able to hold a steady job and live semi-independently with some supports in place since moving out of our home five years ago, but Sam recently had a behavior crisis that involved a run in with the police and resulted in a pending court appearance. After this incident, he was placed in a hospital setting. We were terrified. While he was hospitalized, as his guardian, I was able to coordinate with several different doctors who were able to provide medication management and outpatient therapy to help him stabilize and get back to his full life outside of our family home as smoothly as possible. His father and I were also able to advocate for him and set him up with appropriate legal representation for his court appearance. Because of the guardianship arrangement, we were also able to make financial decisions for Sam while he was in the hospital so he was not late with his bills. Otherwise, we would not have been able to have a say in his medical or legal decisions during this difficult time for us.

A guardianship of the property of a minor is most common when a minor receives an inheritance or proceeds from a lawsuit or settlement. Some states will allow these proceeds to be managed by the child's parent without a court appointment, but other states require a guardian to be appointed to manage and administer these funds if the value of the proceeds exceeds an amount set out in the state's statutes. The guardian of the property is typically required to obtain a bond and is responsible for investing the funds, filing tax returns, and making distributions for the minor in accordance with the law. A guardianship of the property of a minor is typically not necessary if the child's only income and resource

are payments from the Social Security Administration. The Social Security Administration will appoint a Representative Payee to receive and distribute these funds for the minor and the Representative Payee will file an annual report with the Social Security Administration accounting for the funds.

Minor guardianships terminate when the child reaches 18 years of age.

Adult Guardian of the Person

Adult guardianship is a court proceeding to appoint an individual to make decisions about a person's health, safety, support, care, and place of residence. The procedure for obtaining a guardianship varies from state-to-state, but generally the process is initiated by an interested party filing a Petition with the court that states probable cause as to why a guardianship is necessary.

The proposed ward and other interested parties – such as the proposed ward's spouse, children and relatives – will receive a copy of the Petition, and the court will appoint an independent evaluator to assess the ward and make a written recommendation about the ward's capacity. A hearing is held after the completion of the evaluation where the court will make a determination regarding the necessity of a guardianship. The ward has a right to hire counsel to represent him or her or the court will provide counsel.

Once a guardian is appointed, the court may limit or terminate the ward's right to consent to medical treatment, establish a residence, change domicile or vote. A guardian of the person may exercise most of the ward's personal rights with the exception of the right to vote. The guardian must make decisions that are always in the ward's best interests, cooperate with the conservator, if any, and encourage the ward's participation in personal decisions so he or she may become more independent and regain the ability to manage his or her own personal affairs. The guardian must also file an annual report with the court to advise of the ward's personal status



Conservatorship

Conservatorship is intended to provide protection and management for the property of adults who lack sufficient capacity to make or communicate significant responsible decisions regarding the management of their property. Conservatorship not only appoints an individual with the authority to make these decisions on behalf of the ward, but it also removes the ward's right and ability to make certain decisions and enter into agreements of his or her own.

Some of the rights that are removed from the ward are:

the right to make, modify, or terminate contracts;

the right to buy, sell or otherwise dispose of property;

the right to conduct business or commercial transactions;

the right to revoke a revocable trust; and

the right to bring or defend an action at law.

The process for obtaining a conservatorship is similar to the process of obtaining a guardianship, and the two are most often done in tandem. Courts generally seek the least restrictive alternative to conservatorship and will tailor the conservatorship so that the ward is allowed to maintain those rights that he or she is still capable of exercising in a responsible manner.

Typically, courts will not require a conservator if the ward's only income and resources are payments from the Social Security Administration. The Social Security Administration has its own process for selecting and appointing an individual to receive and administer Social Security payments on the behalf of individuals who lack sufficient capacity to manage the payments themselves. This process is called the Representative Payee program and the Representative Payee will be responsible for accounting to the Social Security Administration for the use of the recipient's funds. Most courts view the Representative Payee program as a less restrictive alternative to conservatorship. Additionally, most courts will often find a durable power of attorney or trust to be a less restrictive alternative, provided they are adequately protecting the proposed ward's interests.

The conservator owes the ward a duty of loyalty, reasonable care, diligence, and prudence and is responsible for receiving, collecting, and making decisions regarding the ward's property. The conservator should strive to encourage the ward to participate in decisions and assist the ward, to the extent feasible, to develop the ability to manage his or her own property. The conservator should consider the ward's expressed desires and values while also acting in the ward's best interest when making decisions on the ward's behalf.

The conservator is required to provide annual accountings to the court and the court will remain involved throughout the conservatorship. Conservators are granted the authority to retain, invest and disburse funds for the ward, but this authority is also limited by state statute. From time-to-time, the conservator will need additional court approval to take certain actions, such as conducting estate planning, gifting or selling personal property, and purchasing or selling real estate. The conservatorship will continue until the ward regains capacity or passes away.

Conclusion

Guardianship and conservatorship laws vary from state-to-state. It is encouraged that local counsel is consulted at the initiation and on a regular basis throughout the administration of the guardianship and conservatorship. It is also important to remember that guardians and conservators are fiduciaries and are therefore held to a higher standard when conducting the ward's business than the guardian/conservator would be when conducting his or her own business.





Finding the Strength to Plan for the Future

**by Shirley Blaier-Stein, author of
Autism Mom: New Ways of Thinking, attorney and autism advocate**

I was sitting at the dining room table looking at the pile of papers I was supposed to read, and the forms I was supposed to fill out. I could hear Dan's wailing from behind the closed door of his room. He was there with Jessica, his BCBA from school. The few hours when Jessica came were the only ones I could step away from Dan, while knowing he is safe with someone he loves and trusts and that would be able to protect him from his own self-injurious behavior.

I was sitting there frozen, looking at the pile of papers. Listening to Dan's crying and Jessica's voice trying to calm him, all I could think was, 'how did we get here? How has autism taken us this far?' The plan was for things to get better, yet despite our efforts we were experiencing such a setback, and Dan has been in so much pain.

Whenever our kids go through rough patches, whether it is frustration for not being able to communicate, physical and hormonal changes, medications that need tweaking, it is so frustrating for us the parents. We think we know what's going on, and for a while things go smoothly, and then our kid changes yet again, suffering, and leaving us too flabbergasted as to what has happened, and how do we go about it this time and salvage the situation?

That day sitting in front of the forms that I was supposed to fill out in order to qualify for Medicaid and for support from our state for a behavioral program at home, the forms were not plain papers where I had to fill simple information. They were a barricade between the life I had believed our family would have and the life we were actually experiencing at the time. These papers represented loads of disappointment and sadness.

I had to reach real deep inside of me to find strength. A ray of light that would help me focus, get this done, and start the ball rolling.

I closed my eyes, took a deep breath, and waited.

I suddenly heard quiet from Dan's room, and then I heard him laugh. Having Jessica around helped. I realized I needed more help, and filling out those forms was going to get that help for me, for him.

I opened my eyes, and suddenly the piles of papers were papers, something practical I needed to do, and I got to it and got it done.

Finding the Right Professional

Finding the right professional team is critical to the success of your Special Needs Plan. “Success” of a Special Needs Plan should be defined as having clarity regarding the path you need to take in order to provide a loving, supportive, and safe caregiving environment for your child during his or her entire lifetime. This means you will need guidance on:

How to navigate the government benefit landscape to maximize your child’s benefits:

Learning to navigate the system to get the most of it, as well as understanding how your own (as parents) choices regarding Social Security Retirement benefits can change your child’s benefits, will be very important.

How to design a Special Needs Trust:

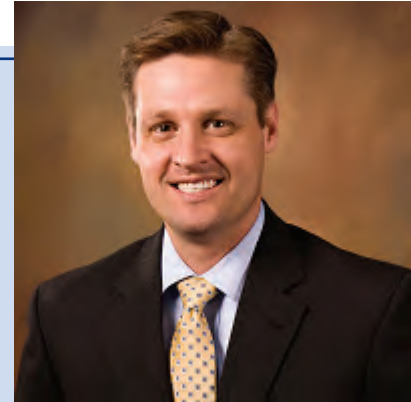
There are lots of questions you may need help answering: Who should be the trustee? Should I have a Trust Protector? How many Successor Trustees should I have? Should I use a company as the Trustee?

How taxes work inside a Special Needs Trust:

The understanding of tax strategy is critical in funding the special needs trust so that the trust assets are not taxed at the highest tax rates versus being taxed at much lower tax rates. Tax strategy is also important in determining the accounts parents are saving in for their own future that will eventually be transferred into the special needs trust. Again, parents would be horrified to realize their hard work turned into more income for the government instead of providing for the support needs of their child

How to determine the amount of funding your child will need over his or her lifetime:

Determining this amount and calculating a specific number will help you understand the percentage of assets that need to be transferred to the special needs trust versus the percentage of assets that are left to other children (or grandchildren).



This section was prepared by Ryan Platt, Chartered Special Needs Consultant, and the Founder of A Special Needs Plan, Inc.

A Special Needs Plan helps families, nationwide, in the creation, implementation and management of an integrated plan that ensures today and secures the future for all members of the family; parents, child with Special Needs, and other children. Ryan is currently working on two more initiatives to help families with education on the topic of Special Needs Planning with HowToSecureTheFuture.com and with support with A Care Plan For Life.

How to educate extended family members:

It will be very important to teach your family members about adjustments they need to make so they do not incorrectly provide resources to your child with Autism and inadvertently cause him or her to lose life-supporting government benefits

How to communicate with those people that will be the next caregiver (Guardian) for your child:

You will want to keep the next caregiver/guardian of your child as informed as possible in regards to letting them know how to care for your child on a day to day basis. For instance, doctor information, prescriptions, pharmacy that fills prescriptions, behavioral and sensory issues, your child’s favorite activities and things, daily routine, your hopes and dreams for them, and more.

It takes a great deal of study, dedication and time to become a Specialist in all these areas; however, it is imperative to your child's future that you find professionals who can help you satisfy this definition of "success" when it comes to having a Special Needs Plan. As families, your search for an expert in Special Needs Planning is analogous to your search for a specialist in the medical field. If a Neurologist is necessary, not just any Neurologist will do, but a Neurologist with the specific education, temperament, continual training, daily focus, and passion is necessary.

So many families search for quite some time before they find the right medical team. It is this same persistence and focus needed to find the right Special Needs Planning professionals. Unfortunately, these professionals are few and far between and many times will not be local to your family, but the search is needed to secure your child's future support.

Questions to Ask

We have assembled a list of questions for families to ask professionals so that they can uncover if the professionals they are working with (attorneys, financial advisors, accountants, trust officers, etc.) are truly specialists, as this is vital in securing the proper and accurate Special Needs Plan.

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

Making the Right Choice

When interviewing them, stay focused on their mannerisms. If the professional you are interviewing is able to answer these 12 questions with authority and you receive positive feedback from the families and professionals you contact, then you have found yourself a highly qualified special needs planner. You should move quickly to hire them. If they are not able to answer these elementary Special Needs Planning questions, keep searching!

With their help, you will begin a journey that will lead to security for you, your loved one, and your entire family. The planning process you go through will provide you answers to many questions, including, "What happens to my child when I am no longer able to care for them or when I die?" Having the answer to this question should release a burden from your shoulders, and should provide peace of mind.

For more information, please feel free to visit ASpecialNeedsPlan.com.

We have been nervous about the future since what seems like the day my daughter was born! A huge help was finding a great lawyer who could explain clearly to us how to set up a special needs trust for her, how it could be funded and what that money could be used for. He has made us feel much more at ease about what lies ahead!



The Basics of Budgeting:

A Step in the Right Direction

The financial aspects of caring for a child with special needs can often seem daunting or overwhelming. Even with support from local school districts or state agencies, many families pay out of pocket for expenses such as prescriptions, therapies, supplements or supplies, to name just a few. As a result, special needs families must be diligent in controlling their spending and saving for an uncertain future.

While budgeting is important to all families, it is a vital component in the financial planning process for the special needs family to address the short and long-term financial needs associated with caring for their children. A comprehensive budget will identify all your resources and sources of income as well as help you gain an understanding of your monthly and annual expenses. By monitoring your expenses over time, you'll be able to identify areas of overspending and work to reduce those expenses so that you can save and invest more.

Intense consideration must be given to the budgeting process, both to meet the needs of the family as a whole, as well as developing a long term plan to provide resources in the future for your special needs child. Creating a realistic budget is the foundation of taking ownership of your financial future and can help you prepare for the road ahead.

Tips to Creating and Managing Your Budget

Involve the entire family: Agree on a budget up front and meet regularly to check your progress.

Stay disciplined: Try to make managing your budget a part of your daily routine.



This section was prepared by Katrena Shipp, a Financial Advisor for Morgan Stanley. Katrena focuses on helping special needs families achieve financial stability. Katrena's son is on the Autism spectrum and is a student in New York. As the mother of a child on the Autism spectrum, Katrena understands the financial challenges and the importance of planning for the future when caring for a special needs child.

Choose your timing wisely, start your new budget at a time when it will be easy to follow and stick with the plan (i.e., start at the beginning of the year, as opposed to right before the holidays).

Find a budgeting system that fits your needs (i.e., budgeting software).

Categorize your expenses, distinguish between expenses that are "wants" (i.e., designer shoes) and expenses that are "needs" (e.g., groceries).

Build rewards into your budget (i.e., eat out every other week).

Build an emergency fund: Accumulate 3 to 6 months of fixed expenses as an emergency reserve. This will make it easier to address life's inevitable surprises or emergencies and allow you to stay on track with your budget without having to utilize your credit cards.

Note: Katrena Shipp's branch of Morgan Stanley is located at One Fawcett Place, Greenwich, CT 06830.

Steps for Creating a Family Budget

I. Estimate Your Monthly Income/Resources:

Wages	_____	State Benefits	_____
Investment Income	_____	SNAP Benefits	_____
Retirement Income	_____	Transportation Assistance	_____
Settlement Assets	_____	Housing Assistance	_____
Social Security (SSI)	_____	Other	_____
Disability Benefits (SSDI)	_____	Total	_____

II. Estimate Your Monthly Expenses:

Housing

Rent/Mortgage	_____
Property Taxes	_____
Utilities (Gas, Electric, Water)	_____
Cable/Internet	_____
Housekeeping	_____
Furniture	_____
Maintenance	_____
Other	_____
Total	_____

Insurance

Health/Dental	_____
Auto	_____
Home/Rental	_____
Long-term Care	_____
Other	_____
Total	_____

Education

Tuition/Fees	_____
Books/Supplies	_____
Tutoring/Special Services	_____
Miscellaneous	_____
Total	_____

Food

Groceries	_____
Restaurants/Eating	_____
Special Diets	_____
Other	_____
Total	_____

II. Estimate Your Monthly Expenses:

Medical/Dental

Medical Visits _____
 Dental Visits _____
 OT/PT/Speech _____
 Other Therapy _____
 Supplies _____
 Medications _____
 Supplements _____
 Other _____
Total _____

Transportation

Car payments _____
 Gas _____
 Maintenance _____
 Taxis _____
 Public Transit _____
 Other _____
Total _____

Insurance

Health/Dental _____
 Auto _____
 Home/Rental _____
 Long-term Care _____
 Supplements _____
 Other _____
Total _____

Personal Needs

Clothing _____
 Haircuts _____
 Cell Phone _____
 Gym _____
 Allowances _____
 Other _____
Total _____

Recreational

Entertainment _____
 Sports/Hobbies _____
 Memberships _____
 Camps _____
 Travel _____
 Vacations _____
 Other _____
Total _____

Care/Assistance

Nursing _____
 Respite _____
 Other _____
Total _____

II. Estimate Your Monthly Expenses:

Miscellaneous

Gifts _____
 Other _____
Total _____

Special Equipment

Wheelchair _____
 Computer _____
 Ipad/Other _____
 Medical Supplies _____
 Software/Apps _____
 Glasses _____
 Service Dog _____
 Hearing Aids _____
 Repairs _____
 Other _____
 Other _____
 Other _____
Total _____

III. Calculate your Disposable Income or Monthly Reserves:

Once you determine your total monthly income, subtract your total monthly expenses. The funds remaining after you meet your expenses is called “discretionary income” and represents the money that can be saved and invested to meet your family’s needs in the future. For special needs families, investing for the future is an extremely important part of the financial planning process.

Budgeting Tools and Resources

Wise financial management requires a series of daily choices. You can learn how to take control of your financial situation with budgeting tips, by creating a budget, monitoring your progress and managing the flow of income and expenses.

Budgeting for the Special Needs Family

There are a variety of tools available to assist families in developing and tracking their budget on a monthly basis. The key to choosing the right budgeting tool is selecting the one that you're most likely to stick with using over time. Here are some of the most popular tools available to assist you:

Quicken

Quicken offers a comprehensive platform of budgeting software products for purchase. Check [quicken.com](https://www.quicken.com) to review their suite of budgeting tools and products.

Mint.com

[Mint.com](https://www.mint.com) is an online budgeting tool, which allows you to track your spending on a monthly and annual basis. It requires that you sync your banking and investment accounts to maximize efficiency.

Budget Tracker

[BudgetTracker.com](https://www.budgettracker.com) is an online budgeting tool that is available via computer or mobile application. Unlike some of the other online budgeting systems, it doesn't require you to sync your banking or investment accounts to track your expenses or progress.

Budgeting for the Special Needs Child (Life Skills)

In the event that your child is able to live independently as an adult, budgeting will be a vital life lesson



that they will need to incorporate into their daily lives.

Today, tools exist to assist families in teaching their special needs child to manage their personal finances. Here are some of the resources that families have found to be helpful:

Practical Money Skills for Life

This site provides lesson plans that enable students with learning disabilities to gain important personal finance skills. Educators or parents can choose from a variety of teaching materials and customize them to meet individual students' learning needs.

Time4Learning

This site provides an online financial literacy program for special needs children from Pre-K through high school that teaches money management skills.

Seek Professional Help

Special needs families have the same financial concerns as other families, but their financial plan must often include longer term goals. An effective budget can be an important first step in accomplishing your goals. Stay positive, focus on your future and seek the advice of a financial professional, if needed.



Tips on Applying for Financial Aid for your Family Member with Autism

***by J-Jaye Hurley, autism mom and
Autism Speaks Autism Response Team coordinator***

1. Print all pages of the application and read them carefully. Twice. . . . These applications are usually lengthy and complex so you must review their own requirements. Many applications ask for similar items (tax statements, IEPs, etc) but they are ALL in a different format. If you do not provide the information they request AND in the format they request, you can be denied. If you do not send in all the information at the same time, you can be denied. Also review their application criteria before you apply. A friend of mine filled out a long application only to realize they didn't provide assistance for the therapy she was interested in. Know all requirements before diving in.

2. Be aware of deadlines. Some family grants are year-round but the majority I applied for had specific deadlines. In fact, I was unable to apply for one that I wanted because I missed their annual deadline. If you are requesting therapy notes or letters of recommendation, make sure you allow plenty of time to gather all information, complete application and send in PRIOR to that deadline. If they receive your application after the deadline, you will be denied.

3. Be concise and honest. Most organizations review thousands of apps, and the majority of the application is financial information. However, most apps ask the parent for some personal information about the child. Make sure you tell them about your child, why you need their help and how this will make a difference for your child and family. They don't need your entire life story, but they do need you

to be honest and upfront about your needs and situation. Most of our stories speak for themselves so just be yourself and speak from the heart. We are passionate parents and advocates by nature so go with what you know – your child.

4. Get recommendations. Some applications say they will accept letters of recommendation but don't require them. I recommend your seeking those letters as they only serve to provide additional information on your child and family to this anonymous committee. Ask your therapists, physicians or family members. You can save letters and use them for multiple applications each year.

5. Have a friend/spouse review your apps. Before you mail in your completed applications, have someone review it for you. My husband caught typos & had suggestions. As a former English teacher, I always recommend having another pair of eyes review your writing. Applications are no exception!

6. Include a picture of your beautiful child! This helps bring a personal and real connection to those reading your applications.

7. If at first you don't succeed, apply and apply again! I was turned down for some of my applications and I plan to re-apply before this year deadlines. Make a copy of your completed application, as it stays basically the same from year to year. It is much easier to update last year's application than start from scratch on a 10 page app. Update your new information and try again.

Financial Assistance

The Autism Speaks Autism Response Team has put together a list of resources to help with financial information and aid in a variety of categories. For additional help and resources, contact ART at familyservices@autismspeaks.org or 888-288-4762 (en Español 888-772-9050).



Treatments and Therapies (Health Insurance)

Obviously a key component to think about when budgeting for your child and planning for his or her future is health insurance. As of December 2015, 43 states in the U.S. have passed legislation requiring insurance carriers to cover the screening, diagnosis and treatment of autism. Navigating the complexities of health insurance can be very challenging – especially when trying to determine your coverage for autism. **Autism Speaks Insurance Link** is an online application developed by Autism Speaks that will help you determine whether your child is entitled to coverage for the treatment of autism under their health insurance plan. If coverage is not available, the tool will equip you with information necessary to effectively advocate for the addition of a meaningful benefit. Find this tool at

AutismSpeaks.org/Advocacy/InsuranceLink.

If you or your partner work for a company with a self-funded insurance plan, the [Autism Speaks Self-Funded Employer Tool Kit](#) can help you approach your employer about adding autism benefits to the company health plan.

Another helpful resource is the Children's Health Insurance Program (CHIP) which provides low-cost health coverage to families that earn too much money to qualify for Medicaid. Each state offers

CHIP coverage. To learn if your child is eligible for CHIP, you can visit InsureKidsNow.gov.

One of the most significant changes in healthcare law that came from the Affordable Care Act of 2010 is that insurers must now cover dependents on a parent or guardian's plan up to age 26, no longer age 18. The Affordable Care Act also allows states to choose whether to expand their Medicaid programs to low-income adults, many of whom have never been eligible for coverage before. The new law allows states to expand Medicaid coverage to most adults with incomes up to 138 percent of the poverty level. You can learn more about these options and enroll in Medicaid at healthcare.gov.

Education

Every child has the right to a free appropriate public education that meets his or her needs. The **Individuals with Disabilities Education Act**, enacted in 1975, mandates a public education for all eligible children and makes the schools responsible for providing the supports and services that will allow this to happen, free of charge. If your school district cannot provide your child with the services he or she requires and deserves, they are required to pay for him or her to access those services elsewhere, whether that be a private school or an outside school district.



If you choose to forego the free public education and pursue a private education for your child, there are some resources out there to help you with the costs. The following websites provide information on scholarships for K-12 private education:

[PrivateSchools.com](#): Financial Aid Information

[Children's Scholarship Fund](#): Sources of Tuition Assistance

[GrantSpace](#): Funding for Private School

In terms of postsecondary education, the sites below provide information about scholarship programs for students with disabilities:

[Autism Speaks Resource Library](#): Postsecondary Education Resources

[CollegeScholarships.org](#): Autism-Related Scholarships

[Fastweb](#)

[FinAid.org](#): Financial Aid for Students with Disabilities

Housing

The [Department of Housing and Urban Development](#) (HUD) can provide you with advice on finding affordable housing. HUD sponsors housing counseling agencies throughout the country to provide free or low cost advice.

For more information, you can call HUD's interactive voice system at: (800) 569-4287. You can locate your local HUD office on [this page](#). They can give you information on affordable housing programs, rental assistance, and more.

There are also a number of programs through the federal government to help families purchase a new home. Some of these include:

[U.S. Department of Agriculture \(USDA\)](#)

[U.S. Department of Housing and Urban Development \(HUD\)](#)

[Federal Housing Administration \(FHA\)](#)

[AmeriDream, Inc.](#)

Community Action Agencies often have funding from state and federal programs to assist with rent and homelessness prevention. [Click here and then select your location to find the agency closest to you.](#)

Assistive Technology (iPads)

If your child needs an iPad or similar assistive technology device to communicate, or it would enable him or her to meet certain IEP goals, you may be able to get funding for the device through your public school system, insurance or grants. To get funding from your child's school, you will first want to ask for an Assistive Technology evaluation to show that he or she qualifies for a device. In order to get funding through your insurance (private or public), you will need to submit letters of necessity based on the evaluation by a professional, such as a speech-language pathologist. Talk About Curing Autism (TACA) has put together a very helpful list of tips to access this funding [here](#). There are also many organizations around the country, including Autism Speaks, that offer grants for iPads or other technology. Contact the Autism Speaks Autism Response Team to learn about what is currently available. It is important to note that speech generating devices are generally covered by a Durable Medical Equipment (DME) benefit from your insurance company.

Safety

Autism Speaks encourages a multi-faceted approach to help keep a person with autism safe across their lifespan and in all settings – at home, at school and out in the community. Funding access to safety resources should be approached just as you would plan to meet any other autism-related needs. You should work with your school district/IEP team, state developmental disability agencies, medical providers and direct service/intervention providers to identify pathways and funding to address safety concerns.

For additional questions on creating a safety plan, visit AutismSpeaks.org/Safety or contact



Respite Care

Research has demonstrated that respite services can make a significant positive difference in the lives of families, allowing them to take a break and increase their social and emotional well-being. There is funding out there that can help get you the break you need and deserve. Medicaid waivers provide the largest federal source of funding assistance for respite. [Click here to find out more about waivers in your state.](#) Some state Medicaid plans will cover respite services. Another option is your state's office of developmental disabilities (DD). Each state offers different programs and supports, but in many states, these programs include funding for respite care. [Find your state's DD office here.](#)

You can find information on respite care in your state and search for respite care in your area on the ARCH National Respite Network and Resource Center website [here](#).

Legal Help

State Disability Protection and Advocacy agencies provide free legal representation and other advocacy services, under all federal and state laws, to all people with disabilities. Autism Speaks has put together a list of P&A agencies [here](#).

Additional options for finding low-cost legal help include:

[LawHelp.org](#) – Legal help for people with low and moderate incomes (and their lawyers), provides referrals to local legal aid and public interest law offices, basic information about legal rights, court forms, self-help information, court information, links to social service agencies and more in your state

[FindLaw.com](#) – Legal information, lawyer profiles and a community to help you make the best legal decisions

[American Bar Association](#) – Useful links to lawyer referral services and pro bono legal help

[Legal Services Corporation](#) – Find Legal Aid – Independent nonprofit established by Congress to provide financial support for civil legal aid to low-income Americans

[National Health Law Program](#) (NHeLP) – Protects and advances the health rights of low-income and underserved individuals and families by advocating, educating and litigating at the federal and state levels.



Emergency

In a crisis, it is often helpful to go to your **Community Action Agency** ([click here to find the agency for your area](#)). Staff can connect you with any available resources, financial or otherwise, that are available in your area. You can also contact your local United Way by calling 2-1-1 to be connected with many services and resources to help, or visit [211.org](#). The Salvation Army can often assist in emergency situations as well, although funding may be limited. They can provide rental and housing assistance, utility help, food, shelter, and more. You can find your nearest center by [clicking here](#).

Autism Speaks Cares is a grant program of Autism Speaks that provides funding for families affected by autism during natural disasters or other catastrophic life events on a case-by-case basis.

To learn more, contact the Autism Response Team at familyservices@autismspeaks.org or (888) 288-4762 (en Español 888-772-9050).

Conclusion

Raising a child involves a lifetime of planning, but as you can see, there is even more to think about when planning for the future of a child with autism. It is our hope that this kit has helped make you feel a little less overwhelmed about the future and a little more prepared for the road ahead. Keep in mind, your plans and your finances are always a work in progress, but with some advocating and advanced planning, you can help position your child for a happy and successful future! Do not give up on accessing the help you need and the benefits your child and your family deserve.

It is important to remember that help is out there. Special needs financial planners, advocates and social workers are just a few of the people who can provide you with guidance along the way. **And as always, if you have any questions or are looking for additional resources or guidance, please feel free to contact the Autism Speaks Autism Response Team at familyservices@autismspeaks.org or 888-288-4762 (en Español 888-772-9050).**

We are happy to help!

