

planning a more secure future for your
Child with Special Needs
a guide for parents and guardians



Every family is different, and each of us must create financial strategies with our particular circumstances in mind. This is especially true for families that care for children with special needs. Parents often need to consider the present as well as the future for their special needs child, including a future where parents are no longer managing their child's day-to-day needs and agenda. As with many of the first decisions we make as parents, these considerations may begin before birth.



WHAT HAPPENS WHEN LIFE TAKES AN UNEXPECTED TURN?

Your child's diagnosis might come during one of your prenatal visits with your health provider. It might come just after your child's birth, or it might not come until years later. It might be that your child suffers an injury as a toddler or in their school-age years. But regardless of when it happens, the moment you first hear your child's diagnosis, your world changes.

But by how much? It's difficult to fully grasp, at first. Consequently, it may feel easiest to focus on the present, so you begin strategizing. You schedule doctor's appointments and form a team of health professionals. You research and mobilize therapies and other resources for your child. You seek out others who can empathize with your situation, then

construct a network of loved ones who can support you and your family, while all of you adapt to your new normal. But as you're busy figuring out the details in the here-and-now, you may have not had a chance to think much about your child's future. Have you considered what their needs might be? Five, 20, or even 50 years from now? Preparing for their tomorrow is just as important as planning for today.

It is important to remember that you always have choices, but as with many decisions of a financial nature, informed decisions may lead to the most optimal results.

UNDERSTANDING YOUR CHILD'S DIAGNOSIS AND GATHERING INFORMATION

Your special needs child's diagnosis might be physical and/or developmental. It might be due to an accident or injury. It

might be caused by genetic variation(s). The etiology might even be unknown. Regardless of the why, however, understanding your child's diagnosis and gathering the latest, evidence-based information from credible and reliable sources are likely high priorities whether you're new to the caretaker community or a seasoned member.

In addition to all the new information you may be collecting, though, you might want to connect with other parents and families who are experiencing the same things you are. Your child's health care team often can help you find those connections, and social media makes it fairly easy to find online groups of people whose children have the same diagnosis as your child. These communities can offer you hope about the future. You're even likely to meet other parents who may have children diagnosed months or years before yours. An added bonus,



they might be able to give you tips and suggestions for how to navigate this new and unfamiliar world.

Once you have gained some perspective on your child's health and the changes in your life begin to feel like second nature (it may happen sooner than you think!), you can start shifting your focus to the future, ensuring that your child has all the necessary arrangements for financial and legal matters, in regard to financial and legal issues, government benefits and insurance, and developmental and emotional support.

POINTS TO CONSIDER **Financial and Legal Concerns**

While other parents may only be planning for their child's college education, the parents of children with special needs are concerned with many additional immediate and long-term financial issues.

There may be many things to consider, depending on your current financial status as well as the costs necessary to provide your child with all the services they require now and may have need for in the future. If your child needs round-the-clock care, for example, your family might need to hire home health care providers who not only offer nursing care for your child, but also respite care for you and your family. Parents might also need to make arrangements for their other children (who do not have special needs) for various necessities, such as transportation, after-school care, or safe and reliable childcare providers, while one or both parents take the child with special needs to appointments.

Sometimes, one parent might need to take a leave from the workforce or change career tracks, which may noticeably reduce the family's household income. Meanwhile, medical bills may

seem to stream in, quickly and often. And the costs associated with these services may begin to feel unmanageable. Unsurprisingly, many families find themselves spread so thinly; they grow concerned that one more large expense could compromise their financial futures.

The good news is that there are many ways you can prepare, both legally and financially. Some preparations may come with fees, but others are free. Getting an overview of your current situation, with the careful eye of a trusted financial professional, and tackling whatever arrangements you are able to make on your own, may help give you some financial confidence.

Name a Guardian and a Trustee

A guardian is the person who will take care of your child if you and your spouse die before your child becomes an adult. Think about how much time you currently spend tending to your child's needs. Who might be willing and able to take on this responsibility? It's worth noting that the guardian you choose should not have control over your child's money; this would be the job of the trustee.¹

The trustee controls the money and handles investing assets thoughtfully and disbursing them responsibly when needed. They will also make objective decisions when stressful or difficult circumstances arise. A trustee can be a family member or a close, trusted, and dependable friend. It could also be an institution, such as a bank or trust company.²

Write a Letter of Intent

A letter of intent is a document written by you, which describes your child's history, their current status, and your hopes and dreams for their future. It is not a legal document, but courts and others rely on this letter for guidance to better understand your child and your wishes for them. It's commonly recommended to keep a copy with your will and also with the child's guardian. A good time to update the letter may be yearly or whenever something changes.

The letter of intent should cover your child's daily routine as well as their daily, weekly, and monthly schedules. It should include your child's medication schedule, their child's likes and dislikes, and any additional helpful community resources. With the letter, create a list of physicians, nurses, therapists, and other health care-related support, including from where emergency care should be sought, if necessary. Include office addresses and phone numbers, and whenever possible, personal addresses, cell phone numbers, and pager numbers.³

Establish a Special Needs Trust

Protect your child's ability to access necessary government programs and services by creating a Special Needs Trust. Children and adults with special needs are eligible for many governmental services as long as they do not own assets worth more than a certain amount, usually \$2,000.⁴ Without a Special Needs Trust, children or adults with special needs could be disqualified from most governmental programs and could potentially be required to pay back benefits already received.

Establishing a Special Needs Trust allows you, your spouse, and other family members to leave money, life insurance proceeds, and property to the trust instead of directly to your child. This trust also protects against creditors and claims.⁵ Your trustee will have the authority to use funds from the trust to help care for your child.⁶

Educate Your Family Members

While grandparents, aunts, uncles, and others might offer to assist you with expenses, make sure your family knows the importance of not putting anything in your child's name. That means, grandparents and others cannot leave anything to your child in their wills or name your child as their beneficiary to life insurance policies, savings bonds, stocks, or cash. They may, however, name the Special Needs Trust as the beneficiary. Be sure your family members understand the role of the trustee and the role the Special Needs Trust will play in securing your family's and your child's financial futures.⁷

Build Your Savings

As soon as you can, take an inventory of your assets and liabilities. Determine your cash flow. Identify sources of income now and any you might have in the future. Put aside whatever you can each month to help you cover the costs of therapies and services your child might need, especially ones that neither your insurance, nor the

school system, will provide. Remember, though, do not put this money in your child's name.

If applicable, find out if your employer offers a Flexible Spending Account (FSA) or Health Reimbursement Account (HRA) to help cover out-of-pocket health care expenses. You can set a specific amount to be pulled from your paycheck to go into this account. One of the best parts of an FSA or HRA is that the money you decide to save throughout the year—up to \$2,750 for an FSA—is available to you at the beginning of the calendar year.⁸ HRA limits are typically set by the employer offering the benefit. Be sure to read all policies about any money remaining in the account that is not used by the end of the benefits year.

Write a Will

According to a 2019 survey, 57% of Americans do not have a will.⁹ A will specifies what will be done with your assets after you die. By having a will, you ensure your assets are left to the Special Needs Trust and not to your child. If you do not have a will, a probate judge could name your child as a beneficiary, and in turn, make your child ineligible for federal benefits. Writing a will also ensures the selected guardian is the one who will take care of your child after you are gone. You might want to have your will written by an attorney who works specifically with families that have children with special needs and also knows your state's disability laws.



GOVERNMENTAL BENEFITS

Depending on the type and severity of their disability, your child might be eligible for certain federal and state government benefits, such as Social Security Income (SSI) and Medicaid. Local, private nonprofit organizations might also offer resources or benefits. Many cities and counties keep a list of these services and post them through local newspapers, online parent groups, United Way, or similar organizations.

The federal Social Security Administration (SSA) is a good place to start to find out about available health care services. If your child is eligible and receives SSI, the SSA also can help you find state and local resources. State agencies have different names, including Children's Special Health Services and Children's Medical Services. Most of these programs offer services through local clinics, private offices, hospital-based outpatient and inpatient treatment centers, or community agencies.¹⁰

Children eligible for SSI will also often be eligible for Medicaid, a health care program for people with low incomes and limited resources. Even if your

family has the means to take care of your child without governmental benefits, experts recommend accepting them if your child qualifies.¹¹

Eligibility requirements differ from state to state. In many states, children who receive SSI payments qualify for Medicaid, but Medicaid may not be automatically granted. In those cases, you must apply for Medicaid separately. In other states, Medicaid is automatically granted with SSI eligibility. Still, other states require you to sign up for each individually. There are cases in which some children receive Medicaid coverage even when they do not qualify for SSI.¹² It is very important to speak with someone at your local Social Security and Medicaid offices to find out how your state works. Sometimes, your child's specialty center has a nurse or social worker who can walk you through this.

EDUCATIONAL RIGHTS

Children with special needs are entitled to receive extra services or accommodations through the public school system. Federal law ensures that every child receives a free and appropriate public education (FAPE).

Section 504 of the Rehabilitation Act of 1973 guarantees that a child with a disability has equal access to an education and that the education is comparable to one provided to those who do not have a disability.¹³

Federal laws exist to ensure that children with special needs have proper opportunities to get a public education. It is often up to the parents to ask for consideration and to provide the necessary information and paperwork. A team of professionals at the school typically reviews each child's case and decides eligibility. Criteria for eligibility, available services, and procedures for each of these laws vary from state to state. Talk with your child's teacher or guidance counselor about having your child evaluated.

(These laws include the following)

- Section 504 of the Rehabilitation Act of 1973, which is known in schools as a 504 plan
- Individuals with Disabilities Education Act (IDEA), enacted in 1975 and amended in 2004
- Americans with Disabilities Act (ADA), enacted in 1990

Each federal law addresses different areas of special education. IDEA addresses which conditions qualify a child for special education. Section 504 requires that schools provide disabled children with reasonable accommodations and that disabled children are not discriminated against. The ADA requires all schools (except for those run by religious organizations) to meet the needs of children with differences or disorders. Under the ADA, children who qualify cannot be denied educational services, programs, or activities. The ADA also prohibits discrimination against students with disabilities.¹⁴

Once it is determined that your child is eligible for these services, you may then develop an Individualized Education Program (IEP) and/or a 504 Plan. These cover additional services and/or accommodations, such as occupational therapy, physical therapy, speech and language therapy, and/or the provision of a classroom aide.

INSURANCE REVIEW

Now is the time to review your health insurance coverage and make sure you understand how it works.

What kind of health care plan do you have?

Is it an indemnity plan (sometimes called an 80/20 plan), a health management organization (HMO), a preferred provider network (PPN), or another type?

Do you have deductibles?

If so, how much are they? And what out-of-pocket costs can be applied to them?

Do you have copays?

If you do, is there a difference in cost for your child to see their pediatrician versus their disease specialist? What about urgent care, emergency room

visits, or hospital admissions? Are there copays for certain imaging services, such as magnetic resonance imaging (MRI), endoscopies, or catheterizations?

Do you use a PPO?

Are all your child's physicians in-network providers? If not, what are the costs for seeing an out-of-network provider?

Does your plan cover prescriptions?

What are the details concerning brand names and generics? What pharmacies are you allowed to use? If your child needs compounded medicines, will your insurance cover that?

Does your plan require preauthorization for certain tests, procedures, surgeries, etc.?

If so, become familiar with what things require preauthorization as well as how the preauthorization process works.

Once a preauthorization has begun, follow up with your child's doctors to ensure the process is moving along and be prepared to jump in if it has stalled.

These are some of the most important questions to cover. Stay aware of any federal changes to health care laws that might affect your child's health care coverage and the effects it might have on preexisting conditions, lifetime maximums, and how long you are able to carry health care coverage on your child.

Also, look at your spouse's and your own insurance policies—especially your life insurance, long-term disability insurance, and extended care insurance. Long-term disability and extended care insurance policies, in particular, could defray costs if you or your spouse becomes ill.¹⁵





EMOTIONAL SUPPORT

You have done everything you can do now for your child with special needs. You have covered potential financial and legal concerns and ensured they are receiving the best care possible through federal, state, and local programs as well as ones available through your private insurance. Therapies and education are set in place.

So, what's next? You and your spouse are. Now it is time to find your own resources. You might or might not need them immediately, but identify them now. That way, if and when you do need them, your list is waiting. If you spend a lot of time in the waiting area at the office of your child's specialty physician, therapist, tutor, nurse, or social worker, ask if they know other families with children who have similar diagnoses and

that would be interested to connecting with you and your family. Other ways to find these families include local agencies and social media. Someone, somewhere, has likely created a foundation or support group for families just like yours.

These other families might be willing to share their stories and experiences with you. And you might find that it is especially helpful if the families are at least six months to a year further along than you are because they can share their successes, mistakes, obstacles, and more. Perhaps, most importantly, they can give you insight on their children's journeys so far. Often, stories like these can provide hope to other families.

We hope you have found this resource useful and informative. Remember, other families are out there and willing to help you walk this path. We also

want to offer ourselves as a resource to you and your family. We are happy to answer any questions about your current situation and how you can best prepare yourselves, your family, and especially, your child with special needs for a stable future. That way, all of you can concentrate on ensuring the highest quality of life possible.

If you have any questions about the information presented in this report, or if you'd like to discuss your specific needs, please contact us. We would be delighted to speak with you.

Sincerely,

FOOTNOTES, DISCLOSURES, AND SOURCES:

- 1 Special Needs Alliance, 2020
- 2 Special Needs Alliance, 2020
- 3 Special Needs Alliance, 2020
- 4 NOLO, 2020
- 5 Investopedia, 2020
- 6 Special Needs Alliance, 2020
- 7 Investopedia, 2020
- 8 SHRM, 2020
- 9 Caring.com, 2020
- 10 SocialSecurity.gov, 2020
- 11 KFF.org, 2020
- 12 SSA.gov, 2020
- 13 Disability Rights Education & Defense Fund, 2020
- 14 Disability Rights Education & Defense Fund, 2020
- 15 Pacer Center, 2020

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