planning a more secure future for your

Child with Special Needs

a guide for parents or guardians

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Everything is set. You met and married the love of your life. You both have great jobs, and your finances are in order. You may even have purchased a home together, or maybe you and your spouse have been together for a few years and have just settled into your forever home. Everything is falling into place just as you dreamed, so you cannot be happier to find out you are expecting a child. It might be your first child, or it might be your third. You and your spouse just know you cannot wait to meet your bundle of joy.

what happens when life takes an unexpected turn?

Your child's diagnosis might come during one of your prenatal visits with the obstetrician. It might come just after birth, or it might not come until years later. It might be that your child suffers a traumatic injury as a toddler or during the school years. Whenever you first hear your child's diagnosis, it is devastating. In that instant, your world changes.

In that first moment and into the early days or months of your child's diagnosis, your focus is on your child's health, finding all the right people to take care of him or her, and adapting to the changes. You likely are not thinking immediately about how your child will be taken care of 10, 20, 50, or even 5 years from now. As your life settles into its new normal, though, planning for your child is one of the most important things you can do.

understanding the diagnosis and gathering information

Your child's diagnosis might be physical—a heart defect, spina bifida, or an accidental, life-altering injury to a limb. The diagnosis might be developmental, such as autism spectrum disorder or fragile X syndrome. It might be caused by a traumatic brain injury later in life, or the diagnosis might be due to any other accident or injury that can occur in childhood.

Birth defects affect 1 in 33 babies born in the United States each year.[1] Birth defects range from those that can be easily repaired or remedied with surgery or therapy to those that are not curable and can cause disabling, lifelong effects. During their younger years, children also could be unintentionally injured. Common accidents include burns, poisonings, near-drownings, falls, choking, and car accidents (including injuries from improperly installed car seats). [2]

Whatever the cause of your child's life-changing diagnosis, your first priority typically is gathering all the information you can so you can fully understand what is happening to your child and what might happen in the future. Likely, you are trying to absorb the impact on the rest of your family and the rest of your lives.

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 connections can offer you hope about the future. Those who received diagnoses months or years before you can give you tips and suggestions for navigating your new and unfamiliar world.

Once you have gained perspective on your child's health, hopefully, you can reach a point when you can turn your focus to ensuring your child has a more secure future regarding financial and legal issues, government benefits and insurance, and developmental and emotional support.

points to consider

Financial and Legal Concerns

While other parents are planning for their child's college education, the parents of children with special needs are concerned with immediate and long-term financial issues. There is so much to consider, depending on your current financial status and the severity of the child's condition and disabilities.

If your child needs round-the-clock care, your family might need to hire home health-care providers who not only offer nursing care but respite care for you and your family. Parents also might need to make arrangements for older or younger children for transportation, after-school care, or safe, reliable babysitters while one or both parents take the child with special needs to an appointment.

Sometimes, one parent might need to quit work or change career tracks, which means a noticeable reduction in income. Meanwhile, medical bills stream in quickly and often, with nearly unmanageable costs. Some families find themselves one crisis away from financial ruin.

You can prepare legally and financially in a number of ways. Some preparations come with fees; others are free. Getting an overview and tackling the arrangements you are able to should give you some peace of mind.

- **Name a Guardian and a Trustee.** A guardian is the person who will take care of your child if you and your spouse were to die before your child becomes an adult. Think about how much time you now spend tending to your child's needs and who might be willing and able to take on this responsibility. The guardian should not have control of the child's money; this is the trustee's job. [3]

The trustee controls the money and handles investing assets thoughtfully and disbursing them responsibly when needed. The trustee also will make objective decisions when things are stressful or difficult. The trustee can be a family member or a close, trusted, dependable friend. The trustee also could be an institution, such as a bank or trust company. [4]

- **Write a Letter of Intent.** A letter of intent is a document you write that describes your child's history, his or her current status, and your hopes and dreams for your child's future. It is

not a legal document, but courts and others rely on this letter for guidance in understanding your child and your wishes. Keep a copy with your will, and make sure your child's guardian has a copy. Be sure to update the letter yearly or whenever something changes. The letter of intent should cover your child's daily routine as well as daily, weekly, and monthly schedules. It should include your child's medication schedule, your child's likes and dislikes, and any helpful community resources. With the letter, create a list of physicians, nurses, therapists, and other medical support. Include their office addresses and phone numbers and, whenever possible, personal addresses, cell phone numbers, and pager numbers. [5]

- **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. It is usually $2,000, but in some states, it is as little as $1,000. [6] Without a Special Needs Trust, children or adults with special needs could be disqualified from most governmental programs and potentially could 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, or property to the trust instead of directly to your child with special needs. This trust also protects against creditors and claims. [7] Your trustee will have authority to use funds from the trust to help care for your child. [8]

- **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. [9]

- **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 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 whatever you decide to save throughout the year—up to $2,600 for an FSA—all the money is available to you at the beginning of the calendar year. [10] HRA limits are typically set by the employer offering the benefit. Be sure to read all policies about money in the account that is not used by the end of the benefits year.

- **Write a Will.** According to a 2015 poll, 64% of Americans do not have a will. [11] 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. Do not write your will on your own. Your will should be written by an attorney who works specifically with families who have children with special needs and knows your state's disability laws. [12]

governmental benefits

Depending on the type and severity of the 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 also might 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. [13]

Children eligible for SSI also often will 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. Your funds can be depleted quickly when the cost for care of a child who has severe disabilities can run as much as $70,000 a year. [14]

Eligibility requirements differ from state to state. In many states, children who receive SSI payments qualify for Medicaid, but Medicaid is not 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. [15] 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. [16]

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 son or daughter 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 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.[17]

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 co-pays?** If you do, is there a difference in cost for your child to see his or her pediatrician versus his or her disease specialist? What about urgent care, emergency room visits, or hospital admissions? Are there co-pays for certain imaging services, such as magnetic resonance imaging (MRI), endoscopies, or catheterizations?

- **Do you use a PPO?** Are all of 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 the preauthorization process. 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 pre existing 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 long-term-care insurance. Long-term disability and long-term care insurance policies, in particular, could defray costs if you or your spouse become ill.[18]

emotional support

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

What is next? You and your spouse are next. Now it is time to find your 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 he or she knows other families with children who have similar diagnoses. Other ways to find these families include through local agencies and social media. Someone, somewhere has created a foundation or support group just for families like yours.

These other families might be willing to share their stories and experiences with you. 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, and obstacles. Perhaps most importantly, they can tell you about their children's journeys so far. Often, these stories give other parents hope.

We hope you have found this resource useful and informative. Remember, other families are out there and are 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 life. 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,

Eastern Planning, Inc.

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