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Protecting the Future for Your Child with Special Needs

Thoughtful planning helps you focus on your family, rather than your finances

For financial advisor Kimberly Greenberg and her husband, the journey of caring for a child with special needs began within hours of the delivery of their first daughter. They have been learning and growing as a family ever since.

Just hours after she was born, during a routine newborn hearing screening, baby Parker was found to have hearing loss. A few weeks later, she was diagnosed with strabismus, a condition in which both eyes do not look at the same place at the same time and tend to cross. Over the next few months, Kimberly and her husband noticed that Parker wasn't meeting the developmental milestones most babies reach in their first year, but they didn't know why. All they knew was they needed answers.

With the guidance of Parker's pediatrician, the Greenbergs began building a team to guide Parker's care. The team included professionals from myriad disciplines, from neurologists, geneticists, ophthalmologists, orthopedists, cardiologists, and audiologists to physical and occupational therapists, speech and language therapists, applied behavior analysis (ABA) therapists, and more. Shuffling among these professionals became not just routine, but the focal point of their daily lives.

In between all the medical visits, the Greenbergs were busy waiting for genetic testing to shed light on Parker's condition. Just before Parker's second birthday, they finally learned that she fit the profile of an extraordinarily rare genetic disorder.

While having these diagnoses helped to alleviate some of their uncertainty, the Greenbergs have learned that expecting—and planning for—the unexpected is essential for moving forward and making progress.

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"When you're juggling immediate priorities like doctors' visits, therapy sessions, professional obligations, and household needs, it's easy to put off long-term planning," says Greenberg. "But when you have a child that needs special care, planning is critical for protecting the financial future, not just for that child, but for your entire family."



Helping families like hers

Even with her experience as a financial advisor, Greenberg found it challenging to plan for the future. To help families in similar situations, Greenberg invested time in broadening her expertise to become a Chartered Special Needs Consultant (ChSNC®), a professional trained to help manage the unique legal and financial planning considerations of families with special needs. Eventually, her dedication paved the way for a professional partnership with Matthew Landry, a financial advisor, Certified Financial Planner® and Certified Investment Management Analyst® who also has a child with special needs.

"There is an instant connection that develops when you're talking to someone who understands the mix of heartache and hope that comes with caring for a child with special needs," she says. "Knowing how planning has helped us face each day with greater peace of mind, we've made it our mission to bring that sense of control and confidence to more families like ours."

Together, Greenberg and Landry are committed to helping families successfully navigate the complexities of caring for children with special needs.

"Every family's situation is unique, but there is always that common thread of wanting to ensure the best possible future for our children," adds Landry. "When you talk to someone who really gets what you're going through, it's that much easier to have meaningful conversations about what really matters."

Building a team around you

The cost of care for a child with special needs or other health issues can be overwhelming. For parents of these children, finding time to plan for those financial obligations can be challenging.

"You get so consumed with the regular routine that gets you from one day to the next that planning gets put on the back burner, even though you know it's important," says Greenberg. "The good news is, you don't have to do all that planning alone. Just as you've built a network to support your child, assemble a team to support you and the rest of your family."

That team should include medical, legal and financial professionals who understand the nuances of caring for children with special needs. These professionals can connect you to local resources and brainstorm solutions with you. They can also help ease the burden of planning, so you can focus on your family. "Finances are an important part of the equation, but most of the conversations we have with families with special needs are about their child's future will look like and what roles each family member will play in ensuring the best possible outcomes," continues Landry. "We share ideas and serve as a sounding board, with goal of making the day-to-day a little bit easier and helping you sleep better at night."

Ensuring continuity of care

Once you have a team in place, one of the first steps to consider is creating a special needs trust that provides your child with assets that can be used for a wide variety of goods and services. Establishing a special needs trust requires the assistance of an estate planning attorney, and you should consult with your legal advisor to see if this strategy makes sense for your situation.

You may also want to develop and document a plan for continuing care. This plan helps ensure that your child with special needs will be well taken care of if something should happen to you. Name a successor guardian or caregiver and consider creating a Letter of Intent or Plan of Care that outlines everything a future caregiver would need to know about your child's care. This would include contact information for members of the professional care team, as well as instructions on housing and educational arrangements and your child's preferences or favorite things. The objective of the Plan of Care is to make any transition of care as seamless as possible for all involved.

Another consideration for ensuring continuity of care is life insurance. Consult with your financial and tax advisors to see if survivorship life insurance may be suitable for your circumstances.

Understanding and preserving government benefits

Public benefits, including Supplemental Security Income (SSI) and Medicaid,

may be available to ease the financial strain of caring for a child with special needs. However, eligibility for these benefits is determined by income and asset limits. Exceeding certain resource thresholds may disqualify your child from government assistance.

"It's important for parents and grandparents to understand the eligibility requirements for government programs," advises Greenberg. "Many programs are based on the child's income and assets, not the parents'. Being mindful of the resources in your child's name can help preserve public benefits, especially as your child transitions into adulthood."



Considering a 529 ABLE account

529A ABLE accounts are a more recent development. These state-sponsored tax-advantaged savings accounts allow families of individuals with disabilities to save for future qualified disability expenses such as education, housing, financial management, and other services or technologies that enhance your child's health, independence, and quality of life.

"Every state has its own legislation and eligibility requirements, so just as with other 529 savings accounts, it's important to do your research to see which program is the best fit for your situation," says Greenberg.

Always looking for the silver linings

Greenberg and her husband have completed a financial plan for Parker, created a special needs trust, opened an ABLE account, and purchased life insurance with Parker's special needs trust as the primary beneficiary.

"We recently celebrated Parker's sixth birthday," shares Greenberg. "Having a plan in place helps us feel more prepared to tackle the future. It also frees us to focus on our family and to appreciate the silver linings. We have three beautiful daughters and we're moving forward every day."



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