

Planning for Your Disabled Child

The right moves today will ensure that your child's needs will always be met.

By Kimberly Lankford

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Matthew Troncone spent the first few years of his daughter Brittany's life in doctors' offices and hospital waiting rooms. From birth, Brittany showed signs of developmental delay, but it took many consultations and months of testing to determine the cause. "My main focus was making sure I understood everything," says Matthew. "I said I'd worry about the finances later."

Children with special needs require so much immediate attention, including managing their health care and navigating the social-services maze, that parents often find it hard to make time to plan for their finances. And many parents with financial resources assume that they won't qualify for assistance to help care for a disabled child, says Gordon Homes, a certified financial planner with MetLife's division of estate planning for special kids.

But if you have a special-needs child, you are entitled to benefits and programs that can help relieve the crushing costs of your child's care. And long-term financial planning is essential to make sure that your child receives the benefits you've worked so hard to secure, even when you can no longer care for him or her yourself.

Get aid you're entitled to.

After Brittany's problem was finally diagnosed -- she was born without the bridge that connects the left and right hemispheres of the brain -- Matthew applied for Medicaid. As an employee of Sony Electronics, he earns too much to qualify for himself. But Brittany's condition makes her eligible for coverage. Matthew's health insurance provides primary benefits, and Medicaid fills the gaps.

Even with good health coverage, Matthew had to pay about 15% of Brittany's medical costs himself before Medicaid kicked in. (Now, almost 100% of Brittany's health care is covered.) But he was able to deduct nonreimbursed medical expenses on his tax return. You are entitled to write off such medical costs after they exceed 7.5% of your adjusted gross income. With co-payments and out-of-pocket costs for tests and travel, the Troncones quickly crossed that threshold.

Schooling for special-needs kids is also subsidized. The federal Individuals With Disabilities Education Act requires states to provide free and appropriate education for children with disabilities until age 18 (most states continue services until age 21) -- potentially saving parents tens of thousands of dollars. Brittany started receiving physical and occupational therapy at age 3 through an early-intervention program in Dutchess County, N.Y., where she and her father live. The county now covers the cost for her to attend a special-needs school, and her father meets with the school district every year to renew her Individualized Education Program.

When local budgets are strapped, however, families with special-needs kids may need a lawyer or advocate to obtain the best educational program available, says Bernard Krooks, a special-needs attorney in New York City. "Parents may not know what their rights are."

Open a special-needs trust.

When Adrienne Arkontaky counsels families with disabled children to make an estate plan, she speaks from personal experience. Her daughter, Jordan, now 15, was born with cerebral palsy, and Arkontaky went to law school to become a special-needs attorney so she could help other families make the most of their benefits.

The biggest mistake families make, says Arkontaky, is to put off estate planning or to use standard strategies that could

actually put a special-needs child at risk. For example, in order to qualify for Medicaid and other benefit programs, special-needs children may not have more than about \$2,000 in their own name. Parents and well-meaning relatives who give a disabled child money -- either now or in their wills -- could make the child ineligible for some benefits, and he or she would need to spend down the money and re-apply.

Some parents think they can solve this problem by disinherit their disabled child and giving the money to a sibling or family member who promises to provide the child's support. But such a solution puts enormous stress on the sibling and still doesn't guarantee that the child's needs will be met.

A better solution is a special-needs trust, which acts as a receptacle to accept money earmarked for the child and may be used to pay for the amenities that government programs don't provide. "The trust can see that children have the opportunity to travel to visit relatives, celebrate birthdays and holi days, and enjoy some measure of entertainment," says Homes.

Brittany was 10 years old when Matthew arranged to meet with Arkontaky to set up a trust for her. By that time, he was divorced and wanted to leave everything to his daughter. "But if the assets were in Brittany's name, her services would be affected dramatically," says her father.

Matthew designated a guardian for Brittany in his will and named the special-needs trust as the beneficiary of his life-insurance policies and retirement plans. He instructed relatives to do the same and wrote a letter of intent explaining the extracurricular activities, such as swimming and horseback riding, that he'd like the trust to pay for.

Arkontaky generally recommends naming co-trustees -- a family member or friend plus a professional trustee, such as a bank or a lawyer, who can choose the investments and manage the taxes (see "In You They Trust," March). It's important to pick trustees who will be able to manage the trust for decades (and keep that time frame in mind when designating a guardian, too).

Many families also boost their life-insurance coverage, especially if they want to leave money to other children as well. "Even kids with Down syndrome can live to normal life expectancy these days," says Krooks. "You need to look at a 70- or 80-year situation."

Because the child could be dependent for more than 20 or 30 years, this is one instance in which a cash-value policy trumps term life insurance. You'll need to buy coverage for both parents, including the primary caregiver. But you can save money, says Homes, by putting most of the money in a second-to-die policy, whose proceeds will be paid directly into the special-needs trust after both parents die. He recommends a universal-life policy that maximizes the death benefit and minimizes the cash value. "It's funding the maximum at death that you're concerned about," he says.

Plan for an adult child.

Your child reaches a major milestone when he or she turns 18. At that point, children automatically become their own guardians, regardless of their ability to manage their lives. If you don't apply for guardianship, you may not have the legal authority to make medical and other decisions for your child. Arkontaky recommends starting the application process at least a year and a half before the child turns 18. Even if your child is only moderately disabled and can serve as his or her own guardian, you should have a health-care proxy so you can make medical decisions if your child is unable to.

The source of your child's benefits also changes at age 18, as he or she moves out of special education and into adult services, says Harry Margolis, a special-needs lawyer in Boston. Many school systems allow disabled children to remain in their programs until age 21, but families must track down a new set of benefits after that.

Your disabled child might qualify for Supplemental Security Income from Social Security, start a job and move out of your home and into group housing (the cost of which may be covered by the state or a nonprofit organization). If your child does get a job, be aware that his or her income could reduce SSI, Medicaid and other benefits.

Amanda Sham of Bala Cynwyd, Pa., was born with microcephaly, a condition in which her skull was too small for her brain to expand properly. Now 26, Amanda graduated from a special-education program at her local high school and works as a teacher's aide in a day-care center, a job she loves and looked for herself.

"She needs help in many aspects of daily living," says her father, Bruce. "She can't shop or cook by herself, and she will never drive." Bruce is a financial planner with MassMutual's SpecialCare program, which focuses on planning for families who have children with special needs.

As long as Amanda doesn't earn more than \$900 per month in 2007, she is eligible to receive Social Security disability benefits. Although she actually earns close to \$1,000, she is allowed to subtract expenses, such as the cost of getting to work, which puts her income below the cutoff. She is covered under her parents' health-insurance policy as a permanently disabled adult, and Medicaid supplements the private coverage. The Shams are glad she has dual coverage because her dentist and doctor do not see Medicaid patients.

In addition to her special-needs trust, Amanda has a so-called OBRA '93 trust in which she deposits the money she earns from her job, plus birthday presents and other gifts, so she doesn't cross the asset limit for Medicaid eligibility. She can use the money for anything that benefits her health, welfare or education. Tops on her list now, says Bruce, is buying furniture for her apartment. When she dies, anything that remains in the trust gets paid back to Medicaid.

Plan for yourself.

Bruce Sham and other special-needs planners say that it's easy to spend most of your time and money on your child and neglect your own finances. But you may need to save for college for other children, and you certainly need to prepare for your retirement -- especially because your child with special needs could be dependent on you long after you retire. Long-term-care insurance for yourself is also a good idea -- and it will allow you to preserve your savings for your child's care.

Savings made a huge difference for Elis Yokelson of Sharon, Mass., who is 80 and has two children in their late forties with special needs -- a son who is bipolar and a daughter who is developmentally disabled -- for whom she still pays out-of-pocket expenses. "We lived below our income and saved like mad," says Yokelson, a retired teacher. "It always helps to have the money -- you get better placement in programs," she says. "If people don't save, I don't know how they're going to do it."

Where to go for help

If you have a child with special needs, it's important to work with a local lawyer and financial adviser because laws and resources vary from state to state. Several new organizations make it easier to find special-needs planning experts, many of whom have disabled children themselves and can also help you navigate the benefits system and track down local resources.

The Special Needs Alliance

is an invitation-only organization of about a hundred lawyers who focus on special-needs planning (www.specialneedsalliance.com).

Specialneedsanswers.com

provides contact information for members of the Academy of Special Needs Planners plus state-specific information.

Several financial-service providers now offer special-needs planning: MassMutual's SpecialCare program (800-272-2216; www.massmutual.com/specialcare), MetLife's MetDESK (877-638-3375; www.metlife.com/desk) and Merrill Lynch's division of special-needs financial services (877-456-7526; or go to www.askmerrill.ml.com and click on "Advice and Planning," then "Special Needs Network").

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