

Financing Special Needs

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Providing for Your Special Child's Future

One of the last things a parent wants to worry about while dealing with their special needs child is finances. Unfortunately, the topic too often can't be avoided. Special needs children often require above average emotional, physical and medical care. This costs money. Long-term care is another concern that needs to be addressed.

Cynthia Gavenda is a special care planner with the MassMutual Financial Group. She is a CPA as well as an MBA and worked on Wall Street for several years prior to having children. All that changed after her son was born with Down Syndrome.

"He was our first child and his diagnosis at birth was unexpected," says Gavenda. "The first few months after we brought him home were very difficult. Not only did I have a difficult time adjusting emotionally to the fact that my child was physically and mentally disabled, but there were a number of unexpected challenges in caring for Alec."

Making Time to Make Plans

As a financial planner Gavenda knew they needed to make financial provisions for their child. "Even though we were quite challenged emotionally that first year, we did make sure that we did what we needed to do from an estate planning perspective to make sure that Alec was provided for in the event that we were not there to care for him," says Gavenda. "When Alec was 4 months old, we retained a special needs attorney to draft our wills, durable powers of attorney and special needs trust. We selected guardians and trustees and obtained life and disability insurance."

Understanding the Costs with Special Needs Children

Mike Byrne is a financial planner with Lincoln Financial Advisors. He, too, has a child with special needs. His daughter was born with Williams Syndrome, a mild form of mental retardation. This type of condition becomes more and more apparent in the middle school and high school years.

"She will always need some sort of outside assistance and never be totally independent," says Byrne. "Financially, the costs in the early years are the same as for any child because of the public school system and extended school year offered by her special school. The real cost will come later in life."

It is that cost that parents must address when considering the financial planning for their special needs child.

"Depending on the needs of the child, the cost in later years could be like putting them through college for the rest of their life," says Byrne. "As parents with children of special needs, we need to take the proper steps to be sure [our] children continue to be eligible for government benefits later in life. Parents must continue to save regularly in order to provide additional financial assistance for quality-of-life items the special needs child requires."

According to Byrne, families must do everything they can to maximize all governmental benefits. To do this often requires the utilization of a special needs trust in order to protect the child's eligibility for benefits while still meeting the family's other needs.

When Gavenda decided to go back to work, she chose to go back into a field very near and dear to her heart – as a financial planner for families with special needs children. "Many parents, such as ourselves, are dealing with so much emotionally those first few years that's it's difficult to find the time and energy to deal with financial decisions," says Gavenda. "However, there are just a few questions that a parent should address early on to ensure that their child is taken care of in the event that the unexpected should happen."

Gavenda says that the peace of mind that comes from planning for your child's financial needs is worth the emotional stress it may initially cause. "Most parents that I work with spend several years dealing with a variety of challenges associated with their child's disabilities before they feel that they are emotionally ready to plan for their future," says Gavenda. "It is difficult to envision what life would be like for your child if you were not there, as the person who loves them the most and understands their challenges better than anyone. It is for exactly that reason that most parents delay planning."

Choices for the Future

Gavenda knows that as a parent of a special needs child there are only a few things she can control. Finding someone to care for their child in a loving and compassionate way is one of the things parents can and should do.

"I cannot take away my son's disabilities," says Gavenda. "However, with just a little bit of planning I can make sure that he is cared for by someone who loves him and can live comfortably for the rest of his life. There are no words to describe the peace of mind that provides me and my husband."

This type of planning includes choosing a guardian to care for the child, covering basic living expenses and choosing how those funds will be provided. "These may be difficult questions to answer, particularly when a child is so young," says Gavenda. "Seeking the help of a special needs planner as well as attorney licensed in your state of residence who specialize in working with parents of disabled children can help guide you through the decision-making process."

"This planning is best accomplished by utilizing both the services of a financial planner and attorney, who have expertise in special needs planning," says Byrne. "The sooner you start the better, but it is essential to begin this process by age 14."

Byrne gives the following tips to start planning for the financial needs of your special needs child:

- Set up a special needs trust and inform family members.
- Never put any assets in the special needs child's name.
- Set up a funding mechanism (i.e. life insurance or investments) to provide for a special needs child after the parents are gone.
- Put a letter of intent in the child's file to explain to future caregivers the needs of the disabled child. This letter of intent should also contain documentation of the idiosyncrasies of these children, which make up a large part of their quality of life.
- Get connected with support groups in order to understand and access the various programs and benefits available for your child.

"They say the prayer of a special needs parent is that their child live a long and happy life, and that we as parents live one day longer to be sure we are there to protect them," says Byrne. "In most cases, that will not be the reality. It's special needs planning, when done right, that will protect our children when we are no longer here."