



# PLANNING A FINANCIAL FUTURE AS THE PARENT OF A CHILD WITH SPECIAL NEEDS

BY SUSAN PASTERNAK

When **Dana Singla** gave birth to her second child **Brandon**, who was born with Down syndrome, a long-term financial plan for her family was the last thing on her mind.

For the first few years of Brandon's life, Dana and her husband **Vinnie** focused on caring for their child, who required open-heart surgery and other medical therapies, as well as tending to their older daughter. Brandon, now 11, now also has a younger sister.

"The first thing you're thinking of is taking care of this newborn, who isn't the newborn you expected," Singla says. "Trying to get through those first couple years is very hard."

The Singla family, like other families with a child with special needs, also faces a different financial future than they likely expected. **The Autism Society of America** estimates the cost of caring for a child with autism ranges from \$3.5 million to \$5 million. Therapies, including speech, occupational and physical, are often capped or not covered by insurance, and parents are often faced with planning for full-life care for their child. These expenses, along with retirement savings and college planning for other typically developing children, is daunting to even the most financially resourced families.

Families with special needs members often look to financial advisors for help, and thankfully, an increasing number of advisors are knowledgeable about the best ways to help these families plan for their futures.

"As a whole, the financial planning doesn't look all that different in the sense that you want to understand what a client's current financial situation is, and find out what their needs and goals are," says **Kris Yamano**, regional leader of planning for the Sun Belt and Central States at **BMO Wealth Management**. "The way you set up funds and accounts has been done in such a way to make sure the child qualifies for government assistance."

To start, most advisors will recommend that the families set up a special needs trust, which enables the child to use the assets held in the trust for his or her benefit while not jeopardizing the receipt of Supplemental Security Income and Medicaid benefits from the federal government, and some state benefits. The parents should ensure that an attorney with expertise in this area is setting up the trust.

ABLE (Achieving a Better Life Experience) accounts, which operate similarly to 529 college savings plans, should also be part of the portfolio. The account's growth is federal tax-free and families can access the funds to pay for qualifying expenses, such as housing or non-covered medical and therapeutic expenses. While some 40 states have passed legislation approving ABLE accounts, only a handful have actually made the program available to date. However, like 529 plans, consumers can apply to programs administered in states in which they do not reside.

Parents should take caution not to over-insure with inappropriate term life insurance, and instead be efficient with the right amount of permanent life insurance, says **Mike Walther**, founder and president of **Oak Wealth Advisors**, a Deerfield-based firm that provides comprehensive support to families with special needs members. Unlike some financial advisors, Oak Wealth Advisors, a member of the Academy of Special Needs Planners, does not sell any products to their clients, and instead serves as an advisor and educator.

When the Singlas first met Walther, they had spent far too much money on life insurance that was not appropriate for their situation. By scaling back on those plans, setting up the correct accounts, and buying the proper life insurance, the family was actually able to save enough money to take a family vacation to Disney World, which prior to their meeting Walther seemed like a pipe dream. Dana Singla, a pharmacist, recently decided to stay at home full-time with her children and credits their financial planning with Walther with her ability to do so.

"We needed someone who had our best interests at heart," Singla says. "Mike helped us revamp our entire financial profile. Financially, we're now way better off and are saving for our future."

Nonprofit organizations can also be a resource for information and assistance. **Easterseals** collaborates with **MassMutual** to offer financial guidance to families with special needs. MassMutual's highly trained financial professionals, including special care planners and those with the chartered special needs consultant designation, provide support and guidance for families with members with special needs, explains **Kelly Piacenti**, assistant vice president at MassMutual, and the mother of a son with special needs.

Walther always suggests that even his clients with abundant financial resources take the appropriate measures to ensure that the child has the option to utilize public benefits. Often job training programs or even programs for teens with special needs are only available through government-run programs.

"We want to create as many opportunities [as possible] for our clients for their loved ones with special needs," Walther said. "You should expect the moon of your child no matter what the diagnosis is. There are so many success stories and we help families figure out how to achieve that."

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