



# Addressing the Financial Puzzle for Autism Families

By Charles J. Massimo

**F**or anyone with a personal or professional connection to autism, the statistics regarding its increasing prevalence in the United States are alarming. In late 2009, the *Journal of Pediatrics* published the report, “Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the U.S.” This Department of Health and Human Services National Survey of Children’s Health report, which relied on data from the Centers for Disease Control and Prevention, estimated that 1% of U.S. children ages 3-17 have an autism spectrum disorder. That’s 1 in every 91 children, and 1 in every 58 boys. Also of great concern are the costs associated with caring for individuals with autism. The Autism Society of America estimates that the costs of treating, educating, housing and providing other services for autistic individuals will reach \$90 billion by 2010 (primarily for adults on the spectrum). Based on the Center for Disease Control’s statistical trends, by 2016 these costs could approach \$400 billion. That’s absolutely staggering!

The road ahead is challenging for parents of children diagnosed with an autism spectrum disorder. Regardless of their social status, level of education, religion or

ethnicity, parental concerns over the well-being of their child are the same and are all-consuming. They cover every aspect of the child and family’s life, from their child’s health, happiness, independence and education to their social needs, housing, employment and overall quality of life. Understandably, finances become one of the family’s greatest sources of stress and only intensify as the child ages and approaches adulthood. Harvard University research estimated that the lifetime cost of treating and caring for an individual with autism could reach \$3 million.

Congress is stepping up to the plate to provide some relief; however, families with children or adults with autism need to take direct control of their financial requirements. They must become

informed and pro-active, taking the necessary steps to develop a plan-of-action designed to address their financial challenges today and into the future. Doing so gives parents much deserved peace of mind and will afford important protections for the child and other family members.

### Calculating the Financial Burden

Families with spectrum children experience a far greater financial burden than do families whose children have other chronic health conditions. This finding, published in the December 2008 issue of *Pediatrics*, was based on a nationally-representative survey conducted in 2005-2006 involving approximately 40,000 children with special health care needs, including those related to autism. The survey found that parents of children with autism incur greater health care costs, spend more time to access and coordinate care than parents of children with other chronic health problems, and are more likely than these other parents to experience serious financial difficulties.

In one example cited, a mother of a 12-year-old son said she spends at least \$15,000 to \$20,000 out-of-pocket annually on various treatments and supplies for her autistic child. She also revealed she was paying off a \$7,000 dental bill incurred because her son required sedation and hospitalization for dental work their health insurance did not cover. This example is just the tip of the iceberg.

Other findings are equally disturbing. The 2008 Easter Seal study sponsored by MassMutual Financial Group highlighted the extreme worry parents of children with autism experience regarding their finances. The "Living with Autism" study reported:

- 47% of parents surveyed worry that the financial drain they currently experience will financially impact their ability to raise other siblings.
- Over 50% of parents surveyed were concerned the financial drain would hinder their retirement plans.

- Nearly 75% of parents surveyed worry about the financial support their children will receive after they can no longer take care of them.
- 61% of parents surveyed incurred debt to meet their family's needs.
- Only 40% of parents with autism spectrum disorders have a designated guardian for the child or have created a will.
- 78% do not have any form of *Life Care Plan*.

Often the greatest hindrance to parents who recognize the need for a financial plan is not knowing where to begin. Unfortunately for these parents, that may be their greatest hurdle. The *Living with Autism* study found that 56% of parents did not know of any financial professional who specializes in addressing their needs. While it's not easy to find someone who understands the unique financial needs of families with spectrum children, resources are available. Finding them just requires some due diligence and commitment to the process. Parents of children with autism should begin by seeking out a professional knowledgeable and experienced in the development and management of Individualized Life Plans (ILPs). The ILP is the financial/life plan equivalent of a child's Individualized Educational Plan (IEP).

### Building a Professional Team

Building the right team of advisors is a key step in financial/life planning. At the helm should be an experienced wealth manager, a financial advisor who takes a holistic, comprehensive approach to truly understanding their clients' needs, family dynamics and complexities. Unlike a financial advisor who serves more as an investment generalist, this professional is highly personalized in his approach, offering an integrated, customized wealth management plan and ILP that reflects the family's unique values, goals, assets, inter-family relationships and complexities along with the child's needs. The right wealth manager will be consultative,

relationship-driven and proactive in approach rather than transaction-oriented and reactive. The ILP he or she creates for an autistic child will also address the concern that keeps every parent of a spectrum child up at night: how will my child be cared for when I am no longer here to do so?

Wealth managers provide personalized attention. According to a 2007-2008 survey by CEG Worldwide, LLC of 2,094 U.S. financial advisors, wealth managers have a higher annual net income and more assets under management, but fewer clients than investment generalists. When that client is a parent(s) of a child with autism, the individualized attention is even more pronounced.

When selecting a wealth manager, parents should seek out a professional who has the proper credentials and experience working with families with spectrum children, and also the resources in place to provide a complete, holistic service.

These resources include strong working relationships with other key team members that may be needed by the family, such as:

- an estate planning attorney who concentrates in special needs families and has experience serving families with an autistic member,
- a certified public accountant to address tax-related issues,
- an insurance consultant with experience in special needs planning, and
- a banker.

Although many families may already have a lawyer, an accountant, or a broker, an important question to ask is whether or not these individuals have specific expertise and experience serving families with autism. If the answer is no, while it may be difficult to change a trusted advisor who has served the family for many years, it should be done to best protect the family and child's long-term interests.

Another key member of the team is a case manager. The case manager's role

## Finding the Wealth Manager Right For You

Sometimes, getting started in fiscal management is as simple as asking the right questions. Use these questions as your guide when selecting a wealth manager.

- What made you decide to provide financial and wealth management advice to families of children with autism?
- What percentage of your clients fall into this category?
- Do you work with other professionals whose expertise I may need to prepare a will, guardianship agreement, estate plan or revocable or special needs trust? Will we have the opportunity to meet and interview these other professionals?
- We have a longstanding relationship with our attorney and accountant and really do not want to change. Is there any way you can work with them in creating the right financial plan for our child and family?
- Our family has a very complex asset situation. Is it necessary that all of our assets be transferred under your control?
- How often will we meet?
- What investment philosophy do you follow to assure our assets will be preserved but still have room for growth?
- If something happens to you, who will take over managing our plan?
- Who else is on your staff and what are their qualifications?
- Do you put your plan in writing for us?
- How can I be sure our money is safe and not exposed to a fraudulent investment scheme or Madoff-like firm?
- We recently relocated to this area. Can you help guide us in accessing other non-financial resources to help our child and family?
- Do you have relationships with doctors who specialize in autism spectrum disorders? Do you have relationships with speech therapists, occupational and physical therapists, psychologists and social workers?
- What about government benefits? Can you explain how they work and assist us in accessing these benefits for our child?
- In addition to reports regarding our wealth management plan, can we expect to receive information and news regarding important developments affecting individuals and families with autism?
- Are there any families you currently serve who would be willing to speak with us about their experience working with you?

needs trust, education plan, housing plan, retirement plan, and risk management vehicles (i.e., insurance and legal needs relating to special needs of the individual on the autism spectrum).

### Developing the Wealth Management Plan and ILP

Led by the financial advisor/wealth manager, the first step in the planning process is a discovery meeting. During discovery, the financial consultant will ask over 60 detailed questions to learn about the family's core values, concerns, complexities, dynamics and top priorities. Once discovery is complete, the financial advisor/wealth manager will review and organize the information, which will then be presented in a second meeting. The purpose of this meeting is to confirm that all information and goals were properly interpreted. The goals and priorities reviewed become the foundation for the wealth management plan.

In a third meeting, the financial advisor/wealth manager will present the components of the wealth management plan, including the financial plan and investment plan developed on behalf of the family. The financial plan is the broad picture encompassing elements related to wealth transfer, distribution and preservation (e.g., special needs trusts, insurance, etc.), whereas the investment plan presents how the family's assets will be allocated to achieve their financial goals. An important aspect of the financial advisor/wealth manager's role will be managing the investment component of the plan. It is very important that parents with autistic children maximize their portfolio's growth in the most prudent manner possible. For families with unique financial burdens such as those presented by an autism diagnosis, one mistake from an investment standpoint can be devastating. However, it is important that the approach taken not limit future wealth. Regardless of a family's level of wealth or financial sophistication, a family with an autistic member needs to maximize portfolio growth.

Following a meeting with the family to present the investment plan, the family is

is to serve as an advocate for the family (and autistic child upon adulthood). This professional will help the family navigate through the various resources the child will need over the course of his lifetime, including medical, housing, social services and government benefits.

The group of professionals must work together, as a team, to develop and

manage an effective and sustainable wealth management plan and ILP. At the core of the wealth management plan should be vehicles designed to accumulate and preserve wealth. Members of the professional team will lend their individual expertise to guide the design of a wealth distribution, accumulation and preservation plan that includes a special

given time to consider it. Upon the decision to go forward, an administrative meeting is held. During this meeting, various documents, forms and related paperwork are presented to the family for completion so all assets (i.e., bank accounts, retirement plans, investments, etc.) can be consolidated and transferred under the management of the financial consultant. While this process is continuing, a meeting is scheduled to conduct a multidisciplinary assessment of the child with autism. The assessment may include developmental, psycho-educational profiles and evaluations and medical screening depending upon the child's life stage. The assessment findings provide the basis for the ILP. Once it is developed, the clinical professionals on the wealth manager's team will begin researching various resources to meet the child's needs.

After approximately a 45-day period, another follow-up meeting will be scheduled to confirm completion of the necessary documentation and begin the investment planning. Advanced planning meetings with legal, accounting and insurance advisors are also scheduled to maintain ongoing communication and planning strategies. Once the financial and investment plans are fully implemented, they are managed on an ongoing basis by the financial advisor/wealth manager working in concert with the family's other trusted advisors. Quarterly and annual meetings are conducted to keep the lines of communication open, and discuss any changes in the family's goals, priorities and/or the autistic child's life care needs that should be reflected in the wealth management plan and ILP.

### Compassion and Finances Do Mix

For many parents, managing the day-to-day activities and needs of their spectrum child is overwhelming enough. When it comes to the financial burdens presented by autism, the challenges can seem insurmountable. First, they need to find the right professionals and then place their trust in these advisors. While the process may seem complicated at first, the right advisor, someone intimately involved in serving families with children on the

# Legacy of Love

Charles Massimo, president of CJM Fiscal Management, a leading wealth management and financial advisory firm, and father of triplets, two of whom are on the autism spectrum, has decided to do something about the lack of resources for the growing number of families touched by autism.

"While my wife and I have first-hand experience coping with the challenges, frustrations and considerable expenses associated with the care and treatment of our sons, I have become increasingly more aware of the enormous financial burdens and equally large void in resources to help families like mine," said Massimo. "I formed Legacy of Love with the goal of providing a fully-integrated planning service for families touched by autism."

To ensure the best resources are available through Legacy of Love, Massimo has formed an advisory board and allied resources across various disciplines. They include: estate planning attorneys, Certified Public Accountants, Board Certified Defeat Autism Now (DAN) physician, Board Certified DAN neurological chiropractor, special education teacher, speech language pathologist, physical/occupational therapists, behavioral ABA Certified therapist, social worker, parent advocate, recreational resources and nonprofit organizations.

"The Individualized Life Plan component of our services will function much in the way an Individualized Education Plan (IEP) does to meet the special education needs of children with autism," explained Massimo. "The difference is that our ILP will cover a broad array of the child's needs, from education and socialization to medical, recreational, vocational, housing and independent living as the child ages."

Massimo added, "We want families touched by autism to know there is a resource available to them to provide the professional planning, support and one-on-one advocacy they need to meet their long-term financial goals for their family and life goals for their autistic child."

Legacy of Love is offering families touched by autism a comprehensive white paper to help them meet challenges associated with autism. Find it at [www.legacyofloveplan.com](http://www.legacyofloveplan.com) or call CJM Fiscal Management, Legacy of Love Division: 631-777-1010.

autism spectrum, can lead his or her clients with knowledge and compassion. In doing so, parents gain a sense of control over their finances and their child's future well-being. They also gain peace of mind, and can sleep a little better at night knowing their son or daughter will be cared for over the course of their life. And that, in the end, is priceless. ■

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