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Dollars & Sense: Special-needs children require special financial planning

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Planning for your financial future is never an easy task. Anticipating changes in tax codes, financial markets and your personal needs is virtually impossible. When you add the possibility of providing for a special-needs child for the rest of his or her life, the equation just got much more complicated.

My older son has been diagnosed with Asperger's Syndrome, one of five Autism Spectrum Disorders recognized by the National Institute of Mental Health. Studies conducted in the past decade indicate 3.4 of every 1,000 children 3 to 10 years old had autism.

Although the term autism has almost become a catch-all for several distinct disorders, all children with ASD demonstrate deficits in social interaction, verbal and nonverbal communication and repetitive behaviors or interests. In addition, they often will have unusual responses to sensory experiences, such as certain sounds or the way objects look.

In most cases, the problems in communication and social skills become more noticeable as the child lags further behind other children the same age. Some parents report the change as being sudden and that their children start to reject people, act strangely and lose language and social skills they had previously acquired. In other cases, there is a plateau, or leveling, of progress so that the difference between the child with autism and other children the same age becomes more noticeable.

A few years ago, MassMutual Financial Group partnered with Easter Seals Disability Services to conduct a study using consumer research company Harris Interactive. The result, “Living With Autism,”

was compiled to call attention to the ongoing and sometimes critical life challenges of families dealing with autism.

Statistics from "Living with Autsim" show that about 20 percent of 16-year-olds with ASD have looked for employment versus 75 percent of typical teens.

Consider these additional statistics. Parents of children with ASD are:

-- Four times more likely to fear their child won't have enough financial support after the parents die.

-- More than three times more likely to fear that caring for a child will cause their own retirement shortfall.

-- More than three times more likely to say the cost of current care is draining their current financial reserves.

-- Five times more likely to say the cost of care will drain their future financial resources.

My son has been deemed highly functioning, so many people don't even realize at first he's different. I pray he'll progress enough that he'll be able to get a job, attend college, live on his own, etc. But my husband and I have to prepare ourselves for the possibility that he won't.

That's why it's important for us and families in similar situations not only to think of his physical and emotional well-being, but also to arrange for his financial future while planning for our own.

"So many people don't even know where to start," said Sam Crossley, a special-care planner with MassMutual. "It's important to look beyond medical care and consider your child's financial well-being."

Crossley helps families assess their needs and navigate government regulations regarding assets and guardianship.

He told a story of a client who had a relative leave a large amount of money for the special-needs child in a will. Because people receiving Social Security

Insurance benefits can't hold property or other sizeable assets, the child had to go off SSI, exhaust all the funds and reapply.

"In essence, the gift was rendered useless," Crossley said. "It really ended up causing more headache and paperwork, although the intention was to help this child."

He suggests parents look for a financial planner with experience in setting up a Special Needs Trust and assigning guardianship.

"It's important to have the family's finances and assets managed in a way that will benefit everyone, including the special-needs individual," he said.

Crossley also offers these tips:

-- If your estate is large, you may want to establish trusts.

-- If your estate is modest, you may want to disinherit the person with a disability. That would ensure neither government benefits nor any inheritance will be jeopardized.

-- Find a life-insurance policy that can help fund financial strategies with living and death benefits.

"It can be overwhelming, but it doesn't have to be if you have the right team in place," Crossley said. "Someone who understands the regulations and keeps up with the changes will help you with short-term and long-term financial situations."

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