



Financial Planning Critical for Children with Special Needs

Posted: Sunday, May. 02, 2010, The Charlotte Observer

Guest Column Written by: Ryan F. Platt and Tom Nichols

As you drive around Charlotte, you may see the billboards that tell us "Every 20 minutes a child is diagnosed with Autism." Most of us have heard more and more about autism over the years. The reason for that is that in the 1970s only 1 in 2,000 people were diagnosed with autism, and now, according to the Center for Disease Control, it is 1 in 110 - a twentyfold increase.

What you may not know is the impact autism, and other special needs, have on the family, especially their financial outlook.

It is not uncommon for families to spend \$40,000 or more on therapies, medications and physicians each year to help their child secure a brighter future. The financial worries don't stop with those added costs. Easter Seals, the leading nonprofit provider of services for individuals with special needs, conducted a study in 2008 titled, "Living with Autism" which spotlighted the anxiety parents face regarding their child's future, and their own.

It found that:

88 percent of parents don't feel their children will ever be able to handle their own daily finances.

47 percent of parents worry that the financial drain will affect their ability to provide for other children.

Over 75 percent of parents are worried about their child's financial future after they are no longer able to care for them.

Those parents are also three times more likely to fear that caring for a child will cause their own retirement shortfall.

"Traditional" financial planning includes retirement, college education, life and disability insurance, long-term care planning, lifetime tax strategies, estate planning with the proper legal tools, plus daily cash flow management. Families with special needs children must plan for all these, but also have the added concern of providing for their loved one after they die.

They must consider:

Government benefits

A major component of planning for a special needs individual is maintaining the eligibility of Supplemental Security Income and Medicaid.

In 2010, the qualification requirements for these federal programs include that the individual cannot have nonexempt assets of more than \$2,000 and must earn less than \$1,000 per month of income. These rules can change every year, so families must stay current in order to qualify. These programs can provide hundreds of thousands of dollars over the lifetime of a person with special needs, but families' finances must be structured properly in order to qualify. If they are not, they will lose access to these benefits and their child will suffer the consequences.

Guardianship

Guardianship is critical and must be thought about in three distinct scenarios. First is if both parents die before their child is age 18.

The second is when the child reaches 18, the age under N.C. law that children are considered adults and capable of making their own legal and medical decisions. Children with severe developmental challenges are often incapable of making these decisions.

The third scenario is when the parents live to a ripe old age and then die, but their child is still alive and needs help with daily life. In all these cases, just naming a guardian is not enough; relatives have to go through the legal process of being named the guardian.

A very special trust

Many families establish a Special Needs Trust to provide income to their children throughout their lifetime. These trusts must supplement the government benefits that the individual is receiving. An incorrectly designed trust or the inappropriate use of trust assets may jeopardize eligibility for Social Security and Medicaid benefits.

Attorneys who are members of the Academy of Special Needs Planners or the Special Needs Alliance specialize in this area. We recommend a combination of a family member or friend as well as a corporate trustee to administer the trust. The corporate trustee is usually a bank or trust company.

Effective communications strategy

Open communication is necessary for the whole family, including grandparents and even friends, to be educated on the rules governing this type of planning so that they don't inadvertently provide a gift or inheritance in a way that destroys the parents' plan and jeopardizes those necessary government benefits.

An example would be a distant relative who leaves \$5,000 in their will to the special needs individual. Wanting to help, the relative has placed the special needs individual over the \$2,000 limit. This problem would have been avoided if the will stipulated that the money be left to the trust established by the parents to benefit the individual.

Get a structure

For many families, their concerns are overwhelming, the information is vast, and the knowledge is elusive. But like an Individualize Education Plan or a therapy plan, processes have been developed to help families navigate the emotional, legal and financial challenges to create the best possible life for their child with special needs.

Ryan F. Platt and Tom Nichols, CFP, are both Special Care Planners with Personal Strategy Group. Platt is also the founder of A Special Needs Plan at www.ASpecialNeedsPlan.com.