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WILL MY ADULT CHILD WITH AUTISM LIVE INDEPENDENTLY? ESTATE PLANNING FOR FAMILIES OF ADULTS WITH AUTISM SPECTRUM DISORDERS

According to the Centers for Disease Control, the prevalence of autism has increased by 6% to 15% annually since 2002, making autism the fastest-growing developmental disability in the United States.

While this trend may be alarming to young couples having children today, there are also families in our country right now dealing with the confusing prospect of providing for adult children with autism spectrum disorders. More than 3.5 million Americans currently live with autism and 35% of young adults (ages 19–23) with autism have not held a job or received any postgraduate education.

Doug, co-author of this article, is the father of an adult son (19 years old) with autism. Together, he and Megan wrote this article to help families understand that there are ways to provide for their autistic adult children without disqualifying those children from available government programs.

That is the heart of the issue: How can you help your child achieve a level of independence appropriate for him or her while also assuring that you keep all government assistance options available?

Your Help vs. Government Benefits

If you are a parent of an adult child with autism, you are likely looking for ways to help him or her today, and you also want to provide for your child after your death. However, there is a dilemma. If not carefully planned, gifts or inheritances from family members or friends can disqualify your child from eligibility for certain potential government benefits. Those benefits, though often modest in amount, may make the difference between your child living independently in adulthood, or remaining at home or possibly being institutionalized after your death.

For example, an adult child with autism often may meet the legal definition of “disabled”

such that he or she could be entitled to Supplemental Security Income (SSI) benefits. The purpose of SSI is to provide income for food and shelter. It was designed to provide recipients with approximately 75% of the threshold amount for the federal poverty cut-off. As of January 1, 2015, the maximum federal SSI monthly payment for an individual is $733. Many states provide a supplemental SSI benefit, which ranges from about $20 to $100 per month, depending on the state. In Wisconsin, the maximum supplemental SSI benefit is currently $84 per month, which makes the total maximum SSI benefit $817 per month for Wisconsin residents.

Some SSI recipients may be eligible for an additional SSI benefit if they have exceptional needs. These benefits are called SSI-E benefits. Exceptional needs generally means 40 hours per week of attendant care, including custodial care. In Wisconsin, for those who qualify, the maximum SSI-E monthly payment is currently $95.99.

While not exorbitant, these payments can help your adult child have some level of financial independence. But, here's the important part for parents to remember: There are strict limits on how much your child can earn and own and still be eligible for SSI. For example, the amount of your child's SSI benefit is reduced dollar-for-dollar by "countable income." This includes gifts or financial contributions (other than SSI) used by your child to pay for food or shelter. There is also a strict limit of how much your child can own and remain eligible for SSI. The asset limit is generally $2,000, with certain important (but limited) exceptions for necessary items such as a car, home, and certain other assets.

Unfortunately, this means that a well-intended gift or inheritance from a family member (such as you, or a grandparent) could result in your child being disqualified from receiving future SSI benefits. However, this dilemma can be avoided with proper estate planning, through which you can develop a comprehensive plan for your child's financial future. Many times, this estate planning involves creating a special needs trust, through which certain financial assistance can be provided without impacting your child's SSI eligibility.

Special Needs Trusts May Help You Achieve Your Goals

Special needs trusts (also called "supplemental needs trusts") (SNTs) have specific provisions pertaining to the needs of disabled beneficiaries. The purpose of an SNT is to preserve the beneficiary's eligibility to receive public benefits while supplementing his or her lifestyle with private funds in order to enrich his or her life. Usually, parents will set up an SNT during their lifetimes to benefit their disabled child after the parents pass away in order to ensure there are adequate funds available for the child's benefit, without worrying that such funds will disqualify the child from receiving public benefits.

Why Use an SNT?

An SNT may be used to retain and expend funds to supplement (not supplant) government benefits without rendering the beneficiary ineligible to receive them. Here are a few examples of expenses that a properly created SNT generally may cover for the benefit of your disabled child:

- Purchase of a residence.
- More sophisticated or advanced medical, dental, psychiatric, or psychological treatment, cosmetic surgery, rehabilitation, and educational or vocational services.
- Paying the differential cost for shelter between a shared or private room in a group home or nursing home.
- Providing entertainment, such as admission to museums and movie theaters, tuition for art courses, restaurant meals while away from his or her residence, cable television service, a computer with games and other software installed, a stereo or CD or DVD player, and tapes or disks.
- Paying for travel for recreation purposes.
- Paying for any services needed by the beneficiary to permit him or her to reside in his or her own home.
- Providing household furniture and furnishings.
- Paying for preparation of income tax returns and paying any income tax liabilities.
- Paying the expenses of a hobby.
- Paying for legal services to obtain, maintain, or regain eligibility for governmental or private agency benefits, to pay for any legal advice and consultation needed by the trustee to administer the SNT properly and to maintain public benefits eligibility.
- Paying for hair grooming and nail care services.
- Paying for writing supplies and postage.
- Purchasing and paying the costs of maintaining pets.
- Purchasing an automobile, including any modifications or special accommodations needed due to his or her disabilities, whether the motor vehicle is operated by the beneficiary or someone else for his or her benefit.
- Paying the costs of making the beneficiary’s living environment more amenable in light of his or her disabilities, whether or not the home in which he or she resides is owned by him or her or by someone else, or is a residence purchased by the SNT, or is a nursing home, or health care center, or community based residential facility.
- Prepaying for funeral and burial pre-arrangements for the beneficiary.

SNTs provide a very powerful financial vehicle to help you provide for your child. But, SNTs are just one estate planning tool you might consider.

If you have a child with autism or other disabilities, you must think strategically about how you might help provide for your child in a way that ensures he or she will be adequately cared for, especially after your death, without taking any actions that might disqualify him or her from receiving government assistance.

If you would like additional information, you may contact either Doug Dehler or Megan Harried at (414) 276-5000.