SPECIAL NEEDS TRUSTS

Planning for loved ones with disabilities.

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Disability, or special needs, affects nearly 1 in 5 Americans regardless of age, gender, race, ethnicity, religion, geography or level of wealth. In fact, there are approximately 56.7 million individuals – about 18.7% of the U.S. population – living with a disability in the United States, with over 12.3 million people (4.4% of those age 6 years and older) needing assistance with one or more activities of daily living (such as eating, bathing, dressing, continence and transferring.)[1] Disability is very diverse, covering a wide range of conditions from mild to severe. While many persons with disabilities successfully pursue personal, educational and professional endeavors, the potential economic impact of disability is well documented. As a group, persons with disabilities experience lower labor force participation (20.1%), compared to individuals without disabilities (68.1%), diminished lifetime earnings, and often incur increased expenses related to their disability.[2] As a result, disability may impact individual and household financial security and wealth planning needs.

It is crucial to have a long-term financial plan in place for parents of children with special needs or for children of (or others financially responsible for) adults with special needs. In this *Insights on…Wealth Planning: Special Needs Trusts*, we will focus on planning for children with special needs. Although many of the planning considerations are applicable to planning for adults with special needs, there are important differences that are outside the scope of this *Insights*. Planning for individuals with disabilities or special needs is highly complex and nuanced, and should involve financial, tax and legal advisors familiar with your particular circumstances and who are familiar with the needs of families of individuals with special needs to add perspective and guidance throughout the planning process.

A NOT SO UNCOMMON SCENARIO

As new parents, John and Mary Smith were delighted to welcome their son David into their family, who was soon followed by the joyful addition of his brother Michael. A secure financial future was a high priority goal for the family. Shortly after welcoming Michael into the world, John and Mary met with their advisors to update their financial and wealth transfer plans and to review their insurance coverage to ensure that they had sufficiently provided financial protection for their family should one of them become incapacitated or unexpectedly predecease the other.

Just prior to his second birthday, Michael was diagnosed with physical and cognitive deficits. A child with such a diagnosis would likely require speech and physical therapy, medical support and additional accommodations throughout his life. At only two years of age, the Smiths were uncertain whether Michael would be able to live independently or support himself financially as an adult. John and Mary understood that they needed a strategy that would allow them to meet their family's current and future lifestyle needs, provide for their children's educations, meet their own goals for retirement and, most importantly, Michael's (possibly extensive) lifelong needs. One of their greatest concerns was what would happen to Michael after their deaths.

A lifetime of care and support

Parents are often faced with the challenge of balancing their own current and future financial needs with those of their children. Particularly for children with special needs, parents are acutely aware that their child will likely require a lifetime of care and support, and that this could place a financial strain on the family's financial resources. Parents should be aware that there are extensive federal and state government benefits and programs that may be available to assist their child in the short and long-term. However, they may soon recognize the need to redesign their current wealth transfer plan to provide for their child's needs without jeopardizing the child's eligibility for such benefits and programs.

During infancy and throughout childhood, there are a variety of programs available to support children with special needs. However, when the child reaches adulthood, he or she will begin to "age out" of certain programs. As the child reaches majority, it is the right time to reconsider the child's long-term financial needs and to determine whether he or she will be able to achieve financial or personal independence at some point in the future.

Once the child's potential needs are evaluated, the family should structure a financial plan and identify resources to meet their needs, understanding that the actual needs may be more or less than projected. Although government benefits play an important role in providing foundational support to meet basic needs, parents often desire to maximize the child's available resources in order to provide an increased level of services and standard of living for their family member with special needs. It is important to understand the need to do so appropriately so as not to jeopardize the government support available.

Government-sponsored programs are important sources of financial support

In order to best plan for supporting a child with special needs, parents must first determine what government benefits the child is eligible for and whether the child is covered by the parents' health insurance (and for how long). Children with special needs may qualify for state specific or federal benefits. These programs can provide considerable long-term economic value to the child and their family providing financial resources to meet disability expenses, medical care and help offset reduced or lost earnings throughout the child's lifetime. Once health coverage and program eligibility is determined, parents can then determine what will need to be paid for out-of-pocket. The following non-exclusive list of government-sponsored benefits may be available.

- **Supplemental Security Income**

  Supplementary Security Income (SSI) is an important means-tested (need-based) government benefit program for individuals and children with disabilities (as defined), who have limited income and limited resources. SSI provides a modest monthly stipend which most states supplement to meet basic needs such as food and shelter. For 2017, the SSI amount for a single person is $735 per month and $1,103 per month for a married couple. The basic SSI amount will be the same no matter which state the individual lives in, but the total benefit may vary due to variations in state benefits.

- **Medicaid**

  Medicaid is a joint federal and state funded medical payment program that provides medical assistance to individuals who are aged, blind or disabled (as defined) with limited income and resources and who meet certain eligibility requirements. Medicaid pays for essential medical costs, including hospital bills and physician services. Medicaid is a state administered program, and eligibility depends on an individual's state of residency.

  Like SSI, there is a cap on the amount of monthly income an individual can receive in order to qualify for Medicaid. The monthly income cap is limited to three times the monthly SSI benefit level. States can set an income threshold of less (but not more) than this amount.

SSI and Medicaid eligibility: countable income and assets

Many are surprised to learn what constitutes "income" for purposes of SSI and Medicaid eligibility. All of the child's income, whether taxable or not, is countable income. Income is defined by the SSI regulations and includes any cash, goods or services used for daily living expenses. Income includes, but is not limited to, the following:

- Social security
- Interests and dividends
- Wages and earnings
- Disability income
- Trust income
- Gifts from family members and others

Also like SSI, eligibility for Medicaid depends on the value of an individual's countable assets. Countable assets include anything of value owned by the applicant that is not exempt by law or otherwise made inaccessible. SSI and Medicaid applicants are permitted to retain a small amount of countable assets, but the amount varies from state to state. However, most states set a $2,000 asset limit for unmarried individuals.

Government programs provide only the most basic financial support and healthcare coverage, and require that the child have few financial resources of their own. These programs provide critical financial support amounting to a considerable financial benefit over the individual's lifetime that cannot be replicated elsewhere. If eligible, government programs can play a significant role in helping offset the family's financial responsibility for a child with special needs. As an example, the out-of-pocket cost of raising a child with autism is estimated to cost a typical family between $1.4 million and $2.4 million over the course of the child's lifetime.[3]

Providing more while maintaining eligibility

Parents may face challenges in trying to simultaneously provide for their child's financial needs while maintaining the child's eligibility for government benefits. Parents are encouraged to examine their own wealth transfer plan with financial, tax and legal advisors familiar with special needs planning to ensure that the parents' plan will not disqualify their child's eligibility for these important programs. Traditional wealth transfer planning may not result in desired outcomes for a child with special needs. Consider the following examples:

> ***Example 1:*** John and Mary plan to leave all of their assets outright to Michael. This is not ideal as Michael would likely be disqualified from government benefits by exceeding the maximum value of countable assets, assuming the value is in excess of $2,000. Leaving the assets directly to Michael could also place those assets at risk of creditors or other claimants. Furthermore, Michael may not have sufficient legal capacity or knowledge to manage the assets.
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> ***Example 2:*** John and Mary plan to disinherit Michael. This would leave him without support if federal and/or state-funded government benefits are reduced or eliminated.
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> ***Example 3:*** John and Mary plan to leave all of their assets to another family member, such as a sibling, so that person may provide for Michael's long-term care. This will place complete and total responsibility on the other family member with a "moral obligation" to use the funds for Michael's care, but there will be no legally enforceable duty to act in his best interests. There is no guarantee that resources will

be used for Michael's care and support, and the assets earmarked for that purpose could be put at risk of creditors or other claims, such as in the event of divorce.

Example 4: John and Mary plan to leave all of their assets to a discretionary support trust for the primary purpose of caring, supporting and benefitting Michael. This type of discretionary support trust will be a countable asset and will likely result in disqualification from any need-based government benefits.

These traditional wealth transfer plans do not achieve the intended result: to give supplemental financial support to a child with special needs that is in addition to, and not instead of, the government benefits that would otherwise be available. Fortunately, there is a special type of trust – a special (supplemental) needs trust – that may be able to achieve this goal without disqualifying the child from government programs.

Special (Supplemental) Needs Trusts

A special needs trust ("SNT"), also known as a supplemental needs trust, is a special type of trust by which parents (or loved ones) are able to provide for the needs of an individual with special needs without jeopardizing his or her eligibility for government benefits. Unlike other types of trusts often used in traditional wealth transfer planning, the primary goal of an SNT is to provide for the child's special needs throughout his or her life. Assets held in a properly structured SNT do not count toward eligibility calculations for public benefits. Additionally, while government benefits provide many basic necessities to individuals with special needs, many parents want to provide a higher quality of life for their child without disqualifying the child from future government benefits. An SNT can help achieve these goals, providing supplemental care and services to children with special needs.

SNTs come in two basic varieties: third-party and self-settled.

1. **A third-party SNT** is established with funds that belong to someone other than the child (the "beneficiary") such as the parents' assets, grandparents' assets, gifts from family members, life insurance proceeds, etc. The trust can be created during the parents' lifetime (inter-vivos) or at their death (testamentary). The primary purpose of the trust must be to s*upplement*, not supplant, state and federal benefits. Assets held in an SNT are not considered to be "available" to the child for determining the child's financial eligibility for government benefits. Assets remaining in the trust after the child's death can be distributed to any beneficiary as provided in the trust instrument.
2. **A self-settled SNT** is established with funds owned by the child. For example, a self-settled trust might be established using a personal injury award or outright inheritance. Without proper planning, an inheritance or personal injury award to the individual with special needs can result in disqualification of means-tested government benefits.
    a. One type of self-settled SNT is a **qualified self-funded SNT**, also known as a (d)(4)(A) trust. A qualified self-funded SNT must meet the following conditions, as provided by 42 U.S.C. § 1396p(d):
        i. The recipient of public benefits must be less than sixty-five (65) years old at the time the trust is established.
        ii. The special needs trust must be established by a parent, grandparent or guardian of the recipient of public benefits, or by a court.
        iii. The special needs trust must be irrevocable.

iv. The trustee of the special needs trust must have sole and absolute discretion over the use of the trust funds for the sole benefit of the recipient of public benefits. This means that the trust must be worded so that the trustee is not required to make any payments of income or trust principal directly to the recipient of public benefits.

v. The trust must include a provision that states that any funds remaining in the trust at the death of the trust beneficiary (the recipient of public benefits) will reimburse the State for its Medicaid costs on behalf of that trust beneficiary since the trust's inception.

b. Another type of self-settled SNT is the **qualified pooled trust**, also known as a (d)(4)(C) trust. This kind of trust is established through a joinder agreement and managed by a nonprofit organization. This type of trust may also be established by the disabled person him- or herself. Separate accounts are maintained for each trust beneficiary, but funds are pooled for investment and management purposes. Upon the beneficiary's death, the nonprofit organization receives assets remaining in the trust, and will reimburse Medicaid for benefits paid to the beneficiary. In some cases, surviving family members may be entitled to receive some or all of the remaining funds.

Funding the SNT

Special needs trusts are commonly established, but not funded, while the parents are alive. Upon the parents' death, transfers will be made to the child's SNT instead of to the child outright or other type of trust for the child's benefit. An SNT can also be the designated beneficiary of particular assets, such as employee benefit plans and life insurance policies. SNTs may be funded using:

- Inheritance and/or gifts from family members
- Life insurance
- Cash
- Investments, such as stocks and bonds
- Retirement plan benefits
- Personal and real property
- Business interests
- Proceeds from a personal injury settlement

Life insurance is frequently used to fund a third party SNT (often via an irrevocable life insurance trust), using proceeds from a life insurance policy on one parent (single life), or both parents (second-to-die policy).

Distributions from SNTs

The assets of an SNT can be used for almost any purpose that is not illegal or contrary to the terms of the trust. Distributions cannot be given directly to the child with special needs and must be used in such a way so as not to jeopardize their eligibility for government benefits. However, the trust's assets cannot be used to pay for items or services that government benefits will otherwise cover; the SNT must *supplement*, not supplant, the government benefits.

While the primary purpose of an SNT is to provide a higher quality of life for the child, trust funds can be used for a variety of purposes including: additional physician visits over the Medicaid limit, cable television and internet, computer software training and repairs, dental work, eyeglasses and hearing aids, entertainment, furniture, haircuts, health club membership, home purchase and maintenance, college tuition and other instruction, private counseling, rehabilitation and physical therapy and vacations, just to name a few.

The important role of the trustee

An SNT must have a trustee, who can be an individual or an institution. The trustee's duties include administering the trust and managing its assets in accordance with the terms of the trust document and to further the objectives of the trust. Selection of the trustee is very important as the trustee will have sole discretion over distributions of the trust income and principal for the benefit of the special needs child.

The ideal trustee should know the child and have an understanding of his or her needs, preferences and family history. The trustee should understand the government benefit programs and the effect the trust distributions will have on the child's eligibility for government benefits. Additionally, income, gift and estate tax implications must be considered in administering an SNT. Due to the complexities, the trust creator will usually name a professional trustee, such as an attorney or financial institution, as the sole trustee or as co-trustee with a family member.

CONCLUSION

Special needs and disabilities involve a wide range of conditions and changing circumstances, and the individuals they affect have varying resources and levels of wealth. Planning around uncertainty can be very challenging, especially where children are concerned. Families should revisit their financial and wealth transfer plans periodically, taking into consideration the potentially evolving needs of a child with special needs. An SNT can enable families to provide the desired support that a child with special needs may require throughout his or her lifetime.

Planning for special needs is highly complex and technical, and the laws that govern SNTs differ from state to state. Errors can be very costly for children with special needs who may not be able to care for themselves in the near or long term. Special needs trust planning should involve financial, tax and legal advisors who are familiar with the planning needs of families of individuals with special needs.

In our example, John and Mary worked with their advisors to review their personal circumstances and long-term goals for their family. As a result, a comprehensive financial and estate plan was developed which included the establishment of a special needs trust for their son Michael's benefit, to provide supplemental resources, while maintaining access to means-tested government benefits. John and Mary had peace of mind, knowing that a plan was in place for their family, which included provisions to provide resources and enhance the quality of life for their son.

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[1] U.S. Census Bureau, Current Population Reports, Americans with Disabilities: 2010, Table 1 (July 2012).

[2] U.S. Department of Labor, Bureau of Labor Statistics, Current Population Survey and Current Employment Statistics Survey (CES); News Release, 'The Employment Situation – December 2016,' USDL-17-0004, released January 6, 2017; Table A-6, Employment status of the civilian population by sex, age and disability status.

[3] Autism Speaks, Lifetime Costs of Autism Average $1.4 Million to $2.4 Million (June 2014).