

PLANNING FOR A FAMILY MEMBER WITH SPECIAL NEEDS

Did You Know?

- Approximately one of every seven children under 18 years of age, or 14 percent of children in the United States, has a special health care need. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chart book 2005–2006. ⁱ
- There are approximately 10.2 million children with special health care needs in this country (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chart book 2005–2006. ⁱⁱ
- 12.9% of females and 11.8% of males in Georgia, of all ages, have a disability. ⁱⁱⁱ
- 62% of parents who have children with Special Needs have no plan to cover their child’s expenses when they are gone. ^{iv}

This is the first of a four part series with the following objectives:

1. Understand the essential planning needs that every family trying to secure the future of an individual with special needs should undertake.
2. Reduce the risk of unintentionally disqualifying an individual with special needs from available means-tested public benefit programs.
3. Describe the different kinds of Special Needs Trusts, trustee’s roles and responsibilities
4. Review funding sources for Special Needs Trusts.

Part I:

What is Special Needs Planning?

Special Needs Planning is designed to improve the quality of an individual’s life by securing his or her financial future without disqualifying the individual from eligibility for means-tested government benefits.

Who Should Implement Special Needs Planning?

Any individual who is “disabled” by virtue of a condition such as Down Syndrome, Autism, mental illness, brain injury, Alzheimer’s and/or Cerebral Palsy, should implement Special Needs Planning. “Disabled” is defined by reference to a person’s inability to perform any “Substantial Gainful Activity.”

Is Special Needs Planning Just for Families of Modest Means?

While families of modest means most certainly can benefit from Special Needs Planning that preserves eligibility for various government programs, even families of great wealth are engaging in Special Needs Planning for their children and other loved ones with disabilities. Most families, however wealthy, do not believe that any amount of personal resources will be sufficient to fund the cost of their loved one’s lifetime needs.

Some of the Biggest Challenges:

Health Care Issues

What are some of the health care challenges someone with Special Needs faces?

- Obtaining affordable and comprehensive health insurance coverage. Many therapies and treatments are not covered even by costly insurance.
- Navigating the healthcare system, and finding providers that will accept the individual's insurance, is time-consuming and frustrating.
- Finding qualified "allied professionals" to implement the complex Special Needs Plan.

While many individuals with special needs do have health insurance, it is often inadequate because of coverage limitations, annual or lifetime caps, or limited acceptance by providers, resulting in high out-of-pocket expenses or not receiving the necessary care.

Employment Issues

Should my family member with special needs try to get a job?

85% of individuals with a disability are unemployed. The earned income from a job, even nominal income from a "supported employment" arrangement, must be weighed against the potential loss of government benefits. Arranging transportation to and from a job is often as challenging as obtaining the employment. Many employers are unaware of tax credits and other incentives for hiring individuals with special needs.

Access to Government Benefits

I have heard it can be complicated to access government benefit programs; why is that?

The age of adulthood for transitioning from school -provided services to government -provided services varies from state to state, from age 18 to age 25. Parents must collaborate with school administrators while their children are still in high school to develop a meaningful transition plan. Qualifying for Medicaid and Supplemental Security Income (SSI) will be covered in a future installment of this series.

Does my child really need to be eligible for Medicaid if he or she has good private health insurance?

Many of the families who do Special Needs Planning to preserve their child's eligibility for Medicaid do have other health insurance available for their child. Many families have multiple tiers of health insurance coverage for their child with special needs, including (i) group health insurance through a parent's employer, (ii) a private health insurance policy under the auspices of the Affordable Care Act (a/k/a Obamacare), and finally (iii) Medicaid. Medicaid is always the health insurer of last resort. However, the Medicaid program also provides critical home-based and community-based support services that enable a person with special needs to live in the community rather than be institutionalized. These programs are known as Medicaid "waivers," and are not available under traditional health insurance policies.

What are Medicaid waivers, and what types of services do they provide?

Each state has various types of "waiver" programs that are designed to support persons with developmental or intellectual disabilities, or closely related conditions. Support services could include weekly visits by a caregiver to assist with light housekeeping, grocery shopping and other household

chores; day programs designed to provide fulfilling and enriching activities; supported and customized employment opportunities; transportation and vehicle adaptation services; congregate living options; and the services of certified nursing assistants or registered nurses for complicated medical tasks performed at home. Typically, these types of “waivered” services in a person’s home are not covered by traditional health insurance coverage, whether through an employer or the Affordable Care Act.

Continuity of Care

How can I secure my child’s future when I, as his or her primary caregiver, become disabled or die?

Providing an “instruction manual” for future caregivers is essential, including your child’s likes, dislikes, routines, and behaviors, as well as a detailed list of his favorite friends, relatives, medical professionals, and community groups that have provided meaningful support to your child. Keep this updated as your child develops and ages.

Assembling a team of “allied professionals” to manage your child’s care is a critical aspect of Special Needs Planning even while you are still capable of handling this care.

Determine which family members will play a role in providing care and oversight for your child, share your instruction manual with them and discuss the steps that must be taken when you are no longer able to manage this for your child.

Financial Support

Individuals with Special Needs usually require a lifetime of financial support. Establishing eligibility for government programs can be challenging without the assistance of experienced professionals.

Establishing your child’s eligibility for government programs and benefits should be a priority as soon as he attains 18 years of age. Life insurance is often used to supplement personal savings to fund the expense of your child’s care and other special needs. This subject will be covered in more detail in one of the next installments of “Planning for a Family Member With Special Needs.”

In the meantime, if we can help any way or answer any of your questions, please feel free to contact us at:

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ⁱ Rockville, MD: U.S. Department of Health and Human Services, 2007

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ⁱⁱⁱ 2013 Cornell University Disability Statistics

^{iv} 2009 Hartford Study