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*A Legal Safe Haven for Parents of Children with Disabilities.*

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## **Your Child with a Disability: Safeguarding Their Dignity and Quality of Life**

by Gregory P. Hawkins, JD

You have spent a lifetime nurturing and protecting your child with a disability — his or her lifetime. Preserving a similar level of care after your death is a priority, now, before the opportunity slips away. Inaction is not an option.

Suppose a mother and father leave a modest estate of \$100,000 to their two adult children — \$50,000 from the equity on their house and \$50,000 from a small insurance policy. The first child pays off her credit card debt, pays down her mortgage a bit and splurges on a cruise to Alaska, the remainder goes to savings. As an adult the money is hers to spend as she chooses.

What about the sibling with a disability? All government assistance abruptly halts because he now has assets in excess of \$2,000 — the government ceiling. These include housing, food, medical programs and, essentially, all other assistance allowed by law. Once his inheritance evaporates and his assets fall below \$2,000, family members and disability advocates can begin, again, the slow and laborious process of reacquiring government benefits.

Fortunately, forward thinking lawmakers have established laws to insure that a special estate planning instrument can protect the basic physical needs you provided for your child during your life — the Special Needs Trust (SNT). In many ways it is similar to the typical Family Trust or Living Trust in that it protects assets, avoids probate and establishes specific guidelines for the disbursement of your estate.

In other ways, it is fundamentally different. The wording must be exact to comply with current law. All Special Needs Trusts are scrutinized by the Social Security Administration and state Medicaid administrators. A few misplaced or missing phrases could prove disastrous and invalidate your careful planning.

The two primary government benefits are SSI (Supplement Security Income) and Medicaid. Of the two, the most important is Medicaid. In Utah, the maximum, monthly SSI payment is \$623 for a non-blind, single person.

Under the best of circumstances, SSI cash benefits for Americans with disabilities provide bare essentials — shelter, food and clothing. We all recognize that life is more than these minimal requirements. When living parents care for their children they provide the extra things that define quality of life. After their deaths, special needs trusts have proven a viable vehicle to continue this support.

In fact, special needs trusts must be designed, specifically, only to supplement government benefits. They cannot replace or supplant government programs. If the trust distributes money directly to the person with a disability the SSI payment will be reduced.. A third party (the trustee) is chosen by you to pay for goods and services for the person with disabilities.

The trustee of the special needs trust can pay for the purchase of goods and services that add pleasure to life (videos, furniture, a television); essential dietary needs; materials for a hobby or recreation; eyeglasses; out-of-pocket medical and dental expenses; trips, vacations and entertainment (a movie, ballgame or concert); transportation (including a vehicle purchase); insurance; rehabilitation; etc. These are items and services that you provide as living parents; with a special needs trust you can still provide them after your death.

The special needs trust is not a legal loophole. It is a legitimate estate planning tool, carefully defined by lawmakers. The SNT can allow you to continue to provide for your child's needs in the way you have provided during your life and avoid the possibility that your child with special needs simply will be "warehoused."  
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