

Your Special Needs Child: Safeguarding Their Dignity and Quality of Life

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You have spent a lifetime nurturing and protecting your special needs child — 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 \$2000 — 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 \$2000, family members and special needs advocates can begin, again, the slow and laborious process of reacquiring government benefits.

Fortunately, forward thinking lawmakers and regulators have established rules 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 and agency rules. All Special Needs Trusts are scrutinized by the Social Security Administration and state Medicaid agencies. A few misplaced or missing phrases could prove disastrous and invalidate your careful planning.

A recurring criticism of special needs trusts inevitably arises among those who misunderstand the mechanism of the SNT. Is it fair for a citizen with disabilities to access government benefits after receiving a substantial inheritance?

Under the best of circumstances, government cash benefits for special needs Americans provide bare essentials — shelter, food and clothing. We all recognize that life is more than these minimal requirements. When parents are able to care for their children they provide the extra things that define quality of life. After the parents' 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. They cannot distribute assets directly to the person with a disability. A third party is chosen 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 (like 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 and regulators. The SNT can allow you to continue to supplement your child's needs in the way you have during your life and to avoid the possibility that your special needs child simply will be "warehoused."