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## What You Need to Know About Special Needs Trusts

by [Sheryl Nance-Nash](#)

For the parents of a child with special needs, concerns about their child's health, well-being and future financial security are magnified, especially if the child may need continued special care and support well into adulthood. It is essential that parents engage in a planning process so that the needs of the child and other family members are met.



A carefully structured Special Needs Trust (also called a Supplemental Needs Trust) is an important cornerstone in special needs planning.

Here's what you need to know.

Over the last decade, estate planning techniques have changed, based on emerging, federal and state legislation, and shifting threshold levels of taxation and net worth. "It is imperative that parents of a child who has special needs have a plan in place, regardless of the size or value of their estate," says Dan Cornwell, president of Cambridge Consulting Group.

While parents are typically the primary caregivers of a child with special needs, what if one or both parents die or become disabled? Other family members may be thrust into the role of primary caregiver, whether they're ready or not. If something happens to the parents, who will become the new primary caregiver? Is that person prepared to provide emotional support and actual physical care? Are there financial resources or financial assistance. These are just some of the questions to be considered, says Cornwell.

### **Why a Special Needs Trust is critical**

A Special Needs Trust permits distributions to a child with special needs to supplement, but not replace, monies available through government assistance. If any trust other than a Special Needs Trust was utilized, under the laws of most, if not all states, the child would be ineligible for Medicaid and Supplemental Security Income (SSI), says Lori Wolf, a member of the law firm Cole Schotz, who specializes in estate planning and special needs planning. The trust is also important to ensure that a trustee selected by family is named to invest trust assets and make trust distributions in the best interests of the child.

"A disabled person can have assets/and or income set aside to pay for any expenses over and above what public benefits will cover without jeopardizing his or her eligibility for public benefits. Also, assets are managed by a trustee and not the disabled person," says Ronald Fatoullah, an attorney with Ronald Fatoullah & Associates, which specializes in elder law, explaining a Special Needs Trusts' chief benefits.

### Avoid pitfalls

As vital as Special Needs Trusts are, there are challenges. For example, when a self-settled trust is used for a disabled person under the age of 65, a parent, grandparent, guardian or a court must establish the trust for the disabled person to avoid certain Medicaid issues. Therefore, if the disabled person does not have a parent, grandparent or guardian, the court must be involved, points out Fatoullah. "Sometimes, it is difficult to find a reliable trustee," he adds.

There is no shortage of caveats. While the trust can own a house where the child lives, however the child must then pay rent for use of the home to ensure that the trust is not funding the child's housing needs, says Wolf.

Another example is if the child moves, the trust will need to be re-evaluated. "A Special Needs Trust should be reviewed with an attorney of the other state to be sure that it will be acceptable in that state as well," says Fatoullah. Although Medicaid and SSI are federal programs, they are administered by states and each state has its own set of requirements of what must be included in a Special Needs Trust, says Wolf.

In the event of a divorce, child support to a child with special needs after age 18 should pass to a Special Needs Trust to preserve the child's eligibility for government assistance.

Be sure that retirement plan assets and life insurance are coordinated with the Special Needs Trust. "I often see that families prepared the right form of trust, but neglected to change the designated beneficiaries of retirement plan accounts and life insurance to ensure that the share of the child with special needs is allocated to his or her trust," says Wolf.

Trustees of Special Needs Trusts must be careful about what is paid from the trust. The trust will document acceptable payments to be made for the benefit of the disabled person. Trustees are fiduciaries, and must act in accordance with the trust agreement and in the best interests of the beneficiaries, says Fatoullah.

What should top your to-do list though, is to consult an attorney who has expertise in Special Needs Trusts to be sure that the trust is drafted properly in conformity with state law.

Know too, that there are two kinds of Special Needs Trusts. A third party trust is funded by assets gifted to or bequeathed to the trust for the benefit of the child. The other, a first party trust is funded with the child's own assets, including assets in the child's name or assets paid for the child through a medical malpractice claim or other such claim. A first party trust has many more onerous requirements than a third party trust, says Wolf. One example, she says, is that there must be a reimbursement for many of the government benefits provided to the child with assets that remain in the trust at the child's death. Assets gifted or bequeathed for a child should not be contributed to a first party trust and the child's own assets should not be contributed to a third party trust.

Make no assumptions. Some families choose to disinherit a child with special needs to ensure that they are not disqualified from receiving benefits. Bad idea says Wolf. "I strongly discourage that. The parents assume that their other children will care for the child with special needs. There are many reasons they may fail to adequately protect the child with special needs," warns Wolf.

Do not keep the trust secret. Let the extended family know of its existence to ensure they coordinate gifts and provisions in their will for the benefit of the child to leave anything passing to the child to the child's Special Needs Trust.