

# Trusts for Children with Disabilities

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Some parents of children with disabilities can be hopeful that their children will grow up to be financially independent and eligible for adequate and affordable health insurance. Unfortunately, for many children with disabilities, this outcome is unlikely. In fact, many capable adults with disabilities are underemployed and/or ineligible for health insurance due to preexisting conditions; others are unable to qualify for well-paying jobs. For these individuals, Medicaid becomes the only option for health care coverage.

While there are state-to-state variations, individuals with assets of as little as \$2,000 may be excluded from Medicaid coverage. Unless these laws change, parents who hope to provide financially for their child and ensure that he or she will receive adequate health care must find ways to avoid conflicts with Medicaid eligibility rules.

## Trusts

Some type of trust is typically the best way to manage property for the benefit of a person with a disability, because the trustee (the person designated by the will to manage the trust) can be given the necessary discretion and flexibility to cope with the beneficiary's special circumstances. However, most trusts are considered "resources" under Medicaid regulations, which state that "resources are considered available both when actually available and when the applicant or recipient has a legal interest in a liquidated sum and has the legal ability to make such a sum available for support and maintenance."

To prevent governmental claims for reimbursement of benefits paid to the individual with a disability, and to prevent the individual from being disqualified from receiving government benefits, a trust established for the benefit of a person with a disability must be set up in such a way as to avoid being considered a resource. The language used in drafting such a trust is essential; for this reason, it is crucial to find an attorney who has experience in estate planning for children and adults with disabilities. (For more information on finding an appropriate attorney, see "Estate Planning: Getting Started," December 1995.)

## The community trust

"Community trusts," which are nonprofit organizations that pool resources for the benefit of people with severe disabilities, may be an option for some families. Community trusts address two major concerns for parents of children with disabilities—preservation of assets and selection of a knowledgeable trustee. A community trust ensures that a beneficiary's interest in the trust will not be considered a resource and protects that interest against claims by creditors. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as trust fund administration, advocacy (for example, participation by community trust representatives in the development of individualized service plans) and/or guardianship.

Currently, only certain states allow the establishment of community trusts. Furthermore, because these trusts are a relatively new concept, we have no long-term data on their success.

## The special needs trust

A "special needs trust" (SNT) gives the trustee absolute discretion to spend trust assets for expenditures that are not covered by public assistance programs. In an SNT, income and principal are alternately used to pay for supplemental or "extra" items that will enhance the beneficiary's quality of life—vacations and field trips, traveling companions, entertainment, medical and dental treatments that are not otherwise covered, social services and transportation. In essence, the SNT is a backup fund intended to supplement, but not replace, public assistance. Thus, care should be taken to prohibit the trustee from spending trust assets on necessities such

as food, clothing or shelter—all of which are currently covered by government assistance programs.

The SNT must be carefully drafted to prevent governmental claims for reimbursement of benefits already paid to the beneficiary, and to prevent the beneficiary's disqualification from receiving future benefits. In addition, the parents' will should provide for an alternate plan to deal with a governmental attempt to "break" the trust (by bringing a lawsuit against the trustee in an effort to force trust assets to be treated as "resources"). In that event, for example, the trustee may be directed to terminate the trust and distribute its proceeds to other relatives, if any, or to an alternate beneficiary (an individual, private foundation or community trust, if one is available) who will use the funds in the best interests of the beneficiary.

#### **Other considerations in drafting the SNT**

The SNT can also require the trustee or another person to make periodic evaluations of the beneficiary's care and needs, including evaluations of facilities where the individual lives or receives treatment. The trustee may also be required to consult state and federal agencies to ensure that the beneficiary is receiving all the benefits to which he or she is entitled.

Most SNTs should also include a "spendthrift clause," which prohibits the beneficiary from selling or giving away his or her interest in the trust. In most cases, this clause will also protect trust assets against claims by creditors.

Finally, it is essential that the SNT provide for dispersal of trust assets following the beneficiary's death. Even if there are no surviving relatives, the estate planner must designate a final repository for trust assets. Parents may consider empowering the trustee to make distributions to a community trust, should that option become available. But in no case should trust assets pass to the beneficiary's estate because this would make the assets liable to claims by creditors.