

# Setting Up a Special Needs Trust

Medical advances, an aging population, a changing political scene and the increase of conditions such as autism are combining to produce a growing need for a particular type of estate planning tool -- the special needs trust.

For example, an aging couple whose adult son has severe autism might want a special needs trust because they are worried about how the child will survive after the parents' deaths. Or a group of siblings may want to set up a special needs trust for their young sister, who is a teenager, but expected to need supervision for the rest of her life.

Many people depend on government benefits, such as Social Security, Medicaid, rehabilitative care and transportation assistance, which are available for children and adults with special needs. However, these benefits can be slashed if an individual's assets exceed a certain level. This can be an amount that is so low that the disabled person cannot live a comfortable existence without additional assistance. If loved ones give the individual too much money, or provide assistance in a way that breaks the rules, the person could lose benefits. This is a trap many families fall into because they view financial planning as too time-consuming and taxing — considering they're already stressed taking care of loved ones with special needs.

A special needs trust allows parents (and others who care about someone with a disability) to comply with government regulations, yet invest and save money to meet a disabled individual's financial needs.

In most cases, a special needs trust is a "stand alone" document, but it can be part of a Will. Assets in a special needs trust aren't considered countable assets for purposes of qualification for certain governmental benefits based on need. (Disqualification from government benefits could occur if an individual's assets hit just \$2,000 and their annual income reaches \$10,000.) Parents and others can also bequeath assets to the trust, rather than directly to the individual.

Funds in a special needs trust provide for supplemental care beyond what the government provides, including expenses such as utilities, medical care, special equipment, education, job training and entertainment. A special needs trust does not belong to the person with a disability, but is established and administered by someone else. The person with the disability is simply nominated as a beneficiary and is usually the only one who receives the benefits. The trustee is given discretion to determine when and how much the person should receive.

Many factors must be taken into consideration including assets and debts; estimated spending; life expectancies of the parents and children; and costs of care. In estimating the necessary size of a trust, one popular method is to estimate an individual's yearly budget and divide by the Consumer Price Index. Planners then determine additional funds that are needed by taking into account the current medical diagnosis and other factors.

The trust must be carefully worded and show clearly that it:

- Is established by the family (persons other than the individual with the disability).
- Is managed by a trustee (and successor trustees other than the person with the disability).
- Gives the trustee the absolute discretion to provide the assistance required.
- Never gives the person with the disability more income or resources than permitted by the government.

The trust wording should also define what is meant by "special needs." It should spell terms related to the unique needs of the disabled person; provide instructions for the individual's final arrangements; determine who should receive the remainder of the trust after the person dies; provide choices for successor trustees; and protect the trust against creditors or government agencies.

Overall responsibilities of trusteeship include:

- Understanding the beneficiary's situation and needs, doing inventory of trust assets, maintaining records for income and principal transactions, and preparing periodic accounting.
- Filing federal and state fiduciary income tax returns, obtaining IRS tax registration for the trust, and establishing accounts for the management of trust assets.
- Monitoring disbursements, hiring and regularly monitoring agents and service providers, communicating with the beneficiary and service providers, and assisting in emergency situations to preserve the beneficiary's lifestyle.

Consult with your estate planning attorney about a special needs trust. Knowledgeable advisors are vital in making sure a trust complies with all regulations. Your attorney can also facilitate communication among family members in emotionally-charged situations.

### **Other Issues to Consider:**

- When planning, take into account the parents' ages. For example, parents in their thirties with an special-needs newborn, may turn to a special needs trust, while older parents and guardians may instead use life insurance, such as second-to-die policies.
- A letter of intent should be prepared detailing the special needs of the individual including the past and present situation, relevant information about hospitalizations, medical history and medication. Include all pertinent information needed to enable future care to be effective.
- Parents should pick a back-up guardian in their Wills. Other positions to fill may include limited guardianship and powers of attorney.
- Consider making two family members joint trustees — rather than naming one sibling. Have trustees meet periodically to alter plans as available assets, benefits, and other needs change. Professional trustees, such as accountants, attorneys or investment advisors, may be the best answer.

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