

When a child has special needs

An overriding concern for the parents of a disabled child is likely to be the child's care once they are no longer available to offer financial and emotional support. "Care" encompasses a broad spectrum: where the child will live, who will manage his or her financial and personal affairs, as well as who will see to special medical and treatment needs.

Selecting a guardian

Parents are the natural guardians of their children only until they reach majority (generally age 18). The fact that a child is disabled and all decisions regarding the child rest with the parents will not change the fact that upon reaching majority, he or she is presumed to be competent.

Agreements among family members will not give anyone formal authority to act on behalf of a disabled child. Thus, if a child is not self-sufficient, it may be necessary to institute formal guardianship (conservatorship) proceedings.

Parents, of course, are the natural choice to serve as legal guardians. But what about the future? In whose care should the child be left? Sensitivity and the willingness to care for the disabled child should be prime characteristics. But other factors should be considered: the ability of the person chosen to handle financial and legal matters; availability to continue as guardian for the long term; and whether or not the chosen individual can devote the time necessary to care for the child.

There are two kinds of guardians, usually referred to as *guardian of the person* and *guardian of the estate*. The former makes decisions as to where the disabled child lives and sees to medical treatment, education, vocational training and other personal matters. The latter is charged with preserving the disabled child's assets and managing his or her financial matters. Although it is perfectly acceptable to choose one person to act in both capacities, one person may not fit the bill. Naming coguardians is a perfectly acceptable alternative.

Choices: bequests to a disabled child

When drafting their wills, parents have several options in deciding how to provide for the disabled child's financial future.

Of course, they can choose to make a direct bequest to their child. However, this choice will most likely disqualify the disabled child from receiving government aid. This choice is, for most people, the least desirable—unless they have the wealth available to make certain that there will always be sufficient funds to care for the child without the need to resort to government assistance.

Another choice is to leave the disabled child's portion to a sibling or other close relative with directions that the portion be used for the child's care. This approach is viable when there are family members who are close to the disabled child and are capable and willing to use the funds that they receive for the child's benefit. However, it must be kept in mind that such a bequest in no way obligates the family member to actually use the funds for the child. This kind of bequest establishes, at most, a moral rather than a legal obligation.

Another choice: the special needs trust

Today many parents establish what is commonly referred to as a *special needs trust*. When properly drafted, a special needs trust may enable parents to establish a trust that can hold an unlimited amount of assets, without these assets being considered for qualification for government programs that are based upon need.

These government programs include Supplemental Security Income (SSI) and Medicaid (sometimes called by other names in certain states). Other government-based benefits include payments for vocational rehabilitation and the provision of subsidized housing. Special needs trusts are intended to supplement, but not to replace, the basic support of the child given by government aid, which is intended to provide, generally, food, shelter and clothing.

Defining “special needs”

A special needs trust can cover a broad array of expenses, most often those that will enhance the child's life, health and welfare. Here are just a few examples for which distributions may be made from the trust (if not otherwise covered): dental, medical and pharmaceutical expenses; therapy or rehabilitation services; wheelchairs and other special equipment; and psychological services expenses.

The expenses may be made for the disabled child's pleasure, as well. For instance, the trust may be able to provide funds for travel (including the cost of a companion to

accompany the child), summer camp, beach trips, movies and social events, a computer and sports equipment.

Keep these points in mind:

- A disabled child must be “impoverished,” a term of art under federal law. A disabled individual with as little as \$2,000 in assets may be disqualified from receiving Medicaid.
- The special needs trust should be established by someone other than the disabled child and managed by a person other than the person with the disability.
- A decision will need to be made whether to establish the trust during the parents’ lifetimes or create it by the parents’ wills, to go into effect after their deaths. A major advantage of the former approach is that it allows other family members (who might not otherwise see the wisdom in making outright gifts or bequests to the disabled child) to make them to the trust.
- Another decision will be whether to make the trust revocable or irrevocable. A revocable trust provides flexibility, allowing parents to add or subtract assets. However, assets in the trust are taxable in the parents’ estates and may be exposed to creditor claims. On the other hand, an irrevocable trust makes it impossible to make changes to any of the provisions in the trust.

A few practical suggestions

Seeking the guidance of professionals with experience in financial planning for the disabled is especially important when considering a special needs trust. Matters often can become very complicated because both federal and state law will come into play.

In addition, it is often recommended that parents write a letter of intent, providing instructions concerning the care of the disabled child. The document should be as detailed as possible. Not only major concerns should be addressed, but also anything that the parents might know and others may not—even such relatively minor things such as the child’s favorite friends, foods and forms of entertainment.

Finally, a successor trustee should be named in the event that any individual originally named as trustee may no longer be able to serve. A corporate fiduciary should be considered. Such a fiduciary can provide for professional management for the assets in the trust, establishing a strategy that is best suited to the child's needs both for the present and the long term.

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Any developments occurring after January 1, 2009, are not reflected in this article.