

Special Needs Trusts

What they are and why you need one



Parker Counsel Legal Services

The basic legal planning tools for parents who have a child with a disability that will prevent the child from providing for their own support and care in adulthood are a good estate plan with a special needs trust.

What is a special needs trust?

A special needs trust, which is also called a supplemental needs trust, is a way for parents and other family members to provide money to help care for a child or family member with a disability without causing them to lose SSI (supplemental security income) and Medicaid.

Do we need a special needs trust?

Probably. Everyone's situation is different, but the vast majority of families who have a child with a developmental disability will need to have a special needs trust in order to properly provide for their child's future care.

When do I need to set up a special needs trust?

As soon as you can get to it. Most families have a special needs trust that will receive the inheritance for their child, including any life insurance or retirement benefits that they may have and want to leave for the care of their child. If you die without having a special needs trust set up for your child, along with a will that directs your child's inheritance into the trust, then some of your child's money will be spent trying to prevent problems and loss of government benefits rather than for your child's care. Estate planning is something that is easy to put off doing, but the consequences to your child if you die before taking care of it can be severe.

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How much money should I put into a special needs trust?

The short answer is, you should put as much money in as you have available for your child's care. The longer answer is that there is no magic dollar amount that triggers the need for a trust. Even parents of relatively modest means may have a house with equity, life insurance, and retirement accounts that will go to their children, and if there is any chance that the child's inheritance will be more than \$2000 (the asset limit to receive SSI and Medicaid), then a Trust will probably need to be part of your plan. Trusts are not just for "rich" people, they are for parents who want to provide a better quality of life for their child with a disability than government benefits alone will provide.

How does a special needs trust work?

Every trust has a person named as Trustee, who is responsible for managing and investing the money and making decisions about how the money will be spent. The Trustee will have complete discretion over how and when the money is spent, but it can only be spent for the benefit of your child. Parents can leave guidance for the Trustee to use in making decisions, letting the trustee know the priorities and goals the parents have for their child. Most parents name a family member to act as trustee, but for trusts with large amounts of money a professional trustee may be named. The Trustee is charged with using the money to enhance the quality of life for your child.

What if I don't have a family member who can be trustee?

There are options, and your attorney will help you figure out the best approach for your family. Even if you have no other family members to help, a special needs trust should still be part of your plan for your child. Corporate trust companies, professional trustees, and professionally managed pooled trusts are all options your attorney can discuss with you.

What happens if there is still money in the Trust when my child dies?

In most cases, parents will make this decision at the time they create the Trust. The remaining money can be left to other children or to family members, or even to a charity. In a few cases, any remaining money may go to repay Medicaid for benefits your child received while alive, but this is not true for all Trusts. Your attorney can explain to you whether the Trust you create must have this provision or not.

What can the special needs trust pay for?

In general, the Trust can pay for anything that benefits your child and is not paid for by SSI or Medicaid benefits. This means the Trust can pay for medical equipment or care that is not covered by Medicaid, can pay for therapies or training not covered by Medicaid, and can pay for assistance your child needs with daily activities if Medicaid does not provide such assistance. The Trust can also pay for toys, activities, trips, and transportation, among other things. The Trust generally should not be used to pay housing costs, but even that can be done in many cases. The Trust can also employ people to help with your child's care, ranging from housekeeping to personal assistance to someone to handle paperwork and phone calls. Basically, the Trust can be used for almost anything that enhances the quality of life for your child.

Why is a special needs trust better than simply leaving money to a relative to use for my child?

If you leave money to someone you trust to use it just for your child, the money may be lost through no fault of the individual you trusted the money to. While it may seem unnecessarily complicated to create a Trust, this is the only way to protect the money and preserve it for your child. If you leave money to a relative, the law considers that money to belong to the relative, and it can be taken to pay for debts if your relative has a serious medical situation, or if your relative dies unexpectedly the money will be part of their estate and will go to their legal heirs, or if the relative gets divorced the spouse may claim it as part of the marriage estate and go after part of it. There will also be a problem if your relative develops a medical problem that interferes with their ability to manage the money. In short, it's a very bad idea to do this. A special needs trust is the only way to ensure that the money you intend to be used for your child is actually used for your child.

Parker Counsel Legal Services focuses on legal planning for families that have children with special needs and developmental disabilities. We have offices in Austin and Dallas Texas, Western Massachusetts, Northern New Jersey, and Portsmouth, New Hampshire. We can help you with special needs trusts, estate planning, guardianships, and more.

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