



Parents and families of children with special needs face incredible tasks on a daily basis. Family life revolves around the child.<sup>1</sup> Throughout the child's life, crucial decisions must be made that have long-term ramifications. The emotional and physical strain on parents and care givers can be massive. Empathy, understanding, patience and commitment are a way of life. Parents are most concerned about what will happen to their child when they are no longer there to care for the child's personal and financial needs. Planning is not optional for such families. It is crucial and can be complex in order to preserve needs-based assistance while assuring that the child will have the ordinary comforts of life that are not provided by governmental agencies. One of the most commonly used techniques to help accomplish this financial goal is the special needs trust. Here are some frequently asked questions that can help provide you with important information for you to consider with the assistance of your tax and legal advisors.

## What is a special needs trust?

The use of the term **special needs trust** can create confusion. There are three distinct groups of special needs trusts so it is important to point out how they differ.

1. There are special needs trusts that are funded by the family or anyone other than the child receiving the public assistance. These are often referred to as **third-party trusts**.
2. The second group consists of those trusts that are funded with assets already legally owned by the child with special needs. These trusts are referred to as **self-settled** or **first-party trusts**. Some common names used for these trusts are **D(4)(A) trusts**, **payback trusts**, and **pooled trusts**. Since the money going into these trusts originated from the child, there are significantly more technical issues and differences in trusts from state to state.
3. The third group of special needs trusts encompasses those funded with the child's money but created before 1993. They are sometimes referred to as **pre-OBRA trusts** and can no longer be created.

The use of the term **special needs trust** throughout this document is a reference to a third-party trust unless stated otherwise.

Reference will often be made to children. That is for simplicity's sake. A third-party special needs trust is by no means limited to benefiting children. Adults can also be beneficiaries of these trusts.

## What are special needs?

Special needs can include both the needs and the desires of a child with special needs. They are those things, tangible and intangible, that can help maintain a measure of comfort and pleasure for a child but are not provided by any public or private agency.

## When is a special needs trust appropriate?

The most common event that creates the need for a special needs trust for an individual who is receiving public benefits is the potential receipt of an inheritance, a life insurance benefit, or a personal injury settlement. Special needs trusts also frequently serve as "holding pots" for intrafamily lifetime gifts.





### What expenses can be paid with funds from a special needs trust?

Virtually any expenses not met by public or private agencies such as:

- Medical and dental expenses not otherwise provided for
- Education
- Training
- Rehabilitation
- Transportation (including the purchase of a vehicle)
- Life insurance premiums
- Computer equipment
- Recreation
- Vacations
- Legal expenses

### Are special needs trusts permitted by Social Security and other such agencies?

Yes. In fact, the Social Security Administration has established rules that allow an individual to be the beneficiary of a special needs trust while at the same time receiving Social Security and other public benefits. Those rules allow the trust to provide benefits in excess of public funding without impairing that funding as long as the beneficiary can neither revoke the trust and use the assets for his own benefit nor control the distributions while the trust is in place.

### Who can establish a special needs trust?

Family members such as parents, grandparents, and siblings generally establish the trust. The individual establishing the trust is called the grantor. If more than one person establishes the trust, they may all be grantors. The trust can receive gifts of cash or other assets from additional persons who are not grantors, such as family members. A common method of funding the trust is through proceeds of life insurance policies on the lives of family members.

### Who can serve as the trustee?

Generally speaking, anyone other than the child with special needs may serve as trustee. However, the choice of trustee is one of the most important considerations that the family will face. Typically, the parents serve as the trustees during their lives. The issue of who will succeed them as trustees at their deaths is the vital one. The trustee will be responsible for custody and management of the trust assets as well as determining what distributions should or should not be made for the benefit of the child. Because of these dual responsibilities, both corporate and individual trustees have advantages and disadvantages. A bank or other financial institution offers continuity, experience in asset management, tax planning, bookkeeping and the like. Most importantly, a financial institution is per-

petual, thus eliminating the problems that would occur if an individual trustee died.

When deciding whether or not to use a corporate trustee, it is important to keep in mind that the trust may last longer than even the average retirement plan, necessitating a long and increasing stream of income. Continuity and financial expertise may be more important than that required for other types of financial planning. However, institutions that serve as corporate trustees come at a cost and generally will not accept small trusts, the definition of which may vary.

Family members, on the other hand, are much better equipped to deal with both personal and distribution issues. They know the needs of the beneficiary better than a corporate trustee and may serve as a better advocate for the child.

A compromise may be to have an institution and a family member serve as co-trustees, with each being responsible for those duties that it performs best.

**Our greatest worry is, "What will happen to our child when we are no longer here or able to provide for our child's care? Is there any way to help insure that he will be well cared for in the manner that we would provide if we were able?"**

No one can provide the standard of care and love that parents can. However, parents can do much to help those assisting the child. The choice of advisors, especially trustees and care givers, is vital, but there is much that you can do to help them to discern your wishes in caring for your child if you are not there to do so yourself. Consider developing a letter of intent.

A letter of intent is a document that is written to serve as an instruction manual for all of the persons who are either financial or personal care givers of the child. Its purpose is to provide instructions to better enable them to manage the day-to-day care of your child, as you would do if you were there. The document should list things that the child likes and dislikes, such as hobbies, and recreational and social activities, as well as allergies and medical history. More importantly, you should include, in detail, your thoughts for his future.

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Any number of matters can be included, such as a desire for job training, schooling, dating, religion, social interaction, and prior family activities. Details on financial matters, especially guidance to the trustee or others involved in making discretionary expenditures, can also be included. The document is not binding, but it is of great assistance to others who must make decisions that will affect your child's life.

#### **Are special needs difficult to establish?**

While they are often a part of the overall estate plan of family members, they are very technical. There are stringent requirements that must be met in order to assure that the special needs trust will qualify as such. Any advisors in this area, especially the attorney, should be very knowledgeable. Not every estate planning advisor is capable of giving proper direction. He or she should not only be a specialist in estate planning, but should also be experienced in special needs planning and have a depth of understanding of special needs trusts as well as current government benefit programs.

While the cost of establishing a trust is a consideration, it is relatively inexpensive and (aside from ongoing trustee and management fees) is usually a one-time cost. In relative terms, a special needs trust that accomplishes its intended goals is a financial bargain.

#### **Can additions be made to the trust?**

Yes. Additional assets can be added at any time by the grantor or any other person. For example, additions may be from lifetime gifts, wills, trusts, life insurance, employee plan benefits, retirement plan benefits and IRAs. Gifts made during the lifetime of the donor may incur gift tax.

#### **What are the requirements that must be met to make sure that the special needs trust does not result in a loss of needs-based benefits?**

Yes. Additional assets can be added at any time by the grantor or any other person. For example, additions There are a number of requirements that have to be carefully met in the trust agreement. The trust must:

- Be established by a person (usually parents or another family member) other than the child with special needs.
- Be managed by a trustee other than the child with special needs.
- Give the trustee full and absolute discretion to either pro-

vide assistance or not.

- Not give the child with special needs funds in excess of those allowed by the needs-based programs.
- Provide for successor trustees.
- Protect the trust assets against attempts by creditors and service providers to reach the assets.

While not required, it is quite helpful to the administration of the trust and for the benefit of the child to:

- Define the special needs and, specifically, the unique needs of the beneficiary.
- Provide instructions for the beneficiary's funeral in case there are no surviving family members who can do so.

It is important to remember that many of the needs-based programs are state administered, and some of the requirements may vary from state to state.

#### **My child will be receiving a personal injury settlement. Will a special needs trust protect the settlement without jeopardizing her state and federal benefits?**

A commonly used trust under these circumstances is a self-settled trust, rather than a special needs trust. (The child cannot place his or her own assets in a special needs trust without affecting needs-based benefits.)

This self-settled trust is the same type of trust that would be used if a child had previously received an inheritance. Assuming that the child is disabled as defined by the Social Security

Administration, a parent, grandparent, guardian or the court may establish the trust. At the death of the dependent individual, the balance of the assets in the trust must be payable to the state providing the services to the extent of reimbursing it for the cost of Medicaid-based services that were provided.

A second option is a pooled accounts trust. If the funds are placed in a pooled accounts trust, the assets that are left over after the death of the child will remain in the pool for the benefit of others.





### **Would you describe a pooled accounts trust in a little more detail?**

Anyone, including the child with special needs, can put money in a pooled accounts trust (also called a master trust). The trust must be established through a charitable (non-profit) institution. The non-profit agency serves as the trustee and administers the individual's assets in a separate sub-account. It administers the trust, makes investment decisions, prepares the tax returns, and makes distributions.

Before the sub-account is established, the parents and/or other family members meet with the charity and explain how they want the assets administered for the child, that is, what they want paid for and with whom to consult regarding the child's benefit and welfare. After the deaths of the parents, the charity consults with those individuals designated. At the death of the child, the assets remain in the pool for the benefit of others in that pool. This will vary somewhat from state to state, with some states requiring some form of repayment.

### **As a parent, is my estate planning any different because I have a child with special needs?**

The answer is clearly "yes," but let's answer the question with a couple of illustrations. Suppose that both parents of a child with special needs die in an automobile accident. Unless they have a will directing otherwise, their assets would pass to their child and likely disqualify the child from public benefit programs until the inheritance is dissipated to earlier levels. If the individual parents died at separate times, the same result would occur at the death of the second parent if there were no estate plan in place to address the issue. Now let's think beyond the immediate family. If grandparents, aunts and uncles, or well-meaning family friends have wills that leave assets to the child or a life insurance policy naming him or her as a beneficiary, the result could be the loss of public assistance. It is important that all

family members review their estate plans with an estate planning attorney knowledgeable in special needs planning to make sure that they don't inadvertently cause a loss of needs-based benefits.

### **The Role of Life Insurance in Funding Special Needs Trusts**

Investments such as stocks, bonds and mutual funds held in a revocable special needs trust are a part of the estate of the grantor or grantors who are usually the parents. As such, the income generated by the assets is taxable to the grantors in their tax bracket. In addition, depending upon the size of a grantor's estate, the trust assets may be subject to federal and state estate taxation. Another important issue is that the assets held in such a trust are subject to any creditor's claims against a grantor's assets.

The alternative, an irrevocable trust, while solving these concerns, presents its own problems. Because the trust is irrevocable, some control is lost. The effect of that loss can be minimized but, it is there nevertheless. Because the beneficiary of the trust is not able to access the assets of the trust on his or her own, it is difficult to avoid the gift tax rules that would impose that tax on additions to the trust. For that reason, it is difficult to place large enough sums of money into the trust that would be necessary to achieve the life-long purposes for which the trust was established in the first place.

Life insurance can be the most cost effective and efficient method for providing the funding to help achieve family goals. Life insurance provides immediate funding of the trust, regardless of the timing of the deaths of the parents or other insureds. The type of life insurance policy that may be the best fit will depend upon a number of other factors including premium structure and the tolerance for risk.

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<sup>1</sup>Not all persons of special needs are children. Many are adults. While we refer to children throughout this piece, all of the material is equally applicable to adults.

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