Establishing a Trust

Personal Planning for the Future

Many parents of children with special needs, and caregivers of adults with disabilities, struggle with understanding how to provide for their loved one's needs. State programs provide money for housing, food and basic needs. However, this may not be enough money for a person with disabilities to lead the quality of life their loved ones would like for them to have. They may not have money for things like movie tickets, new clothes or trips. A special needs trust is a way for a person with developmental disabilities to have spending money while keeping their eligibility for Medicaid and other public assistance programs.

There are several things to think about when deciding if a special needs trust is right for your loved one's situation. Does your loved one qualify for a special needs trust? How much money will be needed? Which type of special needs trust would be best? Who can be the trustee (person responsible for the trust)? Is there a local lawyer who can create the trust so it reflects your wishes?

What is a trust?

The purpose of a trust is to be able to provide for a person but in a way that is according to your wishes. A trust is an account that a person sets up to provide for another person (in this case a person with disabilities). The person responsible for the trust is called the trustee and is usually chosen by the person who set-up the trust. The person who sets up the trust is called a settler. The person who is provided for by the trust is called the beneficiary.

A trust allows a person with disabilities to have extra money but not lose their eligibility for public assistance, like Medicaid. This is because, legally, the person with disabilities does not own the money in the trust; the trust owns it. Therefore, the person with disabilities does not have to claim the money as an asset and remains eligible for public assistance.

The trust is usually housed in a financial institution, such as a bank, where it is 'managed'. This means that the money in the trust is continuously invested so it keeps making money. There are different trusts for different reasons. This fact sheet only talks about special needs trusts, also called supplemental needs trusts. This type of trust provides non-essential items, such as movie tickets or baseball cards, for a person with disabilities. Beneficiaries of special needs trusts never gain control of the trust. The trustee will always be the person who controls the money in the trust.

Types of special needs trusts

The most basic special needs trust is created only with the assets and income of a person with disabilities under the age of 65. The income can come from Supplemental Security Income (SSI), retirement, inheritance or a court settlement. A basic special needs trust (legally refered to as OBRA 93) can only be set up by a parent, grandparent, or legal guardian of a person with disabilities or by a court order. A person with disabilities cannot set up his/her own trust.

A second common type of special needs trust is called a family special needs trust. It is also called a third-party special needs trust. This trust allows various people, like family members and friends, to add money to the trust over time. The family special needs trust does not have to be funded entirely up front. Since multiple family members, such as siblings, can put money into the trust, the burden of setting up a fund is not solely on one family member or the beneficiary's income. Family members can also leave gifts to the trust as part of their estate planning, for example through their wills.

A third type of special needs trust is called a pooled trust. This trust is set up by a non-profit organization and provides support for multiple beneficiaries. The purpose of this trust is to give people with low incomes the opportunity to set up a trust to provide for their loved ones with disabilities. To set up a pooled trust, multiple people give small amounts of money to make one big trust. In other words, a group of people 'pool' their money together to create a trust. This trust serves two purposes: (1) people with low incomes can take care of their loves ones with disabilities, and (2) a large enough amount of money is collected to make it worthwhile for a bank to manage the trust. Unless a trust can be established with a certain amount of money, a bank will not want to put forth the effort to manage it.

A fourth type of special needs trust is a court ordered special needs trust. This is often used in court settlements when large amounts of money are awarded to a person who is not able to manage money on his/her own. These trusts are different from other special needs trusts because the person with disabilities actually owns the funds. A court ordered special needs trust is considered income for the person with disabilities. As a result, this person may no longer be eligible for Medicaid and other state programs.

Eligibility

The beneficiary (person for whom the trust is set up) cannot own anything that has value over $2,000. The person with disabilities is not required to be on Medicaid or Supplemental Security Income (SSI) for a trust to be made in their name. However, the eligibility requirements for SSI and Medicaid are used to decide if a special needs trust can be set up for your loved one. Usually, the person's income from SSI is used to start a special needs trust.

Funding a trust

There are several ways to fund a special needs trust. Funding a trust depends on the type of trust you choose.

- Basic special needs trusts are funded by the beneficiary's (person with disabilities) income. This trust is primarily for the beneficiary to be have extra pocket money while living off the income from SSI and other public benefits.

- Family special needs trusts must be funded by people other than the beneficiary (in this case the person with disabilities). This trust can be funded through a family's personal resources, like life insurance benefits, investments or deposits made by family members.

There is no need to fund the trust as a whole from the start. You only need enough money to start the trust. The amount needed is decided by the financial institution, like a bank, that will manage the trust.

Affording a trust

You can set up a trust without being able to fully fund it. Remember, money in a basic special needs trust cannot be used to cover costs of living, such as housing or food. Public benefits, such as Medicaid and SSI, are meant to cover these expenses. A special needs trust is for life's extras, like movie tickets, hair cuts, and money for trips. For a basic special needs fund, you need just enough funding to improve the quality of life for your loved one with disabilities when coupled with public assistance.

Where do I go to start a trust? Who do I contact?

To start a trust, you need an irrevocable inter-vivos trust agreement. This is a document that a lawyer writes that creates the trust. You must hire a lawyer to write this document for you. The lawyer will take care of writing the trust agreement; finding a bank to manage the trust; making arrangements with the trustee (making sure the person in charge of the trust wants the responsibility and knows how to manage a trust); and telling Medicaid and the Social Security Administration about the trust.

What items can be paid for by the trust?

A special needs trust may pay for:

- Recreation and related equipment, like an adaptive bicycle
- Transportation, such as an adaptive van
- Dental care and eyeglasses
- Telephone, internet services and television
- Hair and nail care
- Extra nursing care, private case management, and a personal care attendant
- Mobility aids and therapies not covered by public assistance
- Private school tuition
- Vacations

Who should I choose as the trustee?

Often times a family member is chosen to be the trustee. This has both pros and cons. A family member who is a trustee can be beneficial because he/she knows the lifestyle that your loved one is used to living and is also familiar with the person's needs. However, a family member may not want the responsibility of managing the trust. This can include dealing with the bank; handling accounting, such as bank balances; and withdrawing money for the beneficiary to use.

Lawyers, banks and private companies can also be trustees. The most obvious drawback is you must pay for their services. The benefit is that they have experience in managing trusts.

What are some pros and cons of a trust?

There are a few things to keep in mind if you are interested in starting a trust.

Cons

- Money can be added to the trust without penalties until the beneficiary (your loved one with disabilities) turns 65 years old. Money added after that may count as income. This may make the beneficiary ineligible for Medicaid.

- Medicaid payback is a legal requirement of a special needs trust. The trust must state that any money left over upon the death of the beneficiary, or closing of the trust, will go to Medicaid, up to the total amount Medicaid spent on care for the beneficiary.

- Funds paid to the beneficiary from the trust count as income for tax purposes.

- There are some costs involved in having a trust. You must pay a lawyer to create the trust; pay fees for a bank to manage the trust; pay taxes; and pay administrative fees, like investment fees and fees for tax return preparation.

- Remember, laws regulate trusts and can change. Currently, special needs trusts do not count as an asset and do not disqualify someone from receiving Medicaid. However, this may change down the road.

Pros

- Special needs trusts cover the cost of non-essential items, like movie tickets, while keeping your loved one eligible for public assistance and Medicaid.

- Trusts offer a way for a person with disabilities to enjoy the quality of life they are used to, even after a family member is no longer able to do so.

What are some things that should be included in a trust?

Be careful to describe the trust as being for special needs, supplemental needs, and emergencies. If you do not do this, the trust may be considered income or an asset. This will make your loved one ineligible for Medicaid.

Make sure to be clear that the funds are NOT for living or health care expenses covered by state programs.

The trust must clearly state that it is created only for the benefit of the person with disabilities. Trusts are required to have a clause stating that the state, or states, which paid out Medicaid benefits during the beneficiary's lifetime will be reimbursed (paid back) with any money left in the trust after the beneficiary's death.

The trust should spell out that the trustee (person managing the trust) can pay for the trust's expenses, like fees and taxes, out of the trust. The trust should also state the trustee's responsibilities: understand all changes in laws that affect the trust; keep the trust up-to-date with banking rules and laws; disburse funds appropriately (pay fees, withdraws for the beneficiary); and follow state and federal reporting requirements.

Resources

The Omnibus Budget Act of 1993 (OBRA 93) is the law that created and set the guidelines for special needs trusts. The Programs Operations Manual (POMS) of the Social Security Administration provides further information on how the law is carried out. You can read it by visiting **https://secure.ssa.gov/poms.nsf/lnx/0501120203**. This link will take you directly to the section of the law that talks about establishing a trust for a person with disabilities.

To find a lawyer in your area who can create a special needs trust, call the West Virginia State Bar Lawyer Referral Service at **304-558-7991**.

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