

## Special Needs Trust

When a family faces the crisis of a catastrophic injury of a loved one, first there is shock, and then there is almost a total submersion into medical decision-making. Before long, however, scary questions arise about how to pay for all the increased living costs and medical care related to a long-term disability. People with and without no-fault insurance coverage must learn quickly about Medicaid, Social Security and Supplemental Security Income (SSI) disability benefits. The family's next set of questions often involves how to set-up a special needs trust that will provide some private funds while preserving governmental benefits. What follows are some tips about the use of special needs trusts.

### *How Can I Set Up a Special Needs Trust?*

Start by recognizing whose money will be funding the trust. A common mistake is to fail to define who will be funding the trust. SSI and Medicaid programs have one set of rules for a parent or "third party" funded trusts and another set of rules for trusts set up directly by the person with the disability. As an attorney who helps clients qualify for benefits, I have seen many instances where even governmental workers apply the wrong rules and incorrectly deny benefits.

If parents want to make sure that their adult child's inheritance will not reduce his or her governmental benefits, they should prepare a **last will** or a **living trust** that leaves a share of their estate to a new special needs trust for the benefit of their son or daughter. Sometimes parents also find it helpful to set up an additional, but separate living (intervivos) special needs trust in their will. This is done to facilitate gifts or bequests by other relatives or to begin building up a trust fund before the parents die.

Both of these third party special needs trusts are quite flexible – even revocable. They can leave a remainder interest to any other party or charity without a Medicaid payback provision, when the loved one passes away. These third party special needs trust options have been widely used for the past twenty-five years.

### **Self-funded Special Needs Trusts**

Third party trusts have one drawback—they cannot be used to shelter assets if a disabled person already holds the money. Fortunately, federal law in the mid '90s began to allow a person with disabilities to self-fund a special needs trust, even with



money that is already "in the pocket" of the disabled person.

For example, an individual with a disability can shelter proceeds from a lawsuit settlement or a large lump sum from Social Security in a special needs trust. This puts the assets in a "non-countable" category and allows the individual to preserve governmental benefits. They can even shelter funds owned prior to the injury, such as a house they no longer live in, bank accounts and IRAs.

The federal statute spells out two different types of self-funded special needs trusts. The first, sometimes called a Medicaid Payback Trust or a Section d(4)(A) Trust, is more individualized and requires that any funds remaining at the death of the beneficiary must be paid back to Medicaid. This option is perfectly fine with many families—they believe it is only fair that any remainder funds after the death of the primary beneficiary should reimburse Medicaid for what it paid during the person's lifetime.

To set up this type of individualized, self-funded trust, the family must identify someone who can serve as the trustee and then hire a private attorney with experience in this area of the law. The individualized nature of the trust makes it a little more expensive to set up but gives the family more individual control over disbursements. They should also be aware that it obligates the trustee to know what disbursements will not jeopardize

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government benefits and make wise investments as a fiduciary.

### **Pooled Trusts Set up by a Nonprofit Organization**

While an individualized, self-funded option is fine for some, others prefer a second self-funded option – the pooled trust. This option may be preferable if:

- the family cannot identify a suitable private trustee
- the bank trust department fees are cost-prohibitive
- the family has a desire to have the remainder funds, after their relative's death, stay in their community to assist other persons with disabilities rather than go back to Medicaid

A pooled trust is authorized by the same federal statute as the individualized Medicaid Payback Trust and is recognized by the Michigan Program Eligibility Manual at item 401. It must be set up by a nonprofit agency. Its most interesting feature is that remaining funds are held by the pooled trust after the person dies, and they are not required to pay back to Medicaid. The remaining funds can be used to help others with disabilities who are known to the nonprofit agency. Administratively, individual funds are not commingled but are pooled for investment purposes to obtain a better return.

Sometimes parents, grandparents, or individuals with disabilities (if no guardianship is in place) can initiate participation in a pooled trust by signing a joining agreement. If a guardian is in place and no other person is able to sign the joining agreement, a petition must be filed in probate court to establish an account in the pooled trust.

### **An Example of a Pooled Trust**

The Brain Injury Association of Michigan has recently entered into an agreement with one of the largest pooled trust projects in Michigan – the Hope Network Pooled Trust. Their goal is to make this option more available to BIAMI constituency.

Individuals with brain injuries or other disabilities can self-fund an account within the Hope Network Pooled Trust and use it throughout their lifetime. If any funds remain after the person passes away, it need not be repaid to Medicaid – a portion of it can be earmarked for use by BIAMI's constituency. It's a win-win situation!

### **What Can a Special Needs Trust Pay For?**

Either the third-party or a self-funded special needs trust can pay for a wide variety of things for which there is no other source of payment. Examples include:

- extra in-home support services
- uncovered health care or therapies
- amenities, trips, or recreational activities

If the beneficiary is receiving SSI, the trustee must be careful not to use the trust funds for items that the SSI is meant to cover, such as food and shelter, so there is not a reduction in SSI benefits.

### **About the Author:**

Daniel Blauw lives in Grand Rapids, Michigan. As a lawyer in solo practice, he primarily helps families across Michigan set up special needs trusts and arranges for services when they have a family member with life-long disabilities. He has served as Director of Creative Housing Services at Hope Network and as Executive Director of the ARC of Kent County, an advocacy group for people with disabilities. Daniel is a 1980 graduate of Valparaiso University School of Law and a 1977 graduate of Hope College. ❖



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