

Testimony

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A special needs trust is a trust designed to protect quality of life for an individual's with disabilities. They are usually established with the goal of protecting an individual (the beneficiary of the SNT) without causing the loss of the individual's eligibility for public benefits such as Medicaid and SSI. In addition to protecting public funding the pooled trust also offers protection from exploitation or misuse of the person's money.

The Law

In 1993, Congress passed legislation to restrict Medicaid eligibility for individuals who transferred their property prior to applying for Medicaid. At the same time, congress specifically created the option for individuals with disabilities to benefit from assets set aside for them without causing the loss of Medicaid. The Omnibus Budget Reconciliation Act of 1993 authorized the use of Pooled trusts managed by nonprofit organizations in 42 United States Code 1396p(d)(4)(C). In 1999, Congress adopted the Foster Care Independence Act, which provided corresponding changes to the statues governing Supplemental Security Income (SSI).

The federal statute which authorizes pooled trust requires that the trust contain specific language: assets in the trust must be used for the benefit of the individual with the disability. Most importantly the trust must contain language that says - to the extent that amounts remaining in the beneficiary's account upon the death of the beneficiary are not retained by the trust, the trust pays to the state an amount equal to the total amount of medical assistance paid on behalf of the beneficiary under the state plan. So to put it quite simply whatever is left in the trust is either retained by the trust for charitable purposes or is paid to the state Medicaid cost recovery unit. I personally call these trusts "Payback Trusts"

What is a Pooled Trust?

A pooled special needs trust is a trust with multiple sub-accounts for different beneficiaries. Usually the beneficiaries are called members of the pooled trust. Joining an already-established trust or a pooled trust is ideal for those with modest means because no new trust needs to be drafted. Federal law allows the beneficiary, his or her parents, grandparents, or the court to establish the sub-account within the pooled trust. As assets are funded to the pooled trust, a separate account is established for each individual member. Because assets are pooled together, the trust is able to maximize the return on investment and at the same time reduce the cost of administration and management.

Now that I have given you background on pooled trust, I would like to speak specifically about some of my experiences administering a Pooled Trust.

I have been the administrator of the Arcare Pooled Trust in Overland Park, KS since its inception in 1996. We currently have 836 active accounts with an average balance of \$24,000.00. We have many accounts with less than \$5,000.00 in assets. Most accounts are funded by back disability payments, modest legal

settlements, and often by money that the person with disability has saved. Keep in mind that a person on Medicaid and SSI cannot have over \$2,000.00 to maintain eligibility for public benefits. So we encourage people with disabilities to work, yet we punish them if they save any of their money. The pooled trust can be used for a vehicle so that the person can save money for things like a vehicle, dental work, assistive technology, etc.

Pooled Trusts and Distributions

As I previously mentioned under federal law distributions from self-settled special needs trust must be for the benefit of such individual. Social Security regulation interprets that to mean that no one else can benefit from assets in the trust. Social Security also sets trust distribution rules for payment to caregivers, vendors, purchases of gift cards, and many other expenses. The POMS which is the SSA manual serves as my guide book for making many distributions from the Arcare Pooled Trust. Although SSA does restrict some distributions, there is no federal law or SSA rules that restrict distributions from a pooled trust to be used only for disability related expenses. Nor is court approval required.

The Arcare Pooled Trust makes about 40 distributions a week. Most frequently the distributions are made for dental work, furniture, home and auto repairs and maintenance, cell phone and cable tv bills, repair and maintenance of assistive technology and mobility equipment, education, public transportation, over the counter medication, vitamins and other nutritional supplements. Most of these things we take for granted but because of one's disability, these things are not affordable.

I am aware that there is concern amongst policy makers that Special Needs Trusts provide a vehicle for wealthy people to shelter money for the purposes of being on Medicaid. I can tell you that is not the case. By putting money in the trust, the person gives up direct access to it, the ability to share it with other family members and ultimately passing it to their heirs. The mandatory payback language and retention by the nonprofit is a huge deterrent to anyone using the trust without a "real need" for public benefits. Many times I have advised against the use of a pooled trust for the reasons mentioned above. A person that can afford to pay for their care, medical needs and have money left over is often not a good candidate for a pooled trust.

In summary, there are federal guidelines for distributions from a pooled trust. These guidelines are in place to protect the state's interest and the beneficiary. By passing legislation that removes the restrictive laws, persons with disabilities in Iowa, will also benefit from the federal law which allows the use of Pooled Trusts.