CHAPTER 9: SUBSTITUTE DECISION-MAKING THROUGH TRUSTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>I.</td>
<td>TRUST TERMINOLOGY</td>
<td>3</td>
</tr>
<tr>
<td>II.</td>
<td>GOVERNMENT BENEFITS &amp; TRUSTS</td>
<td>8</td>
</tr>
<tr>
<td>III.</td>
<td>THIRD-PARTY TRUSTS &amp; FEDERAL BENEFITS</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>A. Third-Party Trusts &amp; SSI Eligibility</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>B. Third-Party Trusts &amp; Medical Assistance Eligibility</td>
<td>11</td>
</tr>
<tr>
<td>IV.</td>
<td>FIRST-PARTY TRUSTS &amp; FEDERAL BENEFITS</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>A. General Rule</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>B. Exceptions</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>1. Special Needs Trusts (Payback Trusts)</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>2. Pooled Trusts</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>3. Undue Hardship Exception</td>
<td>22</td>
</tr>
<tr>
<td>V.</td>
<td>DUTIES OF TRUSTEES &amp; LETTERS OF INTENT</td>
<td>22</td>
</tr>
<tr>
<td>VI.</td>
<td>RESOURCES</td>
<td>24</td>
</tr>
</tbody>
</table>
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**Trusts** are frequently created to benefit persons with disabilities. While the main purpose is often to assure that the individual with disabilities does not lose essential government benefits, the result is that the individual does not have direct control over the money or other assets in the trust. Instead, a third-person controls those assets and, essentially, is charged with making decisions about how those assets should be used. In this sense, trusts are a form of financial substitute decision-making for individuals with disabilities.

Trusts in general can be a very complex topic. Trusts designed for individuals with disabilities can be even more complex. This is an area in which consultation with an attorney who specializes in this field is essential. Given the important role of trusts for many persons with disabilities, however, this chapter is intended to familiarize people with some of the terminology used in this area, the different types of trusts used to benefit people with disabilities, and the role of the **trustee**.

### I. TRUST TERMINOLOGY

It is important to understand the different words and phrases that relate to trusts. Understanding trust terminology, though, can be difficult because multiple words can describe the same thing and because different people sometimes use the same words to mean very different things. Below is a list of some key terms, definitions of those terms, and, when appropriate, a list of alternative terms that can describe the same thing.
"Trust" -- A trust is a property interest where the property is held by an individual or entity called the "trustee," who is designated to use the property for the benefit of another person, known as the "beneficiary."

"Grantor" -- A grantor is the individual who creates the trust by providing assets or property to be held for the beneficiary and who creates the terms of the trust that says how it should be invested and spent. A trust may have more than one grantor. A trust can be created by a grantor who is acting through another person if the other person is legally authorized to do so (such as the parent of a minor child or the court-appointed guardian for an adult). The grantor is also known as a "settlor."

"Trustee" -- A trustee is a person who holds the legal title to property for the use or benefit of another person under the terms of the trust agreement. A trustee can be an entity (such as a bank or non-profit association) as well as a person. A trust can have more than one trustee.

"Beneficiary" -- A trust beneficiary is a person for whose benefit a trust exists. A beneficiary does not hold legal title to the property in the trust, but does have an "equitable ownership interest" in it. There can be more than one trust beneficiary.

"Trust Agreement" -- The trust agreement is the document that governs how the trust will be implemented, including: identifying the trustee and beneficiary; stating whether it can be revoked and, if so when; and detailing any specific instructions for how the trustee can invest and spend the trust property.
"Trust Principal" -- The trust principal is the property that is placed in the trust by the grantor. The trust principal can consist of cash, stocks, bonds or other personal property, or real property (such as a house or land). The trust principal includes any earnings on the trust that may accumulate, such as interest, dividends, or rent. The trust principal is also sometimes referred to by the Latin word "corpus."

"Trust Earnings" -- Trust earnings are the amounts earned by investment or management of assets in the trust. This can include interest, dividends, rent or other returns on investment, depending on how the trust principal has been invested. Trust earnings can also be called trust income.

"Discretionary Trust" -- A discretionary trust is a trust in which the trustee is given total discretion as to how, when, or even if to make any distributions to the beneficiary.

"Mandatory Trust" -- The opposite of a discretionary trust, a mandatory trust requires that the trustee pay trust earnings or principal to the beneficiary at certain times. For example, it may require payment of a specific sum each month or it may require the trustee to pay specific bills for the beneficiary.

"Inter Vivos Trust" -- An inter vivos trust is a trust that is established during the lifetime of the grantor. It is sometimes called a "living trust."
"Testamentary Trust" -- A testamentary trust is a trust that is established by the grantor's will and is effective at the time of grantor's death. This is a common estate planning method used by relatives of people with disabilities.

"First-Party Trust" -- A first-party trust is a trust in which the grantor or a person acting on his or her behalf (such as a parent or legal guardian) creates a trust using the grantor's property as the trust property and in which the grantor is also the sole beneficiary. For example, when a person with a disability receives a legal judgment or an inheritance or gift, it may be critical to place that property in a certain type of trust to maintain his or her continued eligibility for government benefits. Note that because a first-party trust is established by an individual for his or her own benefit, this can only be an "inter vivos" trust and never a testamentary trust. A first-party trust is also known as a "grantor trust" or a "self-settled trust."

"Third-Party Trust" -- A third-party trust is a trust established for the benefit of a person other than the grantor and that is not funded with assets of the beneficiary. For example, a parent may establish a trust for his child using the parent's savings. A third-party trust can be established during the grantor's lifetime (inter vivos) or by his or her will (testamentary).

"Revocable Trust" -- A revocable trust is a trust in which the grantor retains the power to reclaim or take back the property in the trust. Generally, the trust agreement will state whether and how a trust can be revoked.
"Irrevocable Trust" -- An irrevocable trust is one in which the grantor has no authority to reclaim or take back the property in the trust. In some states, even a trust that is termed an "irrevocable trust" may be deemed revocable under state law.

"Supplemental Needs Trust" -- A supplemental needs trust is a third-party trust that includes language that states that the intent of the trust is to supplement, and not supplant, government benefits such as Supplemental Security Income (SSI) or Medical Assistance (MA) and that limits the trustee's authority to make distributions in a manner that assures that the beneficiary's government benefits will not be jeopardized. This is sometimes called a "common law trust" because whether the trust will jeopardize the beneficiary's federal benefits is determined by state judicial decisions and not by federal or state statutes.

"Special Needs Trust" -- A special needs trust is a type of first-party trust that, if it meets the requirements established by federal and state law, will not count as a resource in determining whether the grantor is eligible for SSI or MA. This type of trust is also known as a "payback trust." You should be aware that sometimes the terms "special needs trust" or "supplemental needs trust" are used generally to denote any type of trust -- including third-party trusts established by a relative to benefit a person with a disability -- that is intended to protect the person's eligibility for government benefits. The Social Security Administration (SSA), however, tends to refer to "special needs trusts" to mean only those first-party trusts that meet federal criteria to protect benefits. Special needs trusts are discussed further in Section IV.B.1, below.
"Pooled Trust" -- A pooled trust is another type of first-party trust that, if it meets the requirements established by federal and state law, will not count as a resource in determining whether the grantor is eligible for SSI benefits or MA. Pooled trusts are discussed further in Section IV.B.2 below.

II. GOVERNMENT BENEFITS & TRUSTS

Individuals with disabilities often receive government benefits for income, housing, and medical care. Eligibility criteria for these benefits vary based on the type of program.

- Benefits Available Regardless of Income and Resources -- Some types of benefits do not have financial eligibility requirements. Key examples of these benefits are Social Security benefits (including Social Security Disability), veterans' benefits, and Medicare.

- Benefits that Depend on a Person's Income and/or Resources -- Some types of government benefits will be available only if a person meets certain financial eligibility criteria. Key among these benefits is SSI and MA. Individuals whose income or resources exceed the low thresholds for eligibility set by federal law will lose their SSI and MA benefits.

Many (although not all) people with disabilities receive SSI benefits, which provide a small monthly cash benefit for people with low incomes and resources. Even more importantly, people with disabilities often receive MA, which provides critical health care, benefits, and services necessary to enable them to remain in their own homes and communities.

To be eligible for SSI and MA, an individual's "income" and "resources" cannot exceed set levels, which are fairly low. Accordingly, if a person with
a disability inherits money or receives payment as a result of a legal judgment or settlement of a lawsuit, those sums more likely than not will disqualify the individual from continued SSI and MA eligibility.

Simply putting money in a trust for a beneficiary with a disability may not protect that individual's SSI and MA eligibility. Sometimes, trust income will count as income to the beneficiary and the trust property may count as a resource for the beneficiary, either of which might cause the beneficiary to lose his government benefits. If structured and implemented properly, however, these assets can be placed in a trust that will enable the person to maintain his or her eligibility for SSI and MA while providing him or her with the benefit of additional funding to meet needs that may not be met by the government benefits.

III. THIRD-PARTY TRUSTS & FEDERAL BENEFITS

Relatives often choose to create trusts with their own property to benefit a person with a disability. They may create the trusts during their lives (an inter vivos trust) or do so through their wills (a testamentary trust).¹ There are both state and federal guidelines that govern the impact of a third-party trust on SSI and MA eligibility.

¹Trusts are one of several estate planning options that may be considered when a relative has a disability. For more information about estate planning in general, review the publication titled "Estate Planning for Families of People with Disabilities" available on DRP's website, http://www.DRPpa.org/publications.
A. Third-Party Trusts & SSI Eligibility

The SSA has established internal guidelines that govern when a third-party trust will be counted as a resource for the beneficiary with a disability for purposes of determining his eligibility for SSI. These guidelines are in the SSA's Program Operations Manual (POMS) § SI 01120.200.²

SSA will count the trust principal as an available resource to the beneficiary if: (1) the beneficiary has legal authority to revoke the trust (and then can use the trust principal to meet his needs for food and shelter); or (2) the beneficiary can direct the use of the trust principal for his support and maintenance under the terms of the trust. POMS § SI 01120.200D.

Generally then, as long as a third-party trust does not authorize a beneficiary to revoke the trust (which almost never occurs) and if the trust is a discretionary trust (rather than a mandatory trust that requires fixed payments to the beneficiary), the trust principal in a third-party trust will not count as a resource to the beneficiary.

While the trust principal of an irrevocable, discretionary third-party trust may not count as a resource, the beneficiary's SSI eligibility may be jeopardized by disbursements from such a trust that may count as income depending on

² The entire SSA Program Operations Manual is available online at https://secure.ssa.gov/apps10/.
who receives the disbursement and the purpose of the disbursement. Specifically:

- Cash disbursements from such a trust directly to the beneficiary will count as unearned income.
- Disbursements to a third-party (that is, a person or entity other than the beneficiary) to pay for the beneficiary’s food or shelter will be considered income in the form of in-kind support and maintenance.
- Disbursements to a third-party for items other than food or shelter generally are not considered income. Thus, the trustee may be able to use the trust principal to pay for the beneficiary’s educational expenses, medical expenses, recreation, and entertainment.

POMS § SI 01120.200E.1.

B. Third-Party Trusts & Medical Assistance Eligibility

If a person loses his eligibility for SSI because his income or resources exceed federal standards, then his continued eligibility for MA benefits also will be jeopardized. Thus, a key prerequisite to the beneficiary of a third-party trust maintaining his or her MA eligibility is to assure that the third-party trust is properly drafted to meet the criteria described above and to assure that disbursements are made in a way that they do not count as income to the beneficiary.

3 If the trust principal of a third-party trust counts as a resource to the beneficiary, then the disbursements from the trust to or for the benefit of the beneficiary do not count as income. They will, however, be considered conversion of a resource. POMS § SI 01120.200E.2.
Simply meeting the SSI eligibility standards may not be enough, however. A third-party trust beneficiary's MA benefits may be jeopardized if the trust does not satisfy state law.

The Pennsylvania courts, in a series of decisions, have held that "supplemental needs trusts" established by third parties can be an effective means of providing for the needs of a person with a disability without jeopardizing his MA eligibility, but only if those trusts meet certain standards. The following are brief summaries of the key state court decisions that analyzed different trusts to determine if they counted as "resources" for purposes of determining a beneficiary's MA eligibility.

- **Lang v. Commonwealth, Dep't of Public Welfare** -- The Pennsylvania Supreme Court in 1987 held that a discretionary, testamentary trust created for the benefit of all of the grantor's multiple children would not count as an available resource to one of the children who had a disability, and thus he remained eligible for Medical Assistance services. The Court identified several factors that supported its conclusion: (1) the trust was a discretionary, not a mandatory, trust (and, as such, the trustee had the power -- but not a duty -- to provide support to the Medical Assistance beneficiary); (2) the trust was established for the benefit of all of the grantor's children, not solely for the child with a disability; and (3) during the grantor's lifetime, the child with a disability received government benefits due to his disability, demonstrating that the grantor intended the trust to supplement other resources available to that child only if those government benefits are not adequate or are discontinued.

- **Commonwealth Bank and Trust Co., N.A. v. Commonwealth, Dep't of Public Welfare** -- The Pennsylvania Supreme Court in 1991 held that the trust principal of a testamentary trust was a resource for purposes of determining the beneficiary's eligibility for Medical Assistance. Although the trust was discretionary, the Court cited the following factors to hold that the trust counted as a resource: (1) the grantor, at
the time he executed his will and created the trust, had a duty to care for the beneficiary (his mother); (2) there was only one life beneficiary;  
4 (3) the trust did not instruct the trustee to consider the impact on government benefits when making distributions; and (4) the bulk of the grantor's estate was not placed in the trust, but, rather, was distributed to other people through the grantor's will.

- **Snyder v. Commonwealth, Dep't of Public Welfare** -- The Pennsylvania Supreme Court in 1991 concluded that the testamentary trust's principal did not count as a resource and, thus, did not jeopardize the beneficiary's Medical Assistance eligibility. The Court focused on the following factors: (1) there were two life beneficiaries (including a Medical Assistance recipient who had a disability), and the trustee was charged with considering the needs of both; and (2) at the time of the grantor's death, the Medical Assistance recipient/beneficiary had been receiving public benefits so the grantor had been aware of the availability of such benefits, and it was unlikely that he intended to deprive him of those benefits.

- **Estate of Rosenberg v. Dep't of Public Welfare** -- The Pennsylvania Supreme Court in 1996 held that the principal of a testamentary trust did count as a resource to the trust beneficiary who was a Medical Assistance recipient. The Court cited the following factors in reaching that conclusion: (1) there was only one life beneficiary (the grantor's widow); and (2) during the grantor's life, the beneficiary received no public benefits.

- **Shaak v. Pennsylvania Dep't of Public Welfare** -- The Pennsylvania Supreme Court in 2000 held that the trust principal was an available resource since the beneficiary was the sole beneficiary and since the beneficiary never received public assistance prior to the creation of the trust.

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4 A "life beneficiary" is a trust beneficiary who will receive distributions from the trust during his or her life. The trust will also identify one or more "remaindermen" to whom the trust principal will pass when the life beneficiary dies.
In sum, there appear to be certain critical factors that must be included in any third-party trust designed for the benefit of a person with a disability to protect it against being counted as a resource and, thus, jeopardizing a beneficiary's eligibility for MA. These factors include:

- A clear statement of intent that the grantor intends the trust to use the trust principal and income to supplement, not supplant, government benefits.

- More than one beneficiary and language that makes clear that the trustee should consider the needs of all beneficiaries in taking any actions.

- The trustee should have absolute discretion over the payment of income or principal to the beneficiary with a disability.

- Evidence that the beneficiary with a disability received government benefits before the creation of the trust.

Although these seem to be the main factors, there are other trust provisions that might be included to help insulate the beneficiary against loss of government benefits. It is essential that persons who are considering placing assets in a trust for the benefit of a person with a disability consult with an attorney with experience in this field and/or with one of the non-profit organizations listed in Section IV.B.2 that have experience in this field.

IV. **FIRST-PARTY TRUSTS & FEDERAL BENEFITS**

A. **General Rule**
There are times when an individual with a disability has or receives assets in his or her own right, such as through an inheritance or as a result of a legal judgment or settlement. These assets can jeopardize the person's continued eligibility for SSI or MA. Congress has enacted strict standards for when a trust funded with the assets of an individual or his spouse (first-party trusts) will count as "income" or "resources" for purposes of determining the individual's eligibility for those federal benefits.

The general rule established by federal law is that first-party trusts will count in determining the grantor/beneficiary's SSI and MA eligibility. 42 U.S.C. §§ 1382b(e)(1)-(3), 1382b(e)(6), 1396p(d)(1)-(3), 1396p(e)(1); see also POMS SI § 01120.201. Specifically:

- If a first-party trust can be revoked by the grantor/beneficiary, then the trust principal is considered to be an available resource and payments to or for his or her benefit will be considered income.

- If a first-party trust is irrevocable, then any portion of the trust principal (including trust income) from which payment could be made to or for the benefit of the individual will be considered a resource and any payments to or for the benefit of the individual will be considered income.

These rules apply regardless of the purpose for which the trust was established, whether the trustees have discretion under the terms of the trust, and whether there are any restrictions on distributions from the trust. See 42 U.S.C. § 1382b(e)(2)(C); POMS SI § 1120.201C.2.d.

B. Exceptions
Although first-party trusts, as described above, will generally count as income and resources to the grantor/beneficiary, Congress established two types of trusts that are exceptions to that rule and that enable people with disabilities to protect their eligibility for federal benefits by putting their assets into such trusts.\textsuperscript{5} These trusts are known as: (1) special needs trusts (or payback trusts), and (2) pooled trusts. 42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)\textsuperscript{6}. In addition, SSA may waive the provisions that count a trust as a resource or income for purposes of determining SSI eligibility to the extent that counting the trust would impose an undue hardship.

1. **Special Needs Trusts (Payback Trusts)**

Congress required that a trust meet all of the following criteria to qualify as a "special needs trust" that will not be counted as income or resources for purposes of determining the grantor/beneficiary's eligibility for SSI and MA:

\textsuperscript{5} These exemptions apply only to trusts established after January 1, 2000 (for purposes of establishing SSI eligibility) or to trusts established after January 1, 1993 (for purposes of establishing Medical Assistance eligibility).

\textsuperscript{6} Although a special needs or pooled trust may protect the individual's entitlement to benefits, it may not always be the optimal choice. If the funds available to the individual with a disability are sufficiently large and can cover the person's needs for most of his or her life, then the benefit of keeping access to the money without limitations may outweigh the cost of placing the money in a special needs or pooled trusts where access to it by the individual with the disability is extremely limited. Conversely, if the individual receives only a small sum of money, then it might make more sense to simply spend it quickly. This may result in a short-term loss of benefits, but it may enable the person to purchase certain things he or she needs or to pay off debts and then to resume eligibility for benefits.
The trust must contain the assets of an individual with a disability who is under age 65 or the assets of his or her spouse.

- The exception will continue to apply after the individual reaches age 65 as long as it was established prior to his or her 65th birthday. Additions to the trust principal after age 65, however, will not be subject to the exception and could jeopardize continued eligibility for benefits.

- "Disability" means that the individual meets the disability standards of SSI.

The trust must be established for the individual’s benefit by a parent, grandparent, a legal guardian, or a court.

- The trust must be for the sole benefit of the person with a disability. This means that the trust cannot provide benefits to any other person during the lifetime of the person with a disability (though payments to third-parties for goods or services for the person with a disability are permitted).

- The individual with a disability cannot establish the trust directly; rather, it must be established by a parent, grandparent, legal guardian, or court. If the individual with a disability is an adult who is legally competent, a parent or grandparent can establish a "seed" trust using his or her own money after which the individual with a disability can transfer his own assets into that trust. You should note that the exception will not apply to a trust created by a parent or grandparent acting pursuant to a financial **power of attorney** executed by a legally competent adult.

- A court can only create a special needs trust if it does so by an order. It is not sufficient for the court to merely "approve" a trust.

The trust must specifically provide that, when the beneficiary dies, the state will receive any amount remaining in the trust up to the amount of MA payments made by the state for the individual.
• The trust must be irrevocable.\textsuperscript{7}

In 2005, Pennsylvania enacted a statute that also establishes requirements that must be met for a special needs trust to be exempt from counting as a resource for purposes of determining MA eligibility.\textsuperscript{62} § 1414. Like the federal requirements, the state law requirements apply only to first-party trusts. The state law has somewhat more stringent standards for a special needs trust to be exempt from counting as a resource, including the following:

• The beneficiary must have "special needs" that will not be met without the trust. Special needs are defined as items, services, or products that are not covered by MA or any other third-party for which the individual or his parents are personally liable and that will increase the beneficiary's quality of life and assist in or be related to the treatment of his disability. Special needs include medical expenses, dental expenses, nursing or custodial care, behavioral health services, rehabilitative services, education, and transportation and travel expenses.

• The trust must provide both that all distributions must be for the sole benefit of the beneficiary and that any trust expenditure must have a "reasonable relationship" to the "needs" of the beneficiary.\textsuperscript{8}

\textsuperscript{7} Although the federal statutory standards do not mention the issue of revocability, the SSA has indicated that special needs trusts must still be evaluated under POMS § SI 01120.200D.1.a (which indicates that only irrevocable trusts will not count as resources) to determine if it is a resource. POMS SI § 01120.203D.1.7. 42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)(A); see also POMS SI § 01120.203B.1.

\textsuperscript{8} While the Pennsylvania law defines "special needs" quite narrowly and seems to exclude needs that are not medical or treatment-related, that definition may only affect whether the beneficiary qualifies to have a special needs trust. In contrast, the Pennsylvania law states that
2. **Pooled Trusts**

Congress required that a trust meet all of the following criteria to qualify as a "pooled trust" that will not be counted as income or resources for purposes of determining the grantor/beneficiary's eligibility for SSI and MA:

- The pooled trust must be established and maintained by a non-profit association. The non-profit association's trust is sometimes called a "master trust."

- Each account must be established solely for the benefit of an individual with a disability. "Disability," for purposes of a pooled trust, means a disability that meets SSI standards. Unlike special needs trusts, there is no age limit.\(^9\)

- Each account must be established through the actions of the individual with a disability or his or her parent, grandparent, legal guardian, or a court. Note that, unlike special needs trusts, a competent adult with a disability can directly establish an account in a pooled trust.

- Each beneficiary's assets must be retained in a separate account, but the assets from all accounts are pooled for purposes of management and investment.

- The trust must provide that, to the extent that amounts remaining in the beneficiary's account upon his death are not retained in the pool distributions from the trust must have a rational relationship to the individual's "needs" -- not "special needs." Thus, it is arguable that distributions from the trust can be used for items or services that do not meet the definition of "special needs" and are not medical or treatment-related.

\(^9\)Although there is no age restriction, persons over age 65 who transfer assets to a trust may be subject to a transfer penalty.
by the master trust, then the trust must pay to the state the amount remaining in the account up to the total amount of MA paid by the state for the beneficiary.

- The trust must be irrevocable.\(^\text{10}\)

42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)(A); see also POMS SI § 01120.203B.2.


More significantly, Pennsylvania's special needs trust statute, discussed in Section IV.B.1 above, also affects pooled trusts. This law places additional restrictions on pooled trusts beyond those in the federal law. Specifically:

- The beneficiary must be under age 65.
- The beneficiary must have "special needs" that will not be met without the trust, as discussed in Section IV.B.1 above.

\(^{10}\) Although the federal statutory standards do not mention the issue of revocability, the SSA has indicated that pooled trusts must still be evaluated under POMS SI § 01120.200D.1.a. (which indicates that only irrevocable trusts will not count as resources) to determine if it is a resource. POMS SI § 01120.203B.2, 01120.203D.2.7.
• The trust must provide both that all distributions be for the sole benefit of the beneficiary and that any trust expenditure have a "reasonable relationship" to the "needs" of the beneficiary.

• A pooled trust cannot retain more than 50 percent of any trust amounts that remain at the time of the beneficiary's death and that the rest must be paid to the Commonwealth up to the amount equal to the total MA paid on behalf of the beneficiary.


In Lewis v. Alexander, this provision of Pennsylvania law was challenged, and a federal appellate court concluded that it improperly created a more restrictive methodology for determining eligibility for MA benefits and was therefore preempted by federal law.

In Pennsylvania, there are several non-profit organizations that administer pooled trusts, including:

• The Family Trust (412-995-5000 ext. 565),
  \url{http://www.achieva.info/trustservices.php}

• The Arc Community Trust of Pennsylvania (610-265-4788),
  \url{http://www.arctrust.org}.

\textsuperscript{11} Although pooled trusts, unlike special needs trusts, limit the state's right to receive reimbursement for Medical Assistance expenditures (because they allow the pool to retain at least some of the assets), at least one Pennsylvania court has held that the Department of Human Services cannot require a Medical Assistance recipient to place his or her assets in a special needs trust rather than a pooled trust. Lewis v. Magee Women's Hosp. of UPMC.

3. Undue Hardship Exception

A trust that would otherwise count as resources or income for purposes of determining SSI eligibility may be exempted if counting the trust would result in an "undue hardship." 42 U.S.C. § 1382b(e)(4); POMS SI § C. An individual must apply to the SSA for an undue hardship waiver in order to invoke this exemption. An undue hardship will be found to exist if:

- failure to receive SSI payments would deprive the beneficiary of food or shelter;\(^\text{12}\) and,

- the beneficiary's available funds do not equal or exceed the Federal benefit rate plus the federally administered state supplement, if any.

This exception only applies to irrevocable trusts and to trusts that specifically prohibit disbursements that would provide for the beneficiary’s support and maintenance.

V. DUTIES OF TRUSTEES & LETTERS OF INTENT

A trustee -- whether a person or an entity -- owes a "fiduciary duty" to the beneficiary. This means, that in dealing with the trust property and income,  

\(^{12}\) A person will be considered to be deprived of shelter if he or she would be subject to eviction from his or her current residence without access to SSI and if there is no other affordable housing available or there is no housing available with necessary modifications for the person's disability.
the trustee must act in good faith and with undivided loyalty to the beneficiary. Thus, for example, the trustee probably should not invest the trust principal in investments in which the trustee has a personal interest. The trustee's fiduciary duty also requires him or her to use reasonable care and skill to preserve the trust property, to make it productive, and to account for it.

It is important to select a trustee with care since he or she will have the authority to manage the key assets for the individual with a disability that will impact his or her quality of life. In choosing a trustee, it is important to consider whether the person is ready to make a long-term commitment to managing the trust; is sensitive to the needs of the beneficiary with a disability; is willing to take the steps necessary to advocate for the individual with a disability to maintain his eligibility for benefits when appropriate; and has the knowledge and experience necessary to make sound investments. While family members can often serve as the trustee, you might also consider having a professional trustee serve as a co-trustee. In selecting a trustee, you should also compare the fees that different trustees may charge for their services.

Although not a legal document that binds a trustee or anyone else, a Letter of Intent may be important. The Letter of Intent reflects what is important to the person with a disability and his family. It may set out the person's routines, likes and dislikes, medical history, habilitation and treatment needs, and future plans. It may also identify people who are important to the person with a disability. This Letter of Intent can help to guide a trustee, as well as the individual with disability's current or future caregivers, to help
assure that he or she has a high quality of life and that his or her wishes are respected. A Letter of Intent should be reviewed from time to time to keep it as current as possible.

VI. **RESOURCES**

Some additional resources and materials related to trusts for people with disabilities are identified below.

**Statutes & Regulations**

42 U.S.C. § 1382b(e) (trusts under SSI)

42 U.S.C. § 1396p(c)-(d) (trusts under Medical Assistance)

62 Pa. Cons. Stat. Ann. § 1414 (Medical Assistance treatment of special needs trusts & pooled trusts under state law; much of the statute relating to pooled trusts was declared invalid in *Lewis v. Alexander* )


55 Pa. Code 178.4 & 178.7 (Medical Assistance treatment of trusts under state law)

**Social Security Materials**

POMS SI 01120.200
POMS SI 01120.201
POMS SI 01120.203

**Case Law**


Lang v. Commonwealth, Dep't of Public Welfare, 528 A.2d 1335 (Pa. 1987)


Lewis v. Alexander, _____ F.3d _____, June 20, 2012 WL 2334322 (3d Cir. 2012)


Snyder v. Commonwealth, Dep't of Public Welfare, 598 A.2d 1283 (Pa. 1991)

Articles


**Contact Information**

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: [intake@disabilityrightspa.org](mailto:intake@disabilityrightspa.org).

The mission of Disability Rights Pennsylvania is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities. Due to our limited resources, Disability Rights Pennsylvania cannot provide individual services to every person with advocacy and legal issues. Disability Rights Pennsylvania prioritizes cases that have the potential to result in widespread, systemic changes to benefit persons with disabilities. While we cannot provide assistance to everyone, we do seek to provide every individual with information and referral options.

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