



Pooled Trust Programs

A general overview for individuals with a
disability and their families

INTRODUCTION

The purpose of this guide is to assist parents, family members or other caregivers of people with mental retardation and related developmental disabilities to learn about a special method of planning called pooled trust programs.

Pooled trust programs enable families or other caregivers, and in some cases individuals with disabilities, to establish relatively inexpensive and effective trust accounts that provide supplemental funds for the person with a disability while protecting him or her from losing important government benefits such as Social Security Income and Medicaid.

Any type of supplemental needs trust add significantly to an individual's quality of life, paying for things that the parents may have paid for during their lifetime.

In a pooled trust program, an individual or a parent/guardian set up a sub-account within the trust. The program then 'pools' these funds to manage and invest as one account. Pooling reduces administrative fees and increases the principal for investment purposes. Pooling may also allow access to better quality investments that pay a higher rate of return than what is available for a small individual trust. Records are maintained so that each person has their own subaccount based on what was placed in trust.

There are several important points to remember as you review the contents of this guide:

- Pooled trust programs can vary considerably, so this guide is a general description of pooled trust programs.
- Do not rely solely on this guide to make a decision about using a pooled trust program or to make any other legal/financial plans. You should also consult with your own attorney and financial planner to determine a plan that is best for you and your child.
- Your family member with a disability is a unique individual. Planning should be tailored toward his or her unique needs, and the individual should be involved in the planning process as much as possible.

It is important to remember that this guide gives a general description and overview of pooled trust programs. Pooled trust programs vary in their operations. It is important to examine the specific details about any program you are considering using. Before signing any papers or investing in a trust, review written information on the particular program that you are considering, consult with your attorney and speak with other families who use the program. Meet with the people who operate the trust to ask questions and insist on clear answers. Carefully explore whether or not the program is a good and solid option for you and your family member.

FINANCIAL PLANNING FOR PEOPLE WITH DISABILITIES*

*The questions and answers in this booklet were drawn from the fact sheet published by The Arc titled *Future Planning: Making Financial Arrangements with a Trust*

Is there a connection between the benefits my child with a disability receives and his/her income and/or assets or resources (such as checking and savings accounts)?

There is a strong possibility that the answer is yes. Many individuals with disabilities receive 'means-tested benefits' such as Supplemental Security Income (SSI), a monthly monetary allowance that in many states makes the person eligible for Medicaid health and community support benefits. Means-tested benefits are benefits available to people with minimal income and minimal assets or resources. If a person's income or assets/resources exceed the specified limit, he or she will not be eligible for the benefit.

Two primary examples of means-tested benefits are Supplemental Security Income (SSI) and Medicaid. Adults are eligible for SSI if they have a disability that prevents them from working and earning a self-sufficient wage, and they do not have more than a certain amount of assets. Minor children (under age 18) may also be eligible for SSI if they have "marked and severe functional limitations" from a physical or mental condition. Minor children living with parents have some of the parent's income and assets countable to their application for benefits, while individuals over 18 only have their own income and assets counted. If they are in school between ages 18 and 21, parent's income and assets may be counted.

In most states, in order to remain eligible for Medicaid, a person cannot have more than \$2,000 (Year 2001 amount) in cash or assets that can be converted to cash. These services are often referred to as 'means-tested' because the individual's means (assets) are part of the eligibility criteria to qualify for services. Sometimes, items such as a home, car or a burial plot may not count as available assets. The home is not countable if the individual with a disability lives in it. It is countable if he or she does not live there.

If my child is receiving Medicaid-funded residential services, will he or she continue to receive Supplemental Security Income?

Usually people with disabilities receiving residential-related services that are paid for by Medicaid must contribute toward the cost of their care with money from earnings or from other sources such as their SSI or Social Security Disability Insurance payments. Cost of care charges are designed so that the person can only keep a small amount of money, usually referred to as a personal care allowance, to pay for many services and items that publicly-funded services do not cover. Non-covered costs may include medical and support expenses not covered by Medicaid or another program, entertainment, travel, books and other items and services that would enhance the individual's quality of life. This personal care allowance is usually small so that parents must

often use their own money to pay for the extra personal items and services their child needs, even if their child is an adult.

Does this replace other offerings such as SSI (Supplemental Security Income)?

No, funds from a Pooled Trust can be used to enhance the monies available to the person with the disability. The current Social Security regulations state that if you have more than \$2,000 in your own name, outside of a house or car, you are required to “spend down” to the \$2,000 or lose your financial support from the Social Security Administration. A pooled trust is a way for individuals to shelter their money and all funds placed in the trust are not counted as assets.

Does this have any effect on Medicaid?

The Pooled Trust may protect the client’s potential eligibility for Medicaid benefits such as care in a nursing facility and health benefits. Pursuant to federal regulations, any assets transferred to a trust established solely for the benefit of an individual under 65 who has a disability (whether or not he/she is the transferor’s child) will not render the transferor ineligible for Medicaid benefits. 42 U.S.C. § 1396p(c)(2)(B)(iv). Individuals should consult with an accountant about the tax implications of the trust and about the impact of the trust upon eligibility for other benefits.

How can I plan for future financial security for my child without jeopardizing his or her benefits?

Often, parents or others leave the child with a disability an inheritance, funds or property passing directly to another individual. If your daughter receives SSI and/or Medicaid and has access to more than \$2,000 in assets (e.g., from an inheritance), she would lose eligibility for SSI and Medicaid. She would have to spend down the amount to below \$2,000 before she could reapply for these benefits.

If she is receiving means-tested public services such as Medicaid, SSI, HUD housing or food stamps, the state might consider the inheritance an asset and the individual receiving it would incur "cost-of-care" charges. Publicly funded residential costs, for example, can amount to several thousand dollars per month. Having to pay even some of these costs can quickly deplete funds that parents intended to supplement the individual’s low personal care allowance. In some states, the state can bill for back cost of care if the individual lived at a state funded institution, even if they do not live there now. In this situation, the inheritance or gift will not have the intended benefit if the result is loss of benefits.

There are ways that you can help plan some financial security for your child with a disability without risking his SSI and related benefits. Some parents do not leave an inheritance to their child.

One way to provide for the financial security of someone with a disability without jeopardizing government benefits is by using a trust. Trusts hold money or property that the grantor, the person who sets up the trust, leaves for the benefit of another person, called a beneficiary. Unlike an outright gift or inheritance through a will, a trust usually contains carefully written instructions on when and how to use the trust's assets.

You or others can fund a trust while still alive or as part of a will. Some trusts make distributions to the beneficiary (or beneficiaries) over time. Others instruct the trustee to distribute just the trust's earnings (from interest or investments) or the amount the trustee thinks the beneficiary needs.

What kind of trusts are used to plan for the future needs of an individual with a disability?

There are many different trusts for various purposes. Laws that affect trusts can also vary from state to state. However, most states have laws that authorize some form of supplemental, discretionary or pooled trusts.

POOLED TRUST PROGRAMS

What are pooled trusts?

Pooled trust programs provide a convenient and economical way to have trust funds administered for people with disabilities that will supplement the benefits offered by entitlement programs.

These programs normally use a discretionary, irrevocable trust for supplemental needs. The assets placed in the trust by parents or others are allocated to a separate sub-account. The assets from all sub-accounts are 'pooled' together to invest and manage as one larger amount.

Records are maintained of the amount of each person's trust and the amount spent for that individual. The program divides the trust earnings among the individual sub-accounts in shares equal to the amount that each sub-account has in the pooled amount. A simple example is that if one subaccount makes up 10 percent of the total pooled amount, then that sub-account would get 10 percent of the pooled account's investment earnings (minus any fees).

A pooled trust program usually undertakes the daily management of the trust sub-accounts. This includes handling requests for and expediting disbursements, maintaining each sub-account's records, reporting to various agencies that might be affected by disbursements, preparing necessary reports (e.g., tax-related reports) and general management of the program.

Pooled trust programs are set up as or administered by a not-for-profit organization. They may be under the auspices of or closely connected with one or more disability-related organizations. Groups like state and local chapters of The Arc, Goodwill, National Alliance for the Mentally Ill (NAMI) and others have been active in establishing pooled trust programs. Members of these organizations often comprise the program's board of directors or other governing body. Pooled trust programs typically work closely with a bank, trust company or other financial institution. Some pooled trust programs have banks serve as trustee for the program's funds, while other pooled trust programs are their own trustees and may use the bank as an investment manager or a co-trustee.

What are the usual steps in establishing a pooled trust account?

The steps or process of establishing an account with a pooled trust program will vary and you should Consult with the trust program about the process for that program. In general, a pooled trust program will usually have you complete and sign a legal document that enrolls you in the trust. It gives the program the information needed about your child, how and when you plan to fund the trust, how you would like to see the trust funds used when it becomes active (when the trust is funded and disbursements begin) and other information.

Once enrolled, the trust program maintains your file and should periodically contact you to update it. Before signing any papers, the program representative should carefully explain the process including fees and other factors that you need to consider. You should then discuss the plan with your own attorney and/or financial planner to decide how you want to fund the trust and to help you prepare any necessary documents. There may also be tax issues to discuss with your attorney before establishing a trust.

Are there fees for pooled trust programs?

Yes. Pooled trust programs usually must charge fees for their services. Programs vary in their fees, and when and how they charge for them. The frequency and amount may depend on the type of trust plus the trust fund amount. The trust may also charge a sliding scale fee based on the amount of the trust account.

Most trusts tend to have an enrollment fee, paid when you sign the joinder agreement (legal document that enrolls you in the trust) or activate the trust. They may also have a periodic maintenance fee (usually annual) to provide ongoing management. Certain fees may change due to inflation or as the trust's principal decreases with distributions.

Banks and other financial institutions also charge fees for a trust account. Pooled trust programs and financial institutions should provide a written copy of their fees and payment schedules. An important consideration about the fees for pooled trust programs is to compare them to those that a bank or trust company would charge for a trust of comparable size and with similar provisions. Banks and other financial institutions often charge much higher fees to manage an individual trust. By pooling resources for investment and management, pooled trust programs can minimize costs, so that fees are usually reduced considerably.

Can I specify exactly how I want the trust used?

A trust program should seek input and advice from you, and whenever possible from the person with a disability, about how the trust funds are to be used. However, the trust is designed to protect SSI, Medicaid and publicly funded services, so the trustee must have sole discretion about how disbursements are made, including how much is spent and items and services that are purchased.

Medicaid or other public services may currently approve trust disbursements for certain items and services, but there is no guarantee that this will not change in the future after you are gone. Changes in the law, new restrictions and other unforeseen events may make it necessary for the trustee to modify the amount of, or reason for, disbursements to help ensure the trust continues to serve its intended purpose.

It is important to remember that disbursements made directly to the beneficiary, or for food,

clothing and shelter on a regular basis may reduce or eliminate essential benefits like Medicaid and SSI. Trusts are designed for meeting supplemental needs rather than basic needs. Beneficiaries will need to use their income from government benefits or employment to meet basic needs.

How do I go about funding a trust account?

Parents can fund a pooled trust account as they would fund an individual trust with a bank. The trust account can be funded by an inheritance through a will, from life insurance, from savings or in other ways. Parents may fully fund the trust when it is established. They may also fund it incrementally over time.

Pooled trust programs usually accept only cash assets; assets such as property are usually difficult for pooled trust programs to manage. A parent, grandparent, or anyone in need of long-term care services in a nursing home may be able to transfer assets into a trust for his or her child, grandchild, relative or other person with a disability, and thus qualify for Medicaid, without having to wait through the 'lookback' period. Consult with your attorney or trust program for more information on this option.

Pooled trust programs allow certain individuals with disabilities to use their own assets in a trust established by a parent, grandparent, legal guardians, court or the individual himself. For many families, funding a trust will not have any significant impact on estate or death taxes. However, you should consult with your attorney and financial planner on these issues including any other tax issues that might arise.

What amount of money can or should I place in a pooled trust program?

Pooled trust programs may have different rules on the minimum and maximum amounts allowable in trust accounts. The pooled trust program should provide you with specific information on any restrictions.

Each person with a disability will have different needs that may affect how the trust is set up and with what amount. The person's age, services being received (or someday received) and other variables can affect these decisions. Families should seek the advice of their own attorney, financial planner and trust program staff for information and guidance on this aspect of planning.

What can a trust pay for?

When the person with a disability is receiving SSI and/or publicly funded services such as Medicaid, a trust normally cannot pay for food, clothing, shelter and basic health care costs. There are sometimes exceptions, but you need to discuss these with the trust program representative.

Pooled trusts, like individual trusts, are normally set up to provide services and items that do not jeopardize means-tested benefits.

What happens to any remainder in the trust if the beneficiary dies before it is used?

If sufficient funding is available, trusts are often set up with the goal of spending all principal and earnings by the time the beneficiary dies. However, the beneficiary may die prematurely, or if the trust account is quite large, funds may remain after the beneficiary dies. How the remaining funds are used depends on the type of trust, conditions set forth by the donor and/or the policy of the trust program.

Can I establish a trust for anyone?

Most pooled trust programs have policies about whom they choose to serve as beneficiaries. To participate in a pooled trust, Medicaid states that the person must meet the Social Security Administration (SSA) definition of disabled. Adults are eligible for SSI if they have a severe physical or mental impairment that prevents them from working and earning a self-sufficient wage, and they do not have more than a certain amount of assets.

Children also are eligible for SSI if they have "marked and severe functional limitations" from a physical or mental condition and their parents do not have more than a certain amount of assets. Sometimes a person does not fit SSA's criteria for 'disabled' but will fit a state's definition of having a disability. If the person for whom you are planning does not fit SSA's criteria, consult with the trust program to determine if the person is eligible under a state definition and if the trust program serves people with the particular disability.

What are the benefits of using a pooled trust program?

There are advantages for individuals with disabilities and their families or others who use the services of a reputable trust program:

- Parents may not have or know someone who is willing to be a trustee. Trust programs usually have knowledgeable staff and volunteers who will serve as trustee or manager of the trust.
- An individual trustee could die, move away or not fulfill the trustee role for some other reason.
- Trust programs offer continuity, as the program does not depend on just one individual.
- The trust document used by programs usually has been developed and reviewed by attorneys with expertise in this area of law. There is also the likelihood that publicly funded agencies have also reviewed the trust document for compliance with their agency regulations.

- Banks and trust companies will not accept or manage a trust that is not funded at a threshold amount. Depending on the bank, the trust account may have to be several hundred thousand dollars or more. Parents who cannot afford to fund a large trust are often able to fund an adequate account in a pooled trust program.
- Pooled trust program staff or volunteers often have expertise and experience with people who have disabilities. The volunteer board of the program may also be comprised of legal and financial experts, family members of people with disabilities and advocates.
- Trust programs usually work closely with banks and trust companies to maintain trust accounts and can tap the expertise of financial institutions. This relationship can help maintain good financial accountability without incurring high fees for the beneficiaries.
- It is also worth repeating that one of the biggest advantages to using a pooled trust program is the expertise brought to managing the trust and making the required reports after it begins to make disbursements.

Are there disadvantages to using a pooled trust program?

Some families and individuals may find that using a pooled trust has some disadvantages. These include:

- Parents or other family members have no direct control over trust disbursements. The trust program usually seeks advice and input from families and others, but may deny requests, especially if the request jeopardizes the person's benefits.
- Trust programs usually pool all the resources for investment purposes. Families cannot direct how their specific family member's trust account is individually invested. Investment policies are usually conservative.
- If you decide to withdraw from a trust program early and have already paid enrollment and/or other fees, you may forfeit some or all of those fees.
- A trust program may have a policy about retaining a portion of assets that remain in a third party trust after the beneficiary dies. However, you may want all remaining assets to go to other individuals and/or organizations.
- A trust program's policy about retaining a portion of remaining assets, plus its full discretion to disperse as much (or as little) of the trust as it decides, raises the theoretical potential that the program will withhold disbursements to increase its share of the amount of remaining assets it might retain. Trustees are required to exercise fiduciary responsibility precisely because of this kind of concern.

What safeguards are in place to ensure that a pooled trust program is operated effectively, my money is safe and that my family member is well cared for?

Federal and state statutes dictate some of what a pooled trust can and cannot do, but there are no enforceable standards for the operation of pooled trust programs. There is no certification or accreditation process for pooled trust programs. Consumers should be cautious about accepting certifications and similar credentials as a definitive sign of quality.

There are also no guarantees with this type of financial planning. Possible changes in SSI and Medicaid regulations or state/federal laws, investment fluctuations, the beneficiary's future service needs and numerous other factors may affect how your individual plan is carried out.

The following questions may assist you in making some judgments about the trust program:

- Does the trust program have the financial and/or volunteer support of one or more well known disability organizations?
- Is the governance board comprised of people with expertise in disability, legal and financial matters?
- Does the trust program use the services of a reputable bank, trust company or other financial institution as a trustee or for account management? If you contact this financial institution, do they know about the program and its operation?
- Do program staff or volunteers provide clear and comprehensive written and verbal information about how the trust operates including its fees and services? Do they answer your questions in easy-to-understand language? Are they knowledgeable about federal/state benefits, laws that affect planning and the reporting requirements after the trust is active?
- Does the program evaluate its services and the satisfaction of families and others already using the trust? Does the program readily share this information? If you speak with others who use the trust program, do they indicate they are satisfied with the program?
- Does the program produce a regular (annual) report of its activities?
- Is it clear that the program is operated in a businesslike manner and with a mission that places the welfare of its clients above all?

I already have an individual trust written into my will, what should I do if I want to consider using a pooled trust?

You need to speak with the trust program and with your attorney about using a pooled trust account instead of an individual trust or possibly using a pooled trust in conjunction with another trust. Your current discretionary (special needs) trust may already allow the trustee discretion to distribute money to a pooled trust account, which in turn, could then make distributions for the beneficiary and ensure proper reporting. However, you should not assume that this is the case. Even if you currently have no desire to use a pooled trust, consider discussing this option with your attorney and a representative of the pooled trust program. This may help ensure a wider array of options in the future.

What is the role of my child with a disability and other family members when considering a pooled trust plan?

A trust program should seek input and guidance from parents, the person with a disability, siblings and significant others. Family members should discuss and understand how the trust program operates and stay involved when the trust becomes active and disbursements begin. Since the individual with a disability and family members may be the ones to request trust fund disbursements, it is important that these individuals know how the program works and have a good relationship with the trust program representative.