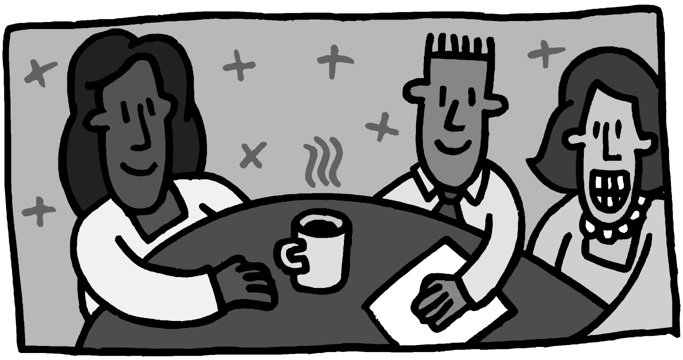
POOLED TRUST PROGRAMS FOR PEOPLE WITH DISABILITIES

A GUIDE FOR FAMILIES



The Arc®

2002

ACKNOWLEDGEMENTS

This publication was developed from the contributions of many individuals knowledgeable about trust programs. It has a long history, beginning with a group of representatives from chapters of The Arc and trust programs who came together to discuss issues related to pooled trusts at The Arc's 1998 national convention in Fort Worth, Texas. There was another meeting the following year at The Arc's convention in Nashville, Tennessee. These chapter representatives shared their knowledge and experience in operating pooled trusts at these meetings. Much of the information in this document was gleaned from these meetings and from materials distributed by participants.

Rick Berkobien, former staff member of The Arc, wrote a first draft of *Pooled Trust Programs for People with Disabilities: A Guide for Families* with assistance from Theresa Varnet, an attorney with Spain, Spain & Varnet. The first draft was sent to willing reviewers who generously offered their time to review and comment on the document. Sharon Davis took over the task of incorporating those revisions after Rick departed for a position with the Oregon State Legislature. Several knowledgeable individuals rigorously reviewed the second draft.

The Arc would like to thank everyone who helped in the production of this document. Attendees at pooled trust meetings and reviewers of the first draft include:

Margaret Lowe, John Burns, Rod Shipley, Mary Jane Michael, Patti Saunders, and Patrick Rumley, Foundation of the Arc of Anchorage, Alaska
David W. Schneider, Special Needs Trust Foundation, California
Kent Olsen, The Colorado Fund for People with Disabilities, Colorado
Alan Kemp, The Arc of Indiana Master Pooled Trust, Indiana
Barbara Helm, ARCare Trust Program, Kansas
Theresa Varnet, Spain, Spain & Varnet, Massachusetts
Joann Baxter, The Arc of New Mexico Master Trust I and II, New Mexico
Lawrence Faulkner, New York
Susan Hartley, Life Plan Trust, Inc., North Carolina
Gretchen Yost, The Arc of Oregon Pooled Trust, Oregon
Tim Pawol,The Family Trust, Pennsylvania
Lisa Rivers, The Arc of Texas Master Pooled Trust,Texas
Renee Lovelace, Texas
Chris Mims, Texas
Roberta K. Welsh, Chesterfield Community Trust, Virginia

The Arc thanks the following individuals who reviewed the second draft:

Alan Kemp, The Arc of Indiana Master Pooled Trust, Indiana
Theresa Varnet, Spain, Spain & Varnet, Massachusetts
Susan Hartley, Life Plan Trust, Inc., North Carolina
Martha Ford, The Arc of the United States

The Arc thanks Alan Factor and Betty Erickson, Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC) and advocate advisors Ray and Marie Murphy for their review of the manuscript.

The Arc is indebted to **Merrill Lynch & Co. Foundation, Inc.** for its grant to convene the Fort Worth meeting that contributed to the development of this publication.

Finally, The Arc thanks the many families who have invested their time and money in helping to establish local pooled trust programs. They have served in leadership roles and demonstrated their support for the programs by establishing accounts for their own family members.

Karen Staley, President
The Arc of the United States

INTRODUCTION

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. Families set up a sub-account with a trust program. 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. Beneficiaries of these trusts usually receive earnings based on their share of the principal. Accounting methods can separate out each person's account. Some states actually use separate trust agreements for each beneficiary, but pool all funds for investment.

More information and details about pooled trust programs are presented in this guide. However, 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 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. It is very important to read the materials from any program you are considering and meet with the trust program representative to discuss the details of the program. You should also consult with your own attorney and financial planner to determine a plan that is best for you and your child.

- There may not be a pooled trust program in your area or state. Many states have one or more pooled trust programs, while other states do not have any. Additionally, a program may have restrictions on who can be served, depending on disability group, financial status or geographic location. However, a growing number of states are exploring the development of pooled trust programs.

- This guide uses certain terms and language when describing the people involved in planning. The people who plan are usually referred to as "parents," even though siblings or others may also set up trusts. The son or daughter with a disability is referred to as their "child," even if this person is an adult. Referring to this person as a child is not meant to demean the individual. It is used only to indicate the relationship.

- Your family member with a disability is a unique individual. Planning should be tailored toward his or her unique needs, and the member should be involved in the planning process as much as possible. The presence of a disability does not necessarily mean that your family member will require ongoing services and/or specialized financial planning.

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 financially planning for an adult or minor child with a disability. The guide focuses on a special method of planning called pooled trust programs. Trusts established to cover supplemental needs add significantly to an individual's quality of life, paying for things that the parents paid for during their lifetime. **Part One** of this guide presents an overview of general financial planning for people with disabilities through a legal trust and is the groundwork for understanding Part Two of this guide. **Part Two** describes pooled trust programs and how they can assist in financial planning.

PART ONE: AN OVERVIEW OF FINANCIAL PLANNING AND PEOPLE WITH DISABILITIES*

*The questions and answers in Part One were drawn from the fact sheet published by The Arc titled *Future Planning: Making Financial Arrangements with a Trust* by Rick Berkobien & Theresa Varnet. Rick Berkobien, formerly with The Arc of the United States, is now with the Oregon State Legislature Policy, Research and Committee Services. Theresa Varnet is an attorney with Spain, Spain & Varnet and has a daughter with mental retardation.

Is there a connection between the benefits my child with a disability receives and his or 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 parents' 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, parents 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--as low as $30 a month in many states—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.

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. Instead, a sibling or other family member receives an additional share of the inheritance to use to benefit the person with a disability. This is sometimes referred to as a "morally obligated" gift. Unfortunately, the assets intended to benefit the person with a disability may not be spent on this person. For example, if the non-disabled sibling divorces or dies early, the extra funds may end up going to the divorced or widowed spouse or another heir.

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. If you establish a trust while still alive, you can be the trustee (the person who manages the trust). You can also assign someone else to be trustee. A trustee can be a person, financial institution (bank), and, in many cases, a not-for-profit pooled trust program. Laws regulating who may serve as trustee vary from state to state.

You may design a trust to distribute assets to one or more beneficiaries at certain times or under certain conditions. 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. Some trusts may require the accumulation of all income for distribution at a future time.

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 even master "pooled" trust. Experts recommend specialized trusts when parents want to protect government benefits that their child needs. Some of these trusts are called "special needs" trusts. (The term “special needs” trust may have a specific legal and/or technical definition to state/federal agencies, attorneys or others.)

Supplemental discretionary trusts - Supplemental discretionary trusts are designed so that the principal (the amount put in the trust account) and its earnings (from interest or investments) supplement the beneficiary's basic care and do not replace the public funds required to pay for this basic care. This kind of trust is good for the SSI and Medicaid recipient whose assets cannot go above a specific level. The trust grantor can carefully direct that the trust not pay for services covered by Medicaid or other benefits received as a result of the child’s disability. Instead, the trust would require the trustee to provide funds for certain items, services or other expenses not covered by SSI and Medicaid. Supplemental discretionary trusts can also be set up for someone who is not on SSI and Medicaid.

Discretionary trusts - Some states allow the trust grantor to give the trustee full discretion in how much or how little of the trust to distribute. This kind of trust can also contain provisions that limit distributions so that the person remains eligible for government benefits. The trustee of a discretionary trust must be careful not to distribute money from the trust for goods and services or outright to the beneficiary in a way that will disqualify him from receiving or remaining eligible for public-funded services. There are several drawbacks to a discretionary trust. The trustee must be knowledgeable about the benefits a person is receiving and how to report correctly on the distributions. The trustee has total power over all distributions and may hold back all or some of the trust’s distributions. It is important that you choose a trustee whom you trust and who will take the time to learn how certain distributions from a discretionary trust will affect government benefits.

The difference between a supplemental discretionary trust and a discretionary trust is that the supplemental discretionary trust includes language that directs the trustee to use the trust funds to supplement government benefits and not supplant them. The discretionary trust simply states that all distributions are in the sole discretion of the trustee. The qualifying language regarding the grantor’s intent to supplement government benefits is not included. Some states have required the trustee of a discretionary trust to pay for basic support when the grantor’s intent to supplement government benefits has not been made clear.

How do I go about setting up a trust?

There are usually two ways to set up a legal trust with your attorney. It can be testamentary or inter vivos (living).

Testamentary - This means the trust is part of a will and does not take effect until after the person who drew up the will dies. Parents can change the trust's provisions any time the will is changed. So, if the intended beneficiary should die first, the will and trust can change. Tax-wise, this kind of trust does not require the person to file or pay income tax on it since there are no funds in it until after that person dies.

Inter vivos (or Living) - This means the person establishes a trust before dying. In doing so, the parents and/or others can make regular gifts to such a trust. Grandparents can make testamentary bequests from their will to the trust set up for their grandchild with a disability. Parents can be the trustee and manage the trust according to their own discretion. They can also assign someone else to be trustee to see how that person would manage the trust.

Which laws affect trusts?

Third party trust is a general term for a trust that a parent or others (the "third party") establish for another person. Third party trusts are based on "common law," which means that trusts can be established by one person for another with certain conditions about how and when the trust is used (e.g., a special needs trust). Some states like New York and Illinois have specific state laws about special needs trusts. If established within certain parameters, third party trusts will not effect SSI or Medicaid eligibility.

The federal Omnibus Budget Reconciliation Act of 1993, called OBRA '93 for short, is a federal law that affects how people with disabilities can have a trust and still qualify for Medicaid. The Foster Care Independence Act of 1999, is a federal law that affects how people with disabilities can have a trust and still qualify for SSI. Both laws allow many people with disabilities to place their own money into a trust and become (or remain) eligible for Medicaid and SSI. For purposes of this booklet, these trusts will be called OBRA trusts. There are limited ways that people with disabilities can place personal assets into an OBRA trust:

- **Individual "special needs" trust.** The person with a disability must be under the age of 65, and the assets are his or her own assets (from an inheritance, personal injury suit, etc.). However, a parent, grandparent, court or legal guardian must establish the trust, and not the person with a disability. If any money is left in the trust after the person with a disability dies, it must then be used to pay back the state to cover the costs of publicly funded services that the person received over his or her lifetime. This is sometimes called a "payback" trust or "self-settled" trust. The Social Security Administration also refers to this type of trust as a "special needs" trust.

- **Pooled trust**. The assets of a person with a disability are placed into a sub-account of a pooled trust program. The trust sub-account in the pooled trust program must be set up and managed by a not-for-profit organization. The trust is established for the individual by a parent, grandparent, court, legal guardian or by the individual himself. Part Two of this guide describes other important aspects of pooled trust programs.

PART TWO: POOLED TRUST PROGRAMS

Many pooled trust programs administer **third party trusts** and **OBRA trusts** as described above. These terms are used throughout the remainder of this guide to distinguish between the two. Remember the important difference between **third party trusts** and **OBRA trusts**:

- **Third party trusts** are set up by parents or others with assets that do not belong to the person with the disability and do not require that the state be reimbursed. The trust remainder can go to other heirs and/or organizations.
- **OBRA trusts** are set up with the money of the person with a disability. OBRA trusts can be individual trusts or pooled trusts. Payback provisions to the state may apply. Depending on the circumstances, the balance (or a portion of the balance) that remains in the trust after the beneficiary has died, will be paid to the state as reimbursement for publicly funded services the state provided to the beneficiary while the beneficiary was alive.

WARNING
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.

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 sub-account 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. Many trust program representatives also spend considerable time meeting with families about the program and assisting families and others with future planning information.

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. The pooled trust staff are usually responsible for expediting disbursements from trusts, tracking and reporting how disbursements are made, assisting with tax preparation and other management responsibilities.

Some pooled trust programs include direct "care coordination" services for their beneficiaries, or contract with care coordinators to provide services. Services vary depending on the agency and amount of services provided, but the care coordinator may visit the beneficiary, be present at meetings about the individual, advocate on the individual's behalf and provide related services as needed. Usually the costs of these services are covered by the individual's trust funds and are charged hourly.

Why is good management of the trust important <u>after</u> it becomes active?

Government agencies often have complex, strict regulations and reporting requirements to monitor the means-tested eligibility of the people with disabilities who receive their services and have trust funds. They want to know when the person receives a trust disbursement and how the disbursement was made (e.g., what was purchased). These disbursements must often be reported and explained according to each agency's regulation and note why neither income nor a countable resource was created. Regulations and reporting rules may vary considerably from state to state and even from agency to agency within a state. Agencies may also change their regulations from time to time, so keeping current on their rules is equally important. Additionally, reporting can be complicated further when the trust recipient is receiving a mix of services that may have different regulations.

Ensuring that the trust disbursements do as they are intended (i.e., improve the individual's quality of life while not interfering with eligibility for means-tested benefits) is an extremely important responsibility. If parents have no one to count on for learning the regulations and making the reports, the trust will not do what they want.

A trust program can and should be responsible for this role. It should know about people with disabilities and know about the regulations and reports. It is responsible for ensuring that disbursements and proper reporting occur in a timely matter. It can also intervene, when necessary, when an agency questions a disbursement or report, which happens from time to time. A well-intentioned family member designated as a trustee may not have the time, inclination or energy to fulfill this important role.

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 may depend on whether the trust is a **third party trust** or an **OBRA trust**. 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.

Pooled trust programs that include care coordination usually require that families meet with a care coordinator to complete a detailed plan for providing these services. Enrollment needs to occur before the grantor dies, so that a care plan can be developed together. This plan may also be updated periodically.

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 (**third party** or **OBRA**) 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. Most bank trust departments require a minimum of $200,000 - $400,000 for a single trust fund, while pooled trust programs are more flexible about the size of trusts they are willing to accept. Most pooled trusts have lower minimums.

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. Both third party and OBRA 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 **third party trust** in a pooled trust program 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 enroll in the trust and not fund it until later, for example, at their death, or they may decide to 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.

OBRA trusts established in 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. These restrictions are often dependent on whether the trust is a **third party trust** or an **OBRA trust**. 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. The trust program may also provide information on the average life expectancies of people at certain ages and how different trust amounts would be spent down over time (based on the amount placed in trust, plus average earnings, disbursements, inflation and fees over the beneficiary's lifetime).

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.

Third party trusts <u>do not</u> require that the state be reimbursed for publicly funded services that the beneficiary may have used during his lifetime. You can usually designate another person, several people or an organization you want to receive some or all funds that remain. You may also designate that the remainder is split between people and/or organizations. The trust program may also have a policy that allows it to retain a portion of the remainder amount after the beneficiary dies. Before establishing a **third party trust**, discuss the program's policy and options for remaining trust funds.

OBRA trusts <u>do</u> require that the state be reimbursed from remaining funds in an account. The pay back is for publicly funded expenses incurred in providing Medicaid services to the person with a disability. However, the law allows the trust program to set a policy regarding the first right to retain any portion or percentage of the **OBRA trust** remainder. After the trust program retains its portion of the remainder, the state can then recoup payment from what is left. If funds remain in an OBRA trust afterwards, provisions in the trust could designate how remaining funds are distributed. However, state funded services are usually extremely costly and can amount to several thousand dollars per month, so it unlikely that an OBRA trust will result in any significant amount of funds that can be distributed to other heirs.

Trust programs put the funds that they retain to good use. These funds may be used to assist other beneficiaries whose trust funds run out prematurely. Funds may also be used to operate the program. When given the option of how remaining funds are distributed, consider earmarking some or all of these remaining funds to the trust program or a related charitable organization.

Can I establish a trust for anyone?

Most pooled trust programs have policies about whom they choose to serve as beneficiaries. To participate in an OBRA 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. Trust programs should advise you conservatively on the benefits and possible risks when planning. These benefits and risks may exist regardless of using a pooled trust program, bank or other method of financial planning. Beware of anyone who promises that a service or program "guarantees" or "ensures" or "assures" a plan for your son or daughter.

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.

PART THREE: LIST OF POOLED TRUST PROGRAMS

The Arc has identified 35 pooled trust programs. Inclusion on this list is not an endorsement or guarantee of the services of these organizations. The list is for information purposes only.

ALASKA:

Foundation of The Arc of Anchorage, 2211 Arca Dr., Anchorage, AK 99508, (907) 277-6677, psaunders@arc-anchorage.org, www.arc-anchorage.org.

CALIFORNIA:

Special Needs Trust Foundation, 9575 Aero Drive, San Diego, CA 92123, (858) 715-3780.
PLAN of California, 1336 Wilshire Blvd., 2nd Floor (LA MHA), Los Angeles, CA 90017, (213) 413-1130.

COLORADO:

The Colorado Fund for People with Disabilities, One Broadway, Suite A-330, Denver, CO 80203, (303) 733-2867.

DELAWARE

Delaware CarePlan, Inc., 1016 Center Road, Suite One, Wilmington, DL 19805-1234, (302) 633-4000, decareplan@aol.com.

FLORIDA:

Advocate Trust, Inc., 1501 N. Belcher Rd., Suite 219, Clearwater, FL 33765, (727) 791-3972, Atrustinc@aol.com.

The Florida Pooled Trust, 2600 First Avenue North, St. Petersburg, FL 33713 (877) 766-5331, www.firstpooledtrust.org.

PLAN of Florida, 4605 Community Drive, West Palm Beach, FL 33417 (561) 684-1991.

ILLINOIS:

Life Plan, Inc., 2801 Finley Road, Downers Grove, IL 60515, (630) 628-7168.

INDIANA:

The Arc of Indiana Master Trust, The Arc of Indiana, P. O. Box 80033, Indianapolis, IN 46280-0033, (317) 259-7603.

KANSAS:

ARCare - Master Trust I & II and Guardianship, 8001 Conser, Overland Park, KS 66204, (913) 648-0233.

MASSACHUSETTS

Berkshire County Arc Pooled Trust, P.O. Box 2, Pittsfield, MA 01202, (413) 499-4241 x 266, bgray@bcarc.org

The CJP Disabilities Trust, Jewish Family & Children’s Service of Greater Boston, 1340 Centre Street, Newton, MA 02159, (617) 558-1278.

MARC Trust, Inc., 217 South St., Waltham, MA 02453, (781) 642-1285.

MICHIGAN:

Pooled Sub-Account Trust, The Arc of Midland, 220 West Main Street, Midland, MI 48640 (989) 631-4439.

NEW HAMPSHIRE

Enhanced Life Options Group, 15 Constitution Drive, Suite 169, Bedford, NH 03110, (603) 472-2543.

NEW JERSEY:

PLAN of New Jersey, P.O. Box 547, Somerville, NJ 08876-0547, (908) 575-8300.

SCARC Guardianship Services, Inc., 11 U.S. Route 206, Suite 100, Augusta, NJ, 07822 (973) 383-7442.

NEW MEXICO:

The Arc of New Mexico Master Trust One and Two Program, 3655 Carlisle NE, Albuquerque, NM 87110-5564, (505) 883-4630.

NEW YORK:

NYSARC, Inc., New York State Guardianship Services, 393 Delaware Ave., Delmar, NY 12054, (518) 439-8311.

F.E.G.S. Community Trust and PLAN, 315 Hudson Street, New York, NY 10013, (212) 366-8008. (in cooperation with UJA-Federation of New York, Inc.).

UJA-Federation of New York, Inc., Community Trusts, 130 East 59th Street, New York, NY 10022, (212) 836-1339 (in cooperation with F.E.G.S. Community Trust and PLAN).

Life Services Third Party-Funded Trust for People with Disabilities, Disabled and Alone/Life Services for the Handicapped, Inc., 352 Park Avenue South, 11th Floor, New York, NY 10010, (800) 995-0066 or (212) 532-6740, disabledandalone@aol.com, www.disabledandalone.org.

NORTH CAROLINA:

Life Plan Trust, 122 Salem Towne Court, Apex, NC, (919) 589-0017, lptsh@earthlink.net.

OHIO.

Community Fund Management Foundation, 1275 Lakeside Avenue East, Cleveland, OH 44114-1132, (216) 736-4540, cfmf@apf.net.

The Ohio Community Pooled Trust, The Disability Foundation, Inc., 1530 Kettering Tower, Dayton, OH 45423-1395, (937) 224-9940, disabilityfdn@daytonfoundation.org.

OREGON:

The Oregon Special Needs Trust, The Arc of Oregon, 1745 State St., Salem, OR 97301, (503) 581-2726 or toll-free 1-877-581-2726, OSNTrust@callatg.com.

PENNSYLVANIA:

Berks Community Trust, c/o The Arc of Berks County, 1829 New Holland Rd., Suite 9, Reading, PA 19607-2228, (610) 603-0227.

The Family Trust, Arc of Allegheny Co., 711 Bingham St., Pittsburgh, PA 15203, (412) 995-5000, www.thefamilytrust.org.

RHODE ISLAND:

Self-Sufficiency Trust of Rhode Island, 1255 North Main Street, Providence, RI 02904, (401) 331-3060.

TEXAS:

The Arc of Texas Master Pooled Trust, 1600 W. 38th Street, Suite 200, Austin, TX 78731, (512) 454-6694.

VIRGINIA:

Commonwealth Community Trust, P.O. Box 29408, Richmond, VA 23233, (804) 740-6930 www.commonwealthcommunitytrust.org.

Norfolk Community Trust, c/o Norfolk Community Services Board, 248 West Bute Street, Norfolk, VA 23510-1404, (757) 441-5300

The Personal Support Trusts, The Arc of Northern Virginia, 100 North Washington Street, Suite 234, Falls Church, VA 22046 (703) 532-3214.

Virginia Beach Community Trust for Persons with Mental Disabilities, c/o Community Services Board, Pembroke Six, Suite 218, Virginia Beach, VA 23462, (757) 437-6079.

WASHINGTON:

Lifetime Advocacy Plus, 11000 Lake City Way NE, Suite 401, Seattle, WA 98125-6748, (206) 367-8055, laplus@laplus.org.

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, Maryland 20910
301-565-3842
info@thearc.org
www.thearc.org

RRTC on Aging with Developmental Disabilities
Institute on Disability and Human Development
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, Illinois 60608-6904
1-800-996-8845 or 1-800-996-8845 (Chicago Relay Access)
http://www.uic.edu/orgs/rrtcamr/index.html

This is a publication of The Arc of the United States and the Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities, funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, under grant number H133B980046. The opinions in this publication are those of the grantee and do not necessarily reflect those of the U.S. Department of Education.