

Planning for Children with Disabilities

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The future financial needs of a loved one with disabilities are an important concern for many people. While in Ohio, a parent's legal obligation to support a child generally ends at age 18, the financial needs of a child with disabilities does not end.

Financial assistance to an adult child is not simple. It is complicated by the very real consideration that many individuals with disabilities must remain eligible for Medicaid and Federal Supplemental Income (SSI). This is particularly true in situations where the child has significant medical needs.

For example, if parents or other loved ones continue to assist and support an adult person with disabilities after the age of 18, the disabled person will not be eligible for Medicaid and SSI. On the other hand, supplemental items can be provided, if done in conformity with Ohio law.

Also, in general, an adult disabled person cannot accumulate assets and still qualify for Medicaid and SSI. Such a person cannot have assets greater in value than \$1,500 and still remain eligible for Medicaid and SSI.

Similarly, if a trust is created to provide for a disabled person's basic needs (food, clothing and shelter), then the income or assets of the trust can disqualify the person from receiving state assistance. The trustee can be forced to use all the trust assets to pay for all of the needs of the disabled person.

With these restrictions, parents and other loved ones often ask us: "How can my child have a house?" "How can I provide for my child's quality of life?" "How should I write my Will?"

This report addresses each of these questions, and provides the alternatives available so that you can assist the adult child with disabilities even after you die.

What if I Leave Money to a Trusted Friend or Relative Who Will Take Care of My Child with Disabilities?

Parents or other loved ones can leave money or other assets to a trusted child or other relative, with the informal, unwritten understanding that the money or other asset will be used to support the unmet needs of the disabled person. However, this approach can result in unforeseen outcomes. For example, the person to whom the money is left could die before the person with the disability, thereby frustrating the original intent. Also, a divorce could result in the money intended for the disabled person being lost in a divorce settlement. Or, this person could have financial difficulties that result in the loss of the money, through bankruptcy, a lawsuit or other ways. Finally, the person to whom the money is left may simply decide to use the inheritance in ways other than to support the disabled person. It is important to consider that with this type of unwritten agreement to support the disabled person is only an *understanding*; it is not legally enforceable.

Using Your Will to Meet Future Needs

A simple approach to planning for the future needs of a child with disabilities is by using a Will. Yet, this approach is not without problems, which should be seriously considered and carefully communicated to all the family members.

A parent sometimes decides to leave a greater share of an estate to a disabled child. This is particularly the case when the disabled child does not need governmental assistance. However, this approach may alienate other family members if the decision is not thoughtfully communicated. Such alienation could result in such discord that the other siblings refuse, or see no need, to assist the disabled sibling after the parents die.

The Will can also name a guardian for the disabled child. After both parents have died, this clause can assist the local probate court in determining who should serve as guardian. It is customary to name two to three alternate choices for guardian, in the event any one appointed person is unable or unwilling to serve at the time.

The concerns and hopes of a parent of a disabled child are sometimes never communicated to other children or loved ones. Also, important financial, medical and other information can be lost if not recorded in a convenient form and stored in an accessible place. Attorneys, financial planners and other professionals can assist the preparation of these important papers.

Creating a Trust to Meet Future Needs

A trust is a legal entity that allows one person to transfer assets to another person, managed by a trustee. The trust document gives the trustee authority to manage the assets and pay funds in the trust to a beneficiary, all according to the instructions given in the trust agreement.

A Trust is particularly helpful in situations where a person who will benefit from the trust (the beneficiary) lacks the ability to make wise decisions about money. These can be created at any time, by signing a trust agreement. Or, the trust can be described in a Will, and will be funded at death (a so-called testamentary trust).

They are also a useful tool to set aside money for supplemental needs of a disabled person (such as vacations, hobbies and entertainment), while still allowing that person to qualify for SSI and Medicaid benefits.

The selection of a trustee (the individual or entity who will manage the assets in the trust and distribute money from the trust) for a trust is an important consideration. If an individual is selected, he or she should have the education and experience necessary to handle investments and accounting. If a financial entity is used, the cost of the fees payable to administer the trust must not be too high. Also, many bank trust departments will not accept trustee responsibilities for trusts with assets below \$100,000. Most often, the trustee is a responsible family member or trusted advisor.

The Four Types of Trusts

Support Trusts. One type of trust is the support trust. This type of trust is used to provide financial support for other people. For example, an uncle of a disabled child could establish this type of trust to provide ongoing support of the child. When the trust assets are depleted, the trust terminates.

A support trust is sometimes established in combination with one of the types of trusts discussed below. This helps ensure that once the assets in the support trust are exhausted, the supplemental needs (the “extras,” such as vacations and hobbies) of the disabled person are still met.

Discretionary Trusts (Supplemental Needs Trust). One of the most common trusts used in estate planning where one of the heirs is a disabled person is the discretionary trust. A discretionary trust is so named because the trustee is given *discretion* over when

to distribute money from the trust, how to do it, for what purposes and to whom. Such a trust is sometimes referred to as a Supplemental Needs Trust.

The advantage of using this type of trust comes into effect on the death of the beneficiary. On death, the remaining assets in the trust can be distributed to other people or charities. This is in contrast to a Supplemental Services Trust (discussed below) which requires that fifty percent of the remaining assets must go to the State of Ohio.

A discretionary trust must be carefully prepared in Ohio. This is because the courts in Ohio have determined that the trust assets can disqualify a disabled person from Medicaid eligibility if he or she is the beneficiary of a trust that includes language that allows the trust assets to be used for the “benefit, support, education, maintenance and welfare” of the disabled person. An attorney can include various protections in the discretionary trust to improve the chances that a court would not challenge the trust. These include the following:

- provide for multiple beneficiaries;
- require that distributions be made only at the complete discretion of the trustee, and even then only for supplemental needs of the beneficiary, not for “benefit, support, education, maintenance and welfare”;
- include a “spendthrift” clause, which makes clear that the beneficiary does not own the trust assets, has no access to trust assets, and cannot force the trustee to make distributions from the trust, and that a creditor of the beneficiary cannot reach the assets;
- allow for automatic termination of the trust and distribute assets to alternative beneficiaries if the trust is successfully challenged or causes a loss of state benefits.

Careful drafting by a qualified attorney is essential if this type of trust is used. Also, the trust should be reviewed on an annual basis by a qualified attorney to determine whether any changes are necessary to comply with Ohio law of Federal SSI law.

In March 2004, the Ohio legislature made important changes to the law. Section 5111.151 of the Ohio Revised Code clarifies that if a trust contains certain provisions, neither the trust assets or income will be considered available to the beneficiary (an “avail-able asset”) provided the following provisions are included:

- the Trustee must have no ability by the terms of the trust to pay for “medical care, care, comfort, maintenance, health, welfare, general well-being, or a combination of these purposes” for the beneficiary;

- a precise statement that requires, without the Trustee's discretion, that the trustee use the trust for a purpose other than "medical care, care, comfort, maintenance, health, welfare, general well-being, or a combination of these purposes" so that it is clear that only supplemental services can be provided for;
- a precise statement that requires, without the Trustee's discretion, that the trust shall be terminated by the trustee if it is ever counted as an available resource.

Even though the affect of a discretionary trust on Medicaid eligibility is fairly predictable, the use of this trust could cause ineligibility for SSI. This risk is discussed in more detail later in this chapter.

Supplemental Services Trusts. The Supplemental Services Trust is authorized under Ohio law and is designed to benefit people receiving services from, or eligible to receive services from, a local or state mental health or mental retardation and developmental disability system (MR/DD). An Ohio law provides that if such a trust is established according to law, the state will not invade trust assets.

The Ohio law (O.R.C. § 1339.51) requires the following:

- the trust can be created in a Will (a Testamentary Trust) or, after October 26, 2001, in a separate trust;
- the trust cannot be created with more than \$224,000 in assets as of 2007 (this amount increases \$2,000 annually);
- the *beneficiary's* assets cannot be used to create the trust;
- the assets of someone with a legal obligation to support the beneficiary *cannot* be used to create the trust;
- distributions from the trust are limited to "supplemental services, which are detailed below."

Upon the death of the beneficiary, fifty percent of the remaining assets in the trust must be transferred to the State of Ohio. The other fifty percent can be distributed in any manner selected when the trust is created. Interestingly, the funds that are transferred to Ohio are used by the state to provide the supplemental needs of others who do not enjoy the benefits of this type of trust. On the other hand, in most situations little will be left to transfer to the state at the death of the beneficiary, since it will have most likely been depleted before that time.

Supplemental services are expenditures, items or services that meet the following criteria:

- The services are in addition to services an individual with a disability is eligible to receive under programs authorized by federal or state law or regulations, and the services do not supplant services that would otherwise be available without the existence of the trust;
- The services are in addition to basic necessities for such items as essential food, clothing, shelter, education and medical care, and the services are in addition to other items provided pursuant to an ascertainable standard; and
- The services are paid for with funds distributed pursuant to a Special Services Trust that meets the requirements of Ohio law, and the services would not be available without payment from the trust.

Supplemental services that meet the criteria outlined above may include, but are not limited to, the following:

- Reimbursement for attendance at or participation in recreational or cultural events;
- Travel and vacations;
- Participation in hobbies, sports or other activities;
- Items beyond necessary food and clothing (e.g., funds for dining out occasionally, for special foods periodically delivered, or for an article of clothing such as a coat which is extra but which is desirable because it is newer, more stylish, etc.);
- Cosmetic, extraordinary, experimental or elective medical or dental care, if not available through other third party sources;
- Visiting friends, companionship;
- Exercise equipment, or special medical equipment if not available through other third party sources;
- The cost differential between a shared room and a private room;
- Equipment such as telephones, cable television, televisions, radios and other sound equipment, and cameras for private use by the individual;
- Membership in clubs such as book clubs, health clubs, record clubs;
- Subscriptions to magazines and newspapers;
- Small, irregular amounts of personal spending money, including reasonable funds for the occasional purchase of gifts for family and friends, or for donations to charities or churches;
- Advocacy;
- Services of a representative payee or conservator if not available through other

- third party sources;
- Guardianship or other protective service;
- Someone other than mental health community support staff members to visit the individual periodically and monitor the services he receives;
- Intervention or respite when the person is in crisis if not available through other third party sources;
- Vocational rehabilitation or habilitation, if not available through other third party sources;
- Reimbursement for attendance at or participation in meetings, conferences, seminars or training sessions;
- Reimbursement for the time and expense for a companion or attendant necessary to enable the individual to access or receive supplemental services including, but not limited to, travel and vacations and attendance at meetings, conferences, seminars, or training sessions;
- Items which Medicaid and other governmental programs do not cover or have denied payment or reimbursement for, even if those items include basic necessities such as physical or mental health care or enhanced versions of basic care or equipment (e.g., wheelchair, communication devices), and items which are not included for payment by the per diem of the facility in which the beneficiary lives; and
- Other expenditures used to provide dignity, purpose, optimism and joy to the beneficiary of a supplemental services trust.

Supplemental services also specifically include expenses for burial and related services for an individual, not otherwise paid for, and in an amount not to exceed four thousand five hundred dollars. Such burial services may be purchased by the trustee in an irrevocable prepaid burial contract while the beneficiary is alive, or paid by the trustee after the death of the beneficiary.

Medicaid Payback Trusts. With a Medicaid Payback Trust, the Federal government allows people to set aside money to benefit a disabled person as long as, on such person's death, the trust pays back to Medicaid the amount of Medicaid benefits received. The term "payback" means that at the death of the beneficiary, whatever is left in the trust must be used to "pay back" Medicaid expenditures.

There are two types of these trusts: the Special Needs Trust and the Pooled Trust. These are discussed separately below.

Special Needs Trust. Federal law and Ohio law authorize the Special Needs Trust. It can be established at any time by a parent, grandparent, legal guardian or a court, for

anyone with a disability. Funds from the beneficiary or from third parties can be used to fund the trust. Also, funds from third parties can be added to the trust. If the statutory rules are followed, the funds in the trust, and the payments from the trust, will not affect the disabled person's eligibility for Medicaid.

The Special Needs Trust is most valuable in situations where the disabled person is entitled to receive and actually recovers funds as a result of a lawsuit or insurance settlement arising from an accident. Another helpful use is in a situation where a beneficiary receives a substantial back payment from Social Security.

What Are "Special Needs" That Trust Assets Can Be Used For? Special needs are expenditures, items or services which meet the following criteria:

- The services are in addition to services an individual with a disability is eligible to receive under programs authorized by federal or state law or regulations, and the services do not supplant services which would otherwise be available without the existence of the trust;
- The services are in addition to basic necessities for such items as essential food, clothing, shelter, education and medical care, and the services are in addition to other items provided pursuant to an ascertainable standard; and
- The services are paid for with funds distributed pursuant to a Medicaid Payback Trust which meets the requirements of Ohio law, and the services would not be available without payment from the trust.

Examples of special needs that meet the criteria outlined above are listed earlier in this chapter as "supplemental services."

Pooled Trusts. A Pooled Medicaid Payback Trust is a trust created by a nonprofit corporation to "pool" together the trust funds of multiple beneficiaries. In general, the requirements for this trust are the same as for the one-beneficiary Special Needs Trust. The important differences are that a Pooled Medicaid Payback Trust can be created by the disabled person, and the assets remaining in the trust at the death of the beneficiary do not need to be paid to Medicaid if the funds are used to cover the overhead expenses of the pooled trust or are used by other beneficiaries of the pooled trust.

In Ohio, there are two pooled trusts: the Community Fund Management Foundation, managed by Fifth Third Bank (call (216) 736-4540 for more information); and the Disability Foundation, managed by the Dayton Foundation (for people in Montgomery,

Greene and Miami counties) (call (937) 225-9940 for more information.) Both trusts allow initial investments of as low as \$5,000.00.

Trust Options Compared

	Discretionary Trust	Supplemental Services Trust	Medicaid Payback Trust
Created By	Anyone Other Than Beneficiary	Anyone Other Than Beneficiary	Parent, Grandparent, Guardian or Court; Beneficiary if pooled trust
Document	Will or Trust Agreement	Will or Trust Agreement	Trust Agreement
Trustee	Any Person or Entity	Any Person or Entity	Any Person or Entity (<i>pooled trusts</i> available)
Assets From	Anyone with no duty to support person	Anyone with no duty to support person	Beneficiary and any other person or entity
Limits	None	\$224,000 (2007)	None
Assets Used For	Not for "benefit, support, education, maintenance and welfare"	Supplemental Services	Supplemental Services (also called Special Needs)
Balance To	Any Person or Charity	50% to Ohio	Medicaid payback
Typical Use	estate planning	estate planning	personal injury settlements

The Effect of a Trust on SSI

The effect of a trust on eligibility for SSI benefits must be carefully considered in any decision to establish a trust. Otherwise, the disabled person may find that the trust is a resource that renders him or her ineligible for SSI, or that the earnings from the trust are income that similarly reduce or eliminate SSI payments.

The Trust as a Resource. To qualify for SSI, the trust must not be a resource for SSI purposes in excess of the statutory maximum. The Trust is not a resource if:

- the beneficiary has no legal authority to revoke the Trust;
- the beneficiary is not the sole beneficiary of the Trust;
- the beneficiary has no authority to direct the use of the Trust's assets for his or her own support or maintenance;
- the beneficiary has no access to Trust principal;
- the Trust does not provide for payments to the beneficiary or on his behalf;
- the beneficiary has no right to Trust earnings;
- the Trust receives no payments (other than earnings) from another source; and
- the Trust contains a spendthrift provision that prohibits anticipation of any Trust payments.

The Trust Distributions as Income. The next question is whether disbursements from the Trust are income to the disabled person. Such will not be the case if:

- no cash will be paid directly to the beneficiary from the Trust;
- no food, clothing or shelter will be received by the beneficiary as a result of disbursements from the Trust to a third party which need to be valued under the presumed maximum value rule, except as described in the next paragraph; and
- only disbursements from the Trust to a third party that result in the beneficiary receiving items other than food, clothing or shelter will be made (e.g., payments to medical provider; improvements to home for bathroom accessibility).

Which Type of Trust is “Best”?

To determine which of these four options is best in any situation, it is important to consult with an attorney. In general, the discretionary trust is the best option, and the Supplemental Services Trust, second best, for a beneficiary that does not receive SSI. If SSI is received, then the Medicaid Payback Trust is favored. For those beneficiaries where only a small amount of assets will be transferred to a trust, the Pooled Medicaid Payback Trust is the only practical option, because of the substantially lower fees involved to create and administer the funds.

The Family Home

The disposition of the family home is a heart wrenching decision for many families of adult disabled children. While with careful planning, an individual can own a home and

still be eligible for public assistance, he or she may be unable to maintain the home, physically or economically. Also, if the home needs to be sold in the future, the money received may make the person ineligible for Medicaid or SSI benefits.

Medicaid Eligibility. It is clear that a person can own a home and remain eligible for Medicaid benefits. The home can be transferred to one of the trusts described above, provided each of the limitations are satisfied. For example, for a Supplemental Services Trust, the value of the home and other assets in the trust cannot exceed \$224,000 in 2007.

SSI Eligibility. If the disabled person receives SSI payments, care, must be taken to comply with the SSI eligibility rules. It is important to understand that just because a trust is acceptable for Medicaid purposes does not necessarily mean that it is acceptable for SSI eligibility purposes.

A general discussion of the considerations relevant to determining whether a trust is a resource is included in the previous section. If the trustee of a trust that is not a resource for SSI purposes purchases and holds title to a house as a home for the beneficiary, the house is not a resource to the beneficiary.

Next is the question whether the beneficiary receives income from the purchase or transfer of the home. Social Security regulations provide that the purchase results in the receipt of shelter in the month of purchase. This results in income in that month. This income is valued at no more than the presumed maximum value. The regulations are clear that the home would be income and would reduce the beneficiary's SSI payment no more than the presumed maximum value *in the month of purchase only*, regardless of the value of the home.

Guardianship

Whether a disabled adult child needs a guardian or not is a question that must be considered in any plan. When a child reaches the age of 18 in Ohio, his or her parents are no longer legally responsible. For a guardian to be appointed for the adult child, the child must be incompetent, and there must be a present need for a guardianship.

Types of Guardianships. Guardianships are available in various forms. They range from full and complete guardianship over a person's life (non-financial matters) and estate (financial matters), to a limited guardianship which is limited to that part of a person's life in which the incompetency arises. Emergency guardianships are also available in Ohio.

A guardian of an adult must live in the state of Ohio. This is because of the need for frequent in person contact between the local county Probate Court (the court that considers guardianship proceedings in Ohio) and the guardian.

If no person can be found to serve as guardian, the Ohio Department of MR/DD can provide the services of an agency that can do so. Information is available from Advocacy and Protective Services, Inc. at (800) 282-9363.

Representative Payee. In situations where the incompetent person has minimal assets, and has only SSI income, it may be possible to avoid a cumbersome guardianship proceeding and annual accountings by having someone appointed as a representative payee. Social security payments would then be made to this payee, who would pay the bills and expenses of the person. Another person could then be appointed guardian of the other aspects of the person's life.

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