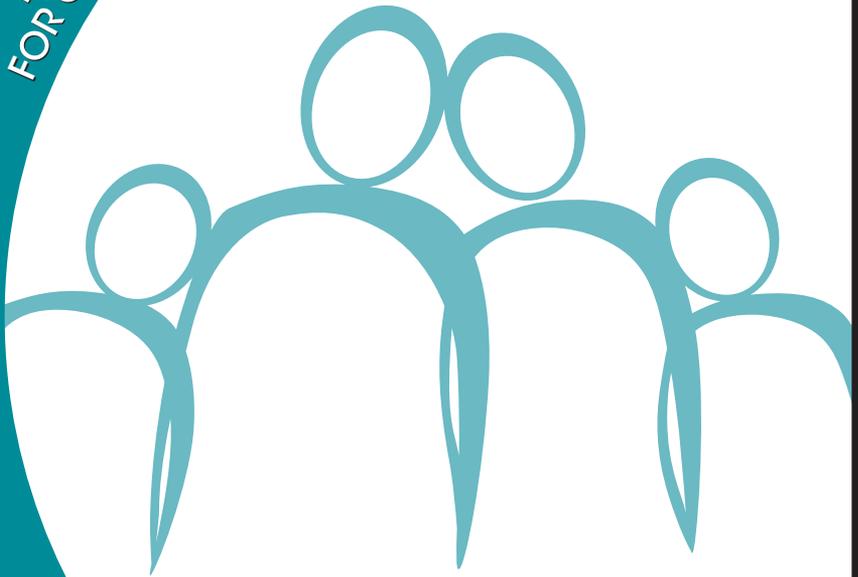


# ESTATE & FUTURE PLANNING FOR OHIOANS WITH DISABILITIES & THEIR FAMILIES

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## Foreword

This booklet attempts to offer a brief, non-legalistic overview of the estate planning options that exist at the time of this writing for people with disabilities and their families in Ohio. It also provides a summary of other areas that might be called “future planning.” Readers should consult their own attorneys before attempting to implement information in this document, which is abbreviated and cannot begin to cover situations unique to each person. With that caution in mind, users are welcome to copy and share this document.

## About the Author

David Zwyer, Esq., has been speaking to people with disabilities and their families about guardianship and estate planning for over 30 years. Dave served as the Chairman of the Disability Law Committee of the Ohio State Bar Association, and he worked for various organizations that serve people with disabilities including The Arc of Ohio, the Ohio Coalition for the Education of Children with Disabilities (OCECD), Advocacy and Protective Services, Inc. (APSI), the Ohio Department of Developmental Disabilities, the Ohio Developmental Disabilities Council (ODDC), as well as a law firm in Columbus. Dave currently works with the Community Fund Management Foundation (CFMF).

## About the Ohio DD Council

The Ohio Developmental Disabilities Council (ODDC) is a planning and advocacy group of approximately 30 members appointed by the governor. ODDC receives and disseminates federal funds in the form of grant projects to create visions, influence public policy, pilot new approaches, empower individuals and families, and advocate for system change.

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## Estate Planning for People with Disabilities: Initial Considerations

In most cases, parents, while they are alive, are able to assist their children financially without jeopardizing their children's eligibility for public assistance benefits. One of the most important purposes of this book is to give parents information about how they can continue to assist their children, even after they die, without jeopardizing necessary benefits.

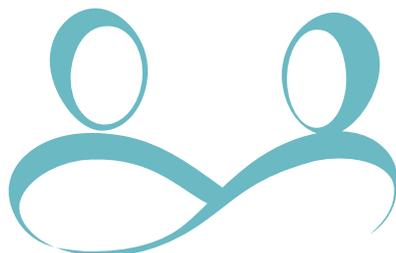
Many individuals with disabilities need to remain eligible for Medicaid and Supplemental Security Income (SSI), especially if they have significant medical needs. As a general rule, in Ohio that means the individual cannot have assets greater than \$1,500 and still remain eligible. (The SSI limit is \$2,000, but the Medicaid limit is \$1,500. Most people need to consider the lower limit.) Care must be taken to determine what might be considered an asset to the individual when a parent dies, including, but not limited to joint bank accounts, payable on death (POD) accounts, life insurance policies, IRAs (individual retirement accounts), life estates and trusts. For example, one question you might ask is, "who are the beneficiaries of a life insurance policy on the life of a parent when the parent dies?" Also, "who owns a life insurance policy on the life of the person with a disability when the parent-purchaser dies?"

In Ohio, parents' legal obligation for support of their child generally ends when the child reaches age 18, the age of majority. There are exceptions, such as when a court extends the obligation as the result of a divorce. [See Revised Code, Sections 2919.21 and 3103.03 and *Castle v. Castle*, 15 Ohio St. 3d 279 (1984).]

Individuals over 18 who are unable to support themselves because of a disability may be eligible for various public assistance benefits including, but not limited to Medicaid and SSI. Keep in mind that eligibility for these programs as well as Social Security Disability Insurance, is contingent upon the applicant being sufficiently disabled. Medical documentation will be needed for this purpose. In some cases a child under the age of 18 may also be eligible for public assistance benefits.

If the disability had its onset before age 22, the individual might be eligible for services from a County Board of Developmental Disabilities (DD). The County Board uses funds raised by county levies in addition to Medicaid to provide a wide variety of residential and employment supports, as well as the assistance of a social work/case management type of person, usually called a Service and Support Coordinator.

Parents typically continue to assist and support their children after the age of 18 whether or not they have a disability. If parents continue to provide full support for a child after he or she reaches age 18, the child will not be eligible for Medicaid and SSI. Even if the parents only provide supplemental items, they must do so carefully in order to retain their child's eligibility.



## Eligibility for Medicaid, SSI and SSDI

*Medicaid* is essentially a needs-based health insurance program that pays for a variety of services for people who are elderly, blind or who have other disabilities. Services include, but are not limited to coverage for prescription medications, adaptive equipment and residential programs and supports. In addition to paying for nursing homes and group homes, various Medicaid Waiver programs (PASSPORT, Home Care, Transition, IO or Individual Options, and Level 1) also provide residential supports. Individuals with disabilities who work may be able to accumulate more than \$10,000 in assets if they participate in the Medicaid Buy-In for Workers with Disabilities Program, but they may also have to pay a premium in order to keep Medicaid as their health insurance.

*Supplemental Security Income* (SSI) is a monthly payment from taxpayer funds that is used to provide food, shelter and other necessities for those who are eligible. As a needs-based program, many people equate SSI with welfare. In 2010, payments ran as high as \$674 per month, but that amount might be reduced based upon the earned and unearned income of the recipient.

A person with too much income or too many assets will not be eligible for either SSI or Medicaid. In some cases, it might be worthwhile to accept a reduction in SSI in order to accept income from another source, because often the reduction in SSI is not dollar for dollar. Also, some income might be offset by qualifying expenditures in a process called “spend down” that would allow a person to qualify. It is important to consult with someone knowledgeable about these benefits in order to set up an estate plan that does what you want it to do.

*Social Security Disability Insurance* (SSDI), on the other hand, is a monthly payment based on the amount of Social Security the recipient or, if they are a dependent, a parent has paid into the system as a wage earner. A person with a disability who worked and paid into the system may be able to draw SSDI as a result of their own work history. A person with a disability who is the dependent or survivor of a parent with a work history may also be eligible for SSDI. A person will not be eligible for SSDI if they are performing a substantial gainful activity (SGA) and have earned income over approximately \$1,000 per month. Monthly SSDI payments are determined by the amount paid into the system and the amount of earned income, not by a person's assets. If a person is receiving SSDI, then Medicare provides their health insurance.

In some cases, it may be more beneficial for a person to receive SSDI rather than SSI. For example, in some cases you might receive a larger amount under SSDI than under SSI, and you don't have to worry about what assets you have. In a small number of cases, a person may be eligible to receive both SSI and SSDI, as well as both Medicaid and Medicare. In the latter situation, the total monthly payment of SSI and SSDI will be limited to the same amount as the maximum monthly SSI payment. Thus, it is important to work closely with Social Security to determine which benefits the person with a disability may be eligible for. If remaining eligible for public assistance benefits is important, then two principles should be kept in mind:

1. An asset does not affect eligibility for Medicaid and SSI unless it is accessible to the individual. Some assets, such as a home, an irrevocable prepaid burial account and a car of minimal value are considered exempt when determining a person's eligibility.

2. If an asset, such as a trust, provides basic necessities of life to an individual with a disability (food, medical care, shelter, education), then Medicaid and SSI will not pay for them. If there is a standard in a trust requiring the trustee to pay for such items, then the trustee will be expected to pay for all necessities for the person with the disability, and the person will not be eligible for Medicaid and SSI.

Not all attorneys are familiar with all of the options discussed in this booklet. In order to identify attorneys who do have some knowledge and interest about this type of estate planning, contact a local organization that serves individuals with disabilities. Examples are County Boards of DD, Community Mental Health or ADAMH Boards, Arcs, and Easter Seals.



## Last Will and Testament

At one time it was thought that parents had to disinherit their child with a disability in order to ensure that he or she would be eligible for various public assistance benefits. Although other options exist today, it is still not unusual for parents who are seeking a simple approach to estate planning to distribute their assets among other children with the unwritten understanding that the other children will use their increased share to provide for the child with the disability. Although this solution is simple, experiences such as death, divorce, bankruptcy and creditor claims may complicate it. Also, such an “understanding” is not enforceable.

If such an approach is taken (i.e., disinheriting a child), a clause might be added to the parents’ Will that affirms their affection for the child with the disability and clarifies the parents’ intent. An example of such a clause might be, *“I am not leaving anything to my child X, not because of any lack of affection, but only because of his [or her] mental disability.”*

Parents may also wish to consider dividing their assets evenly among their children. It may be an error to leave a greater share to the child with a disability without open communication and agreement with the other children. After all, parents don’t want to risk alienating the siblings they hope will step in when they are gone.

The Will also can be used to state who the parents want to serve as guardian for the child, if that should ever become necessary. This will help ensure that someone is available to step forward to file an application for guardianship in probate court if a parent or current guardian dies, a support system disappears or other circumstances change and make the guardianship necessary.

Because children often outlive their parents by 30-40 years, it is advisable to name guardians three deep:

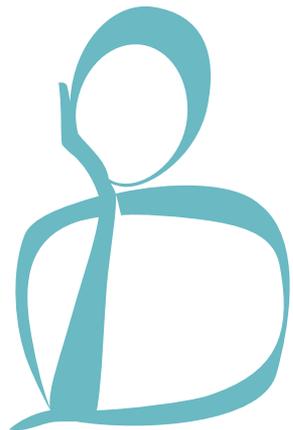
- A primary;
- A first backup; and
- A second backup.

At least some of those named should be the same age or younger than the individual with the disability.

A document that might be used to more fully explain the intent of a person making a Will is called a Letter of Intent. It may make sense to more fully express one's wishes in such a Letter of Intent than in a legal instrument such as a Will or a Trust. An increasing number of attorneys and financial planners have forms for completing a Letter of Intent, that when filled out, would provide very helpful information to future guardians or residential providers.

It is possible for people with developmental disabilities to make their own Will if they:

1. Know what they own;
2. Know who are "natural objects of their bounty" (legal language meaning family and friends); and
3. Can decide to whom they want to leave their assets and possessions.



## Trusts: General Considerations

Trusts are flexible legal documents in which one party leaves assets to another party (a trustee) to be used for the benefit of another person, charity and so on. The trust instrument gives specific instructions as to how to pay out the assets. Trusts are not only for the wealthy. They represent a way to withhold assets from someone who may not be old enough, have enough experience or have the ability to make wise decisions.

Trusts may be Testamentary or Living, Revocable or Irrevocable. Testamentary Trusts are created in a person's Last Will and Testament, often from the proceeds of the deceased person's estate. Living Trusts are more of a contractual arrangement, possibly with a bank or professional person as the trustee, or possibly with a family member other than the beneficiary as trustee. Living Trusts are sometimes promoted as a means to avoid probate. However, in some situations it may be wise to have the distribution of the estate supervised by a probate court.

A Revocable Trust may be amended or revoked. An Irrevocable Trust generally may not be amended or revoked, although there may be some exceptions to the general rule.

Selecting a trustee can present its own problems. For instance, trust departments of many banks in larger cities will not act as trustee for a trust with a balance of less than \$200,000. On the other hand, if a family member is going to be asked to serve as trustee, that person should have skill in handling financial matters or be willing to hire someone who has such skill to assist. It may also make sense for the trustee to be someone other than the person's guardian. This section includes examples of some programs where a trustee is provided. However, an advisor to the trust also may be needed or desired.

Finding a qualified attorney with whom to explore options is extremely important. A knowledgeable attorney will help clients accomplish their purpose with the trust, without affecting the beneficiary's eligibility for Medicaid, if that is the clients' wish.

The purpose of creating trusts for people with disabilities is to improve the quality of life for the beneficiaries by paying for items that public assistance programs do not. These are items that parents or other relatives would have continued to pay for if they were still alive. Using trusts to enhance the happiness of the beneficiaries and to keep them more engaged in meaningful activities can reduce behavior problems, reduce peer-to-peer incidents and reduce costs to the public. Federal and state laws now allow trusts to be created for people with disabilities without affecting their eligibility for Medicaid.

If the purpose of the trust is to pay for supplemental items or luxuries only, it is worth remembering that it may not take a great deal of money to accomplish that limited purpose.

Several different trust options are now available that allow providing for people with disabilities without affecting their eligibility for Medicaid. A brief summary of each follows. But first, it is important to consider where the money that will be used for the trust will come from.



## Which Trust is Right for You?

The source of the money to be used to fund a trust determines which trusts can be used in given situations. If the money comes from someone other than the person with a disability, for example, a relative or a friend, then the only types of disability trusts that can be created are either a Wholly Discretionary Trust or a Supplemental Services Trust. If the money belongs to a person with disability, then there are two other options—either a Special Needs Trust (i.e., a regular Medicaid Payback Trust) or a Pooled Medicaid Payback Trust.

## Trusts Funded with Assets From Family and Friends

### *Option 1: Wholly Discretionary 3rd Party Trusts*

A Discretionary Trust is one in which the trustee is given a great amount of “discretion” as to when and how assets in the trust are distributed. The term “Wholly” Discretionary Trust refers to recent changes in the Ohio Trust Code which give greater recognition and support to the intent of the creator of the trust. “3rd Party” means that the creator of the trust is using it to benefit a third party—the person with a disability—not himself.

A Discretionary Trust is one of the most common estate planning tools for families of children with disabilities in Ohio and in many other states. How useful this trust is depends on the regulations, laws and court decisions of each state. The Medicaid regulations and laws in effect at the time someone applies for Medicaid will determine whether that person is eligible for Medicaid.



The primary advantage of a Discretionary Trust in Ohio is that there is no requirement that a portion of the trust be turned over to the state upon death of the beneficiary. That is logical because the funds in the trust never “belonged” to the beneficiary. However, such a trust must be carefully drafted, or its purpose may be defeated, once again pointing out the need to seek a qualified attorney.

Since 1968, the State of Ohio has been able to invade trusts (old method) or to declare a person ineligible for Medicaid (current method) if he or she is the beneficiary of a trust containing words like “for the benefit, support, education, maintenance and welfare” of the individual with the disability. A court can order the trustee of such a trust to pay support to the beneficiary of the trust based on this enforceable standard. It is easy to determine the cost of items such as food, clothing, and shelter. While the trustee is paying for this support, the beneficiary would be ineligible for Medicaid. [See *Kreitzer v. Bureau of Support*, 16 Ohio St. 2d 147.]

In 1996, use of a Discretionary Trust for a person with a disability came before the Ohio Supreme Court. The court upheld Medicaid eligibility in that case because the trust assets were not accessible to the beneficiary. [See *Young v. Department of Human Services*, 76 Ohio St. 3d 547.]

In March 2004, Ohio Revised Code Section 5111.151 was enacted into law. (See also Section 5101:1-39-27.1 of the Ohio Administrative Code.) The most striking provisions of that law are as follows.

- A trust is considered to be an available asset—and would make the beneficiary ineligible for Medicaid—if the trustee is permitted 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. [See subsection (G)(2)]
- The trust is not considered to be an available asset if it contains a “clear statement” that requires (that is, no discretion) the trustee to use the trust for a purpose other than medical care, care, comfort, and so on, as above (that is, for supplemental items, luxuries, and so on). [See subsection (G)(4)(b).]
- Most importantly, the trust is not considered to be an available resource if it contains a “clear statement” that requires (that is, no discretion) the trustee to terminate the trust if it is counted as an available resource. This section appears to give the grantor the ability to use the trust to pay for necessities as long as this “poison pill” clause is included in the trust. [See subsection (G)(4)(d).]

Thus, a Discretionary Trust may now be set up for a person with a disability in such a way that the trustee can even pay for necessities, without having a negative impact on the beneficiary’s eligibility for Medicaid. The state has no incentive to challenge such a trust when the only result will be that the trust will terminate and assets will be distributed to people other than the beneficiary and the person will still be eligible for Medicaid. Careful drafting, including following the rule/statute on Medicaid Trusts, remains important.



The real impact of Discretionary Trusts that are used to pay for necessities may not be on Medicaid eligibility, but on eligibility for SSI. Parents, as well as attorneys and financial planners advising them, will have to consider if it is worth setting up a trust that might reduce or eliminate SSI benefits, no matter which type of trust is used.

As a result of the Kreitzer and Young decisions and the subsequent enactment of Section 5111.151 of the Ohio Revised Code, the following drafting techniques are often recommended:

1. Avoid an enforceable standard (e.g., “benefit, support, education, maintenance and welfare”) and give complete discretion to the trustee;
2. Include a termination, “poison pill” or “booby trap” clause that causes the trust to “blow up” and trust assets to be distributed outright to alternative beneficiaries if the trust becomes subject to invasion or causes a loss of benefits;
3. Include a spendthrift clause clarifying that the beneficiary does not own the assets of the trust, cannot require the trustee to make distributions, and that creditors cannot reach the assets (that is, the beneficiary does not own, control or have access to the assets);
4. Require that distributions be made only for supplemental items over and above necessities of life; and
5. List more than one possible beneficiary.

## *Option 2: Supplemental Services Trusts*

In 1993, Ohio authorized the creation of Supplemental Services Trusts to benefit people with disabilities who are being served—or who are eligible to be served—either by state or local Mental Health or Developmental Disability (DD) systems. The primary advantage of a Supplemental Services Trust is that it provides a statutory safe harbor (safe from invasion or challenge by the state if the trust meets certain conditions set forth in the law). [See O.R.C. Section 5815.28, O.A.C. DD Section 5123: 2-18-01 and O.A.C. Mental Health Section 5122-22-01.]

To meet requirements of the law, the Supplemental Services Trust cannot be created with more than \$234,000 as of 2011. The limit on the trust amount increases by \$2,000 each year. An earlier version of the law that limited Supplemental Services Trusts to Testamentary Trusts has been eliminated.

Assets used to create this trust must come from someone without a legal obligation of support and cannot belong to the beneficiary. Expenditures from the trust are limited to those items defined as “supplemental services,” that is, non-necessities such as recreational items, vacations, or items for which Medicaid or other third-party payers have denied payment. Expenditures may also include an amount up to \$4,500 (Department of Mental Health) or \$5,000 (Department of DD) for burial, but Social Security may question that expense if it occurs after the beneficiary dies. As a result, expenditures from the trust for the funeral, burial, marker, vault, etc. should be paid for the beneficiary with irrevocable pre-paid arrangements prior to the death of the beneficiary of the trust.

The primary disadvantage of the Supplemental Services Trust is that at least 50 percent of whatever remains in the trust at the time of the beneficiary's death goes to the State of Ohio. That amount must be deposited into a fund in the State Treasury to be used for the benefit of others who do not have such trust arrangements. People may want to consider this type of trust for smaller amounts (for example, \$25,000). That way the amount paid back will never be substantial. In addition, if a trust accomplishes its primary purpose of enhancing the life of the beneficiary, the 50 percent forfeiture when the beneficiary eventually dies may seem to be of little consequence.

However, despite the fact that Section 5815.28 of the Ohio Revised Code gives a roadmap to attorneys who do not have much experience with disability trusts, most people will choose to use a Discretionary Trust instead because of the absence of a payback requirement.





## Trusts Funded with Assets of the Beneficiary

### *Medicaid Eligibility and Windfalls*

What options exist when a person with significant disabilities, for whom health insurance/Medicaid is an absolute necessity, comes into a windfall of a significant amount of cash?

- Option 1: the person could go off Medicaid and pay for everything himself until those funds are gone.
- Option 2: the person could spend the funds down below \$1,500 and stay on Medicaid (e.g., purchase clothing, furniture, an irrevocable pre-paid burial account, and even repay what Medicaid has spent on him). Keep in mind that a person has nine months to get back under \$1,500 in assets if the funds came from a back payment in governmental benefits such as SSI or SSDI, but only until the end of the month they received the funds if they came from another source.
- Option 3: the person could put the money in excess of \$1,500 into a Medicaid Payback Trust and retain eligibility for Medicaid.

It is not an option to give away an asset (e.g., to a friend or family member) in order to obtain or keep Medicaid eligibility. Such a “gift” might trigger a period of ineligibility, and may even be considered to be Medicaid fraud.

Examples of windfalls that a person with a disability might receive include, but are not limited to back payments from Social Security (SSI or SSDI), from a settlement or recovery from a personal injury lawsuit, from an IRA as beneficiary, from an annuity or life insurance policy on someone else’s life or from an inheritance.

### *Medicaid Payback Trusts*

Federal legislation passed in 1993 allows another type of trust called a Medicaid Payback Trust. The name comes from the fact that this type of trust must “pay back” Medicaid expenditures made on behalf of the beneficiary from whatever is left in the trust at the death of the beneficiary, even if repayment claims the entire amount left in the trust. In other words, the government allows us to set aside money now for people with disabilities if we agree to pay back Medicaid in the future if there are funds remaining at the time of the beneficiary’s death. The payback is limited to the funds in the trust at the time the beneficiary dies, but there is no requirement that there be funds left in the trust at that time.

There are two types of Medicaid Payback trusts:

- Special Needs Trusts, and
- Pooled Trusts.

Assets in both types of Medicaid Payback Trusts must come from the beneficiary. Expenditures are not limited to supplemental needs or “supplemental services.” [See 42 USC 1396p(d)(4)(A) & (C) and O.R.C. Section 5111.151 (F) (1) & (3).]



## *Medicaid Payback Trusts: Option 1 Special Needs Trusts*

The Special Needs Trust is the “regular” Medicaid Payback Trust. It may appear to be much like a Discretionary Trust. In order to be successful as a statutory safe harbor, it must comply with both state and federal law and the regulations of the Ohio Department of Job and Family Services. This type of trust can be created for anyone with a disability by a parent, grandparent, legal guardian or a court. The trust must be funded before the beneficiary reaches age 65.

Although a Special Needs Trust must be created with assets that belong to the individual with the disability, funds from other parties can be added once this trust has been established. Special Needs Trusts will normally be created as Living Trusts, and must be Irrevocable.

## *Medicaid Payback Trusts: Option 2 Pooled Trusts*

Pooled Trusts are called “pooled” because the funds from many trusts are pooled for purposes of investment. However, a separate account must be maintained for each beneficiary.

Pooled Medicaid Payback Trusts must be established and managed by nonprofit corporations. That does not mean that a lot of nonprofits offer Pooled Trusts or that it is easy or quick for a nonprofit corporation to establish a Pooled Trust, because there are special requirements in Ohio law for a person or agency that holds itself out as doing business as a “trustee” and handling funds for other people. In Ohio, the trustee normally has to be a bank, savings and loan or a charitable foundation.



The requirements for Pooled Trusts are very similar to those for Special Needs Trusts in the following respects:

1. In the normal course of events, funds remaining in the beneficiary's account at the time of his death must first be used to repay the state for past Medicaid expenditures; and
2. The Pooled Trust can be created by a parent, grandparent, guardian or a court.

Differences between Pooled and Special Needs Trusts include the following:

1. A person with a disability may establish a Pooled Trust, in addition to the parent, grandparent, guardian, or the court.
2. The Pooled Trust provides a Trustee or acts as the Trustee.
3. The person creating a Pooled Trust can leave trust assets in the trust for use by other beneficiaries or to cover overhead expenses of the Pooled Trust instead of paying back Medicaid.

### *Pooled Trust Programs in Ohio*

Pooled Trust arrangements exist in virtually every state. A listing of Pooled Trust Programs in Ohio and in other states can be found on the Internet at [www.specialneedsanswers.com/resources/directory\\_of\\_pooled\\_trusts.asp](http://www.specialneedsanswers.com/resources/directory_of_pooled_trusts.asp). A brief description of two pooled trust programs in Ohio follows.



The Community Fund Management Foundation (CFMF), was created by the Cleveland Federation for Community Planning and the Cuyahoga County Board of DD. CFMF administers both a Pooled Trust and a Master Trust. (The Master Trust is a carefully drafted Wholly Discretionary 3rd Party Beneficiary Trust.) The CFMF accepts clients from anywhere in Ohio. Anyone with any type of permanent disability may be a beneficiary under the trust. Contact CFMF directly at (216) 736-4540 or at [www.CFMF.org](http://www.CFMF.org) for more information and their fee structure.

CFMF also offers a type of Pooled Trust called a Roll-In Trust that allows individuals with a disability to send in small amounts each month until enough money accumulates to activate a trust. This seems to be the only option that allows people with disabilities to set aside money for their own retirement.

Another Pooled Trust Program in Ohio is called the Disability Foundation. The foundation works closely with the Dayton Foundation and offers its services statewide, but with a focus primarily on serving people in the Miami Valley area (Montgomery, Greene, and Miami Counties). The Disability Foundation offers two types of trust programs. The Ohio Community Pooled Annuity Trust (OCPAT) uses annuities to create a guaranteed stream of funds for supplemental services for the beneficiary. In addition, the creator of the trust may be able to deduct a portion as a charitable deduction. The second type of trust is called the Flexible-Spending Trust. Call (937) 225-9939 or see [www.disability-foundation.org](http://www.disability-foundation.org) for further information.

## Summary of Disability Trust Options

If it is important that a person with a disability retains eligibility for Medicaid and SSI, there are several options other than disinheritance that might be considered, all of them trusts. Trust assets cannot be accessible to the person with a disability and should, in most cases, be used only to purchase supplemental items.

If the money for the trust comes from a relative or a friend, there are only two trust options: a Wholly Discretionary Trust or a Supplemental Services Trust. If the money for the trust comes from a person with a disability who will also be the beneficiary of the trust, there are two other trust options, both Medicaid Payback Trusts: the Special Needs Trust and the Pooled Medicaid Payback Trust.

The only option that does not require that at least a portion of the funds be paid back to the state or forfeited when the beneficiary dies is the Wholly Discretionary Trust. Keep in mind that type of trust cannot be created or later funded with the beneficiary's money.



## Support Trusts

A Support Trust is a trust that is used to pay for the necessities of life for the beneficiary, such as food, clothing, or shelter. Those items are often covered by the trust standard of “benefit, support, education, maintenance and welfare,” or words to that effect, a standard to be avoided in the disability trusts referred to in the previous sections. Support Trusts might be used to support a surviving spouse who is not very good at managing money, or to support surviving children and pay for their college education. Thus, Support Trusts are very common.

A Support Trust will make a beneficiary with a disability ineligible for Medicaid and SSI. However, if there is a lot of money available to support a person with a disability, then retaining eligibility for public assistance benefits for the beneficiary may not be important. Consider the examples of a very wealthy family whose only child is a person with a disability, or of a situation where a person with a disability wins several million dollars in a lottery or as the result of a lawsuit. Eligibility for public assistance may not be important if there are sufficient private dollars to purchase better services than those available through public assistance programs, i.e., if a person has the funds to privately pay for services. Further, having a Support Trust might eliminate the need for a person with a disability to have a Guardian of the Estate.

However, in situations where the funds in a Support Trust might run out before the beneficiary dies, one of the disability trusts referred to in the previous sections might be created in addition to the Support Trust. Then the disability trust will continue to provide extras in the beneficiary’s life over and above what the government will pay for, just as parents did during their lifetime.

## Leaving The Family Home

An individual can own a home and be eligible to receive public assistance benefits. The primary disadvantage of home ownership by someone with a mental disability is that a disreputable person might attempt to exploit the individual and move into, or attempt to gain ownership of, the home. Therefore, a mechanism needs to be in place to prevent financial exploitation by others. Also, if the individual has to move out of the home for medical or other reasons, the home might need to be sold. As a result, the individual might lose his or her eligibility for Medicaid and SSI when he or she receives proceeds from the sale of the house.

Another disadvantage of home ownership is that other resources may be needed for the individual to live in the home. It may be necessary to provide funds beyond those left in the trust—that is, if the trust funds can only be used for supplemental needs or services—for purposes such as supervision in the home, maintenance of the home, utilities, cleaning, cooking and property taxes.

It might be possible to allow other people to move into the home to share household expenses. If those other people are also people with disabilities, there might be public funds available to help support the household, such as County Board of DD funds. Creative solutions may be needed—including, for example, allowing someone who works for a disability program in an adjoining county to live in the home rent-free in return for providing assistance with cooking, cleaning or driving.

Although it is possible to leave a home in trust for an individual with a disability without affecting eligibility for Medicaid, those arrangements are often complex and require careful planning. For example, it might be necessary for the individual with a disability to pay rent to the trust so that the value of being able to live in the home is not attributed to him or her as income.

A person might also be given the right to live in a home during his or her life (that is, a life estate in the home). But even a life estate could affect a person's eligibility—especially for SSI—if the monthly value of being able to live in the home is seen as income.

It might also be possible for a family to leave a home to a nonprofit housing corporation associated with a County Board of DD, a residential provider or to other siblings with the understanding that the individual with the disability will be able to continue to live there.

Tying the individual to the family home may also not be a good idea because the person's needs change over time. For example, a two-story family home with all the bedrooms upstairs could no longer meet his needs if he loses his mobility.



## Guardianship

A discussion of future planning would not be complete without considering guardianship. The natural guardianship of parents ends when their children reach the age of 18 in Ohio. Many parents struggle to decide if they need to remain guardians after that. If they decide to retain guardianship, they must complete an application for guardianship and submit it to their local probate court. In some counties it is necessary to have an attorney file for guardianship.

There are two prerequisites for guardianship in Ohio law:

1. The individual must be incompetent in at least one important area of his or her life. That determination is often easy to make as a result of real-life experiences; and
2. There must be a present need for the guardianship. A person may have significant deficits in his or her life, but the support network may be so strong that guardianship is not necessary. The expression, “If it ain’t broke, don’t fix it” may be applicable.

There are several types of guardianship.

- ***Full or Plenary Guardianship*** gives the guardian authority over all aspects of a person’s life.
- ***Guardianship of the Estate*** involves only financial matters.
- ***Guardianship of the Person*** involves all matters other than financial.

- ***Emergency Guardianship*** allows a court to intervene to appoint someone on short notice and for a short period of time. However, probate courts are reluctant to appoint emergency guardians.
- ***Interim Guardianship*** allows a court to appoint someone on a temporary, interim basis because the former guardian is no longer available.
- ***Limited Guardianship*** allows a probate court to appoint someone as guardian only over the portion of a person's life in which he or she is both incompetent and has a need. Thus, you might have a Limited Guardian for medical purposes only (that is, to provide consent for medical procedures), or for placement purposes only or for the limited purpose of approving behavior plans and/or psychotropic medications. This is the least restrictive form of guardianship. [See O.R.C. Section 2111.02.]

Guardianship of the Estate, or Full or Plenary Guardianship, may not be necessary. If the only significant income a person receives is a Social Security benefit, a Representative Payee may be able to handle all relevant financial matters. A Guardian of the Person, or a Limited Guardian, could handle other matters.



A person is not required to live in Ohio to be appointed as guardian for minor children pursuant to a parent's Will. In addition—and this is a change in Ohio law that became effective in 2008—a person is not required to live in Ohio to be appointed as a guardian for an adult who is incompetent if the proposed guardian has been named by the adult individual's parents in a legal writing such as a Will or Power of Attorney. However, it is difficult for a guardian to perform adequately if the guardian does not have frequent face-to-face contact with his or her ward (the subject of the guardianship).

For a “writing” other than a Power of Attorney to be effective as a nomination, “the writing shall be signed by the person making the nomination in the presence of two witnesses; signed by the witnesses; contain, immediately prior to their signatures, an attestation of the witnesses that the person making the nomination signed the writing in their presence; and be acknowledged by the person making the nomination before a notary public.” [See O.R.C. Sections 2109.21(C), 1337.09(D), and 2111.121(A).]

Ohio law also provides personal immunity for a person who becomes guardian while he or she is acting as guardian. To have protection under this section of the law, it is necessary only that the person make it clear that he or she is acting in official capacity as guardian. [See O.R.C. 2111.151.]

The Ohio Department of DD also provides the services of an agency to act as guardian for those who need it and have no one else available. For more information, contact Advocacy and Protective Services, Inc., (APSI) at (800) 282-9363 or see their Web site at [www.apsiohio.org](http://www.apsiohio.org).



There are alternatives to guardianship, especially for financial purposes. As mentioned before, if a person's only assets are payments from Social Security, then a Representative Payeeship may be the simple solution. Another alternative is one of the trusts discussed earlier, or a Durable Power of Attorney for financial purposes. See the later discussion on powers of attorney (POA), and note that the makers must be competent when they give/execute the POA.

Finally, for those who are competent mentally but who have a physical disability, Conservatorship may be an option. An individual selects his own Conservator who is then appointed by the probate court. An individual can terminate the Conservatorship at any time.



## Advanced Directives

A few years ago, Ohio passed legislation authorizing use of advanced directives, known as Living Wills and Durable Powers of Attorney for Health Care. Since passage of the legislation, the Ohio State Bar Association and the Ohio State Medical Association jointly prepared standard forms for both types of directives. These forms are the ones most commonly used in Ohio. [See O.R.C. Sections 1337.11 et. seq. and O.R.C. Chapter 2133.] The forms are available to different constituencies through many different agencies including the Ohio Hospital Association, the Ohio Osteopathic Association, the Ohio State Bar Association, and the Ohio State Medical Association. See, for example, the forms available on the Web site of the Ohio Hospice and Palliative Care Organization at <http://associationdatabase.com/aws/OHPCO/pt/sp/livingwills>.

Federal law requires health care facilities to provide certain information to all people prior to admission, including the opportunity to sign advanced directives. The health care facility cannot refuse to admit someone on the basis of whether they complete an advanced directive. This is simply a notice provision. ICF/MRs (intermediate care facilities for people with mental retardation) are not required to give such notice.



## *Powers of Attorney for Health Care*

To understand Powers of Attorney for Health Care, it is important to understand Powers of Attorney in general. A Power of Attorney is a legal document by which one person gives another (that is, the Attorney-in-Fact, who need not be a lawyer) power to do certain legal acts in his or her absence. People must be competent when executing a Power of Attorney, and they cannot give someone else more legal authority than they themselves have. For example, a daughter with an intellectual disability cannot give her mother more authority than she herself could exercise.

Examples of Powers of Attorney include the power to renew one's automobile registration or to sell a specific piece of property. Nondurable powers of attorney expire when the maker becomes incompetent. A "Durable" Power of Attorney (one that states an intent to make it durable) has the added feature that it will continue to be valid even if the maker of the power becomes incompetent.

All powers of attorney expire when the maker dies.

A Power of Attorney for Health Care allows a person (designated as the Attorney-in-Fact) to make medical decisions on another person's behalf if something happens that restricts the person from making decisions on his or her own.

The Power of Attorney may provide guidelines as to how those decisions are to be made. The Attorney-in-Fact is to make decisions as the creator of the Power of Attorney would have. At the very least, some discussions should take place as to the creator's wishes.

## *Living Wills*

A Living Will is a legal document in which a person states what medical care he or she would like to receive or not receive in given situations. Probably the most difficult decision to make in completing this document is whether a person wants nutrition and hydration (food and water by artificial means such as feeding tubes and IVs) in the event he or she becomes permanently unconscious.

Ohio law requires the maker of Advance Directives to be “of sound mind” at the time the documents are executed. It is recommended that, if there is some doubt about the competency of the maker, the maker be required to summarize what he or she is signing in his or her own words in the presence of witnesses. It is this writer’s opinion that it takes a much greater level of competence to understand the complexities of a Living Will as opposed to the comparatively minimal level of competence required to sign a Durable Power of Attorney for Health Care.

Just like a Will, a Living Will and Durable Power of Attorney require that the person signs the document. No one has the authority to sign advanced directives for someone else, not even a parent, a court-appointed legal guardian, or the court itself.

The General Assembly has now recognized an Advanced Directive for Mental Health Care. This new Advanced Directive allows people to indicate what medications or treatments they consent to, which physicians they want to see, and whom they want to act on their behalf if certain conditions occur. It would seem wise for people with mental illness to use such a document to state how they want to be treated, based on past personal experience. A standard form is available on the Web site of the Ohio Legal Rights Service at [olrs.ohio.gov](http://olrs.ohio.gov). [See O.R.C. Sections 2135.01 through 2135.14, and 1337.14(D).]



## Do Not Resuscitate Orders (DNRs) or No Codes

It is common for parents or next of kin to make medical decisions for their family member in certain situations, such as when the person is comatose in the hospital after a serious accident or stroke. One such decision is a Do Not Resuscitate (DNR) Order, or No Code, generally understood to mean a physician's order for the non-application of cardiopulmonary resuscitation (CPR). In the normal course of events, a DNR is authorized by the individual or his or her guardian, and is signed by a physician. A DNR is not a request not to treat, although in some cases the treatment provided may be limited to comfort care, that is care to relieve pain. Medical personnel are still required to provide care and treatment according to acceptable medical standards as long as it does not conflict with the DNR.

Ohio law authorizes a guardian of the person to approve health care and treatment. Ohio law also specifically authorizes the guardian or next of kin in a descending order of priority to withhold or withdraw life-sustaining treatment for an individual who does not have a Living Will, if the individual has a terminal condition or has been in a permanently unconscious state and unable to make an informed decision for at least 12 months. Ohio law does not specifically allow physicians to make those decisions. [See O.R.C. Sections 2111.13(C) and 2133.08.]





A DNR is more appropriate when the individual is in the final stages of a terminal condition, or when to treat aggressively would be simply prolonging the process of dying rather than providing a realistic hope of recovery. A DNR may also become appropriate when the person is suffering from a very serious medical condition that makes the application of CPR painfully invasive, ineffective or both.

It is not appropriate for a residential facility or a nursing facility to require that every resident have a DNR on his or her medical chart. Nor does it seem appropriate for a guardian to authorize a DNR when the ward is in relatively good health or has a long life expectancy.

Ohio specifically recognizes two types of DNRs:

1. DNR Comfort Care. The trigger for DNR Comfort Care is the completion of a DNR Order or a Living Will with that provision in it. In other words, only comfort care will be provided once the document has been signed.
2. DNR Comfort Care Arrest. The trigger for DNR Comfort Care Arrest is a cardiac or respiratory arrest. In other words, all normal care and treatment is provided up until cardiac/respiratory arrest occurs.

Ohio law provides immunity for health care workers (including physicians and emergency squad personnel) who follow the patient's directions, but they are still held to a reasonable standard of care. Standard forms of identification can be used including bracelets, necklaces, and wallet cards. [See O.R.C. Sections 2133.21 et seq. and O.A.C. Sections 3701-62-01 et seq. See also, the Department of Health Web site at [www.odh.ohio.gov](http://www.odh.ohio.gov).]

## PLAN in Ohio

Many parents, especially those whose only child has a disability, look for someone to monitor and support their children after they are gone. The Planned Lifetime Assistance Network, also known as PLAN, provides such services. Originally established on the East Coast, many different PLAN organizations have been created around the country. There are three in Ohio. The oldest and most established, PLAN of Northeast Ohio, is in Cleveland and serves more than 110 clients, many of them with mental illness. It provides case management-type services including therapeutic recreation and counseling. There are also PLAN units in Southwest Ohio and Central Ohio.

Although each PLAN organization looks a little different, they all price out services over the projected lives of their clients. Parents can “buy” those services by using one of the estate planning mechanisms (i.e., trusts) discussed in this booklet. For further information about PLAN in your area, contact your local public and private County Board of DD or mental health agencies.









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