

Planning for Bright Tomorrows

*Estate and Future Planning for Ohioans
with Disabilities and Those Who Love Them*

Published by



**Ohio Developmental
Disabilities Council**

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About the Ohio DD Council

The Ohio Developmental Disabilities Council (ODDC) is a planning and advocacy group of over 30 members appointed by the Governor. The ODDC receives and disseminates federal funds in the form of grant projects in order to create new ideas, pilot new approaches, empower individuals and families, and advocate for systems change to more fully include people with disabilities in their communities.



www.ddc.ohio.gov



Foreword

It is our pleasure to offer this book to the community. Building on the prior version written by David Zwyer, this book offers a comprehensive overview of estate planning for individuals in the disability community: persons with disabilities, their families and others. We hope this book will help people understand the strategies available to plan for an individual with a disability, eliminate the myths surrounding estate planning and provide guidance so that all individuals in Ohio live as happily, productively, and independently as possible.

Estate Planning is an important step in gaining and maintaining control over our affairs. It is especially important for families who have loved ones who have a disability, which affects their ability to control their own person or affairs.

This book is not legal advice, but instead offers general information that may or may not be applicable to any one situation. A competent professional should be consulted about specific situations and choosing the correct strategies for each unique situation.

Over the years, we have provided information to individuals, parents, friends, and relatives, about estate planning for individuals with disabilities. This book contains a description of some of the most common estate planning terms, along with questions we have been asked and the answers we give.



Best,

Logan Philipps and Bill Root

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What is Special Needs Planning?

Special needs planning is estate and financial planning when a disability is involved. Special needs planning combines planning for assets, Guardianship, and alternatives to Guardianship. In 2018, the DD Council published a book entitled *Guardianship in Ohio* that described Guardianship and alternatives. There is a natural overlap between this book and that one.

Individuals seeking information about Guardianships, Powers of Attorney, Health Care Directives, etc. should consult that book available at www.ddc.ohio.gov.





*W*hat is an estate?

There is a common misconception that “estates” are exclusive to the wealthy. Most people do not realize what actually makes up an “estate.” An estate includes everything a person owns in his or her own name individually or with another person or persons, everything payable to him or her, and everything controlled by that person. An estate can be comprised of a residence, cash, stocks, bonds, and other investments, as well as any ownership, full or partial, of a business. An estate also includes any retirement plans, such as IRAs and 401ks, and life insurance death benefits. It even includes personal property such as vehicles, collectibles, and other treasured items. A home owned by an individual, no matter how large or small or how much mortgage debt is owed, is part of an estate.

*W*hat is estate planning?

WealthCounsel, a national organization of estate planning attorneys, provides the following description of estate planning:

I want to control my property while I am alive and well, care for myself and my loved ones if I become disabled, and be able to give what I have to whom I want, the way I want, and if I can, I want to save every last tax dollar, attorney fee, and court cost possible.

Why is estate planning essential for all individuals in the disability community?

Many individuals with disabilities need to maintain eligibility for public benefits like Medicaid and Supplemental Security Income (SSI) in order to maintain an independent, happy life. Many of these benefit programs limit eligibility to individuals who have under \$2,000 in assets.

This book is intended to help people with disabilities and those who love them plan for the future. For family members with loved ones with disabilities, estate planning usually means, ***“how can I make sure my child is cared for when I am gone?”***

For individuals with disabilities, estate planning means, ***“how do I control my property and make sure I stay eligible for benefits, and how do I give what I have to who I want when I die?”***





What are some of the most common misconceptions about estate planning?

Here are the “Great Myths,” as we call them:

Myth 1: My estate isn’t large enough to need estate planning.

Reality: If your estate is fairly small, it will likely suffer a greater percentage of shrinkage from final expenses, probate costs, and so on, than will a larger estate. In addition, *any* amount not properly planned for may adversely impact an individual with a disability.

Myth 2: Most people just have a will; that’s all I need.

Reality: Depending upon whose statistics you read, only about 40 to 60 percent of the population has a will, and it’s true that a will is a must in every estate plan. A “standard” will is not sufficient on its own to plan for a person with a disability, and it will not help you avoid probate court.

Myth 3: I don’t need an estate plan. I will disinherit my child with a disability and let his or her sibling take care of him or her with the money I leave them. (Explained more fully later in this book.)

Reality: Even through no fault of his or her own, a sibling may lose the money that was intended to care for their sibling with a disability. A sibling could be sued, could get a divorce, could become incompetent and be forced to spend those assets to qualify for benefits themselves. Without an estate plan, there is no assurance that after you are gone, money you planned for your child with disabilities and left to a sibling for that child’s benefit will be used the way you want it to be used.

What are the traditional methods of estate planning?

Before discussing estate planning specific to the disability community, it is important to explain some of the common estate planning concepts. There are five techniques that are traditionally used in basic estate planning, and everyone, in some manner, is using at least one of these techniques.

Intestacy. A majority of Americans die without a will or a trust. This is called intestacy. Intestacy is considered a method of estate planning because by leaving no will, a person's assets will be distributed according to the laws of the state in which the person resided. Assets that pass by intestacy go through a probate process called administration which is almost identical to the probate process for a Last Will and Testament.

Many assets will not go through probate administration because even though a person may die without a will or trust, they have done estate planning without even knowing it because of the next two types of planning.

Joint Tenancy with Right of Survivorship. There are different ways that people own assets, one of which is joint tenancy with right of survivorship. Joint tenancy means that two people own something together. The right of survivorship means that the survivor acquires the entire interest in the property upon the death of the other joint tenant.

Because a joint tenant's interest automatically passes by law to the surviving joint tenant at death, its ownership is not controlled by that deceased joint tenant's will or by the law of Ohio if intestate. For example, suppose Bob and David own a piece of property as joint tenants with right of survivorship. Bob intends for his son to inherit all his property at his death. When Bob dies, despite the fact that his will states that upon his death all of his property should go to his son, David will own the entire property by himself and Bob's son will not inherit it.



Beneficiary Designations. Some types of property pass, at the death of their owners, to those listed in their beneficiary designations. Life insurance policies, annuities, individual retirement accounts (IRA), qualified retirement accounts, and pension plans are examples of these types of property.

The advantage of having named beneficiaries is that the property avoids probate. The disadvantage is that because the proceeds from beneficiary-designation property pass directly to the named beneficiaries and are not controlled by terms in a will or trust, the proceeds may not pass to whom the owner wants or in the way he or she wants. Like joint ownership, beneficiary designations supersede the terms of a will or intestate administration.

Will-Planning Probate. A Last Will and Testament is a legal document that describes how a person wants his or her estate distributed at death. Many people plan their estates by creating a Last Will and Testament.

Unfortunately, wills have major disadvantages: (1) A will does not control how or when all of the will-maker's property is distributed outside of probate. See the previous sections describing property owned in joint tenancy with another person, life insurance proceeds, and retirement, etc; (2) A will guarantees probate court involvement and consequently is not private. Upon the will-maker's death, the will must be filed with the probate court in order to be administered, where it becomes a public document. The will, along with all the person's assets controlled by it, can be viewed very easily by anyone interested - usually by simply performing a computer search.



Exhibit A: Wills vs. Trusts

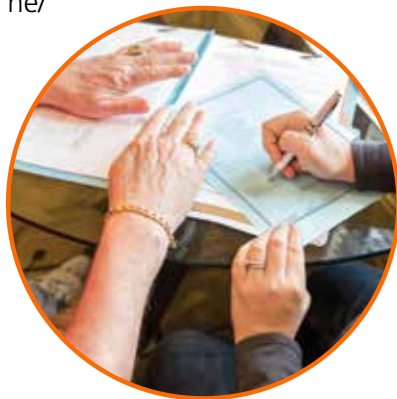
	WILL	TRUST
Privacy	No privacy. All documents and proceedings after death are public.	Totally private, unless court intervention is required (usually due to failure to fund the trust or a challenge to the trust).
Disability Planning	No provisions for mental or physical disability. The person with disabilities is subject to the court process for guardianship.	Handles assets upon disability without court intervention. A power of attorney is still needed for non-trust assets. A trust can provide the disability be determined without court intervention.
Creditor/Predator Protection	None while alive. Creditors have only a specified amount of time to present claims or they are forever barred. Testamentary trusts can give creditor protection to beneficiaries, but such trusts will be subject to court oversight.	None while alive, but subject to same time limitation for presentment of claims after death (although most trusts require just debts be paid). Trusts that become irrevocable at death can give creditor protection to beneficiaries.
Effort Required	Less effort now, but a great deal of work for your heirs after disability or death.	More effort now to properly design the trust to meet your goals for disability and after death, but far less work for your heirs after disability or death.
Out-of-State Property	Property in another state is subject to probate administration in that state, as well as the state of Ohio.	Avoids probate in any state in which assets are owned or funded to the trust.
Out-of-State Executor	An adult who is an Ohio resident is preferred, although Court may appoint an out-of-state resident if they post bond equal to 2.5 times the value of the probate estate.	Trustee can be anyone over the age of 18, regardless of where they live and no bond required.
Cost Now	Less than a Trust.	More than a Will.
Cost to Amend	Similar (commonly done through a Codicil).	Similar (commonly done through an amendment).
Cost Later	Probate costs are unpredictable and can cost thousands of dollars after death.	If a trust is properly funded then there are no probate fees and only minimal cost to direct distributions.

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A will that directs assets to a person with disabilities is problematic and may require that those assets be placed under the control of a guardian and then placed in a special needs trust for the benefit of the person with disabilities that is subject to control by the probate court for the child's lifetime, resulting in unnecessary expense and red tape.

Living Trust. A Living Trust is a document that instructs how assets are to be distributed. A Living Trust is an agreement that a Trustee will hold property and distribute property as instructed by the trustmaker for the benefit of the trust's beneficiaries. It is called a Living Trust because the trustmaker makes the trust while they are living. A properly funded trust keeps a person's assets private and controlled by the people they trust, not the probate court. With a properly drafted and funded living trust, a trustmaker can be confident that the many disadvantages of the four preceding traditional forms of estate planning have been eliminated. Some people like to think of a trust as a treasure chest. The trustmaker makes the treasure chest and places "treasure" in it. The trustmaker can do this either while he/she is alive or when he/she dies. The Trustee has the keys to the treasure chest and decides what stays there and what comes out for the benefit of the beneficiary or beneficiaries. Just like a real treasure chest that might hold diamonds, rubies or gold, this "treasure chest" can hold different items, such as a home, money, bank accounts, etc.



Multiple people can be trustmakers. Many husbands and wives create a joint living trust.

See Exhibit A for a comparison between wills and trusts.

NOTE: All of the techniques described so far are ineffective to plan for an individual with a disability.

Why do parents of children with a disability need to do estate planning?

A family with a child with a disability faces many challenges, but perhaps none is more troubling than trying to deal with an uncertain future and making an estate plan for that child. We work with parents to ensure that their assets can be used for the child but do not interfere with government benefits.

In our years of working with parents, without a doubt, their number one fear is that their child will not be cared for when they are gone. These parents want a way to leave money for their child's care without threatening eligibility for benefits.



Government benefits come in many forms. The most common are Medicaid and Medicaid Waivers, Supplemental Security Income (SSI), Social Security Disability (SSDI), Adult Disabled Child Benefits, food stamps, housing vouchers, etc.

Medicaid and SSI are means tested, meaning that a person becomes ineligible for benefits if he or she has more than \$2,000 in countable assets. Most parents will leave at least that much to their child. Medicaid has a higher limit for workers with disabilities. This

important program is beyond the scope of this book but is discussed briefly on the next page.

Proper planning can guarantee that an inheritance will not negatively impact a child's eligibility. Most of these plans will make use of a "special needs trust."



Why do people with a disability need to do estate planning?

Individuals with a disability, if able, should be able to control their property when they are alive and, if able, select those individuals that they trust to control their property should they become unable to make decisions. This type of estate planning that involves controlling property while an individual is alive was the subject of a different book titled, *Guardianship in Ohio*, available at www.ddc.ohio.gov. Guardianship and alternatives including Supported Decision Making and powers of attorney are discussed in detail.



Generally a person with a disability may not accumulate assets over the \$2,000 limit either by saving their own money, by gift, or by inheritance. If a person with a disability accumulates more than \$2,000, that person will need to take action to “move” those assets out of the person’s name. The person will need to spend the assets very quickly, use a special needs trust or a STABLE Account to remain eligible for benefits.

There is an exception to the general asset limit of \$2,000. This exception is the Medicaid Buy-In for Workers with Disabilities (MBIWD) program for individuals with disabilities who are working. Individuals who are saving assets while working can hold countable assets up to \$12,382 in 2020 (adjusted annually) and still remain eligible for Medicaid.

A person with a disability who receives an inheritance can suddenly find themselves over the resource limit. Proper planning can eliminate this problem.

What is a special needs trust and why do people have them?

In short, a special needs trust allows assets over the resource limit to be available to care for and spend on an individual with a disability, while allowing the individual to remain eligible for benefits. In order to answer this question clearly, an explanation of a trust is necessary.

What is a trust?

A Trust is a legal document in which one party leaves assets to another party (a trustee) to be used for the benefit of a beneficiary (another person, charity, pet, etc.). Trusts provide flexibility for each party. The trust instrument gives specific instructions as to how to use the assets.

One way to think about a trust is as a treasure chest. Assets are left inside a treasure chest. The trustee has the keys and must use the assets to benefit the beneficiary (See page 11.).

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.

Special Needs Trusts

A special needs trust is a trust for a person with a disability in which the assets contained in the trust are not counted as a resource. In short, a special needs trust can have more than the resource limit of \$2,000 in it and the person can still receive benefits.

It is important to be aware that in the disability community the term “special needs trust” means different things to different people.



Generally, parents, individuals with a disability, and lay people refer to any trust that protects a person's eligibility for benefits as a "special needs trust." However, the State of Ohio and its employees identify a "special needs trust" as a specific type of trust commonly called a "payback trust." The various types of special needs trusts are discussed in detail further in this book.

No matter the type, a special needs trust protects eligibility for public benefits by supplementing rather than replacing government benefits that a person may be receiving or might later be eligible to receive from various assistance programs.

The purpose of the special needs trust is to cover items that government benefits do not pay for, such as trips to visit family members, reading material, educational tools, concert tickets, passes to theme parks, over-the-counter medicines, training, education, treatment, rehabilitation not covered by public benefits, recreation, entertainment, and consumer goods, etc. A well planned and well managed special needs trust will serve as a safety net to provide for your child throughout his or her life.

What benefits are available to people with disabilities that must be protected?

It is beyond the scope of this book to discuss in detail the various government benefits available to individuals with special needs. The major benefit programs are discussed generally in this section. Individuals should seek assistance from their county board of developmental disabilities, the DD Council, county department of job and family services, or the Social Security Administration for information about benefits. The two major benefits that are available to people with disabilities that are "means tested" are Medicaid and Supplemental Security Income (SSI).

What is Medicaid?

Medicaid is 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.

How do I qualify for Medicaid?

In Ohio, a parent's legal obligation to support their child generally ends when the child reaches age 18, the age of majority. Individuals over the age of 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 (SSDI), 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 including Medicaid and SSI. This situation is discussed further in this book.

Many individuals with disabilities need to remain eligible for Medicaid and SSI, especially if they have significant needs. In Ohio, an individual cannot have countable resources greater than the resource limit.

What is a resource limit?

The resource limit is the maximum value of the assets an individual is allowed to own and still remain eligible for Medicaid. Countable assets include cash, stocks, bonds, investments, all checking and savings



accounts, and real estate in which one does not reside. Assets that are considered exempt (non-countable) include personal belongings, household furnishings, an automobile, irrevocable burial trusts, and an individual's home, provided that the Medicaid applicant or their spouse lives in the home and the home is valued under \$585,000 (in 2020).

There are two resource limits in Ohio. The general limit is \$2,000. This means a person may not have countable assets worth more than \$2,000 and still remain eligible for Medicaid. An individual who is working may have countable resources in excess of \$2,000 and remain eligible for Medicaid under the MBIWD (Medicaid Buy-in for Workers with Disabilities) program or STABLE Accounts. These situations are discussed elsewhere in this book. Care must be taken to determine what might be considered a countable asset to the individual when a parent dies so that eligibility is not placed in jeopardy.

*W*hat is a Medicaid Waiver?

Formally known as a Home and Community-Based Services (HCBS) Waiver but more commonly known simply as a "Medicaid Waiver," waivers allow individuals with disabilities to receive care in their homes rather than in long-term care facilities, hospitals, or Intermediate Care Facilities. Individuals must require a specific "level of care" and not own countable assets in excess of the resource limit in order to qualify for a HCBS Waiver.

*W*hat is "Level of Care"?

The scope and amount of services that an individual will need determines their level of care and the type of Medicaid services for which they are eligible. Level of care is not a financial eligibility component of the

Medicaid long-term care programs. An individual who wants to be enrolled in a waiver program must meet the specific level of care that is required for that waiver.

Developmental Disabilities Level of Care: The developmental disabilities level of care is necessary for enrollment onto a Medicaid HCBS waiver. The Ohio Department of Developmental Disabilities administers three waivers that require a developmental disabilities level of care: Individual Options Waiver (referred to as the “IO Waiver”), Level 1 Waiver, and SELF (Self Empowered Life Funding) Waiver.

What does a Medicaid Waiver pay for?

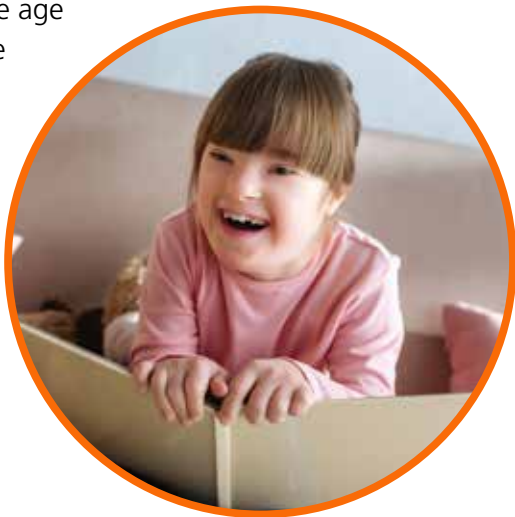


A Medicaid recipient does not actually receive direct cash benefits but, rather, receives benefits by way of payments made directly to his or her health care providers, such as hospitals, doctors, nursing homes, medical testing facilities, pharmacies and dentists.

Exhibit B on pages 20-21 contains a brief description of the types of Medicaid Waivers and the services each provides.

Are there other sources of support if I don't have a Medicaid Waiver?

If the disability had its onset before age 22, the individual might be eligible for services from a county board of developmental disabilities. The county board uses funds raised from property tax levies to provide a wide variety of residential and employment supports, as well as the assistance of a social work/case management type of person, called a Service and Support Administrator (SSA).



What are the major differences between Social Security, Medicare and Medicaid?

Social Security: Social Security is a federal program that provides retirement, disability, and survivor benefits to wage earners and their spouses, former spouses, widows and widowers, and children. A wage earner's eligibility for retirement benefits is based upon his or her work history (the years during which the wage earner paid taxes into the Social Security trust fund).

Medicare: Medicare provides health care benefits for (1) people 65 years of age and older, and may include some individuals with disabilities who are under the age of 65; (2) spouses, divorced spouses, and widows and widowers of eligible wage earners; (3) children with disabilities of certain

Exhibit B: Medicaid Waivers in Ohio

Level One	SELF (Self Empowered Life Funding)	Individual Options (IO)
<p>Available Services:</p> <ul style="list-style-type: none"> • Homemaker/Personal Care • Participant-Directed Homemaker/Personal Care • Remote Support • Environmental Accessibility Adaptations • Community and Residential Respite • Non-Medical Transportation • Transportation • Group Employment Support • Individual Employment Support • Career Planning • Vocational Habilitation • Adult Day Support • Waiver Nursing • Waiver Nursing Delegation • Specialized Medical Equipment • Assistive Technology • Money Management • Home Delivered Meals 	<p>Available Services:</p> <ul style="list-style-type: none"> • Participant-Directed Homemaker/Personal Care • Participant-Directed Good and Services • Participant/Family Stability Assistance • Community and Residential Respite • Non-Medical Transportation • Transportation • Group Employment Support • Individual Employment Support • Career Planning • Vocational Habilitation • Adult Day Support • Waiver Nursing Delegation • Support Brokerage • Functional Behavioral Assessment • Clinical/Therapeutic Intervention 	<p>Available Services:</p> <ul style="list-style-type: none"> • Homemaker/Personal Care • Participant-Directed Homemaker/Personal Care • Remote Support and Equipment • Environmental Accessibility Adaptations • Community and Residential Respite • Non-Medical Transportation • Transportation • Group Employment Support • Individual Employment Support • Career Planning • Vocational Habilitation • Adult Day Support • Waiver Nursing • Waiver Nursing Delegation • Adaptive and Assistive Equipment • Money Management • Home Delivered Meals • Nutrition • Interpreter Services

More information is available on the Ohio Department of Developmental Disabilities website (www.dodd.ohio.gov).



Exhibit B: Medicaid Waiver Funding Limits

Funding Limits: Level One	Funding Limits: SELF	Funding Limits: Individual Options (IO)
<p>\$5325 Using the L1 Waiver, the total limit for the following services alone or in combination can never be more than \$5,325 per waiver eligibility span</p> <ul style="list-style-type: none">• Homemaker/Personal Care• Participant-Directed Homemaker/Personal Care• Community and Residential Respite• Money Management• Transportation• Remote support	<p>Listed in each person's service plan are the start and end dates for a waiver, or the waiver span. Waiver spans are usually 12 months long.</p> <p>The SELF Waiver has a limited amount of money you can spend on needed services in a waiver span.</p> <p>For adults, the limit for services is \$40,000 in each waiver span.</p> <p>For children, the limit for services is \$25,000 in each waiver span.</p>	<p>Each person enrolled in an IO Waiver is assigned a funding range or an individual funding level, based on the results of an assessment and the services in their service plan.</p> <p>Some services may have specific limitations.</p>
<p>\$7500 The services in this section alone or in a combination can never be more than \$7,500 within a three-year period</p> <ul style="list-style-type: none">• Specialized Medical Equipment• Environmental Accessibility Adaptations• Home-Delivered Meals• Assistive Technology	<p>Some services have specific funding limits.</p> <ul style="list-style-type: none">• Within 12 months, Support Brokerage costs cannot be more than \$8,000 of the total funding available in a waiver span.• Functional Behavioral Assessment at a cost of no more than \$1,500.	
<p>\$8,520 Payment for emergency assistance under the L1 waiver cannot exceed \$8,520 within a three-year period.</p>	<p>Funding limits for Adult Day Supports, Career Planning, Group Employment Support, Individual Employment Support, and Vocational Habilitation are calculated for each person when they complete an assessment.</p>	

wage earners; and (4) those with permanent kidney failure. Within the program, there is Medicare Part A, Medicare Part B and Medicare Part D. Medicare Part A is the hospital insurance program; Part B is the medical (non-hospital care) insurance program. Medicare Part D is the prescription drug benefit to subsidize the costs of prescription drugs and prescription drug insurance programs for Medicare beneficiaries.

Medicaid: Medicaid is a joint federal and state program that provides healthcare benefits for persons with limited income and resources. Each state manages its own program and develops its own rules for administering its program. See additional description of Medicaid provided previously.

hat is Supplemental Security Income (SSI)?

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. In 2019, payments provided were as high as \$771 per month. This amount may change yearly and is announced by the Social Security Administration. In 2020, the payment amount will be as high as \$783 per month. The specific amount paid to an individual may be reduced based upon the earned and unearned income of the recipient and other support the individual receives (often called in-kind support and maintenance). For example, if an individual lives in another's home without paying for the shelter, the Social Security Administration calls that in-kind support and maintenance and will reduce the SSI benefit of that individual.

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."



What is Social Security Disability Insurance (SSDI)?

Social Security Disability Insurance (SSDI) 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. 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 engage in Substantial Gainful Activity (SGA). SGA is generally determined by income from work. The income limit for an individual in 2020 is \$1260.00. (Individuals who are blind may earn \$2110.00.) 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.

What are Disabled Adult Child Benefits and who is eligible?

Disabled Adult Child Benefits (also known as Childhood Disability Benefits) are benefits paid to an adult individual with disabilities who became disabled before the age of 22 if the individual's parent is deceased or starts receiving retirement or disability benefits. The Social Security Administration considers this a "child's" benefit because it is paid on a parent's Social Security earnings record.

To be eligible for the “adult child” benefit, the individual must be unmarried and at least 18 years of age. An adult child can include an adopted child, or, in some cases, a stepchild, grandchild, or step grandchild. The amount paid is 50% of the parent’s benefit while the parent is living and 75% of the parent’s benefit when the parent is deceased. This payment does not reduce the parent’s benefit.

*W*hat types of “Special Needs” Trusts are there?

There are four types of trusts that allow the accumulation of assets in them that will not count towards the resource limit. They can be broken down into two broad categories: **Payback and Non-Payback.**

Payback trusts require that upon the death of the beneficiary, money left in the trust must be left to the State of Ohio or retained in the trust to be used to assist other individuals with special needs.

Non-Payback trusts allows for any money left in the trust after the death of a beneficiary to remain in the control of the trustee and distributed as directed by the Trustmaker(s), often to relatives of the initial beneficiary.

In order to avoid a loss or reduction of benefits, expenditures from all these trusts are limited to/for items not covered by Government Benefits. Generally, these are considered quality of life expenditures: recreational items, vacations, clothing, legal fees, or other items/events for which Medicaid or other third-party payers have denied payment. Extreme care should be exercised by the Trustee when administering and spending funds from a trust.



Which trust is right?

The type of trust available for a person depends on whose assets are funding the trust. In order for a Non-Payback trust to be used, the assets funding the trust must never have been owned by the beneficiary with special needs.



Non-Payback Trust

Third Party Discretionary Trust: As the name suggests, only a third party – not the individual for whom the trust is established – can establish a Third Party Discretionary Trust, and only assets that never belonged to the beneficiary may fund this trust.

A Discretionary Trust is one in which the trustee is given “discretion” as to when and how assets in the trust are distributed. A Discretionary Trust is one of the most common estate planning tools for families of children with disabilities in Ohio.

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.

Most parents will use a Third Party Discretionary Trust as part of their estate planning. This trust allows them to leave assets to be spent on and for their child while he or she is alive and then pass those assets on to other relatives, often siblings, when the child with a disability dies.

ayback Trusts

Supplemental Services Trust: Only a third party can create a Supplemental Services Trust and assets used to create this trust must come from someone without a legal obligation of support and cannot belong to the beneficiary. To meet requirements of the law, the Supplemental Services Trust cannot be created with more than \$252,000 as of 2020. This amount increases \$2,000 per year.

Expenditures from the trust are limited to those items defined as “supplemental services”: non-necessities such as recreational items, vacations, or items for which Medicaid or other third-party payers have denied payment. Even permitted distributions could reduce SSI benefits.

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 is paid 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. 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.

A Supplemental Services Trust can be created by any individual other than the individual with disabilities.

Special Needs Trust: A Special Needs Trust is a Medicaid Payback Trust. This type of trust can be created for anyone with a disability, by the person with a disability, a parent, grandparent, legal guardian or a court. The trust must be funded before the beneficiary reaches age 65. 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 requires the State of Ohio receive the assets remaining in the trust, if any, when the beneficiary dies, in an amount equal to the expenditures from the state for the benefit of the beneficiary.

This trust is commonly used when the individual with disabilities has financial assets of his or her own that exceed the resource limit. This can happen in a number of circumstances, including if the individual has saved his or her money from work or gifts, received a gift or inheritance over the resource limit, or received a personal injury settlement and needs to qualify for SSI or a Medicaid Waiver. This type of trust has become less frequently used since 2016 when STABLE Accounts were established.

A Special Needs Trust can be created by an individual with disabilities, parent, guardian, or court.

Pooled Medicaid Payback Trust: Pooled Medicaid Payback Trusts (Pooled Trusts) are called “pooled” because the funds from many individuals are pooled together into one trust for purposes of investment and management. However, a separate account is maintained for each beneficiary.

Pooled Medicaid Payback Trusts must be established and managed by nonprofit corporations.

In the normal course of events, funds remaining in the beneficiary’s account at the time of his or her death must first be used to repay the state for past Medicaid expenditures before distributing funds to beneficiaries. However, the person creating a Pooled Trust can allow the trust to retain the assets in the trust for charitable purposes including providing supplemental services to other beneficiaries who qualify or to cover overhead expenses of the Pooled Trust instead of paying back Medicaid.

The Pooled Trust can be created by an individual with disabilities, parent, grandparent, guardian or a court.

For quick reference, Exhibit C contains a description and comparison of trusts used for special needs planning in Ohio (page 28).

Exhibit C: Types of Trusts

Third Party Discretionary Trust	Supplemental Services Trust	Special Needs Trust	Pooled Trust
<ul style="list-style-type: none"> • Funds belong to a 3rd party • Trust created by the 3rd party • Trustee has absolute discretion in determining how the assets are to be distributed • No state payback. Funds remaining can go to another child, grandchild, or anyone else – Trustmaker decides • Doesn't require that beneficiary be "disabled" • No age or funding limitation • Usually includes "poison pill" provision to ensure qualification as a non-countable resource 	<ul style="list-style-type: none"> • Funds belong to a 3rd party • Trust created by a 3rd party • Distributions only for supplemental services – See OAC 5122-22-01 • At beneficiary's death, 50% of remaining balance must be paid back to the state • Beneficiary must qualify for services through the State Department of Developmental Disabilities, the County Board of Developmental Disabilities, Department of Mental Health and Addiction Services, or a board of alcohol, drug addiction, and mental health services • Maximum principal contribution is \$252,000 in 2020 	<ul style="list-style-type: none"> • Funds belong to a 3rd party or beneficiary • Trust created by beneficiary, Parent, Grandparent, Guardian, or Court • Trustee authorized to pay for goods/ services that public benefits do not cover. If trustee pays for covered services a reduction in benefits might occur. • At beneficiary's death, State reimbursed for total amount of assistance paid (100%) on behalf of beneficiary, if funds available • Beneficiary must be age 65 or younger when established and be "disabled" 	<ul style="list-style-type: none"> • Funds belong to beneficiary • Trust created by a beneficiary, Parent, Grandparent, Guardian, or the Court • At beneficiary's death, Trust either retains assets remaining or State reimbursed for total amount of assistance paid on behalf of beneficiary, if funds available • No age limitation • Non-profit organization– 501(c)(3) designation– serves as the trustee (e.g. Community Fund Management Foundation)

Adapted from Musielewicz, Lisa. "Medicaid and 'Special Needs Trusts' in Ohio." www.lsc.ohio.gov, Legislative Service Commission, 23 Feb. 2007, www.lsc.ohio.gov.

Who can act as trustee of a special needs trust?

A trustee is the person or entity that administers the trust. The trustee must follow the instructions of the trustmakers and the law regarding trusts and distributions.

The trustmaker determines who will serve as the initial trustee or trustees. Often the trustmaker, if not the beneficiary, will name his or herself or themselves as the initial trustee. Successor trustees are named by the trustmaker.



A Successor trustee is the person or entity that administers the trust after the initial trustee.

Naming a trustee, whether initial or successor, is of great concern to trustmakers. Many times, trustmakers are fortunate enough to have a trustworthy and responsible person in their lives or families who can be named as a successor trustee. Because a sibling or other relative will likely be very familiar with the needs, wants, and desires of the beneficiary with a disability, they are often chosen for this important role.

Professional Trustees like banks and trust companies are often good choices to serve as successor trustees of special needs trusts. Family members or the individual beneficiary can advise a corporate trustee about the wants and needs of the beneficiary, but the trust company would have the responsibility of managing trust assets, making lawful distributions for the beneficiary, and filing the necessary tax returns to keep the trust in compliance with state and federal laws.

There are requirements related to who may serve as a trustee of the trusts discussed in this book. A person with a disability cannot serve as a trustee of his or her own trust. There are other restrictions that may apply in a specific situation that should be discussed with a competent attorney when establishing a trust.

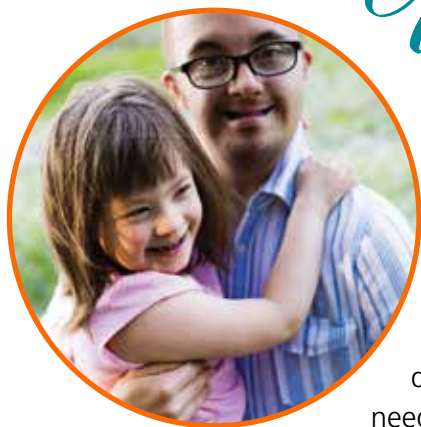
What assets can be held in a special needs trust?

Any kind of asset may be held by a trust, including cash, personal property, real property, and houses. The trust becomes the owner of the property. Just like a treasure chest can hold gold, diamonds, rubies, etc., the trust (acting like a treasure chest) can hold different assets. Some pooled trusts will not hold certain types of assets but that is a case-by-case situation. Often, particularly in Third Party Discretionary Trust situations, no assets or few assets are put into the special needs trust until the death of the trustmaker, in which case the trust is an empty shell waiting for a future event. However, that trust can be used as a repository (like a treasure chest) for gifts from grandparents, uncles, aunts, and others who may wish to make a gift to an individual with a disability.

How do I/we allocate the assets of our estate to protect our child with a disability?

Parents of children with disabilities are often concerned that their own needs for retirement or medical care may deplete their estates, leaving little or nothing for their child with a disability. They require a retirement plan for themselves and a special needs plan for their child. Parents may wish to divide their estate equally among their typical children and purchase life insurance to fund the special needs trust at their deaths. An insurance policy on the parents either individually or together, can be designated for the special needs trust. In this way, an estate can be divided among typical children and the life insurance can create an independent and liquid estate for the child.





What is a memorandum of intent or Roadmap?

The parents of a child with a special needs trust cannot place instructions or guidelines to a trustee on how to spend trust assets for their child with a disability. However, parents can prepare a memorandum of intent, or Roadmap, or other document describing their child, his or her wants, needs, and activities that make him or her happy. The memorandum of intent or other

document, once created, should be updated regularly as the needs of the child will change over time.

Can I leave the family home to my child with a disability at my death and still preserve that child's government benefits?

Yes, but considerations should be taken to determine if this is the best thing to do.

A home owned by an individual is not a countable resource for Medicaid or SSI while the individual lives there, but it can be if the individual moves out. If the home is sold, the proceeds from the sale of the home will be considered a countable resource.

Another caution is that a disreputable person might attempt to exploit the individual and move into, or attempt to gain ownership of, the home.

For these reasons, it may be preferable to leave a home to a trust. These decisions and the impact they may have on the individual with disabilities and benefits should be considered carefully.

STABLE ACCOUNTS

The STABLE Account is a tool that allows people with disabilities to have the most control over their finances without endangering their eligibility for other government programs. STABLE is Ohio's ABLE Account. Ohio was the first state to offer these accounts.

What is the ABLE Act?

The ABLE Act falls under Section 529 of the Internal Revenue Code. The Act allows people with disabilities and their families to save money in a special account that allows the accumulation of assets above the Medicaid and Social Security resource limit. Funds in a STABLE Account are generally not considered assets for SSI and Medicaid. Funds placed in a STABLE Account can be placed in different types of investment or savings accounts, chosen by the account owner. STABLE Accounts can earn interest or increase in value based on investment performance. It is also possible for a STABLE Account to lose value based on investment performance. Earnings on a STABLE Account are not taxed, provided they are spent on qualified expenditures.

How do savings in a STABLE Account affect SSI or Medicaid?

The first \$100,000 in a STABLE Account is exempted from the SSI individual resource limit (\$2,000). If a STABLE Account exceeds \$100,000, any amount over \$100,000 will count as a resource towards the \$2,000 SSI limit. However, all amounts in a STABLE Account are exempted from the Medicaid resource limit.

Who is eligible for a STABLE Account?

The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age.



*A*re there contribution limits?

A qualified individual may have only one STABLE Account. If the qualified individual is not employed, the total annual contribution by all contributing individuals, including the qualified individual, family and friends, is \$15,000 (in 2020). The annual contribution limit is tied to the federal gift tax exemption limit. If the qualified individual is employed, he/she can contribute an additional \$12,490 in wages (in 2020) for a total of \$27,490. The maximum account value limit is the same as Ohio's limit for education-related 529 savings accounts, which is \$482,000 in 2020, meaning that once the maximum value is reached, no new contributions can be made to the account.

In addition, if a beneficiary has contributed to a defined contribution plan during the taxable year, the beneficiary may not contribute income to the STABLE account during that same taxable year. A defined contribution plan is an account like a 401k, 403(b), or Simple IRA.

*W*hat happens to any money left in a STABLE Account when the beneficiary dies?

Every STABLE Account has a payback provision. This means that Medicaid will be paid back for any services that were provided to the account holder with funds remaining in the account after the death of the beneficiary. If there are outstanding bills for any Qualified Disability Expenses, the money in the STABLE Account can be used to pay those expenses before Medicaid is reimbursed. STABLE Accounts can also be used to pay for funeral and burial costs. Importantly, Medicaid can only seek repayment from a STABLE Account for amounts it paid after the STABLE Account was opened (or, in the case of an account rolled over from another STABLE plan, after the original STABLE Account was opened).

Any remaining funds, after payback, will be distributed to the beneficiary's estate.

What expenses are allowed to be paid by STABLE Accounts?

A “qualified disability expense” means an expense related to the designated beneficiary as a result of living a life with a disability. These include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services.

How does someone open a STABLE Account?

STABLE Accounts are completely online. Visit www.stableaccount.com to learn more and open an account.

Is a STABLE Account all a parent needs when planning to leave an inheritance for a person with disabilities?

Because of the yearly contribution limits and the payback provision, the STABLE Account may not be the answer to all concerns for many families and individuals, particularly when leaving an inheritance for a child, but may instead be a component of an estate plan for an individual with a disability. For many families, a STABLE account will be used in conjunction with a Third Party Discretionary Trust.

Please see Exhibit D for a comparison of STABLE Accounts and Third Party Discretionary Trusts.

STABLE 
ACCOUNT



Exhibit D: STABLE Account vs. 3rd Party Discretionary Trust (DT)

Issues	STABLE Account	3rd Party DT	Main Difference
Who can use?	Only persons disabled before age 26	Any person with or without a disability	STABLE is limited; 3rd Party DT can be used by anyone
Who can fund?	Anyone, including person with disability	Anyone, except person with a disability	Unlike the 3rd Party DT, STABLE can be funded with assets of the person with disabilities
How many can a person have?	One	Unlimited	Person can only have one STABLE account, but unlimited number of 3rd Party DTs
Who can control?	Person with a disability, a parent of a minor child, legal guardian, conservator or agent	Trustee, anyone except the person with a disability or their spouse	STABLE allows person with a disability to retain control, while 3rd Party DT requires someone else to be in charge
How much can be paid into per year?	\$15,000 in 2020 (tied to annual federal gift tax exclusion amount) plus beneficiary's income up to \$12,490 (tied to federal poverty limit for single income household)	Unlimited	STABLE is limited in how much can be funded, while 3rd Party DT allows unlimited funding
Is funding gift-tax free?	Yes	No	STABLE can be funded gift-tax free; 3rd Party DT is subject to gift tax (if funded during lifetime)
Is there a cap on how much can be in the account?	Yes, currently \$482,000 (2020); Amounts over \$100,000 are included as resources for SSI	No	3rd Party DT can contain any amount. STABLE assets over \$100,000 are included as resources for SSI
How is income taxed?	No income tax	Taxed as non-grantor trust	3rd Party DT will be taxed on income earned, while STABLE account will not
What type of distributions can be made?	"Qualified disability expenses" as defined by applicable law	No limitation so long as they don't displace government benefits and certain disbursements may reduce SSI	STABLE has restrictions on how funds can be used
Who inherits on death of person with disability?	Medicaid Payback provision (After payback, if any, funds go to beneficiary's estate)	No Medicaid Payback (Trust controls who inherits funds)	3rd Party DT has no Medicaid Payback (STABLE is subject to Medicaid Payback)

Final Thoughts

It is our sincere hope that this book has provided you with some answers to questions that you have. Because every individual is unique, each situation regarding estate planning is unique. If you have additional questions, you should ask other parents, the Ohio DD Council office, other trusted advisors, or an attorney with a focus on Special Needs Planning for additional information.



*A*bout the Authors

Logan K. Philipps, Principal Resch, Root, Philipps & Graham, LLC

Logan has been an attorney since 2006. As an estate planning attorney, Logan helps people plan for bright tomorrows for themselves and their loved ones.

An area of concentration for Logan's practice is planning for families with children with special needs. Before becoming a lawyer, Logan taught elementary school in Cincinnati, Ohio. He utilizes his teaching background to educate individuals, parents, grandparents and loved ones about the strategies available to protect family members. His experience with special needs started as a teenager when his father remarried, and he gained a stepbrother who has special needs.

Logan lives in Grandview Heights with his wife, Molly, and three boys.



William (Bill) K. Root, Principal Resch, Root, Philipps & Graham, LLC

Bill has been an attorney since 1980. Bill has limited his practice to estate and business planning, which allows him the opportunity to work with individuals and business owners to help them plan their personal estates, and for the successful transition of their business interests.

Bill's special needs planning practice started in 1985 with the birth of his second child, Erin. He and his wife attended more IEPs, school meetings, seminars, doctor's appointments and consults that he can begin to count. They participate in a number of special needs organizations. They also established the Erin Root Fund for Children at the Columbus Foundation and have directed their charitable giving to organizations created to serve children with special needs.

Bill lives in Dublin with his wife, Tina.



NOTES

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