

SPECIAL NEEDS

PLANNING GUIDE



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The Centers for Disease Control and Prevention estimates that one in four Americans lives with some form of disability. Difficulty with mobility or independent living and cognitive difficulties are the most prevalent types of disabilities in the United States. For those living with a disability, there are often substantial associated costs, forcing many individuals to rely on federal and state government assistance programs that help provide income, medical care, food and housing.

Estate planning for people with disabilities is often different from estate planning for able-bodied individuals, and these differences also affect parents, grandparents and other loved ones of the person with a disability. One of the most common methods of planning for a loved one with a disability is a special needs trust. These trusts, which were created by federal statute, help to protect assets from being counted against an applicant for certain means-tested government benefit programs, such as Supplemental Security Income and Medicaid.

In order to appreciate the benefits of using a special needs trust, it is important first to understand which government benefit programs are means-tested and how eligibility for such programs is determined. This booklet will explain the most common government benefit programs available to people with disabilities and then describe how special needs trusts and ABLE Act accounts can be used to help maintain eligibility for these vital programs.



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1. Government benefit programs

Some of the government benefit programs most commonly accessed by people with disabilities are Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare and Medicaid. Both SSI and Medicaid are “means-tested” benefit programs, meaning that the applicant must have less than a specified amount of income and assets in order to qualify

A. Income programs – SSDI & SSI

I. Social Security Disability Insurance (SSDI)

If you’ve worked in jobs covered by Social Security and you become unable to work for one year or more due to a disability, you may qualify for a federal program called Social Security Disability Insurance (SSDI).

The requirements to receive SSDI are:

1. You have paid in to Social Security through previous employment; and
2. You have been unable to work for at least one year due to disability; and
3. Your condition must be severe enough to significantly limit your ability to perform basic work tasks, such as “lifting, standing, walking, sitting and remembering”; and
4. You must be unable to perform the work you did previously, and unable to perform any other type of work despite your impairment; and
5. Eligibility for SSDI is not means-tested, meaning you are not required to prove that you have less than a certain threshold of income or assets at your disposal.

II. Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a federal program that provides a basic income to people with few resources, who meet certain criteria.

To qualify for SSI, you must:

1. Be age 65 or older; or
2. Be totally or partially blind; or
3. Be unable to work due to a severe medical condition that is expected to last at least one year or result in death.
Note that this requirement is similar to the requirement to receive SSDI. Many people with disabilities are concurrently eligible for both SSDI and SSI. In some situations, you may be eligible to receive benefits under both programs.

In addition to meeting one of the previous criteria, in order to be eligible for SSI you must have less than \$2,000 in countable assets (\$3,000 for a married couple living together), and your income must not exceed a certain level determined by a complex formula. The maximum income an SSI applicant who is claiming eligibility due to a disability could have in 2020 is just \$1,260 per month.



If you meet the criteria to qualify for SSI, you will usually also be able to qualify for other government benefit programs for people with limited resources, such as Supplemental Nutrition Assistance Program (SNAP) and Medicaid. Because of SSI’s requirement that an applicant have few resources in order to qualify, it is considered a means-tested benefit. This feature will be important in our later discussion of how special needs trusts can help a person with a disability maintain eligibility for certain means-tested government benefits.



What assets are countable when determining eligibility for SSI?

The Social Security Administration defines the following as “countable resources,” meaning the value of these resources will be counted against the \$2,000 limit when determining eligibility for SSI.

- Cash and bank accounts
- Cash value of life insurance policies, in excess of \$1,500
- Stocks and bonds
- Household goods and personal effects, in excess of \$2,000
- More than one automobile
- Real estate, other than the applicant’s home

Assets that are not countable toward the \$2,000 limit include:

- A home, if it is the claimant’s principal residence
- One car, if it is valued at \$4,500 or less
- Wedding rings
- ABLE accounts, if the value is less than \$100,000 for those disabled before age 26
- PASS savings (income contributed to a “Plan for Achieving Self Support” account)
- IDA savings (money in an Individual Development Account for individuals receiving support from the Temporary Assistance for Needy Families program)
- Prepaid burial expenses, up to \$1,500
- Certain support payments, including:
 - » Relocation assistance payments
 - » Crime victim’s assistance
 - » Earned income tax credit payments
 - » Grants, scholarships, fellowships or gifts used for tuition and educational expenses
 - » Child tax credit payments

Who is considered “disabled” when determining eligibility for SSI & SSDI?

The Social Security Administration defines disability as “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.” A child is considered disabled if they have “a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations.”

Obtaining a determination of disability is often a significant hurdle that may take several years and multiple appeals to finally receive.

Certain very serious conditions will receive an automatic qualification for disability benefits. These conditions comprise the Compassionate Allowances List, and include:

- Acute leukemia
- Lou Gehrig’s disease (ALS)
- Stage IV breast cancer
- Inflammatory breast cancer
- Gallbladder cancer
- Early-onset Alzheimer’s disease
- Small cell lung cancer
- Hepatocellular carcinoma
- Pancreatic cancer
- Anaplastic thyroid carcinoma

Conditions on the Compassionate Allowances List qualify for expedited review and approval, upon confirmation of diagnosis. There are also five additional conditions on the Listing of Impairments Manual used by the Social Security Administration that will also qualify for disability benefits upon confirmation of such condition. These include:

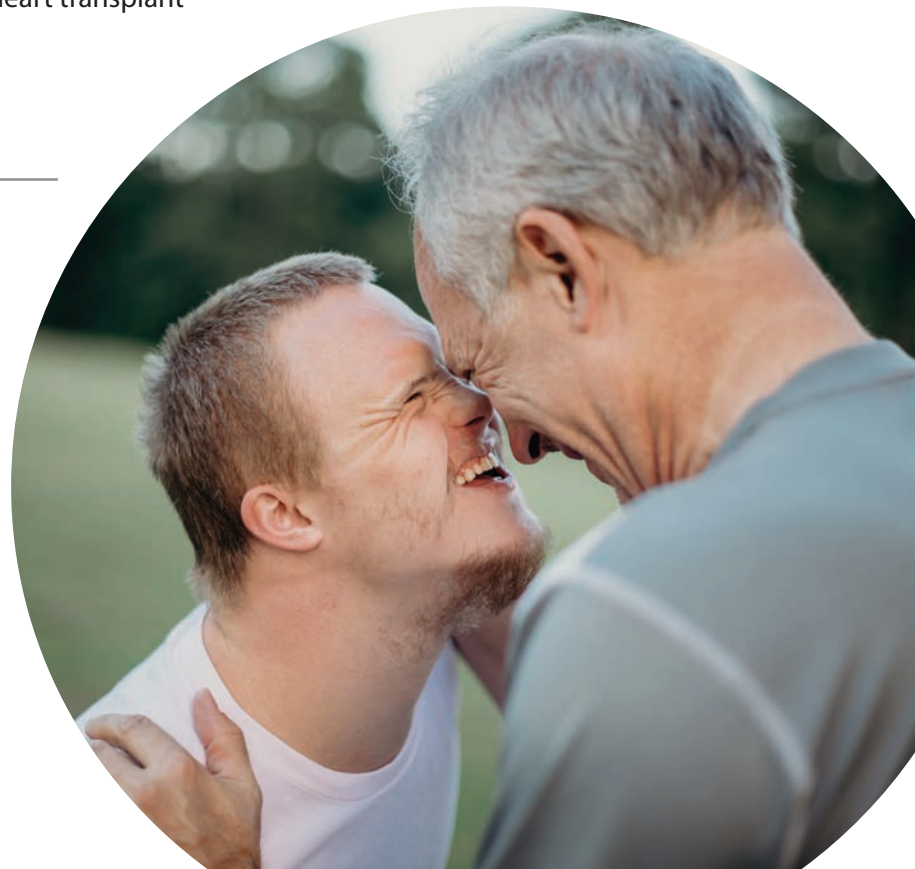
- Kidney transplant
- Liver transplant
- Cochlear transplant
- Lung transplant
- Heart transplant

All other disabilities, other than those listed above, must be proven via medical records and reports. The top five conditions for which people with disabilities receive benefits from Social Security every year are:

- Arthritis
- Degenerative disc disease
- Cancer
- Paralysis
- Parkinson’s disease

In addition to physical disabilities, people with intellectual disabilities (ID), such as autism spectrum disorder and Down’s syndrome, make up 14% of all adults receiving SSI and SSDI benefits.

As will be discussed below, a person must qualify as “disabled” under the Social Security Administration’s regulations in order to be eligible to be the beneficiary of either a first-party special needs trust or an ABLE Act account (but not a third-party special needs trust).



B. Medical programs - Medicare & Medicaid



I. Medicare

Medicare provides hospitalization and medical coverage for individuals age 65 or older, some people with disabilities under age 65, and people with end-stage renal disease.

Everyone eligible for SSDI also becomes eligible for Medicare, after a 24-month waiting period. Medicare has two parts – Part A is hospital coverage, and Part B is medical coverage. Medicare Part B requires the payment of monthly premiums. Like SSDI, Medicare eligibility is not means tested.

II. Medicaid

Medicaid is a joint federal and state program that provides certain medical services to over 72 million Americans, including elderly people, people with few resources, blind people and people with disabilities. For our purposes, we will be addressing a program known as the Medicaid “Aged, Blind or Disabled” program (commonly called ABD Medicaid, Regular Medicaid or State Plan Medicaid). Eligibility criteria for this Medicaid program mirrors the criteria for SSI (see above), so in most states, if you qualify for SSI, you also qualify for Medicaid.



Medicaid covers more than 7 million non-elderly adults with disabilities. It often provides services and supports that cannot be accessed with private insurance and which allow people with disabilities to live independently. Because Medicaid provides specialized services to people with disabilities, some of which are unavailable in the regular medical marketplace, Medicaid is often the most important benefit that a person with a disability receives.

The Medicaid ABD program has extremely restrictive limits on monthly income, as well as a limit on the total value of assets that an applicant can own.

**State Limits on Income & Asset Levels for
Single Medicaid Applicant in 2020 (Aged/Blind/Disabled Medicaid)**

State A - M	Monthly Income Cap	Asset Cap	State M - W	Monthly Income Cap	Asset Cap
AK	\$1,455	\$2,000	MO	\$904	\$4,000
AL	\$803	\$2,000	MS	\$783	\$2,000
AR	\$783	\$2,000	MT	\$783	\$2,000
AZ	\$1,063	n/a	NC	\$1,064	\$2,000
CA	\$1,294	\$2,000	ND	\$883	\$3,000
CO	\$783	\$2,000	NE	\$1,063	\$4,000
CT	\$874.38 - \$984.49	\$1,600	NH	\$797	\$1,500
DC	\$1,063.33	\$4,000	NJ	\$1,063	\$4,000
DE	\$783	\$2,000	NM	\$783	\$2,000
FL	\$961	\$5,000	NV	\$783	\$2,000
GA	\$783	\$2,000	NY	\$875	\$15,750
HI	\$1,224	\$2,000	OH	\$783	\$2,000
ID	\$836	\$2,000	OK	\$1,063	\$2,000
IL	\$1,063	\$2,000	OR	\$783	\$2,000
IN	\$1,063	\$2,000	PA	\$805.10	\$2,000
IA	\$783	\$2,000	RI	\$1,063	\$4,000
KS	\$475	\$2,000	SC	\$1,063	\$7,730
KY	\$235	\$2,000	SD	\$783	\$2,000
LA	\$783	\$2,000	TN	\$783	\$2,000
MA	\$1,063	\$2,000	TX	\$783	\$2,000
MD	\$350	\$2,500	UT	\$1,063	\$2,000
ME	\$1,063	\$10,000	VA	\$851	\$2,000
MI	\$1,063	\$2,000	VT	\$1,175	\$2,000
MN	\$1,064	\$3,000	WA	\$783	\$2,000
MO	\$904	\$4,000	WI	\$605.78 (plus shelter)	\$2,000

**Medicaid recipients may lose their eligibility if their income or
asset levels exceed the allowable maximum limit**

What are the limits on income and assets that must be met in order to qualify for Medicaid?

Medicaid's income and asset requirements are regulated by the states, so your income and asset limit will be based on where you live.

As you can see from the chart, the amount of resources that a Medicaid recipient is permitted to have is extremely low. Because these qualification criteria are similar to the criteria for SSI, in 41 states SSI recipients automatically qualify for Medicaid benefits as well.

What assets are countable when determining eligibility for Medicaid?

Most states apply the federal SSI eligibility rules when determining which assets are countable for Medicaid eligibility (see chart).

How can an inheritance disqualify someone from Medicaid?

Imagine a scenario in which a child has muscular dystrophy. By the time he reaches adulthood, his mobility is severely limited, and he needs the assistance of certain means-tested government benefits, such as Medicaid, in order to live independently. Through the Medicaid program, he is able to have access to in-home care that allows him to attend college or maintain employment. Without such in-home care, higher education and regular employment would simply not be possible.

His current caregiver, who is provided by Medicaid, has been with him for several years, knows his needs and preferences, and the two have developed trust and a good working relationship.

Now imagine this child's well-meaning aunt passes away while he's in

college. The aunt loved her nephew and wanted to help him have an easier life, and she figured the best way to do that would be to leave him an inheritance through her estate. She wasn't wealthy, but she was able to leave him \$20,000 as her way of helping.

Starting in the month after the nephew receives his inheritance, all of his means-tested government benefits, including Medicaid, will be suspended. The benefits can only be reinstated after he proves that he has spent down the money in his account, and the account balance is once again below the Medicaid asset limits.

Depending on the level of skilled care required for the nephew to be able to attend college, \$20,000 may not even last through one school year. Add to that the disruption of losing his regular caregiver who has been with him for years, because that person works for a program that is solely funded by Medicaid.

The school year has just started, but instead of focusing on his studies, he now has to focus all of his time on finding a new qualified and affordable caregiver before his Medicaid benefits are suspended at the end of the month. Even

after he finds a new caregiver, that person will need to be trained and it will take time for him to develop a similarly trusting relationship as he had with his Medicaid-provided caregiver. And, of course, just at the point when the new caregiver will start to become knowledgeable and effective with his care routine, the \$20,000 inheritance will run out, the Medicaid benefits will be reinstated, and the whole process of switching caregivers will have to start all over again.

Already facing many challenges and obstacles due to his disability, the nephew may feel the added stress of dealing with Medicaid suspension/reinstatement and switching caregivers multiple times is simply too much for him to be able to continue with college this year.

And so, a well-intentioned gift from a loving relative, rather than enhancing this young man's life, has now caused so much disruption that he will need to temporarily leave college until his Medicaid benefits can be reinstated and his caregiving can be stabilized. This kind of unexpected consequence could very easily have been avoided through the establishment of a special needs trust to which the well-meaning aunt could have directed her gift.

2. Using a special needs trust to preserve eligibility for government benefits

As illustrated in our example of the well-intentioned aunt, above, it doesn't take much to disqualify someone from means-tested government benefits, such as SSI and Medicaid, and disruptions to government benefits can have serious negative repercussions in the life of a person living with a disability.

There are safe and legal ways to provide additional resources for a person with a disability without causing their Medicaid or SSI benefits to be reduced or suspended.

How can I transfer money to my disabled child without disqualifying them from government benefits?

Two of the most common ways of providing additional resources to a person with a disability, either during your lifetime or after your death, include special needs trusts and ABLE Act accounts. These strategies will be explained in detail below, but it is important to keep in mind that preserving eligibility for government benefits is fraught with traps for the unwary, and is best accomplished by consulting with an experienced attorney who can help you achieve your goals.



Are there different types of special needs trusts?

There are three types of special needs trusts (which are sometimes also referred to as “supplemental needs trusts”):

1. Third-party special needs trusts; and
2. First-party special needs trusts (also called (d)(4)(A), self-settled or Medicaid payback trusts); and
3. Pooled special needs trusts (also called (d)(4)(C) trusts).

Don't let the monikers confuse you – the primary difference between the first two types of special needs trusts is whose money is being used to fund it. A first-party special needs trust is funded exclusively with money that belongs to the person with a disability; while a third-party trust is funded with money that belongs to someone else (such as parents, grandparents, etc.).

A. Third-party special needs trusts

A third-party special needs trust is established and funded by someone other than the beneficiary. Parents of children with disabilities who will likely need to rely on means-tested government benefits for the remainder of their lives commonly form third-party special needs trusts to (1) preserve eligibility for government benefits and (2) provide supplementary resources or assistance not provided by government benefits.

Third-party special needs trusts have more flexibility than first-party special needs trusts, and therefore tend to be the preferred way to establish a trust for a person with a disability.

How can I create a third-party special needs trust?

You may form a special needs trust either during your lifetime (known as an “inter vivos” trust) or you can create a special needs trust in your will that comes into existence after your death (known as a “testamentary” trust).

Should I create a third-party special needs trust in my will even if none of my beneficiaries are currently disabled?

Planning for the unexpected is part of the estate planning process. It is precisely because none of us can see the future that we create estate plans to protect our loved ones after we die. By creating an optional third-party special needs trust in your will, you can give your executor the flexibility to use it if any of your beneficiaries have a disability at the time of your death.

What assets should be used to fund a third-party special needs trust?

There are no restrictions on what types of assets a third-party special needs trust can hold. However, because the purpose of a special needs trust is to be able to provide supplemental resources for the beneficiary, it works best if the trust is funded with liquid assets, such as cash or stocks. Life insurance is another common funding source for third-party special needs trusts.

Can other friends or relatives contribute to a third-party special needs trust?

Yes – if you create an inter vivos third-party special needs trust during your lifetime, you will establish a bank account to hold trust assets. Friends and relatives may contribute to the special needs trust, either by transferring money or other assets into the trust during their lifetimes or by leaving a bequest through their will. Contrast this with first-party special needs trusts, which cannot accept contributions from anyone besides the person establishing the trust (more on this below).

If there is money left over in the third-party special needs trust when the beneficiary dies, to whom does it go?

One of the features that sets third-party special needs trusts apart from first-party trusts, is the ability to direct the ultimate distribution from the trust. When you establish a third-party special needs trust for someone, you may select who receives the balance of the trust when the beneficiary passes away.

In contrast to first-party special needs trusts, there is no Medicaid payback requirement for third-party special needs trusts.

B. First-party special needs trusts

Like a third-party special needs trust, a first-party special needs trust can be used to provide supplementary assistance to a person with a disability who qualifies for means-tested government benefit programs such as SSI and Medicaid. A first-party special needs trust is funded with assets that are owned by the person with a disability. This type of trust is subject to greater scrutiny and additional requirements, which may include review and approval by the state Medicaid agency before it can be funded.



What are the differences between first-party and third-party special needs trusts?

Unlike a third-party special needs trust, a first-party special needs trust:

- Must be established by a parent, grandparent, guardian or by court order.
- Must be irrevocable (unchangeable).
- Can only be established for a beneficiary who is under age 65. (The trust will remain exempt after the beneficiary reaches age 65, but any assets contributed to the trust after the beneficiary turns 65 will be subject to the Medicaid transfer penalty rules.)
- Must be funded with assets owned by the beneficiary.
- Is required to reimburse the state Medicaid agency after the beneficiary's death.

When is a first-party special needs trust appropriate?

First-party special needs trusts are useful to help a person with a disability avoid being disqualified for means-tested government benefits due to receiving large or lump sum payments in situations like:

- Inheritance
- Lawsuit settlement/judgment
- Divorce settlement/judgment





Is a first-party special needs trust required to pay back Medicaid after the beneficiary's death?

The most significant difference between first-party and third-party special needs trusts are the Medicaid payback rules. Because first-party special needs trusts are funded with the disabled beneficiary's own assets, when the beneficiary passes away, the first-party special needs trust is required to reimburse Medicaid for benefits paid during the beneficiary's lifetime. Because of the high cost of health care, this frequently exhausts all of the assets of a first-party special needs trust, leaving nothing to pass on to loved ones.

Can I create a first- or third-party special needs trust myself?


Because there are specific regulations that govern what language must be used in order to create a special needs trust that will be officially recognized by SSI and Medicaid, you should work with an experienced attorney to ensure that it is properly drafted. The consequences of getting it wrong can be severe and may result in the person with a disability becoming ineligible for vital government benefits.

What types of expenses can a first- or third-party special needs trust pay for?

The purpose of a special needs trust is to supplement – not replace – support that a beneficiary receives through government programs. Therefore, a special needs trust is not able to pay for expenses that are being provided by a government program. For example, Medicaid pays for routine visits to the beneficiary's regular physician, so the special needs trust cannot pay for that expense. However, the trust can pay for supplemental or optional treatment that Medicaid does not provide, such as chiropractic treatments.

Typically, a special needs trust should avoid paying for food, shelter or utilities and should not give cash or cash equivalents (like gift cards) to the beneficiary. Some of the items a special needs trust can pay for include:

- Medical/dental expenses not covered by government benefits
- Elective surgery
- Massage therapy
- Chiropractic/acupuncture
- Over-the-counter medications (including vitamins and herbal supplements)
- Gym membership and fitness equipment
- Equipment such as wheelchairs or specially equipped vans
- Therapy or rehabilitation services
- Home improvements/repairs
- Furniture
- Curtains/blinds
- House cleaning service
- One automobile/van
- Gasoline
- Vehicle maintenance and repairs
- Ride share, bus/rail pass or other transportation
- Education
- Vocational training
- Dry cleaning/laundry services
- Travel, which can include the cost of a companion
- Pets and pet supplies
- Attending conferences
- Tickets to concerts or sporting events
- Dues/memberships (e.g., for health clubs, service clubs, advocacy groups, museums, zoos)
- Recreation and entertainment (summer camp, movies or social events, videos, sports equipment)
- Hobbies
- Computers, software and internet service
- Appliances (TV, washer/dryer, microwave, refrigerator)
- Legal/accounting services
- Insurance
- Burial expenses



Can a first- or third-party special needs trust be terminated if the beneficiary's disability is cured?

Yes – the terms of the special needs trust may permit the trustee to terminate the trust and distribute trust assets if the trust is no longer necessary. Additionally, most state probate codes enable a trustee to petition the court to terminate a trust if there are changed circumstances, such as when the original intent behind setting up the trust no longer applies. There may be tax consequences to terminating a special needs trust.

Whom should I select as trustee of a first- or third-party special needs trust?

The selection of a trustee for your special needs trust is an important decision, as the trustee is the one who must approve all distributions and ensure that expenses are permitted by the terms of the trust and the relevant state and federal laws. In certain situations, it may be advisable for the trustee to hire an attorney to review expenditures and help prepare any necessary periodic reports.

Any individual, other than the beneficiary of the trust, may be appointed to serve as trustee, and in the case of larger trusts a professional fiduciary (such as a bank or trust company) may agree to serve in that role. In the event that there is no suitable individual or professional trustee available, the family may want to consider utilizing the services of a pooled special needs trust to serve as trustee.

C. Pooled special needs trusts

Pooled special needs trusts may be funded either with assets owned by the disabled beneficiary (as with a first-party special needs trust) or by someone else (as with a third-party special needs trust). What makes a pooled special needs trust different isn't how it is funded, but rather who administers the trust.

In a pooled special needs trust, a nonprofit entity, rather than an individual, serves as trustee and the trust pools the assets of many special needs beneficiaries for purposes of management and investing. Pooled special needs trusts may be a viable option for trusts without many assets or where the family is unable to identify a suitable individual trustee.

The final disposition of any remaining assets in a pooled special needs trust depends on the policies of the specific pooled trust and on state Medicaid payback laws. Typically, some or all of the assets remaining in the trust after the beneficiary's death will either be used to repay Medicaid, or they will be retained by the nonprofit entity managing the trust for the benefit of other disabled beneficiaries.

3. ABLÉ Act accounts

The Achieving a Better Life Experience (ABLE) Act of 2014 allows contributions of up to \$15,000 per year to a tax-advantaged savings account that can fund expenses for a person with a disability. In order to be eligible to be the beneficiary of an ABLE Act account, the beneficiary must have a disability that began before the beneficiary reached age 26. Contributions to an ABLE Act account are not tax-deductible, however, like 529 educational savings plans, funds in an ABLE Act account grow tax-free and are not subject to gift tax restrictions. The first \$100,000 in an ABLE Act account is excluded from consideration for SSI/Medicaid eligibility. If the account balance exceeds \$100,000, the beneficiary's eligibility for benefits is temporarily suspended until the account balance drops back down to \$100,000 or less.

What expenses can an ABLE Act account pay for?

Withdrawals from an ABLE Act account can be made for "qualified disability expenses" which include:



Medical treatment



Education, tutoring and job training



Special needs transportation



Assistive technology



Housing



Legal and administrative fees

An advantage that ABLE Act accounts have over traditional special needs trusts is that ABLE Act accounts may pay for expenses related to housing, such as rent, mortgage, taxes or utility payments. In addition, there is no requirement to have a trustee manage an ABLE Act account. The beneficiary may manage their own account and decide which qualifying expenses will be paid from the account.

For many families, an ABLE Act account will be a useful supplementary option to a special needs trust, but it is not meant to replace a trust.

Comparing Special Needs Trusts & ABLE Act Accounts

	Third-Party SNT	First-Party SNT	ABLE Act Account
Who can establish the trust?	Anyone other than the beneficiary	Parent, guardian, grandparent, or court only	Anyone, including the beneficiary
When can the trust be created?	During lifetime (inter vivos) or after the death of the person creating the trust (testamentary)	Must be created before the beneficiary reaches age 65	Any time during the beneficiary's lifetime, provided the beneficiary's disability began before age 26
Beneficiary must meet strict SSI test for qualifying disability	No	Yes	Yes
Age of onset of disability	None	None	Before age 26
Whose assets fund the trust?	Anyone other than the beneficiary	Beneficiary	Anyone, including the beneficiary
Limits on contributions?	No	No	Yes (\$15k/year, plus possible additional contributions from the disabled beneficiary's earned income; \$100k maximum before benefits are suspended)
Distributions subject to trustee approval?	Yes	Yes	No
Can be used to pay for housing expenses?	No	No	Yes
Mandatory Medicaid payback?	No	Yes	Yes

An experienced attorney can help you create a customized plan that may include one or more special needs trusts and ABLE Act accounts to provide for your loved one with a disability

All things considered

For parents or family members who want to be able to provide for a child or other loved one with a disability in their estate plans, speaking with an experienced attorney who understands the intricacies of special needs planning is advisable. The world of government benefits and special needs trust law is highly dependent on state law and varies from state to state. A properly drafted special needs plan, which may include one or more special needs trusts and an ABLE Act account, can help ensure that your loved one will be well cared for both now and in the future, while also retaining their eligibility for government benefits.



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