

Special Needs Planning





What Is Special Needs Planning?

Special needs planning is the process of providing for the personal and financial security and well-being of an individual with a disability.

Depending on the circumstances, planning for special needs can be done by the:

- The individual with a disability alone
- The individual's loved ones
- The individual and loved ones together

The individual with a disability may be a:

- Minor or adult child
- Sibling
- Spouse
- Parent
- More distant relative or friend

The Statistics

12.7% of U.S. residents (all ages) report having a disability

- 4.3% of persons under age 18
- 10.3% of persons ages 18 to 64
- 33.5% of persons aged 65 and over

Source: U.S. Census Bureau, ACS 2018, accessed January 2022

1 in 44 American children has an autism spectrum disorder

Source: Centers for Disease Control and Prevention, Data and Statistics, cdc.gov, accessed January 2022

1 in 9 older Americans has Alzheimer's dementia

Source: Alzheimer's Association report, 2021 Alzheimer's Disease Facts and Figures



Goals of Special Needs Planning

- Balance your present and future needs with your loved one's present and future needs
- Create and implement personal care, financial, and legal plans
- Communicate such plans to all relevant persons
- Review and revise plans as circumstances change
- Assure family members that loved one's needs have been adequately addressed

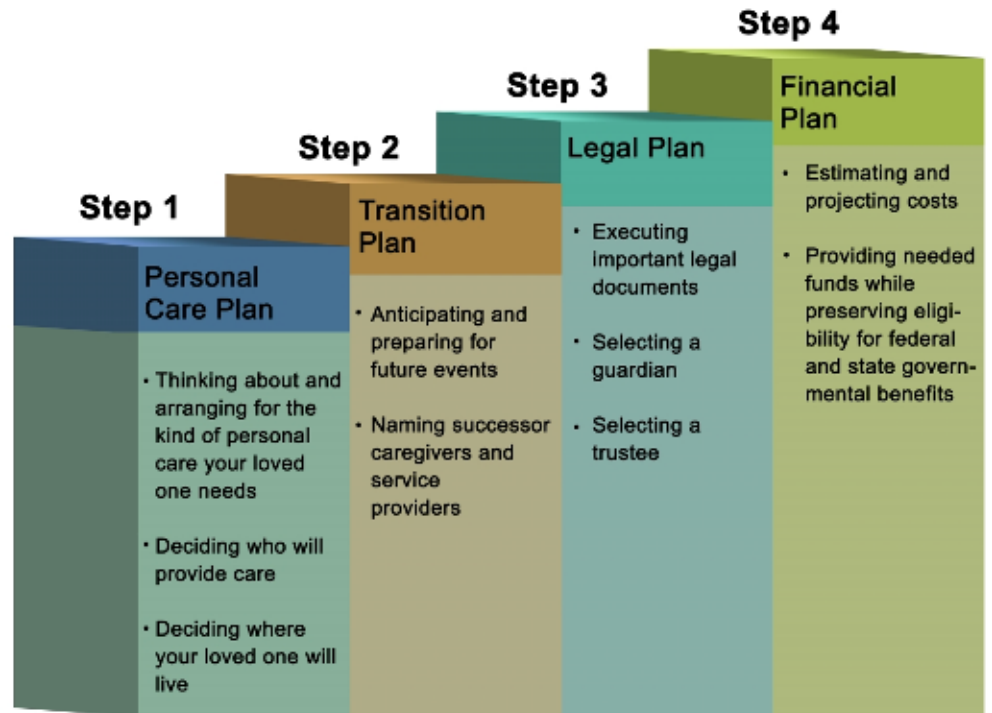


Finding Educational and Advocacy Resources and Emotional Support -- Disability-Related Organizations

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| • Alzheimer's Association | • Disabled American Veterans (DAV) |
| • American Association of People with Disabilities | • Easter Seals |
| • American Disability Association | • Families USA |
| • Autistic Society | • Institute for Independent Living |
| • The Arc (formerly Association for Retarded Citizens of the United States) | • National Disability Rights Network (NDRN) |
| • Consortium for Citizens with Disabilities | • National Information Center for Children and Youth with Disabilities |
| • Disability.gov | • National Organization on Disability |
| • Disability Resources, Inc. | • TASH |
| | • Through the Looking Glass (TLG) |



Special Needs Planning Steps





Important Legal Documents

Health-care directives

- **Living will** - a document that lists the types of medical treatment you would want, or not want, under particular circumstances
- **Durable power of attorney for health care (health-care proxy)** - lets one or more family members or other trusted individuals make medical decisions for you
- **Do not resuscitate (DNR) order** - a legal form, signed by both you and your doctor, that gives hospital staff permission to carry out your wishes

Property management tools

- **Joint ownership** - allows another person to have the same access to the property as you do
- **Durable power of attorney** - lets you name family members or other trusted individuals to make financial decisions or transact business on your behalf
- **Living trust** - a successor trustee can step into your shoes to manage property in the trust if something should happen to you



Last Will and Testament

A written directive that includes instructions about who is to settle your estate (the executor), who is to be the guardian for any minor children, and how estate property is to be distributed to your heirs.

Letter of Intent or Instruction

A written document in which you can express specific, personal wishes regarding the ongoing care of your loved one.

Be aware, however, that such a letter is not legally binding.



Estimating Expenses Worksheet

Monthly Expenses for Individual with Special Needs	
Food (meals and dining out)	
Clothing (including laundry)	
Housing (including utilities and maintenance)	
Transportation services or auto/van, gas, maintenance	
Insurance	
Medical/dental care (including drugs and therapy)	
Special medical equipment (including maintenance and repairs)	
Employment (e.g., training, workshops, attendants)	
Education (including books, fees, and materials)	
Personal needs (haircuts, etc.)	
Care assistance (live-in, respite, custodial)	
Social/recreational (computer, camps, sports, etc.)	
Other	
Total	



Federal Government Benefits

The U.S. government has over 1,000 benefit and assistance programs for persons with disabilities or special needs. Potential benefits include:

- Career development assistance
- Child care/support
- Counseling services
- Disability assistance
- Disaster relief
- Education/training programs
- Energy assistance
- Food/nutrition
- Grants/scholarships/fellowships
- Health care
- Housing insurance
- Legal services
- Living assistance
- Loan/loan repayment
- Medicaid/Medicare
- Social Security
- Tax assistance
- Veterans assistance
- Volunteer opportunities

Visit www.benefits.gov.



Medicaid	Supplemental Social Security Income (SSI)
Medicaid is a joint federal and state needs-based program that helps with medical costs for some people with low incomes and limited resources. Medicaid programs vary from state to state, but most health-care costs are covered if you qualify for both Medicare and Medicaid. People with Medicaid may get coverage for things like nursing home care and outpatient prescription drugs that are not covered by Medicare.	Supplemental Social Security Income is a needs-based program that provides monthly income to people age 65 or older, or who are blind or disabled, and who have limited income and financial resources. Someone can be eligible for SSI even if he or she never contributed to Social Security.
Visit www.ssa.gov	



Special Needs Trust (SNT)

What is a special needs trust?

- A special needs trust is also called a supplemental needs trust
- SNTs were given "official" legal status in 1993
- Assets in a properly drafted and administered SNT will not be counted as available assets for Medicaid and SSI eligibility purposes
- Trust disbursements will not be counted as income under the rules that apply to Medicaid and SSI

What kind of property can an SNT hold?

An SNT can hold virtually any kind of property, such as:

- Cash
- Securities
- Personal property
- Real property

An SNT can also own, or be the beneficiary of, life insurance. An SNT can also receive an inheritance and personal injury settlements or judgments.

Note: *There are costs and expenses associated with the creation of trusts.*

An SNT may provide for extra basic needs, such as:

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| • Insurance, such as long-term care and life insurance | • Transportation, including the purchase of a motor vehicle |
| • Medical treatment, including alternative treatment | • Clothing |
| • Physical therapy | • Education |
| • Medical equipment and aids | • Entertainment |
| • Home health aid and companionship services | • Trips and vacations |
| • Housing, in certain cases | • Computers and other electronic equipment |
| • Furniture and furnishings | • Athletic training and competitions |
| • Some utilities | • Sporting equipment |
| | • Hobbies |



Types of Special Needs Trusts

	Self-Settled or First-Party SNT	Pooled SNT	Third-Party SNT
Can the individual with a disability create for himself/herself?	Yes	Yes	No
Who can it be created for?	Individual with a disability who is under age 65	Individual with a disability who is under age 65	Individual with a disability who is age 21 or older, depending on state law
Triggers Medicaid/SSI penalty period?	No	No	Maybe, depending on state law
Must Medicaid be paid back?	Yes	Yes, or may be directed to help others in pool, depending on state law	No





Selecting the Right Trustee

Family member

One possible choice of trustee for a special needs trust is a family member. It might be comforting to know that the beneficiary has a loved one looking after him/her. However, family members may lack the expertise to properly administer the trust, thus jeopardizing its intended purpose.

Professional trustee

A professional trustee, such as a bank, may be in a better position to ensure that the terms of the trust instrument are met, and that the assets are properly invested and administered. However, a professional trustee may not be as familiar with the day-to-day and long-term needs of the beneficiary as family members.

Co-trustees

Combining a family member and a professional as co-trustees can provide the balance of personal touch with specialized knowledge. With multiple trustees, however, there is always the chance that disagreement may delay important decisions.

Trust protector

A trust protector is an individual, committee, or entity that has power over the trustee and can make major changes to the trust document. A trust protector does not manage the day-to-day administration of the trust; that is the job of the trustee. The purpose of a trust protector is to give flexibility to the trust, and to have a check and balance against trustee failures and abuse.

The duties of the trustee include:

- Acting with loyalty and care on behalf of the beneficiary
- Disbursing funds to the beneficiary in accordance with the trust terms
- Receiving and maintaining an inventory of trust assets, and arranging for their security and safekeeping
- Investing trust assets in a "prudent" manner
- Keeping good records of all income and principal transactions, and preparing periodic accountings
- Handling tax matters, such as filing annual tax returns
- Ensuring the maintenance of any government benefit entitlements
- Communicating with the beneficiary, family members, and all service providers
- Assisting in emergency situations



ABLE Account Basics

An ABLE account is a tax-advantaged savings vehicle that can be opened by, or on behalf of, an individual with a significant disability that began before age 26. The individual must be entitled to Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits based on blindness or disability, or obtain physician certification.

SSI and Medicaid, along with other public benefits, provide much-needed support. But to remain eligible for them, individuals with disabilities can have only \$2,000 in personal assets, which is not enough to pay for most disability-related expenses. ABLE accounts help address this problem. Because funds in an ABLE account will generally not count toward the personal asset limit for SSI and Medicaid, individuals with disabilities now have the opportunity to save and invest for their future needs without sacrificing their eligibility for these benefits.

The total annual contribution to an ABLE account from all sources is limited to the federal annual gift tax exclusion, which is \$16,000 in 2022. Account owners who work and who don't have an employer-sponsored retirement account may save an additional \$12,880 from their income in 2022 (\$14,820 in Hawaii and \$16,090 in Alaska.) Lifetime contribution limits also apply and vary by state. However, only account balances under \$100,000 are exempt from the SSI asset limit. SSI benefits will be temporarily suspended if an account balance exceeds \$100,000. And upon the death of a beneficiary, funds remaining in an ABLE account may be subject to a reimbursement claim by a state Medicaid program (not all states will pursue payback).

Contributions to an ABLE account are made with after-tax dollars, and any earnings accumulate tax deferred. In addition, distributions are tax-free when used to pay qualified expenses. These include various expenses related to living with a disability such as housing, health care, transportation, assistive technology, job training, and personal care. Though no federal income tax deduction is available, some states may offer an income tax deduction or other tax incentive to residents. State tax benefits should be considered when choosing an ABLE program.

Investors should consider the investment objectives, risks, charges, and expenses associated with ABLE programs before investing, including the risk that investments may lose money or not perform well enough to cover future expenses. More information is available in the official statements and applicable prospectuses, which contain information about the investment options, underlying investments, and investment company. Read these carefully before investing. Also, before investing, consider whether your state offers an ABLE program that provides residents with favorable state tax benefits. Consult a tax professional. ABLE accounts may be protected from creditors if you invest in your own state's program, depending on the state.



The federal Achieving a Better Life Experience (ABLE) Act, passed in 2014, authorized ABLE programs. Most states have already opened ABLE programs, while others are in the process of implementing them. Most states will open their programs to residents of any state, so you will have multiple options even if your state is not offering one. Program details will vary, and each will offer various fee structures and investment options, so you will need to compare programs carefully before choosing one. Ask your state about the potential impact of your ABLE account assets on public benefits.

For more information on state ABLE programs, visit the ABLE National Resource Center website, ablenrc.org.



Planning for an Emergency

Note: These instructions were copied directly from www.FEMA.gov.

If someone close to you has a disability or a special need, you may have to take additional steps to protect yourself and your family in an emergency.

Check for hazards in the home

During and right after a disaster, ordinary items in the home can cause injury or damage. Anything that can move, fall, break, or cause fire is a home hazard. Check for items such as bookcases, hanging pictures, or overhead lights that could fall in an earthquake or a flood and block an escape path.

Be ready to evacuate

Have a plan for getting out of your home or building (ask your family or friends for assistance, if necessary). Also, plan two evacuation routes because some roads may be closed or blocked in a disaster.

- Create a network of neighbors, relatives, friends, and coworkers to aid you in an emergency
- Discuss your needs and make sure everyone knows how to operate necessary equipment
- Discuss your needs with your employer
- If you are mobility impaired and live or work in a high-rise building, have an escape chair
- If you live in an apartment building, ask the management to mark accessible exits clearly and to make arrangements to help you leave the building
- Keep specialized items ready, including extra wheelchair batteries, oxygen, catheters, medication, prescriptions, food for service animals, and any other items you might need
- Be sure to make provisions for medications that require refrigeration
- Keep a list of the type and model numbers of the medical devices you require
- Wear medical alert tags or bracelets to identify your disability
- Know the location and availability of more than one facility if you are dependent on a dialysis machine or other life-sustaining equipment or treatment



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Content in this material is for general information only and not intended to provide specific advice or recommendations for any individual. All performance referenced is historical and is no guarantee of future results. All indices are unmanaged and may not be invested into directly.

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