



PLANNING FOR INDIVIDUALS WITH SPECIAL NEEDS

Taking care of those who need help caring for themselves



“To the world you may be one
person, but to one person you
may be the world.”

– Heather Cortez, Poet

Labor of love. Enduring commitment.

Taking care of an individual with special needs can be a lifelong commitment — and beyond.

Medical advances that have resulted in the general population living longer have also resulted in individuals with special needs living much longer. For example, the life expectancy of an individual with Down Syndrome has increased from 25 years in 1983 to about 60 years today, an increase of 35 years!* And with continuing medical advances, it's not hard to envision that a baby born today with Down Syndrome could live into his or her 80s. Caregivers of these individuals need to consider who will take care of them after the caregiver is gone.

What steps to take?

Many of the steps are similar to estate planning steps that all caregivers should take to protect their loved ones, including:

- Last will and testament
- General durable power of attorney for financial affairs
- Durable power of attorney for health care

But caregivers of individuals with special needs should take the following additional steps:

- Draft a "Letter of Intent" (explained on page 4);
- Have a guardian appointed (upon reaching the age of majority if your loved one is not able to manage his or her own affairs); and
- Provide financial security for the person with special needs by establishing a special needs trust.

General estate planning steps

The basic estate planning documents — a will, power of attorney, etc. — allow you to ensure that your personal and financial affairs are organized in the event of death or mental incapacity. This further ensures that your loved ones are protected when you are gone or can no longer protect them.

Will

A will is the foundation of any estate plan. Without a will, the state distributes your assets according to its intestacy laws. Usually this means that, upon your death, some or all of your assets may be distributed directly to your children. This distribution method may cause your loved one with special needs to be ineligible for government benefits if he or she is your child. However, it is also important to note that even with a will you should ensure that it is properly written to not leave any assets directly to your loved one with special needs.

Also, without a will, the state will determine guardianship of your minor children and of any adults with special needs who are incapable of making medical or financial decisions for themselves. A properly written will, in conjunction with other estate planning documents, can ensure that your loved one with special needs is taken care of properly, and by the guardian of your choice.

General Durable Power of Attorney for financial affairs

A durable power of attorney (DPOA) is a written document that gives another person the power to manage your financial affairs and property if you should become incapacitated. A general DPOA typically allows the person you designate as your agent or "attorney-in-fact" to do every legal act that you could do.

* "Down Syndrome Life Expectancy Is Higher, But Not For Everyone." Nationwide Children's Hospital, 21 July 2021, www.nationwidechildrens.org/newsroom/news-releases/2021/07/down-syndrome-life-expectancy

Durable Power of Attorney for health care (DPOA)

The durable power of attorney for health care is a limited durable power of attorney created solely for the purpose of making health care decisions. It gives your agent the power to make medical decisions for you when you have lost the ability to do so.



Your DPOA should be drafted specifically to permit your agent to make discretionary non-support distributions to or for the benefit of an individual with special needs.

Special needs estate planning steps

Estate planning for a family that includes an individual with special needs requires extra steps to provide for the individual's future.

Drafting a Letter of Intent

In addition to a will, you should also consider writing a letter of intent. This is not a legal document. Instead, it is a guide filled with important information about the person with special needs. It allows you to explain the diagnosis, the individual's level of functioning, and how you wish him or her to be raised (if a child). Also, it provides personal information about the person, like favorite color, nighttime rituals, religious preferences, favorite foods, and special educational or vocational arrangements. This type of document can ease a difficult transition.

Creating a guardianship

A guardian is a person lawfully invested with the power, and charged with the duty, of taking care of a person who is considered incapable of administering his or her own affairs. Designating a guardian and successor guardians is a critical aspect of drafting a will. An individual with special needs may still need a guardian upon reaching the age of majority.

Typically, once children reach the age of majority, they become their own legal guardians, regardless of their ability to manage their lives or financial affairs. If yours is incapable of making medical or financial decisions, you will need to file with the court for legal guardianship.

You will want to give special consideration to who you name as guardian, and power of attorney for financial decisions, as they require different skills.

Providing financial security

Individuals with special needs generally require higher out-of-pocket medical and/or educational expenses than those without. Also, many of the available government benefits are need-based. If there are assets and/or income in excess of certain dollar amounts owned by an individual with special needs, his or her benefits may be jeopardized or payback for benefits received may be required. Planning for the financial security of an individual with special needs should involve consideration of any impact to qualification for government benefits. A special needs trust funded with life insurance may be the right solution.



AuguStar's Letter of Intent Workbook can help with the drafting of this important document. Once complete, it should be updated on a regular basis to ensure that it still fulfills its purpose. Select one day a year to review your letter of intent and make any needed changes.

Creating a special needs trust

A special needs trust enables you to leave assets in trust knowing that they will be used to support the person with special needs. A special needs trust is created to take care of any supplementary needs that are not covered by government benefits. Once the basics of food, shelter, medical care, and education are met by the government, the trust can provide additional funds to enhance the quality of life of the person with special needs.

A third-party special needs trust (also known as a supplemental needs trust) is generally established by the caregivers of the individual with special needs and is funded with the caregivers' assets. The loved one with special needs is the beneficiary of the trust, but the trustee is given the discretion to determine when and how much the individual should receive. The trustee would generally make money available to provide much needed services and items that the government benefits don't provide. Upon the death of the beneficiary, the remaining assets are distributed to the other natural beneficiaries of the parents.

Using a special needs trust allows you to provide for a loved one with special needs without jeopardizing his or her eligibility for need-based benefits.

Alternatives to creating a special needs trust

There are primarily three other possible methods of providing for the future care of a person with special needs and, for each, the disadvantages generally outweigh the advantages.

Distribute assets outright

The caregivers distribute their assets directly to the individual with special needs.

Advantages: The individual receives the funds directly.

Disadvantages: By giving the loved one with special needs the assets directly, the individual may be disqualified from receiving any need-based government benefits, such as Medicaid and Supplemental Security Income (SSI). And, he or she may not be able to manage the assets received.

Disinherit the person with special needs

The caregivers disinherit the person with special needs in order to maintain the need-based government benefits.

Advantages: The individual is not disqualified from receiving need-based government benefits.

Disadvantages: The individual does not have a safety net if the government benefits are reduced or taken away, and the person has no supplemental money for transportation, education, purchasing a computer, or taking a vacation.

Leave property to another family member

The caregivers leave property to another family member with the understanding that the property is to be used for the benefit of the loved one with special needs.

Advantages: The individual retains his or her need-based government benefits.

Disadvantages: The "understanding" is not legally enforceable so there is no guarantee that the individual with special needs will receive the benefits from the property. Also, if that family member has any creditors, the creditors would be able to go after the property.

Beneficiary review checklist

It is important to make sure that the loved one with special needs is not inadvertently listed as a beneficiary (or contingent beneficiary) on any of your financial assets. If overlooked, old and forgotten designations may destroy the individual's qualification for government assistance. And, he or she may not have the capacity for managing these resources.

Beneficiary and transfer-on-death (TOD) designations (both primary and contingent) on all of the following should be reviewed on an annual basis or in the event of a life change:

- Life insurance policies (personally-owned, group-term or other policy acquired through work)
- Non-qualified annuity
- Individual retirement account or annuity (IRA)
- 401(k) or other profit-sharing plan
- 403(b) tax-sheltered annuity or account
- Pension plan
- 529 plan
- Bank accounts
- Brokerage accounts
- Wills
- Trusts (other than personal special needs trust)



While a special needs trust can be created during lifetime or upon death, consider establishing one as soon as possible. This will provide a safe and easy way for other family members to provide gifts and/or inheritances to the individual with special needs without putting his or her needs-based government benefits at risk.

Funding a special needs trust

Finding a way to fund a special needs trust can be daunting. Yet, in many cases, life insurance on a caregiver's life is the start to a good plan, since the individual with special needs may be forever in need of financial support. In addition to much-needed capital for the loved one with special needs after your death, permanent life insurance products may also provide a source of income (i.e., through policy loans) while you are alive. It also has the added benefit of retaining the remainder of your estate for other family members; by funding the trust with life insurance, your other family members may benefit from other assets remaining in your estate.

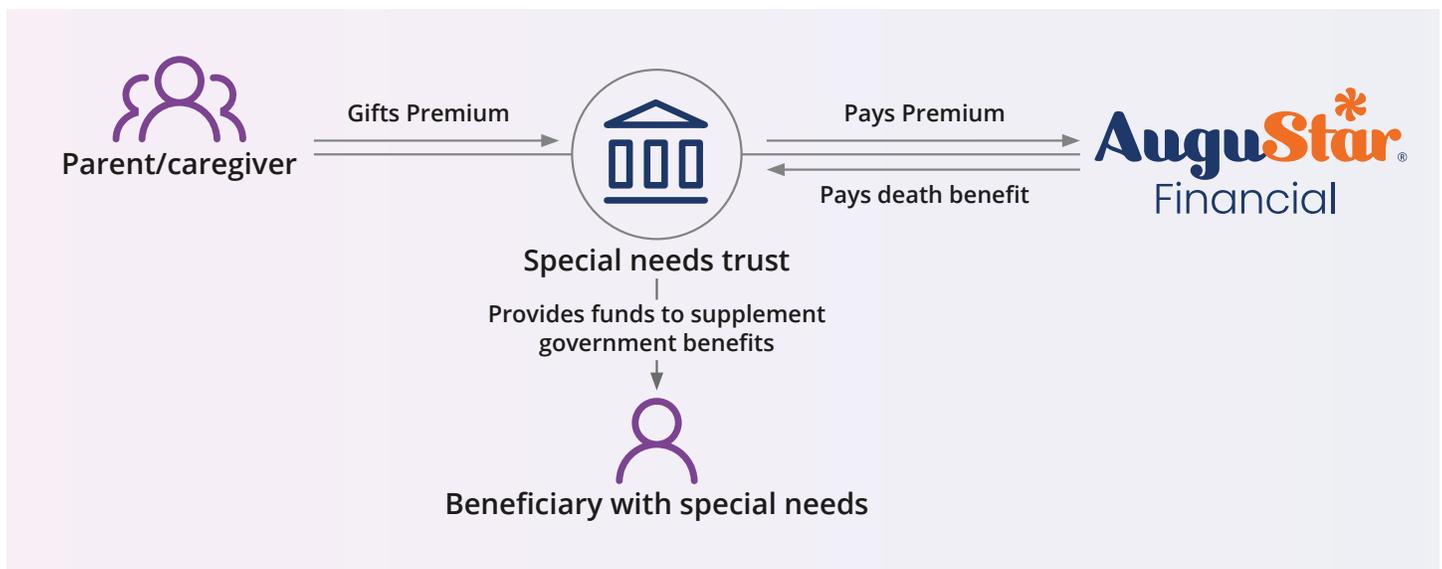
Life insurance continues to be one of the most common ways to fund a special needs trust. Insurance proceeds are usually received free of income tax and pass outside of probate. In many cases, you may prefer to own the life insurance policy outright and simply name the trust as the primary or contingent beneficiary of the policy. If you have concerns about estate taxes, divorce, or creditors, you may decide to have the trust own the policy in addition to being named the beneficiary. If the trust owns the policy, insurance proceeds can be excluded from your estate if the special needs trust is properly structured as an irrevocable trust during your lifetime. Funds gifted

to the irrevocable special needs trust will need to fall within the lifetime gift exemption in order to avoid the imposition of gift taxes.

There are different types of life insurance products. Because the need for financial support is often a lifetime need with no determined ending point, permanent insurance is usually preferred over term insurance for funding a special needs trust. Your individual needs and circumstances will determine which product will work best for you.



Use of the annual gift tax exclusion for gifts to the trust and its subsequent need for special notices giving the beneficiaries the right to demand the money will jeopardize your individual's eligibility for need-based benefits.



How much should be in the trust?

How much should be transferred to the trust? It depends. As with any needs analysis, you should consider a number of relevant factors, make certain assumptions, and arrive at an estimate of the future need. Follow these four steps to help determine your estimated goal:

- **Estimate your needs.** The first step is to estimate your financial needs. It does little good to fully fund a special needs trust if you fail to provide for yourself. As the primary emotional and financial support system, you must financially care for yourself in order to best allow you to care for others.
- **Evaluate the future capabilities of the individual with special needs.** What is the prognosis? What will his or her needs be in the future?
- **Take stock of what you already own or have.** How much do you currently have in savings, other liquid assets, and existing insurance?
- **Identify current and future income sources and living expenses for the individual with special needs.** Can he or she earn an income? What government benefits does he or she receive now and might in the future? (A list of possible income sources and expense items is below.)

- **Estimate the amount required.** Based upon your assumptions about inflation rates and rates of return and the life expectancy of the individual with special needs, calculate the amount you will need to provide financial security to your loved one with special needs during his or her lifetime.



Ask your financial professional about the **Special Needs Planning Data Taker and Calculator** available through AuguStar. These tools are designed to help you and your financial professional determine the amount of life insurance needed. You can also access the calculator directly at augustarpro.com.

Current and Future Income and Expenses

Income categories	Expense categories		
<ul style="list-style-type: none"> • Salary/wages • Government benefits (federal and state) • Investment income • Other income 	<ul style="list-style-type: none"> • Rent/mortgage • Utilities and telephone • Food, groceries, etc. • Clothing and cleaning • Transportation • Taxes • Vacations/travel 	<ul style="list-style-type: none"> • Recreation/entertainment • Education • Medical and dental <ul style="list-style-type: none"> - Doctor visits - Therapy visits - Prescription drugs 	<ul style="list-style-type: none"> • Special needs <ul style="list-style-type: none"> - Respite care - Custodial care - Nursing care - Special equipment (e.g. wheelchair, braces, special computer equipment) • Other

Final thoughts

Planning for the future of your loved one with special needs can be overwhelming and, yet, it can also be the most satisfying and worthwhile endeavor you undertake. It is important to contact experts for help and a team approach is generally recommended.

Working with your financial professional, attorneys and others who specialize in estate and financial planning for families with special needs is highly recommended.

A **Special Needs Attorney Locator** Guide is available through AuguStar for help in acquiring the legal partners for your team. While AuguStar does not promote or endorse specific attorneys, our locator guide contains helpful suggestions for locating an attorney in your area.

Additional resources

The ARC of the United States

www.thearc.org

The ARC works to promote the interests of people with intellectual and development disabilities.

Internet Resources for Special Children

www.irsc.org

The IRSC provides information on the needs of children with disabilities.

Special Needs Alliance

www.specialneedsalliance.co

This group is a not-for-profit organization of attorneys dedicated to the practice of disability and public benefits law.

Disability.Gov

www.disability.gov

This is the United States Government website dedicated to providing information and opportunities to the disabled community.

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