

Planning When Someone You Love Has Special Needs



**Special
Olympics**



Gathering the Necessary Documents, People, and Other Resources

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Life is often more rewarding, yet more complicated, for families who have a loved one with special needs. It's not easy to find adequate guidance to plan for your own needs as well as your family members'. In addition to creating the necessary lifetime plans, you may be concerned about how to manage care for your loved one and your assets when you are gone.

Creating your own plan and establishing a life plan for your family member can help ensure they have the support they need. You will gain peace of mind as well as a sense of control.

This brochure is meant to supplement other resources available from Special Olympics. But it is NOT a substitute for the good counsel of an experienced attorney and financial advisor, particularly those who specialize in life and estate planning for people with special needs and their families.¹ This brochure provides some general insight into possible options as you work with your advisors to ensure your loved one is protected and cared for long term, and that their possible government assistance and benefits are not jeopardized.



1. Planning for Yourself

When caring for others, we often forget to care for ourselves. Providing care to a loved one with special needs can be stressful and feel lonely. You may feel overwhelmed and should be alert to signs that you need more support. To be a good caregiver, you must first take care of yourself.

Some of these suggestions have been drawn from the experiences of caregivers like you:

- **Share decision-making.** To the extent possible, your loved one with special needs should be an active partner in their care decisions.
- **Make time for yourself and those who are important to you.** Try to eat a healthy diet, get enough sleep, and do some physical activity each day.
- **Start early.** Give yourself more time to anticipate needs and how you might meet them.
- **Involve others.** Connect with other caregivers and parents. Seek out a therapist, religious or spiritual counselor, or a good friend. Take advantage of the programs offered by Special Olympics to help expand your circle of friendship and that of your child.

In addition, creating the documents and other plans you'll need to provide for yourself also helps you provide for your loved one and care for yourself at the same time.

- **Create or Update Your Will or Living Trust**

With a will and/or trust, you can detail your specific wishes. If you pass away without a will, state law determines how your assets are distributed, along with other key decisions, such as guardianship of minor children.

¹ You may find that <https://www.specialneedsalliance.org> can be a useful resource. Special Olympics does not endorse or recommend any outside resources, but offers this for informational purposes only.

- **Establish Guardianship**

- One of the most critical decisions made when planning your estate is identifying the person who would become legal guardian of your children if both parents die or become incapacitated. It is even more critical if one of your children has special needs. The person or persons you choose will be responsible for caring for your children and ensuring that they receive the care they need to live a happy, active life.
- Choose someone you know well and who shares your goals, values, and parenting style. It's also important that you believe they will take good care of your child with special needs. It is best to choose an additional one or more contingent guardians in the event your first choice is unable to take on this role.

- **Prepare a Letter of Intent**

- This letter informs trustees, guardians, advocates, and others involved in the care of your loved one of their functional abilities, routines, interests, and likes and dislikes, which may be especially important for a child with special needs.
- This is not a legal document but an important practical document, and it should be updated regularly.

- **Create or Update Beneficiary Designations**

- It is important to know that a beneficiary designation form — NOT your will or trust — determines how financial assets such as retirement accounts and life insurance policies are distributed. Make sure to review and update these documents regularly to ensure they reflect your current wishes, life events, and beneficiary needs. You can usually easily download new beneficiary designation forms from the website of your financial institution, or update your beneficiaries directly online.
- Retirement plans have their own planning considerations, which may be different if your beneficiary is an adult child with special needs. Adults with special needs who are named as beneficiaries of retirement plans or IRAs may become ineligible for government assistance programs, including SSI and Medicaid, after their parents' deaths.
- If your primary assets are in retirement plans and you will need to use these assets to support your loved one after your lifetime, it's important to work with your attorney to determine the best and correct way to transfer these assets.

- **Grant Powers of Attorney for Health Care and Financial Decisions**

- A letter of authorization documenting power of attorney (POA) legally designates someone to make health care and financial decisions for you if you are unable to. Many people grant both powers to their spouse or partner, but you can choose anyone you trust.
- The person or persons you choose as your POAs should know you and your loved one well, be trustworthy, and be able and willing to make difficult medical and financial decisions on your behalf.

• Create an Advance Health Care Directive

- Your POA for health care will be responsible for talking to doctors and others on your health care team on your behalf and will make serious decisions based on your directions. The best way to ensure that your POA understands your wishes, and that your health care providers honor those wishes, is by deciding now about what kind of treatment you do and don't want, and putting those decisions in writing.

• HIPAA Releases

- Health care providers are required to protect the privacy and confidentiality of patient health information, under the Health Insurance Portability and Accountability Act of 1996 (HIPAA).
- Doctors and other health care providers must obtain written authorization from a patient before sharing most health information with a third party, including relatives and caregivers.
- You can obtain a HIPAA release form from your health care provider to name trusted people to communicate and receive health care information on your behalf.
- You may want to include the names of other authorized caregivers when filling out a release form on your child's behalf.

2. Planning for Your Loved One with Special Needs

As the parent or caregiver of a minor child with special needs, you can make health care decisions on their behalf without prior written authorization. But once your child reaches age 18, you will be concerned with ensuring that medical and financial decisions will continue to be made in the child's best interests.

In most states, once a child reaches age 18, they are presumed to have decision-making capacity and the parents' legal authority ends.

It's possible to petition the court to obtain guardianship or a conservatorship over your adult child. But there are possible ways to avoid this onerous process. Legally, a person with even a significant developmental, cognitive, or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority. As long as your loved one has sufficient capacity to understand these documents, they can create the same documents discussed in the previous section, including their own:

- Will or trust
- A document granting someone power of attorney for health care and finances
- An advance directive
- A HIPAA release form



Keep in mind that for both you and your adult child, any change in your or their situation — marriage, a new job, or moving to a new state, etc. — should lead to a review and possible updating of these documents.

3. Insurance Considerations

Maintaining health insurance coverage is critical for you and your loved one. Especially in an uncertain environment for health insurance in the United States, it's important to review and compare plans to understand your benefits and out-of-pocket expenses.

4. Financial Considerations

Careful financial planning can help you and your loved one live a longer, happier life.

Because of the complexities involved in financial planning, the following information is solely informational and presents a summary of options to consider. You should consult an experienced special needs planning attorney to assist you in understanding these options and creating your plans.

Government Benefits: You may be able to lower your out-of-pocket costs if you qualify for assistance from state-based programs, which may help fill gaps in primary health insurance coverage. Needs-based benefits like Supplemental Security Income (SSI) and Medicaid have limitations on benefits in addition to eligibility requirements. These programs vary by state, so work with experts in your area to learn what may be available to you.

Special Needs Trusts (SNT): A special needs trust, sometimes called a supplemental needs trust, holds assets for a special needs beneficiary with a general purpose to provide supplemental goods and services for the beneficiary without impacting eligibility to receive other benefits. Trust assets can be used for many things as long as the distributions are made to enhance the quality of life of the beneficiary, including:

- Caregiving
- Travel and entertainment
- Pet care
- Personal items

Important: There are two types of special needs trusts, and it is critical to consult with an experienced special needs planning attorney to determine whether your son or daughter with special needs would benefit from one or both types and the best way to establish the SNT in order to protect their right to receive means-tested public benefits.

The two types of special needs trusts are first-party special needs trusts and third-party special needs trusts² The type of trust depends upon whose property is funding the trust:

- **If the property funding the SNT originates with the SNT beneficiary, then it is a firstparty SNT.**
 - First-party SNTs are most often used when the person with a disability inherits money or property outright or receives a court settlement.
 - These SNTs also are useful when a person without a prior disability owns assets in his or her name, later becomes disabled, and then needs to qualify for public benefits that have an income or asset limitation.

² Information on special needs trusts from www.specialneedsalliance.org.

- These are statutory trusts under federal law, and are subject to various requirements, including that the person with a disability is under the age of 65 when the fund is established and funded.
- After the beneficiary's death, all assets remaining in the first-party SNT, up to an amount equal to the total lifetime Medicaid-funded benefits paid on behalf of the beneficiary by the Medicaid program(s) of any state(s), are first repaid to those state Medicaid program(s). **Only if there are remaining funds after this Medicaid payback may any balance be distributed to other remainder beneficiaries.**



You may be able to leave funds remaining in a third-party special needs trust to Special Olympics after the beneficiary's lifetime, enabling Special Olympics to continue providing opportunities for full social inclusion of people with intellectual disabilities far into the future.

- **If the property funding the SNT always belonged to someone other than the SNT beneficiary, then it is a third-party SNT.**
 - Third-party SNTs are commonly used by persons planning in advance for a loved one with special needs.
 - Typically, the parents of an individual with disabilities or special needs will be the persons who establish and fund a third-party SNT, although a grandparent, a sibling, or any other person (other than the beneficiary) may establish and/or fund the third-party SNT.
 - Third-party SNTs can be included in a will, established within a living trust, or drafted as a stand-alone trust.
 - These SNTs are typically funded upon the death of the beneficiary's parents or the other individual(s) who established the SNT.
 - Upon the beneficiary's death, the third-party SNT is not required to use the remaining assets to reimburse any state(s) for the Medicaid benefits received by the beneficiary during his or her lifetime. Thus, assets remaining in the third-party SNT may be distributed to remainder beneficiaries, including charitable organizations like Special Olympics.

529 ABLER Accounts: Some states offer programs whereby people under the age of 26 with disabilities or special needs can open tax-free savings accounts. These accounts are subject to Medicaid payback requirements. Whether an ABLER account³ might be a useful tool in conjunction with an SNT or other financial planning options is best addressed by your experienced special needs planning attorney.

³ Not all states have ABLER accounts (yet), and each state will have slightly different rules and procedures for opening and using an ABLER account. For more information, visit www.ablenrc.org.

- **Additional Financial Needs**

Many individuals with special needs are living long, healthy, vibrant lives, and are realizing their dreams of attending college, pursuing careers, getting married, and starting families. For that reason, it's important to plan for these important needs, such as paying for college, a wedding, or travel. It's also important to teach your child with special needs financial literacy, with the expectation that, just like any other child, they will assume responsibility for all or much of their own finances as adults.



5. When to Update Your Plan

Plans may need to change as your life's circumstances change. Here's a checklist to let you know when it may be time to update your plans:

- Your wishes have changed
- You have new family members
- Your marital status has changed
- You moved to a new state
- You have changed jobs, or obtained new health insurance
- You or your loved one has turned 18
- Family members have passed away
- You wish to change guardians, trustees, or executors
- Your assets have increased or decreased in value, or you have obtained or sold a significant asset
- It's been more than five years since you reviewed your plan

6. Creating Your Legacy of Joy and Hope

We often hear from individuals and their families about the important role Special Olympics has played in their lives. As you plan for your loved ones, you may also consider including a gift to Special Olympics through your will or trust, or by beneficiary designation. There are many benefits:

- You can leave a gift to Special Olympics and take care of loved ones. Making Special Olympics a contingent beneficiary puts us next in line to receive the funds after your pets and your family.
- You are not locked in to a decision you make today — you can change your beneficiaries at any time.
- You can designate Special Olympics to receive a percentage of an account's value, leaving the remainder to your heirs.
- There is no immediate cost to you. You retain full control of your assets for as long as you need them.
- There is often no need to go to the trouble or expense of consulting a lawyer to create or update your will; leaving a gift can be a simple matter of filling out or changing a beneficiary designation form.
- There is no minimum donation.

What You Need to Complete Your Gift

When you create or update your will, simply ask your attorney to include a gift to Special Olympics and discuss the type of gift that fits your plans.

You can also name Special Olympics and/or your local chapter affiliate as beneficiaries of your retirement plan. To support the Special Olympics movement in the U.S. and around the world, you will need our legal name and tax ID number:

Special Olympics International
Tax ID 52-0889518

To include a gift to your local Special Olympics chapter affiliate, you will need their legal name and tax ID number. Please contact your local chapter, or contact Connie Grandmason at (866) 690-3951 or plannedgiving@specialolympics.org. Connie will be happy to provide your chapter's legal name and tax ID number.



Do You Have Questions?

Special Olympics gift planning staff is available to help you explore how to make room in your planning for a legacy gift to Special Olympics.

If you have already left a gift to Special Olympics in your will, trust, or by beneficiary designation, we hope you will let us know so we can properly thank you, ensure that your wishes are carried out, and welcome you as a member of our legacy society, The Champion's Society®.

**Access our complimentary planning library at
specialolympics.org/planned-giving/resources**



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