Planning when Someone You Love Has Special Needs

Gathering the Necessary Documents, People and Other Resources.
Planning when someone you love has special needs

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 is it 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. This brochure provides some general insight into possible options as your 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**
  
  o 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.

  o 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**
  
  o 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.

  o This is not a legal document, but an important practical document and it should be updated regularly.

• **Create or Update Beneficiary Designations**
  
  o 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.

  o 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.

  o 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**
  
  o 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.

  o 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 Advanced Healthcare Directive**
  
  o 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.
• **HIPPA 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 (HIPPA).
  
  - 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 HIPPA 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.

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**Healthy Athletes**

As many as 200 million people worldwide have an intellectual disability, yet much of this population has little or no access to proper health care, even in nations with extensive health care systems or services for people with intellectual disabilities. Healthy Athletes screenings have found that Special Olympics athletes are at increased risk of multiple, secondary health issues such as untreated tooth decay, obesity, poor hearing and low bone density.

Special Olympics learned the extent of the problem among its athletes in 1995, the first year it offered free health screenings at its World Games. There, 15% of the athletes screened had such dramatic health conditions that they had to be referred to the emergency room for urgent care.

Officially launched in 1997, Special Olympics’ Healthy Athletes organizes events in a welcoming, fun environment and removes the anxiety people with intellectual disabilities often experience when faced with a visit to a doctor. Each event educates athletes on healthy lifestyle choices and helps identify problems that may need additional follow-up in categories such as Fit Feet (podiatry), FUNfitness (physical therapy), Special Smiles (dentistry) and Strong Minds (emotional well-being).

Healthy Athletes has the world’s largest database of health data for people with intellectual disabilities.

Today, Healthy Athletes has provided more than 2.1 million free health screenings in more than 135 countries, given out more than 160,000 eyeglasses and trained 240,000 health professionals to better treat people with intellectual disabilities.
2. Planning for Your Loved One with Special Needs

As the parent or caregiver of a minor child with special needs, you can make healthcare 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, she/he is 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 HIPPA release form.

Keep in mind that for both you and your adult child, any change in you 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.

- **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**

  A special needs trust, sometimes called a supplemental needs trust, holds assets for a special needs beneficiary in order to supplement the beneficiary’s income without impacting eligibility to receive other benefits. Even a small inheritance or gift could disqualify you and/or your child from much-needed benefits. You can avoid this by creating, with the advice and assistance of an experienced lawyer, a special need trusts to which you or others can leave property.

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2The Academy of Special Needs Planners, https://specialneedsanswers.com/ and the Special Needs Alliance, https://www.specialneedsalliance.org offer directories of experts who may be helpful. Special Olympics does not endorse any outside organization or resource; this information is offered for reference only.
• **Special Needs Trusts**
  Trust assets can be used for many things as long as it enhances the quality of life of the beneficiary, including:
  - Caregiving
  - Travel and entertainment
  - Pet care
  - Personal items

• **529 ABLE Accounts**
  Increasingly, states offer programs whereby people under the age of 26 with disabilities or special needs can open tax-free savings accounts. They allow the account holder to save significant sums without jeopardizing eligibility for needs-based assistance. This may be an alternative to a traditional special needs trust.

  Money can be withdrawn tax-free when the funds are used to pay for qualified expenses. Qualified disability expenses include education, job training and support, healthcare and financial management.

  The contribution for 2018 is $15,000 (the amount of the annual gift tax exclusion) and many states have total contribution limits that exceed $300,000. However, if a person’s 529 ABLE account balance exceeds $100,000 they will no longer be eligible for SSI benefits. Also, if the beneficiary dies, states will be able to recoup some of expenses through Medicaid.

• **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 5 years since you reviewed your plan

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3Not all states have ABLE accounts (yet), and each state will have slightly different rules and procedures for opening and using an ABLE account. For more information, visit www.ablenrc.org.
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 loves ones, you may also consider including a gift to Special Olympics through your will, 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.
- You can designate your gift for the Special Olympics program of your choice.
- There is no minimum donation.
We’re Here to Help

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 that we may properly thank you, ensure that your wishes are carried out, and welcome you as a member of our legacy society, The Champion’s Society®.

Your Gift, Your Way

We welcome unrestricted gifts, as well as those designated for a specific initiative. Leaving your gift unrestricted enables Special Olympics to address the greatest needs at the time your gift is received. To designate your gift for a particular program, please discuss your objectives with a member of our staff. We would also like to work with you to create a statement of intent that ensures your wishes for your estate gift are honored as you intended.

If you have already left a gift for Special Olympics, we hope you will let us know. We would like to thank you and welcome you to The Champions Society®, our way of recognizing the exceptional individuals who have made Special Olympics a part of their lasting legacy.

To make a gift in your will for Special Olympics, we recommend using the following language:

I hereby give, devise and bequeath _______ (dollar amount or percentage) to Special Olympics, a nonprofit organization located at 1133 19th Street NW, Washington, DC, 20036, Federal Tax ID #52- 0889518, for Special Olympics’ general use and purpose.

Or, to benefit a local Special Olympics chapter affiliate:

I hereby give, devise and bequeath _______ (dollar amount or percentage) to Special Olympics (insert local chapter affiliate name here along with their city, state), for its general use and purpose.

Access our complimentary planning library at play.specialolympics.org/plans

The materials available in this publication are for informational purposes only and not for the purpose of providing legal or financial advice. You should contact your attorney to obtain advice with respect to any particular issue or problem.