

Exceptional Children Need Exceptional Life Care Planning

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“Ten Steps for Families with Special Needs”

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Ten Steps for Families with Special Needs

“What will happen to my family member with special needs when I am gone or no longer able to provide care”?

This question haunts many families. Fortunately, there are steps you can take to help assure the long-term financial security of a loved one with special needs.

STEP 1:

Start Now

Whether your loved one is four or forty, you never know how long you will be here. Studies done by The American College of Financial Services indicate 90% of special needs and disability caregivers and family members admit retirement planning isn't their main priority: caring for their loved one through special needs financial planning is.

**Source: American College of Financial Services
Special Planning for Special Needs Individuals: an inside look
May 18, 2020**

STEP 2:

Discuss Who Will Provide Care

Who is available to help? Don't assume that other family members will take responsibility. Discuss the topic openly, so that each member can decide what role, if any, he or she will assume. Remember, these decisions often involve a lifelong commitment.

STEP 3:

Draft detailed written instructions in a Letter of Intent

This should include general information and background about your loved one, medical history, present and future housing arrangements, daily living skills, favorite leisure activities, rights and values you want to preserve, legal papers and their location, circle of friends and professionals, final arrangements and whatever else will help caregivers enable your loved one.

STEP 4:

Select guardianship carefully

Your family member's future guardian will be selected for a number of qualities – financial discretion, knowledge of care, likes and dislikes, as well as a genuine interest in the person's future. The guardian should be able to make decisions as needed and according to the Letter of Intent.

STEP 5:

Don't Put Assets in the Name of the Special Needs Family Member

It may disqualify your loved one from future financial aid and could also trigger reclaiming of past benefits, especially by Medicaid. This is why it's often recommended to avoid outright gifts or naming the individual with special needs as a direct beneficiary in your will and life insurance policies.

STEP 6:

Consider establishing a Special Needs Trust

If properly drafted a Special Needs Trust can help maintain eligibility for public programs. These assets are considered separate from those of the family member with special needs. The trust also provides professional money management of assets and funds for your loved one's care.

STEP 7:

Arrange Funding

A Special Needs Trust is of no value without funding. Since assets cannot be removed from the trust, it is often recommended that minimal funding take place during the parent's lifetime. Instead, many people purchase life insurance on the parent, naming the trust as the beneficiary. It's also possible to make the trust the beneficiary of wills, annuities and qualified plan assets. Other family members and friends who want to help out can be encouraged to put money directly into the trust.

STEP 8:

Don't forget other family members...

Such as other heirs, especially other children. Provide for them in your will separately. This is vital because assets in a Special Needs Trust cannot be removed except for the benefit of the special needs individual.

STEP 9:

Be aware of differences in state laws

Medicaid, for instance, is a federal program regulated and managed by the states.

Guardianship laws and eligibility guidelines used to qualify for benefits differ across states' borders.

STEP 10:

Seek professional advice

Many people will want to help, but few are qualified in this complex field. Find specialist with an expertise in special needs planning, including attorneys who specialize in special needs situations.

What is Supplemental Security Income (SSI)?

SSI is a federal program, administered by the Social Security Administration (SSA), which provides low/no-income, aged, blind and disabled persons with a **modest monthly cash payment for food and shelter.**

NOTE! *Any countable income or assets* received by an SSI recipient may reduce or eliminate the recipient's monthly SSI payment.

N.J.A.C. 10:49 -2.2

N.J.A.C. 10:71 -5.2

What are the SSI Asset Limitations?

For Countable Assets:

An individual SSI recipient's countable assets (in their individual name) **cannot exceed \$2,000.**

Countable assets include *any asset that can be liquidated*, the proceeds of which can be utilized for their support.

What is Medicaid?

Joint federal and state funded program providing medical services for individuals with the *same qualifications* that would make them eligible for SSI.

Medicaid normally includes:

- ⤴ Physician services
 - Includes psychological
- ⤴ Hospital services
- ⤴ Home health care
- ⤴ Physical therapy

Medicaid applications are normally filed through the county board of social services. Contacts and basic information can be found online

THE STAKES ARE HIGH

***Poor Special Needs planning
may make your loved one
ineligible for these
government programs!***

How Do I Preserve My Loved One's Eligibility for Government Aid?

- **Disinherit** your Special Needs loved one.
- **Leave assets to caregiver** (e.g., a sibling) and hope the assets will be used to provide for the Special Needs person.
THINK: What will happen if the caregiver experiences any one of the following?

Death

Disability

Divorce

Creditor Problems

Establish a SPECIAL NEEDS TRUST for your loved one.

Which Trust is Right For My Loved One?

What are Special Needs Trusts?

Two Basis Types:

I. Third-Party Special Needs Trusts

Normally established and funded by the parents or other relatives of the Special Needs person.

- Can be established by will or while the parent/other giver is alive by way of **revocable or irrevocable** trust agreements.
- The trust assets **will not be counted** as assets of the Special Needs person for purposes of qualifying for SSI and Medicaid.

II. Self-Settled Special Needs Trusts

Sometimes called “1396p(d)(4)(A) trusts”

- **Funded with the Special Needs person’s own assets**
- **Irrevocable**, inter-vivos trusts established by a disabled beneficiary’s parents, grandparents, legal guardian or court
- The beneficiary **must be under 65** years of age
- Includes **Medicaid payback requirements** (not applicable to third-party Special Needs Trusts).

What is a Medicaid Payback Provision?

A **self-settled special needs trust** [(d)(4)(A)] must provide that upon the death of the Special Needs person, the state Medicaid agency *must be paid an amount equal to the amount paid under the Medicaid program* for services provided to the Special Needs person during the trust's existence.

What Do I Need to Plan My Estate?

Will

Power of Attorney (POA)

Health Care Directive/Living Will

+ Trust(s)!

Summary

Advance planning can help:

- Enhance quality of life for your loved one
- Preserve public assistance
- Protect assets and reduce taxes
- Select caregivers/fiduciaries of your choice
- Coordinate planning with
grandparents, other relatives, and friends

The Bottom Line

Creating a financial and estate strategy for a family member with special needs can be demanding, time-consuming and frustrating. But your effort will be worth it down the road, both for you and other family members. Above all, the preparations you make now can help assure your loved one with special needs and other family members will be financially secure when you are no longer able to provide for them.

*ADDITIONAL
QUESTIONS?*

HELPFUL MATERIALS

Special Needs Estate Planning Questionnaire

Letter of Intent Template

Caring for Special Needs Children

Financial Strategies for Families with Special Needs

How to Create a Special Needs Financial Strategy

Helpful Resources for People with Special Needs

THANK YOU

for attending this seminar!

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