Financial and Legal Planning for Families with Special Needs

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About Me

Financial Planner 9 years with Thrivent

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The Role of Government Benefits: SSI, SSDI, Medicare, and Medicaid

Overview

The cost of lifetime care for a person with a disability can prove astronomical.

Few families have the resources to provide for children with disabilities through private means.

It is therefore essential for most families to create a plan assuring eligibility for governmental benefits to assist in the care of a disabled child

The Three-Legged Stool

Public Benefits

Resource-Dependent:

- Supplemental Security Income (SSI)
- Medicaid (Medical Assistance or MA)
- Medicaid Waiver Programs
- Others (Food Stamps, Section 8 Housing, etc.)

Not Resource-Dependent:

- Social Security Disability Insurance (SSDI)
- Social Security Retirement Benefits
- Medicare

Needs-Based Programs

- AVAILABLE ONLY IF INDIVIDUALS MEET PRESCRIBED INCOME AND ASSET REQUIREMENTS.
- IF INDIVIDUALS RECEIVE TOO MUCH INCOME OR OWN TOO MUCH PROPERTY, ELIGIBILITY IS AT JEOPARDY FOR NEEDS-BASED PROGRAMS.
- SOCIAL INSURANCE PROGRAMS (I.E., SSDI) ARE POTENTIALLY AVAILABLE REGARDLESS OF INCOME OR ASSETS, AND TYPICALLY DEPEND ON THE AMOUNT CONTRIBUTED TO THE PROGRAM, SUCH AS SOCIAL SECURITY WAGE TAX

Special Needs Trusts -I

- Purpose- to allow financial resources to assist an individual who receives public benefits. Trusts also protect resources form invasion by Medicaid agencies – No year lookback if properly funded.
- Three types of SNT's:

Special Needs Trusts - II

Self funded/Payback/First party Special Needs Trust – funded by the individual out of assets, such as include lawsuit settlements, inheritances, or work earnings.

- Special Needs individual is the sole beneficiary
- Fully funded by age 65
- Can be established by parent, grandparent, guardian, court, or beneficiary
- Irrevocable
  - Management is at the total discretion of the Trustee
- Supplement, not supplant
  - Payback to the state for Medicaid first, even before funeral expenses.

Special Needs Trusts - III

Third party funded (Supplemental Needs Trust)

- Funded with money not owned by the beneficiary
- Created via will or living trust
- No Payback to State Medicaid agency
- Support, not supplant
- Trustee has discretionary power.
- No allowance for beneficiary

Special Needs Trusts - IV

Third Party Funded Special Needs Trust Funding

- By Will
- By Life Insurance (2nd to die policy or others)
- Lifetime gifting – donor can gift up to 18K per year
- IRA's – traditional IRA can get a lifetime stretch (as opposed to 10 years)

Special Needs Trusts - V

Keep in Mind:

Coordinate entire Estate Plan with the SNT

- *Assets that pass under the will*
- *Assets that pass outside of the will*

Watch out for accounts in a child's name – UTMA/UGMA, 529 plans. – these could affect eligibility for SSI

Secondary beneficiaries permitted on SNT's

Special Needs Trusts

Pooled Trust

- Administered by nonprofit and pools funds from many sources.
- Residual remains in trust for other persons with special needs upon the death of the beneficiary.
- Can be established by anyone on behalf of a beneficiary with special needs
- Usually for smaller trust amounts

Special Needs Trust Administration

- "Supplement not Supplant"
- What can be purchased? – Items, goods, and services for the beneficiary, including prepaid funeral and burial expenses.
- What cannot be purchased? No cash (considered income by SSA and considered a resource, No major gifts to others
- Sole Benefit rule – money is for the primary benefit of the beneficiary. Not to be read to prevent collateral benefit to someone else.
- Treats food and shelter that is less than FMV as in-kind income

ABLE Accounts (Achieving a Better Life Experience Act)

- Savings account like a 529 plan
- Contributions grow tax free
- Use is for Qualified Disability Expenses (QDE's) – this could include, education, transportation, vehicle, health & wellness
- Not used in the correct way, 10% penalty & taxes
- Beneficiary must be set up before the age of 26, However, increasing to age of 46 on December 31, 2025
- https://illinoisable.com/

ABLE Accounts (Achieving a Better Life Experience Act)

Limitations:

- 18K/yr. gifting limits, anyone can contribute
- up to 100K total limit
- Useful for person with smaller settlement or trust or special needs person earning a small wage

Letters of Intent - I

- A document that ensures your trustee knows your child's functional abilities, routines, interests, and particular likes and dislikes. In addition to describing your special child, the letter of intent identifies specific doctors, services and resources that will help your child enjoy the highest level of independence and self-reliance. The document is a valuable tool that communicates knowledge only parents may know, including specific hopes and desires for their child's future well being, to the very people who will be caring for the child after the parents no longer are able to do so. After all, who knows a child better than a parent?

Letters of Intent - II

- The letter of intent serves as the foundation of any comprehensive life-plan for a child with special needs. By compiling as much information as possible, parents are equipping future care providers with the knowledge and insight needed to increase the likelihood of good choices to maximize the child's quality of life and avoid the need for caregivers to learn by trial and error. A child also may participate in creating the letter of intent so that his or her own wishes are acknowledged and recorded.
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Thank you

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