Hauptman & Hauptman, PC

GUIDING FAMILIES THROUGH LIFE'S TRANSITIONS

Elder, Estate, & Special Needs Law

The Consumer's Guide to Special Needs Planning

INCLUDING:

- **How to provide for the present and future needs of a person with disabilities**
- **First-Party and Third-Party Special Needs Trusts**
- **The Role of the Trustee**
- **Powers of Attorney, Guardianship, and Conservatorship**

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INTRODUCTION

The *Consumer's Guide to Special Needs Planning* is designed to help provide you with information and answers to some of the questions that you will encounter. These are questions that we, as special needs law attorneys, deal with on a daily basis.

Our clients have found this guide to be a valuable resource, and we are confident you will find it useful as well.

This guide is brought to you as a service of:

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The Consumer's Guide to Special Needs Planning

SPECIAL NEEDS CARE CRISIS

The special needs population is growing, funding is shrinking and a crisis is upon us for millions of parents. Government data suggest that 1 in 59 U.S. children has autism and there is evidence that the rate is increasing. Within the next 10 years, more than 500,000 kids with autism will reach adulthood. While there are many services and programs available to children and young adults who are still in the school system (under 23 years of age) there is little available to the adult child with special needs. More than half of young adults with autism remain unemployed and unenrolled in higher education in the two years after high school. Whether the basis for one's special needs is autism or another form of mental disability, finding appropriate housing and paying for it is one of the biggest challenges. Residential facilities are in short supply, even for the well-off and well connected. The government's answer to this situation has been to tell parents to set up "unofficial" group homes with a few other families.

When children with special needs are younger, the day to day obligations consume most parents: the hours of therapy, the doctor visits, the financial pressures and the heightened anxiety that comes with handling it all. With medical and social advances, the lives of individuals with special needs have improved. For instance, people with Down syndrome once only lived to age 25 in 1983; today the average lifespan is 60. Many adults today who are worrying about their own long-term care have the added burden of not knowing how to provide for their adult child with special needs. Aging parents must think about providing for their adult child decades after their own deaths. Long-term care planning for these

families must focus on the aging parents and the special needs child at the same time. Special needs lawyers utilize trusts and help clients find ways to fund them.

It is so imperative that families of children with special needs seek the guidance of a special needs lawyer when drafting their will, health care directives and powers of attorney. Specific language is necessary to protect the child with special needs and preserve eligibility for government needs based programs in the future. Many parents faced with the challenges of raising a child with special needs and struggling to make ends meet delay thinking about long-term care planning till the future. That could be a costly mistake.

SPECIAL NEEDS TRUSTS

Special needs trusts are established to provide for the present and future needs of a person with disabilities. These trusts are able to receive, hold and manage assets such as an inheritance, a financial gift, a personal injury settlement or other assets of the person with disabilities, in such a way that the person's eligibility to receive needs-based government benefits, such as Medicaid and Supplemental Security Income, is preserved. The disabled individual is the beneficiary of the trust but should not be the trustee.

A special needs trust's usefulness, however, goes beyond preserving eligibility for government sponsored benefits. It can also create or maintain eligibility for valuable community programs and services that provide social and vocational opportunities. Where there is no special needs trust, or where a trust has been drafted improperly, an unexpected financial gain or an inappropriate disbursement could deprive the person who has a disability of his or chance to participate in life-enriching opportunities.

There are generally, two types of special needs trusts. It is important to understand the difference between the two and when each is appropriate.

SELF-SETTLED or FIRST-PARTY SPECIAL NEEDS TRUST

A self-settled or first-party special needs trust is funded with the personal assets of the disabled person. It is important to note that the person must be disabled. Disability is defined as being "unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months".

If the person is under age 18, then disability is defined as "a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months".

Up until recently the disabled individual was not able to establish the trust as a grantor even though he/she will contribute his or her own personal assets. Now a self-settled or first-party special needs trust can be established by: (1) the individual; (2) parent; (3) grandparent; (4) legal guardian; or (5) a court. Additionally, the individual must be 65 years of age or younger, in order to fund the trust. When the individual lacks the mental capacity to establish their own trust and there is no living parent or grandparent or legal guardian, then the only choice is to petition a court to establish the trust. In that case, the creation and approval of the trust must be obtained by court order signed by a judge.

First-party special needs trusts must include specific language to be in compliance with federal and state law. For example, a payback provision is necessary, whereby upon the death of the beneficiary the State is to be reimbursed for benefits paid on behalf of the individual.

There are very technical guidelines regarding how trust funds can be spent, in order to prevent the loss of government benefits. A special needs trust is

designed to provide for the "special needs" of the beneficiary and to enhance the quality of his or her life. These needs could include, for example, a trip, stereo, special mechanized wheelchair, etc. There could be a reduction in government benefits if the money is used for the basics of daily living such as rent, food, heat, etc.

THIRD-PARTY SPECIAL NEEDS TRUST

A third-party special needs trust may be created by the parent(s) or grandparent(s) of, or anyone who has interest in benefitting a person who has a disability. This type of trust is funded with assets owned by someone other than the disabled beneficiary. It is also important to note that there is no definition of disability that must be adhered to as in the case of a first-party trust.

Third-party trusts allow family and friends to provide for the person with special needs, while still preserving his or her government sponsored and needs-based benefits. This type of trust can be established during the lifetime (an inter vivos trust) of the person who creates the trust, or it can be established in an estate plan by way of a Last Will and Testament (a testamentary trust).

Third-party trusts are attractive for many reasons. Without them, families must choose between leaving assets outright to the disabled person, disinheriting the person completely or leaving the person's share to a family member and hope that member is trustworthy enough to use it for the disabled person's benefit.

Because these assets go directly to the trust, and are never owned by the person with disabilities, the third-party trust does not have a payback provision. The person establishing the trust is free to name contingent beneficiaries of his or her choosing to receive any trust funds remaining after the beneficiary's death.

SPECIAL NEEDS TRUST SPENDING

To receive SSI a person may not own more than $2,000 in countable resources. Social Security considers the following items to be "countable" or "in-kind support and maintenance" that will reduce the SSI benefit: **DO NOT** use trust fund money for the following:

- CASH (Above $20.00 per month)
- Mortgage
- Rent
- Real estate taxes
- Heating fuel
- Gas
- Electricity
- Water
- Sewer
- Garbage removal
- Homeowner's insurance(if required by a lender)
  condominium charges that include any of the above items
  food or cash to buy food (restaurant meals)
- ANYTHING THAT MEDICAID COVERS

The Social Security Administration has not specifically stated which expenses are not countable. However, most advocates agree that if you are on SSI/Medicaid you **CAN** pay for the following items:

Housing:

- Telephone
- Cable television
- Premiums for personal property insurance

- Paper products
- Furniture and furnishings
- Repairs (plumbing, insulation/weatherization, electrical, etc… to a home that the recipient owns)
- Cleaning supplies
- Lawn care
- Housecleaning and homemaker services
- Cooking and eating utensils/dishes

Medical:

- Medical insurance premiums
- Co-payments for medical bills
- Deductibles and other out of pocket medical costs
- Wheelchairs, modified scooters, specially trained animals and their maintenance
- Eyeglasses

Dental Treatment

Recreation Expenses:

- Club Membership (YMCA, NY Sports)
- Movie and concert tickets
- Home entertainment (big screen TV, stereo equipment)
- Personal computers
- Paid companion (one-to-one assistance) from a specially trained staff
- Books or musical instruments
- Vacations and Travel (vacation packages sometimes include food and shelter which are usually prohibited items, however the current rules say that a temporary absence from home such as a vacation (away for at least 24 hours) allows you to receive food and shelter without

penalty. Please note that you are prohibited from paying for others who accompany you. If a person can't travel alone and a companion is necessary, the First-Party Special Needs Trust can only pay for a skilled healthcare trained professional, however a Third-Party Special Needs Trust does not have that limitation.

Transportation:

- Car (an individual on Medicaid can only own one car)
- Gas
- Maintenance and repairs
- Insurance

We suggest to our clients that they just keep accurate records of everything going in and out of the trust in a notebook and maintain all receipts just in case they are ever questioned. Additionally, to the extent any expenditure exceeds $5,000.00 the Trustee/Co-Trustees must provide notice to DMAHS (State of New Jersey Division of Medical Assistance and Health Services) not less than 45 days prior to the expenditure.

TRUSTEES

A trustee is "a person or entity who holds legal title to property for use of the benefit of another." Since there are considerable responsibilities associated with administering a special needs trust, the choice of trustee is of critical importance in special needs planning. Depending on the type of trust, the nature and amount of assets owned by the trust and the needs of the beneficiary, the trustee may be an individual or a corporate trust department. The chosen trustee must have the best interests of the beneficiary in mind at all times.

Awareness of public benefits, taxation and investments are other traits that make for a good trustee. The trustee need not be an expert in these areas but should have the good judgment to seek out proper advice and counseling.

There are advantages and disadvantages to choosing an individual (family member or friend) versus a corporate trustee. An individual trustee is less expensive, has personal knowledge of the beneficiary and his or her situation and has greater availability. An individual however may lack experience, may not possess sufficient knowledge regarding investments, may be influenced by friends and family members and may die before the beneficiary.

The corporate trustee has expertise regarding trusts and investments, unbiased decision making and will keep meticulous records of the trust. The corporate trustee however may be costly, may not be fully aware of the beneficiary's needs and desires and may have minimum balance requirements.

POWERS OF ATTORNEY

A durable power of attorney is a power of attorney by which a principal designates another as his agent in writing. It remains effective even after the onset of a disability or incapacity. A power of attorney must have specific language indicating the principal's intention that it is to be effective even when the principal is disabled or incapacitated.

A principal may choose to make the powers to the agent effective immediately or upon a contingent time period or situation in the future (known as a springing power of attorney). A power of attorney may be revoked at any time by the principal provided he/she has mental capacity.

For the document to be effective, it must be properly drafted, comply with statutory requirements and most importantly, the principal must possess the necessary mental capacity to understand and execute the document. A power of

attorney must be signed and dated by the principal either before a notary public or two witnesses 18 years of age or older.

While a power of attorney is an important tool in planning for individuals with special needs, it is vulnerable to abuse if broad powers are given to the wrong person. The powers conferred upon an agent typically include the ability to conduct banking transactions, pay bills, manage investments and insurance matters etc. It is possible to name multiple agents (co-agents) who may be required to act together or permitted to act separately.

In order to maximize an agent's authority and ability to engage in special needs planning, the power of attorney must contain specific provisions that are not necessarily addressed in boilerplate powers of attorney obtained on the internet or drafted by an attorney who does not specialize in disability law. A document that simply confers upon the agent all powers to do anything that the principal could do, or something to that effect, is too broad and lacks definition. The agent is likely to run into difficulties with financial institutions and insurance companies, for example, who may refuse to honor the document. It is important, therefore, that the power of attorney be tailored to meet the specific needs of the principal.

GUARDIANSHIP

While a power of attorney is a useful tool for any kind of estate/long-term care planning, including special needs planning, it is not always a feasible option. If a child over 18 years of age, born with special needs, does not possess the mental capacity required to execute a Power of Attorney what then? What options are available? In that case a guardianship may be necessary.

A guardianship proceeding is a procedure established by law as a means for the court to deem a person incapacitated and appoint a suitable fiduciary to assist

the incapacitated person in handling his/her personal and financial needs. Because a guardianship proceeding requires court involvement, it can be lengthy and costly.

In New Jersey for a person to be deemed incapacitated, the prospective guardian must file with the Court, amongst other documentation, a certification from two medical providers (a physician and/or a licensed psychologist) who has examined the alleged incapacitated person within the past 30 days and deemed him/her unable to handle personal and financial affairs. After guardianship papers are filed, the court will appoint an attorney to represent the alleged incapacitated person and file a report. In some circumstances where the alleged incapacitated person's wishes and what is in his/her best interest are not the same, the court may also appoint a third attorney to serve as a guardian ad litem.

All attorneys involved will submit their fees to the court for review and if approved will be paid out of the estate of the alleged incapacitated person. Guardianship is usually decided by way of a hearing before a Judge unless a trial by jury is demanded. Following testimony and the signing of an Order deeming an individual incompetent and appointing a guardian, that guardian will be subjected to court rules and guidelines that he/she must follow while the guardianship is in effect. Unlike a power of attorney which has no court oversight of the agent's conduct, the guardianship requires continued court involvement and has reporting requirements. Additionally, a guardianship may not be revoked by the incapacitated person or guardian unless an application is made to the Court, unlike a durable power of attorney which can be revoked at any time by the principal as long as he/she has the relevant capacity.

In New Jersey, as a result of guardianship the incapacitated individual will lose civil liberties, such as the right to marry, drive, and choose where one lives, etc. In some states, the individual will lose the right to vote. The court does however recognize and support limited guardianships whereby the individual can

keep some civil liberties but not others. Both the physicians or the physician and psychologist examining the alleged ward and the court appointed attorney shall set forth in their reports, if applicable, the extent to which the alleged ward should retain the right to manage certain areas of his/her life such as residential, educational, medical, legal, vocational or financial decisions. Limited guardianship tends to be utilized in cases involving individuals with special needs. Parents often want their children to retain some rights and there is always the thought that their children's cognitive abilities will improve through technology and medicine. A guardianship can only be terminated upon the person's return to competency or death.

CONSERVATORSHIP

A conservator may be appointed for a person who has not been judicially declared mentally incapacitated but who due to advanced age, illness or physical infirmity is unable to care for or manage his or her property or has become unable to provide for him/herself or others dependent upon him/her for support. A conservatorship only covers the management of the conservatee's finances. The conservator is not empowered to make any medical or personal decisions for the conservatee.

A conservatorship is a voluntary act whereby the conservatee consents to the appointment of a conservator and either serves as the plaintiff in the application to the court for this relief or consents to having another serve as the plaintiff on his or her behalf. A conservatee can terminate the conservatorship upon application to the court. Like a guardianship, a conservatorship requires court involvement and has reporting requirements. A conservatorship does not result in the loss of civil liberties.

A conservatorship does not require medical examinations by two medical providers (a physician and/or psychologist) but a judge is free to require it if necessary. The court may appoint an attorney for the conservatee if it concludes it is necessary to protect his or her interests. If the conservatee is unable to attend the hearing by reason of a physical or other disability, the court will appoint a guardian ad litem to conduct an investigation to determine whether the conservative objects to the conservatorship. In no case, however, can a conservator be appointed if the conservatee objects to it.

ABLE ACT

On December 19, 2014, President Barack Obama signed into law the ABLE (**A**chieving a **B**etter **L**ife **E**xperience) Act of 2013. The Act amends Section 529 of the IRS Code to create tax-advantaged savings accounts for individuals with disabilities. The New Jersey ABLE Act became law on January 11, 2016.

The Act's purpose is to allow people with disabilities to open special accounts. The interest earned will be tax free. The funds in the account can be used to pay for education, transportation, healthcare, housing and other expenses. Although the ABLE Act is a step in the right direction for people with special needs that want to plan, there are some restrictions which prevent it from being very effective or replacing the need to establish a Special Needs Trust.

To open an ABLE Account, you must have a qualified disability under Social Security and have been disabled before the age of 26. Only the first $100,000 in an ABLE Account is exempted for SSI eligibility. The annual tax-free contributions to the account may not exceed the annual gift-tax exemption amount (currently $16,000 in 2023). In an ABLE Account, the disabled individual will have access to the account even if the person is not able to handle or understand finances. Additionally, any money left in an ABLE Account first goes back to the

State that paid out benefits before passing to the designated beneficiaries. None of these restrictions set forth above pertain to a third-party special needs trust and therefore it may be a better estate planning option to establish a third-party special needs trust rather than set up an ABLE Act Account.

SPECIAL NEEDS PLANNING

As you can gather from reading these materials, planning for individuals with special needs can be complicated. As special needs planning attorneys we find that our clients experience a great peace of mind once they have worked with us.

When you are faced with a child or family member with a lifelong disability, it is the family's responsibility to become fully informed – to get smart – about these things. We have personally reviewed many books and literature commonly given to families on the subject of special needs planning, and we've given and attended public workshops and lectures. And we've found that they leave out most of the critical financial and legal information you need to know.

That's why we wrote this guide entitled ***The Consumer's Guide to Special Needs Planning***. And that's why we've been on a legal crusade of sorts, to make sure that families who have a loved one facing a lifelong disability become smart about planning.

The time to act is now. With proper planning, you will insure that you've taken the best steps possible to protect your loved ones and their financial security and carry out your wishes.

If you would like the guidance of a law firm which has helped hundreds of New Jersey families successfully deal with these issues, then call Hauptman & Hauptman, P.C. at 973-994-2287.

Imagine the peace of mind you'll have when you stop reacting to your situation and start putting into place a positive action plan which will allow you to protect yourself and your loved ones.

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