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Estate Planning for Families with a Child with a Disability

Proper estate planning is vital, especially for families of a person with a disability. This article explains how estate planning and the use of Wills, living wills, durable powers of attorney and Special Needs Trusts can help you:

- ensure the greatest amount of your estate passes to your intended beneficiaries;
- ensure you and your family pay the least amount of taxes;
- avoid or minimize probate;
- designate guardians of minor children and persons with a disability;
- plan for your own incapacity; and,
- plan for charitable giving.

Q: Why is estate planning so important?

Regardless of wealth, estate planning can help ensure family members are protected, assets are not needlessly depleted, and tax exposure is minimized. Done well, estate planning can help ensure continued eligibility for your child with a disability for services and supports now, as well as, in the future. Special Needs Trusts and other legal arrangements are often needed to help assure a secure and comfortable future for the beneficiaries.

Q: What is an estate plan?

A good estate plan is a set of legal documents that describe plans for both financial and personal matters. An estate plan typically includes a Will, a Special Needs Trust, Durable Power of Attorney, Advanced Medical Directives, and other documents.

Q: What is a Will?

A Will is the most commonly used legal instrument for the distribution of property and assets after a person dies. A Will arranges for the distribution of property and assets, and names the person - an executor - who will ensure your wishes are followed. For parents of a young child, a Will can be used to name a guardian and create a trust for the benefit of *non-disabled* minor children. In the case of an adult child with a disability for whom the court has appointed the parents as guardians, the Will should also name a successor guardian.

Q: What is a Special Needs Trust?

A Special Needs Trust (SNT) can be thought of as an empty cup - a legal structure intended to 'hold'

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funds that will allow a beneficiary with disabilities to receive gifts, lawsuit settlements, and other funds without risk of losing eligibility for important government programs. SNTs are written such that the funds held in the trust are not considered when determining eligibility for means-tested public benefits, such as Medicaid and SSI.

Q: Who can establish a SNT?

A SNT agreement is a very technically written document and must contain very particular language. It is not enough to simply title the trust a “special needs trust.” A SNT must be a separate document – never part of a Will. Only a properly drafted SNT will preserve eligibility for government programs and shelter the assets left to the person with a disability.

Special needs trusts are frequently created by a parent or other family member for a child with disabilities, even though the child may be an adult by the time the trust is funded. Such trusts can also be set up as a way for a friend, grandparent, or other relative to leave assets to an individual with a disability.

Q: What is Durable Power of Attorney?

Durable power of attorney allows an individual to name another person to handle his or her affairs in the event he or she becomes incapacitated. The guardian of a child with a disability should include the temporary delegation of guardianship in the durable power of attorney. A durable power of attorney should expressly permit the transfer of assets to other children or to the SNT.

Q: What is Advanced Medical Directive?

An Advanced Medical Directive, sometimes called a Living Will, allows an individual to specify

healthcare decisions in the event he or she becomes incapacitated. In the case of a family of a child with a disability, parents should include information on specific healthcare decisions regarding the treatment of the child or adult with a disability.

Q: What is a Living Trust?

A living trust can be used for a variety of purposes including minimizing estate and inheritance taxes, holding life insurance, avoiding probate, and permitting the management of assets in the event of deteriorating capacity.

Q: What is a Letter of Intent?

A letter of intent is not a legal document, but it can be an important part of an estate plan. It is prepared by the parents of a child with a disability to summarize important information concerning the child, such as information regarding the child’s disability, health, doctors and programs, as well as the parents’ wishes and expectation for the future. This letter should be used as a guide for the successor guardians of the child with a disability and the trustees of the SNT. An example of a letter of intent can be found on the firm’s website (www.hinkle1.com).

Q: What happens if there is no estate plan?

Absent an estate plan, state law dictates the distribution of a person’s assets – often that means that assets are split between children. Even if the family has a modest estate – a small home and/or savings or retirement accounts - this could result in the child with a disability losing eligibility for essential government benefits.

Funding Your Special Needs Trust

When should a SNT be funded? A SNT may be set up at any time, but it is usually funded when both parents have died. The Will for each parent provides that on the death of the second parent, a certain portion of his or her estate will go to the SNT.

How do we fund the SNT? Life insurance is a cost effective way to guarantee assets are available to fund the SNT. For younger parents, life insurance can provide a significant source of cash to fund a SNT at a relatively low cost. Older parents may want to consider a joint survivorship policy – a life insurance policy written on two lives. Any life insurance policy purchased to benefit a child with disabilities must designate the SNT as the beneficiary. In cases where parents have purchased a significant amount of life insurance, other arrangements, including an Irrevocable Life Insurance Trust (“ILIT”) should be created. An ILIT can allow for the value of the life insurance to be excluded from the parents’ gross estate for federal and state estate tax purposes.

How much is enough? An individual with mild to moderate disabilities will likely qualify for fewer government benefits; and therefore, may require more funds in a trust than a person with severe disabilities. As a general rule, more funds are needed before an individual is situated in an adult residential placement. However, the way most states provide residential services is changing, with increasing reliance upon Medicaid and “Fee for Service.” As a result a properly drafted and sufficiently funded SNT is more important than ever.

What can the funds in the SNT be used for? Funds in a SNT must be used for the benefit of the person with a disability for needs that cannot be met through

government programs. A SNT can also hold real estate in which the individual with a disability will reside. In some instances, funds in a SNT can be used to purchase or lease an automobile, even if the person with a disability cannot drive. The SNT should allow the trustee to assess the quality and significance of a program, as well as grant the trustee discretion to privately purchase programs of higher quality and ignore programs of marginal value.

How can the SNT improve quality of life? The most important factor affecting the quality of life for the person with a disability is family involvement, especially after the death of the parents. Therefore, funds in the SNT should be available to defray costs that might be incurred by family members when overseeing and arranging for the care of the person with a disability. These costs include travel, childcare, hiring persons to help the family member monitor the care being provided and hiring clinical and legal services, in the event problems arise.

How can we be sure the funds are used correctly? In every SNT, a trustee must be named. The trustee makes investment decisions and authorizes expenditures from the SNT. Family members are usually the best choices for trustees. In some cases, a financial institution or other professional serves as trustee or co-trustee along with a family member. Naming multiple trustees provides a system of checks and balances. A SNT should specify a successor trustee and the mechanism for an appointment of a successor trustee. The family can also appoint a “Trust Protector” to periodically oversee how the trust is being used. The Trust Protector is an independent third party, such as an attorney or advisor, with no interest or day-to-day involvement

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of the SNT. Hinkle Prior & Fischer is often appointed as Trust Protector.

How does the SNT protect assets? Most states have laws that allow the state to recoup funds expended on residential services, like a group home, for a person with a disability. Therefore, if a person with a disability has received residential services, and then inherits money, the state can make a claim against the funds inherited – often claiming all of it. When the inheritance is directed through the Will to a SNT for the benefit of the child with a disability, the funds are protected from a claim by the state.

How does the SNT protect benefits and services?

Eligibility for vital programs, such as Medicaid and Supplemental Security Income (“SSI”) require the person to be disabled; have limited income; and, have less than \$2,000 in resources. For purposes of eligibility for most government programs, an inheritance is considered a resource. Therefore, it is essential any assets the person with a disability may inherit pass to a SNT, not directly to the person with a disability. These government programs provide essential services – medical coverage, rental assistance, and funds that can be used to purchase food, shelter, and clothing.



Hinkle Prior & Fischer is a multi-state law practice with offices in Lawrenceville, Cherry Hill, Florham Park, Paramus, and Wall, New Jersey. The attorneys lecture and write frequently on topics of elder law, estate planning, special needs trusts, guardianship, special education, Medicaid and accessing adult services. The attorneys are available to speak to groups in New Jersey and Pennsylvania at no charge.

Hinkle Prior & Fischer *Attorneys at Law*

Hinkle Prior & Fischer, P.C., Attorneys at Law
2651 Main Street, Lawrenceville, New Jersey 08648-1012
(609) 896-4200 • (215) 860-2100
hinkle1.com

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