ESTATE PLANNING & GUARDIANSHIP FOR FAMILIES WITH SPECIAL NEEDS

By: Valerie A. Powers Smith, Esq.

I. ESTATE PLANNING COMPONENTS

A. Last Will & Testament

A Will establishes who will receive your property at death. It also establishes, where applicable, who will serve as guardian of your children and as trustee of any trusts created under your Will. Lastly, your Will designates who (i.e., the Executor) will see that your wishes are carried out.

B. Special Needs Trusts

Most parents want to leave assets to their children when they die; however, if a person with a disability receives assets, the results can be disastrous. The person will lose Medicaid and SSI, and the assets may also be subject to recoupment by Medicaid, or by the State if the person is receiving residential services.

It is, therefore, recommend that parents establish a special needs trust (SNT). A SNT can protect the assets while, at the same time, making the assets available to protect and enrich the life of the person with a disability without jeopardizing benefits available from the government. A SNT is a unique legal document that contains a set of instructions describing how assets placed into trust will be administered on behalf of a person with a disability. It must be carefully worded and is best written by professionals familiar with disability services and programs.

Parents and other family members can use a SNT to hold assets for a disabled person. Even families with modest assets should establish a trust; typically, such trusts are not funded until one or both parents die. A SNT can be funded through life insurance or estate assets distributed through one's Will. So long as the assets have never vested in the person with a disability, the SNT need not contain a provision reimbursing Medicaid and other providers.

Trust funds can be used to purchase independent professional opinions as necessary, fill in gaps in services, provide additional recreation and other amenities, pay for a private residential placement, or a vehicle used to transport the beneficiary of the trust.

At the death of the beneficiary, any remaining trust property is disposed according to the instructions written in the trust document by the donor. For example, property might go to other family members or to a charity.

C. Legal Documents to Aid in Decision Making

A **Durable Power of Attorney** is a document an adult with capacity can create to appoint another, called their attorney-in-fact or agent, to perform duties and make decisions concerning their own financial business when they are not able to do so generally during periods of incapacity.

A **Medical Directive**, also referred to as an Advance Directive or Living Will, is a similar document to the durable power of attorney, but deals with medical decision-making, including end-of-life decision making, when one is incapacitated and unable to do so for themselves. The agent or proxy is to make decisions that the individual would have wanted with regard to their medical care.

II. GUARDIANSHIP

In the eyes of the law, even those with a significant developmental disability are legally permitted to make decisions on his or her own behalf at the age of 18. Therefore, if due to a disability, a person is not capable of making his or her own decision, it is necessary to secure the judicial appointment of a guardian.

A guardian is someone appointed by the court to make decisions on behalf of another person who cannot make decisions independently. There are two types of guardians: a guardian of the person usually has the power to make decisions concerning living arrangements, day programs, medical care, and other personal decisions. A guardian of the property usually has the power to make decisions regarding whether and how to sell, trade, or invest property. They do not, however, have power over assets held in trust unless the guardian is also the trustee.

In order to have this authority, a court must first find that the person cannot make decisions about him/herself or his/her property. If a court determines this to be the case, it will appoint someone to take on this responsibility; in most cases, one or both parents. The court may also appoint a brother or sister to serve as guardian with the parents, or alone, after the parents have died. Once they have secured guardianship for an adult child, parents can appoint a successor guardian in their will, or can temporarily delegate guardianship through a written document called a power of attorney.

The guardian's job is to make sure that the person with a disability or mental illness is to make decisions in the best interest of the person under guardianship and make sure he/she is safe. The guardian does not bear any risk for the person's acts or debts, and is under no legal obligation to provide direct care to the person. There is no 'downside' to serving as a guardian.

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Valerie A. Powers Smith, Esq., Of Counsel, Slovak Baron Empey Murphy & Pinkney, LLP, is licensed to practice in New Jersey, New York, Pennsylvania, and California and specializes in the following special needs and disability law subject areas: health care insurance, Medicaid, Medicare, special needs trust, trust administration, estate planning & administration, guardianships, and accessing federal and state government disability-based benefits. Valerie can be contacted at powers@sbemp.com, 609.655.3393 or 760.322.2275.