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### **ESTATE PLANNING FOR PARENTS OF CHILDREN WITH DISABILITIES**

Estate planning is often the last thing that parents of children with disabilities think about. Apart from the fact that there simply isn't time to accomplish all of the things we generally set out to do, estate planning is an issue that is so emotionally charged that it is usually relegated to the side lines. As a result, most parents of school-aged children have no estate plan. This is especially critical for the parents of disabled children. Worse yet, the plans that are sometimes created make no provision for the disabled child.

**Having No Estate Plan:** A parent who has failed to create an estate plan has placed his or her family at a distinct disadvantage. Generally, most parents would prefer for assets to be left to their surviving spouse who would naturally support and provide care for their children. However, under New York State's laws of intestacy, the laws that govern the distribution of the assets of one who has died without creating an estate plan, fifty percent of the assets pass to the surviving spouse and the other half is divided among the children of the deceased. Also, the half of the assets that pass to the children are subject to Court supervision. If a child is under the age of eighteen years, a guardian, who is not necessarily the surviving parent, is appointed by the Court to protect the child's person and/or property. The Court may, and in most cases does, require the guardian to secure a bond. The child's share of the funds is held by the guardian for the child's benefit until he or she has turned eighteen. There are limitations on the manner in which the funds can be invested by the guardian. Expenditures are subject to Court approval and the guardian must account for them annually. The costs of the guardianship are paid for out of the child's funds. Moreover, since it is a parent's obligation to provide support for their children, the surviving parent cannot freely access the funds for expenditures such as clothing, food, religious training or even education. Also, unless the child has been designated by the Court as either mentally retarded or developmentally disabled, upon turning eighteen years of age the assets belong to the child to do with as he or she wishes regardless of whether the child is capable of managing the assets and irrespective of the amount of money available.

The problem is exacerbated if both of the parents perish without completing an estate plan. Apart from the trauma of losing their parents, where no succeeding care giver has been designated by the parents to serve as the guardian for the underage children, they suffer additional harm from the discord that results when family members vie for who is best able to raise the

children. What may be worse is when the children are divided or when the family members responsible for raising the children are not the ones the Court designates for managing their money.

**Do It Yourself Planning:** Some parents have tried to undertake planning on their own. Often, because they do not seek advice from a qualified attorney and are not aware of all the options, they intentionally disinherit their disabled child thinking that it is the best way to protect that child's eligibility for governmental programs and benefits. This usually occurs as parents age and their children reach the age of majority. Typically, a last will and testament is created that divides the assets among family members but leaves no share for the disabled child. Sometimes it is coupled with a tacit understanding that the assets inherited by other siblings will be used, in part, for the disabled child's benefit. This strategy fails for a variety of reasons. For instance, circumstances beyond the recipient's control may prevent them from carrying out the wishes of their parents. They may suffer financial reversals, they may have their own family hardships or, as a result of divorce, they may lose control of the resources that were to be utilized to enhance the quality of their disabled sibling's life. They may die prematurely without having segregated the assets causing the funds intended for their disabled sibling to pass to their own spouse and family. Occasionally, a sibling may elect to disregard the understanding and justify their own use of the funds.

**Planning For The Needs of the Disabled Child:** When parents undertake responsible planning for their children it requires the designation of caregivers. These individuals may or may not also be imbued with the responsibility for managing assets. Trusts should be created for the benefit of underage children which can specify the manner in which the assets should be invested, the use for which they are intended and, if the child will ultimately be entitled to obtain direct control of the assets, the age or ages at which that will occur.

More importantly, it is unnecessary for parents to exclude a disabled child from his or her inheritance. By utilizing a Supplemental Needs Trust, parents can ensure that their assets will be set aside and available to enhance the quality of their disabled child's life for his or her lifetime without interfering with or replacing governmental benefits to which he or she may be or become entitled.

A Supplemental Needs Trust is an estate planning tool that enables a disabled individual to retain eligibility for needs-based governmental entitlement programs, such as Medicaid and Supplemental Security Income. The funds protected in a Supplemental Needs Trust are used to supplement rather than supplant governmental benefits. Thus, assets intended for the benefit of a disabled child can be protected and preserved to provide quality-of-life enhancements throughout life such as specially equipped vans or other

transportation, vacations, a home, a computer, an entertainment center, special furnishings, vocational training, personal care givers - essentially, any "need" that is not provided through government entitlements, or any luxury . The fund can also be utilized to pay for private insurance coverage. The government entitlement becomes a baseline rather than a standard of living and the disabled individual is not dependent upon the benevolence of siblings or others. Depending upon the circumstances under which the trust is created, the assets may be utilized during the life of the intended disabled beneficiary and then "remaindermen", typically other family members, can be designated who will receive the remaining assets after the beneficiary has passed away.

For older families, parents who recognize that they may require care themselves can also utilize Supplemental Needs Trust planning to protect assets in order to hasten their own eligibility for governmental programs. The transfer of assets to or for the benefit of a disabled adult child can constitute an "exempt transfer" by the parents who are applying for their own Medicaid benefits. For maximum effectiveness, planning of this nature should only be undertaken with the advice of a qualified attorney who has interdisciplinary competence in areas that affect the aged and disabled: estate planning, asset protection planning, retirement distribution planning and elder law. For more information, please contact Berwitz & DiTata LLP.

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