

Estate Planning Getting Started

by Frank L. Brunetti

Estate planning always involves difficult decisions. The process is even more complicated for those families who must be concerned with the care, comfort and well-being of a child with disabilities, especially if it is clear that the child is unlikely to be able to provide for his or her own support or make mature day-to-day decisions. Such parents often worry about who will care for a son or daughter after their deaths; they also worry about ensuring that the child's needs will be provided for financially.

To begin the estate planning process, parents must focus on two tasks. The first is to perform an "inventory." The second is to retain an attorney with expertise in estate planning for children with disabilities.

The inventory

An "inventory" involves gathering and putting into order the most important documents that your fiduciary will need for the care of your child. (A "fiduciary" is the person you have selected as the personal representative of your estate, such as an executor, a trustee or both.) This inventory, which, for ease of reference can be kept in a three-ring binder, will include the following sections:

- **Part I: The Profile**—The profile should cover important information about the child's educational, therapeutic and medical history. It should include names, addresses and phone numbers for all the child's doctors, therapists and other service providers. It should also include key medical records, along with the names and dosages of all current medications. Finally, the profile should offer a complete description of the child's disability, and its likely effects on the child's life, both now and in the future.
- **Part II: Documents**—This section of the inventory should include the following: the child's birth certificate (original or duplicate copy), the child's social security number, parents' social security numbers, name and address of the parents' estate planning attorney, name and address of the child's school or day care provider and a guardianship order and/or any other legal documents regarding the legal status of the child in the case that parents become unable to maintain responsibility for his or her care.
- **Part III: Living Plan**—A plan, written by the parents, describing how they expect the child to live out his or her life. The life plan should cover everything from the child's favorite activities and foods, to a list of friends and relatives—those with whom the child may live, others with whom the child should maintain contact. The plan should also include burial instructions for the child.

The preparation of the "living plan" need not be a "parent-only" task. In many cases, the child and other family members can participate in the process and may contribute useful information and ideas.

Finding an attorney

While parents are completing the inventory, they can take steps to find an attorney who has experience in estate planning for children with disabilities. Parent organizations or Parent Training and Information centers may be able to refer parents to a local attorney with expertise in this area. County bar associations may be another referral source.

It is important to retain an attorney with specialized knowledge because estate planning for a child with disabilities requires knowledge of federal tax law; regulations governing SSI, or

"Supplemental Security Income," the federal program that pays a monthly stipend to people with disabilities, dependent on income but regardless of age; state guardianship law and state Medicaid regulations. In addition, some states have enacted special legislation related to estate planning for children with disabilities. For example, certain states allow the establishment of "community trusts," nonprofit organizations that pool resources for the benefit of people with severe disabilities. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as administration of trust funds, advocacy (for example, participation by community trust representatives in the development of individualized plans developed by service providers) and/or guardianship.

Typically, most attorneys will give a free or reduced-rate initial interview. Parents should go to the initial interview with a specific goal—to determine whether this attorney can properly serve their needs, and for a reasonable fee. To be capable of making this determination, parents need to know something about relevant legal issues before going to the interview. These issues might include the Medicaid "resource" rule (the way their home state considers assets when determining eligibility for Medicaid coverage) and regulations for establishing legal guardianships in that particular state. This type of information is available through various publications and national organizations.

Financial needs and liquidity

Before the estate planning process can begin in earnest, parents must determine the financial condition of their estate and decide if and to what extent their estate will provide for beneficiaries other than the child with a disability (for example, siblings). They will need to prepare an updated financial statement, as well as a family profile that outlines their particular estate planning needs. For example, if parents' assets include a family-owned business, they need to consider whether the business will be passed on to heirs or be sold. If the business is to be inherited by children in the family, the estate planner must find a way to pass the business on to the designated heirs without its assets being depleted by estate or inheritance taxes. If it is to be sold, sales arrangements should be made as part of the estate planning process.

Many families face the common estate planning problem of liquidity. "Liquidity" refers to cash or the ease with which other assets can be converted into cash. Because treasury bonds can be easily converted into cash, they would be considered "liquid assets." Real estate, on the other hand, would be considered "illiquid."

Liquidity is an important estate planning issue because parents need to determine whether their estate will have enough cash to pay for liabilities such as federal and local estate/inheritance taxes. In addition, if parents hope to set aside funds for the care of a child with disabilities, they need to think about where these funds will come from. Do they need to purchase life insurance, or should they transfer new or existing insurance coverage to an irrevocable inter vivos trust (a trust established during the lifetime of its creator, which cannot be revoked)?

Writing a will

Once these preliminary steps have been completed, parents can begin drawing up a will. Because many forms of government assistance are denied to individuals with substantial assets, the will must exclude the child with a disability from inheriting or find an alternative way—such as a "special needs trust"—to maintain the child's eligibility for benefits and insulate the inheritance from government claims seeking reimbursement of previously paid benefits.

Another important feature of the will is the appointment of the executor (or executrix). The executor is the person charged with making sure the will's provisions are carried out. The executor must gather the assets, pay the liabilities, file tax returns and fund any trusts. Typically,

the executor will be a family member or close friend. In some cases, particularly with complex estates, the executor may be a bank or trust company. An attorney or accountant usually assists the executor in handling the estate.

If the will provides for a trust, a trustee must be appointed to manage the trust until its termination. While the executor's term will be short-lived, the trustee may serve for years, even decades. Next to selecting a guardian, the choice of a trustee is the most difficult decision. The trustee must have several qualities: trustworthiness, sensitivity to the physical and emotional needs of the child with disabilities and ability to handle the financial affairs of the trust. A trustee must act almost as a surrogate for the parent. In some cases, two trustees may be needed—one to administer the financial aspects of the trust and another to carry out the more personal duties of the trustee such as personal visits with the child and advocacy on his or her behalf.

In addition, the parents must have properly drafted "powers of attorney," which grant another person the legal authority to carry out their affairs if they become unable to do so. In this event, it will be important that another individual is ready and willing to take on the role of "successor legal guardian," a role that gives this person legal responsibility to care for and act on behalf of the child with disabilities.

It's only human to put off making difficult decisions, but in most cases, parents of children with disabilities will have started the estate planning process without necessarily labeling it as such. Most parents will have information needed for an "inventory" readily available—though perhaps not yet organized in a three-ring binder. Many parents have already drafted a "living plan"—in their minds if not in writing. Some parents may have already discussed the issue with an attorney. All that remains is some basic organization and a decision to complete the estate plan within a specific time frame.

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