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Providing for Your Child with Special Needs After Your Death

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Why is estate planning important when you have a child with special needs?

Preparing for the day when you won't be around to care for your family is a challenge that all parents face. But as a parent of a child with special needs, your estate planning needs are especially complex. Your will, and other estate planning documents you prepare, must address your unique concerns. These concerns may include:

- Providing for adequate lifetime care or assistance
- Appointing someone to manage your adult child's finances
- Maintaining your child's eligibility for government benefits
- Avoiding family conflicts

An attorney and other financial professionals experienced in planning for children with special needs can help you draft a comprehensive estate plan to ensure that your child is well provided for after your death. If you already have an estate plan in place, you should have all existing legal documents reviewed (and revised, if necessary) to make sure they address your family's needs.

Wills

A will is the cornerstone of any estate plan. It ensures that your money and property are distributed according to your wishes upon your death, and allows you to select a guardian for your child. Without a will, probate assets will pass according to the laws of intestacy, which generally assign a portion of the assets to the surviving spouse and a portion to the children. If your child requires more financial resources than other beneficiaries, it's especially important to prepare a will that reflects your wishes.

Trusts

A trust is a legal entity that enables you to leave assets to your child with special needs (and others) outside of your will. You can create a trust during your lifetime (a living trust) or in your will (a testamentary trust). As the creator of a trust, you can decide what assets will be transferred to the trust, who the beneficiaries will be, what the terms and conditions of the trust will be, and who will manage the trust. Trusts are typically used to:

- Avoid probate
- Manage assets
- Provide for minor children
- Avoid estate taxes
- Protect assets from creditors

One type of trust, called a special needs trust, can play an important role in your estate plan. Specifically designed for the benefit of individuals with special needs, a special needs trust can allow you to provide for your child without jeopardizing his or her eligibility for government benefits, an advantage not offered by traditional trusts.

Why use a special needs trust?

Government benefits, such as Medicaid and Supplemental Security Income (SSI), can be vital sources of support for your child with special needs, especially if he or she is unable to buy or afford private health insurance. But because these government programs are need-based, your child will become ineligible for benefits if his or her countable assets (e.g., cash and other liquid assets) exceed $2,000, the limit that applies in most states. An inheritance, a gift from a relative, or a personal injury award may push your child's assets over the limit, resulting in the loss of government support.

Unfortunately, government benefits generally provide only basic support. The portion of assets your child is allowed to keep and the small allowance for personal care he or she receives under government benefit eligibility rules may not be enough to pay for necessary items and services, such as eyeglasses and dental care. It is almost certainly not enough to allow the child any

"luxuries" such as vacations or gifts for others.

If you want to provide funds that can be used for expenses not covered by government benefits while preserving your child's eligibility for those benefits, consider establishing a special needs trust. Because assets deposited into, and income generated by, a properly drafted special needs trust will not be considered "available" to your child, they won't jeopardize his or her eligibility for Medicaid and SSI.

In addition, establishing a special needs trust is often the best way to guarantee that funds you leave are used for your child's benefit. Although disinheriting your child or leaving money to other family members on his or her behalf may initially preserve your child's eligibility for government benefits, your child may someday be left without adequate support if these benefits are reduced or eliminated. Another concern is that creditors may attach money left to a family member if, for instance, that family member is held liable for an auto accident or declares bankruptcy.

If you are interested in establishing a special needs trust, consult an attorney who is experienced in special needs issues (including Medicaid planning), and the laws governing special needs trusts in your state.

Note: *An additional planning tool you may want to consider is an ABLE account. Money in an ABLE account generally does not count toward SSI and Medicaid asset limits. An ABLE account may be opened by an individual whose disability began before age 26. As a parent, you may also be able to open and oversee an account on your child's behalf. Your child will be the account owner and the account beneficiary. Contributions to the account can be made by you, your child, and others who want to provide financial support. Earnings on contributions accumulate tax deferred at the federal (and sometimes state) level, and distributions will be tax-free if they are used to pay qualified expenses. These include housing costs, transportation, health care, personal assistance, education, and many other types of expenses related to living with a disability. ABLE accounts are intended to supplement, but not supplant, benefits from other sources, and may be used in addition to a special needs trust.*

Letter of intent

A letter of intent is a document that describes how you want your child to be cared for after you're gone. Although it's not a legal document, it can provide important information to guardians, trustees, family members, and others involved in the care of your child. The letter may address such issues as your child's medical needs, daily routine, interests, likes and dislikes, religious practices, living arrangements, social activities, behavior management, and degree of self-sufficiency. Such a letter can prove invaluable to your child's caregivers after you're gone, and can also make the transition to a new living situation as smooth as possible for your child.

Beneficiary designations

With certain assets (such as life insurance policies, retirement plans, and annuities), you must designate beneficiaries and/or contingent beneficiaries. You'll also name beneficiaries under your will. Although your first inclination might be to name your child with special needs outright as your beneficiary, such a designation could jeopardize his or her entitlement to government benefits. Instead, consider establishing a special needs trust for your child and designating the trust as your beneficiary.

Guardianship issues

Although you are the natural guardian of your child with special needs during your lifetime, who will care for your child after your death? Selecting a guardian who can act on your child's behalf after you die is one of the most important decisions you face. The person you choose must be able to handle the complex financial, legal, and personal needs your child may have.

Depending on your child's needs, you may also need to choose a person who is committed to serving as guardian even after your child reaches adulthood. The law doesn't assume that an adult with special needs is incapable of handling his or her affairs. After reaching the age of majority (generally age 18), your child is a legal adult. He or she will be judged capable of handling his or her own affairs unless declared incapable by a court. If such a determination is necessary, the guardian you choose now may need to serve as guardian throughout your child's life.

Guardian defined

A guardian is someone with the legal power to care for another person and manage that person's personal and/or financial affairs. A guardian can advise your child, manage assets, and oversee your child's care after your death. Generally, you'll nominate a guardian, along with several contingent guardians, in your will. The court has final approval, but it will usually approve whomever you nominate, unless there are compelling reasons not to do so.

Types of guardians

There are two basic types of guardians: a guardian of the person, and a guardian of the estate. A guardian of the person is someone authorized by a court to make only personal and medical decisions about your child. Any medical procedure performed on a child requires consent from the parent or guardian. A guardian of the person is empowered to give such consent for medical procedures and also decide where your child will live. Usually, the court clearly specifies the scope of the guardian's power. (The guardian will have to report to the court on a regular basis.)

A guardian of the estate (also called a conservator) protects and manages your child's money and other assets. The guardian has the following legal duties:

- To take possession of real and personal property and manage it for the benefit of his or her charge
- To spend the estate for the necessary care and support of his or her charge
- To productively invest estate assets

You can nominate different people as guardian of the person and guardian of the estate, or you can nominate one person to handle both functions.

Caution: *Each state has its own laws regarding guardianship. Consult an estate planning attorney before choosing a guardian.*

Full guardianship

A full guardianship is also called a plenary guardianship. In this case, the guardian has control over both the personal issues and the estate of your child. This is the most common type of guardianship. Typically, you will choose a full guardianship if your child's issues are so severe that he or she cannot make any informed decisions at all.

Limited guardianship

In a limited guardianship, the guardian has authority over his or her ward only in specifically defined matters. Otherwise, the child with special needs retains some control over his or her own life. The court has to pay careful attention to this type of arrangement to be sure it remains appropriate for the child.

Caution: *One problem with limited guardianships is that your child may encounter a legal situation you haven't considered. You have to anticipate the future when you set up a limited guardianship.*

Temporary guardianship

If the court appoints a temporary guardian, it specifies the limited problem or limited time of the guardian's power. Usually, a temporary guardian is appointed only in a situation caused by drugs or momentary illness or in a special medical case.

What to consider when choosing a guardian

You may want to select a relative, friend, or trusted legal professional as the guardian for your child. Here are some points to consider as you make your decision:

- Does the potential guardian live close to your child?
- Does he or she have enough time to devote to your child?
- Does he or she have the interpersonal skills necessary to be an effective advocate for your child?
- Is he or she willing to take on the responsibility?
- Do you trust him or her to keep your child's best interests in mind?
- Does he or she already have a relationship with your child?
- Is he or she willing to keep up with new programs and opportunities for your child?
- Will he or she adapt to your child's changing circumstances?
- Does he or she have the financial ability to manage your child's estate?

Caution: *Make sure to periodically review your choice of guardian. Your child's needs may change, or the person you initially chose may become unable or unwilling to serve as guardian.*

What if you die before nominating a guardian for your child?

If you fail to nominate a guardian in your will, or otherwise die before making arrangements for a caregiver, the court may appoint a guardian for your child. If a relative does not wish to serve or does not qualify, the court may appoint a professional guardian who is a stranger to your family. The guardianship process can be expensive, time consuming, emotionally draining, and open to public view. In some cases, though, there are advantages to having a guardian with professional expertise.

Public guardian

If a child with special needs has no individual guardian, the court will appoint a public guardian for the child. Usually, this guardian has many other clients as well, so he or she may not have time to watch your child's affairs as closely as you wish. A public guardian is paid out of public funds, but since the guardian often negotiates with public agencies, he or she may experience a conflict of interest. Public or nonprofit agencies may also be public guardians.

Caution: *A public guardian is usually considered a guardian of last resort.*

Corporate guardian

A corporate guardian is part of a company that sells guardianship services. A professional staff or a volunteer manages your child's care. This type of guardianship is usually funded by advance payment from parents, life insurance policies, or bequests. The United Way and other charities also support corporate guardians.

What if your child does not need a guardian?

Even if your child does not need a guardian (if, for instance, he or she is already a legally competent adult), he or she may continue to need care, advice, and support throughout adulthood. You may want to ask a family member, friend, or other individual to act as a caregiver or mentor for your child. Make sure, though, that the caregiver you've chosen has the power to act on behalf of your child should he or she become incapacitated. This can be accomplished by having your child execute certain legal documents, including a durable power of attorney and advanced medical directives.

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