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A CHILD WITH SPECIAL NEEDS, NEEDS SPECIAL PLANNING

AMERICAN ACADEMY of Estate Planning Attorneys

While planning for the care of a child with special needs certainly tops the list of emotionally-charged topics, the peace of mind parents gain from a well-designed estate plan is immeasurable.

The mere idea wrenches the heart of any parent: if untimely death or disability strikes, who will care for your children? Because no one is immortal, most of us recognize the need for an estate plan, preferably one that appoints a suitable guardian for our children, sees to their financial needs, and avoids probate.

In the best of circumstances, it's a task requiring clear thinking and good legal advice. But when a child has special needs, the challenge intensifies.

Before we explore estate planning strategies for parents of children with special needs, let's look at why all parents need an estate plan.

A PAGE FROM OLIVER TWIST

"A ward of the court" may sound like something out of the nineteenth century. But that's precisely what becomes of children who are legally disabled or deceased parents have failed to plan for their care. Unless you've created an estate plan that spells out who should assume responsibility for your child, the courts will step in. And that's true whether you've left behind an estate worth millions or nothing at all.

When children take center stage in probate court, it's because the court wants to ensure that a responsible person is supervising their physical needs and financial affairs. The court will appoint a guardian to assume responsibility for your child's personal care. To oversee your child's financial affairs, the court will appoint a financial guardian. Often, the financial guardian is not one person, but an entity, such as a bank or a professional money management institution.

Probate judges have tremendous discretion in whom they may appoint as guardians. So, there's very little assurance that the judge's appointments will be the same individuals you would choose. In fact, if qualified family members aren't available or deemed suitable, the judge may very well appoint professional guardians who may be strangers to you and your child.

The guardian will be supervised by the probate court judge assigned to your child's case. The guardian is usually required to obtain judicial approval before undertaking any significant financial transactions on your child's behalf. Busy schedules and heavy caseloads often mean that it can take weeks—or even months—before a financial transaction can be reviewed and approved by the supervising judge. That may create devastating delays in providing care and comfort for your child.

Because the court is involved in supervising their activities, guardians frequently hire attorneys to help them navigate through the legal system. The fees for these attorneys—as well as the fees

charged by the guardian and the probate court itself—all come out of the estate you've left behind for your child's benefit. These expenses leave less money to provide for your child's care, education, and other requirements.

UPPING THE ANTE: PLANNING FOR A CHILD WITH SPECIAL NEEDS

Clearly, every parent has a responsibility to plan for the unthinkable. But when the child has physical, emotional or mental disabilities, careful estate planning is even more crucial for three important reasons.

First is the simple fact that children with special needs have different needs than children without special needs. Depending on the degree of their needs, they may require specialized treatment that encompasses therapy, housing, education, adaptive equipment, and in-home care, among many other costly services. The need for this care may extend throughout their childhood and last well into adulthood, or even their entire lives. Providing the appropriate degree of care requires careful financial planning.

Here's the second critical reason why parents of a child with special needs require a specialized estate plan: it is the only way to ensure that you can provide for your child without jeopardizing the child's eligibility for government and private benefit programs.

Finally, for parents of children with special needs, estate planning is the only way to protect the child's financial interests today as well as in the future, when you may no longer be on the scene.

THE HORNS OF A DILEMMA

It's a painful dilemma that parents of a child with special needs often face: to keep their child eligible for important federal and state benefit programs, the child can have few assets. That leaves parents with a difficult choice: provide a legacy for their special child and hope it will be sufficient for all his needs, or make the child a virtual pauper and retain his or her eligibility for government assistance.

Fortunately, there is a simple answer within reach of nearly everyone: the Special Needs Trust.

HOW THE SPECIAL NEEDS TRUST WORKS

The Special Needs Trust allows a parent, grandparent or guardian to provide funds for a child with special needs without disrupting the child's eligibility for government aid. Setting one up is a fairly simple process.

Working with your estate planning attorney, you appoint trustees for your child's trust. The trustees will manage the assets you transfer to the trust for your child's benefit. In the event of your disability or death, the trustees will also supervise your child's finances.

During your lifetime, you can serve as trustee and remain in complete control over your child's finances. Should you die, however, your successor trustees will step in and take care of your child's finances on your behalf.

Unlike the guardian, a probate court might appoint, your successor trustee is someone you know and trust. Relatives or close family friends can be appointed to supervise your child's finances. To work with financial institutions and manage the estate, you may also want a trusted financial advisor to serve as trustee.

As part of setting up your child's Special Needs Trust, you will provide detailed written instructions to direct your trustees' activities. By law, trustees must follow these instructions. So you can rest assured your child's education, housing, and other needs are being taken care of.

Best of all, the Special Needs Trust will preserve your child's eligibility for federal, state and charitable benefit programs. This is accomplished by providing that the funds can only be withdrawn from the Special Needs Trust for purposes other than those covered under the governmental and private benefit programs.

PLANNING WHEN THE INDIVIDUAL WITH SPECIAL NEEDS HAS ASSETS

One of the most heart wrenching aspects of having a disability is that it may be the result of negligence or preventable error. A doctor's misdiagnosis, a mistake at the hospital, or a product defect, for example, may create a lifelong impairment for a child. When that's the case, a lawsuit – and sizable settlement – can be the result.

In most cases, the child will be the recipient of the funds. And that can make the child ineligible for government support.

When the federal government enacted the Omnibus Reconciliation Act of 1993 (OBRA '93), one of its intents was to close the door on Medicaid abuse. Legislators realized that taxpayers sometimes deliberately impoverished themselves – and often used trusts to do so – to retain eligibility for Medicaid and other government aid programs. OBRA '93 resoundingly closed the door on that abuse. In fact, Americans who give away their assets to qualify for government aid can be effectively "blackballed" from federal assistance for a period of time which varies depending on the value of the assets given away.

Fortunately, however, OBRA ’93 left the door open for individuals with disabilities who receive damage awards. The law allows them to use their own money to fund a trust very similar to the Special Needs Trust without jeopardizing their eligibility for federal, state and private charitable benefit programs. Going by such names as a “Disability” Trust or “Medicaid Pay-back” Trust, these trusts are similar to the Special Needs Trust with one significant exception. When the disabled individual dies, any money left in his or her trust will be used to repay whatever government assistance that was received during his or her lifetime.

Although these trusts are authorized by federal statutes, many states have not as yet officially approved them. That’s why you may need the assistance of an estate planning attorney well versed in this aspect of the law if your child’s situation fits into the scenario described above.

BUYER BEWARE: ESTATE PLANNING SHORT-CUTS THAT CAN DERAIL YOUR GOALS

While acknowledging the need for estate planning for their children, some parents take short-cuts that create as many problems as they solve.

One of the biggest mistakes parents make – and it happens with alarming frequency – is naming their children as beneficiaries of their insurance policies, qualified pension plans, stocks, and other financial instruments.

Unfortunately for these parents and their children, neither the financial institutions or the probate courts will hand that money over to minor children. Instead, the money will be turned over to a guardian who will hold the money in trust for the child. If you haven’t appointed a guardian, the probate court will do so for you, and once again, you’ll have little guarantee that those in charge of your child will be the people you would have selected.

PLANNING FOR THE UNTHINKABLE

As difficult a subject as it might be, all parents owe it to their children to ensure they’re well cared for, come what may. Parents of children with special needs face an even greater imperative to do this essential planning.

ABOUT THE ACADEMY

This report reflects the opinion of the American Academy of Estate Planning Attorneys. It is based on our understanding of national trends and procedures, and is intended only as a simple overview of the basic estate planning issues. We recommend you do not base your own estate planning on the contents of this Academy Report alone. Review your estate planning goals with a qualified estate planning attorney.

The Academy is a national organization dedicated to promoting excellence in estate planning by providing its exclusive Membership of attorneys with up-to-date research on estate and tax planning, educational materials, and other important resources to empower them to provide superior estate planning services.

The Academy expects Members to have at least 36 hours of legal education each year specifically in estate, tax, probate and/or elder law subjects. To ensure this goal is met, the Academy provides over 40 hours of continuing legal education each year. The Academy has also been recognized as a consumer legal source by *Money Magazine, Consumer Reports Money Adviser* and Suze Orman in her book, *9 Steps to Financial Freedom*.