

## Planning for Parents of Children with Special Needs

Parents of children with special needs face many unique and distinct challenges. These challenges include caring for a minor child, planning for a child's transition to adulthood, and planning for the parents' own disability or death.

### **Surrogate Decision-Making for an Adult Child with Special Needs**

When a child reaches 18 years of age, the law considers him or her to be an adult. For parents of children with special needs, this often means that they must make a decision about how they will assist their child in making decisions. There are several options for surrogate decision-making for families with children with special needs:

#### **Power of Attorney / Advance Medical Directive**

If the child has the legal capacity, then he or she can execute a General Durable Power of Attorney for financial and educational decision-making and an Advance Medical Directive for medical decision-making.

An advance medical directive and general durable power of attorney can help preserve an adult child's independence and his or her legal rights. Such documents can streamline decision-making. However, the adult child can revoke these documents.

#### **Guardian and Conservator**

If the child lacks legal capacity, then the parents can petition the court to be appointed as the child's legal guardian and conservator.

The Guardian has the authority to make personal, medical, residential, and educational decisions for the child. The Conservator has the authority to manage the child's finances.

Guardianship and conservatorship can provide additional protection for the child, but the court order usually revokes the child's legal rights. In addition, some

providers may prefer to work with an independent adult child rather than with a guardian or conservator.

#### **Representative Payee**

If the child is receiving Social Security benefits, then the parent can request the Social Security Administration to appoint him as the Representative Payee for the child.

### **Disability Planning for Parents**

Parents of children with special needs should also ensure that their own estate plans include provisions so agents can provide for the children. For example, the parents should have their own General Durable Power of Attorney that authorizes their agent to spend funds to support minor children and children with special needs, as well as provide for other services needed by the special needs child.

### **Providing for the Child with Special Needs After the Parents' Death**

There are several ways parents can provide for their child with special needs after the death of the parents:

- **Disinheritance**: Although some parents are led to believe so, it is not necessary or recommended to disinherit a child with special needs.
- **Outright gift**: It is not recommended to provide outright gifts to a child with special needs because such gifts may make the child ineligible for needs-based public benefits such as Medicaid and Supplemental Security Income (SSI).
- **Distribute to siblings**: It is not recommended to distribute the share for a child with special needs to a sibling with the moral obligation to spend the funds for the benefit of the child.
- **Support trusts**: Trusts that direct the Trustee to spend funds for the child's "health, maintenance, education and support" are support trusts that can make the child ineligible for needs-based public benefits such as Medicaid and SSI.

- **Third Party Special Needs Trusts:** A Third Party Special Needs Trust is the recommended and preferred vehicle for providing for a child with special needs after the death of the parents.

## Third Party Special Needs Trusts

There are two types of special needs trusts (1) pooled third party special needs trusts, and (2) individual third party special needs trusts.

### *Pooled Third Party Special Needs Trusts*

Pooled third party special needs trusts are established by a non-profit association, and are designed to manage resources for the child's benefit without affecting the child's eligibility for needs-based public benefits. Each beneficiary has his or her own pooled trust subaccount, but the assets in the subaccounts are pooled for investment purposes. The parents can set up the subaccount during their lifetimes and can fund the subaccount during their lifetimes or after their deaths. Because the pooled trust subaccount is funded by a third party (the parents), at the beneficiary's death the funds will be distributed to successor beneficiaries named by the parents. No Medicaid payback is necessary.

### *Individual Third Party Special Needs Trusts*

A private third party special needs trust provides a means to manage resources for the child's benefit without affecting the child's eligibility for needs-based public benefits. The private third party special needs trust can be created under the parents' revocable living trust or as a separate inter vivos trust. The trust will name the initial trustee and successor trustees, and the trust will specify what happens to the remaining trust assets upon the death of the special needs child.

## Funding Special Needs Trusts

The parents can fund the third party special needs trust in various ways:

- **Life insurance** – Parents can name the trustee of the trust as beneficiary.
- **Retirement plans** – Parents can name the trustee of the trust as beneficiary.
- **Probate Assets:** The parent's Will can direct some or all of the probate assets to the special needs trust.

## Letter of Intent

Parents are also encouraged to write a letter of intent to keep with their estate plan. The purpose of the letter of intent is to provide information regarding the child with special needs to the persons who will be assisting or taking care of the child after the death of the parents.

The letter can include:

- A description of the child's history.
- A description of the child's current status:
  - Medical
  - Educational
  - Social
- A description of the parents' desires for the child's future, including:
  - Residential placement
  - Educational goals
  - Employment goals
  - Socialization
  - Religion
  - Medical care
  - Final arrangements

## Conclusion

Planning for parents of children with special needs is complex. Parents should consult with an experienced elder law attorney in order to design the plan that will work the best for their family.

## Learn More

Call Oast & Taylor at 757-452-6200 or visit [www.OastTaylor.com](http://www.OastTaylor.com) to schedule a consultation with an attorney at one of Oast & Taylor's convenient office locations in Virginia Beach, Portsmouth, Chesapeake, or Elizabeth City, North Carolina.

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