

# SPECIAL REPORT

## Planning for Parents of Children with Special Needs

Parents must plan their estates carefully when they wish to provide for a special needs child. The plan may greatly affect the quality of the child's life.

Many people believe that they have so few assets that an estate plan is not necessary. This is an error. We often have many more assets than we realize. Some assets, however, are only important after our death, i.e. life insurance.

Additionally, a poor estate plan for a parent of a special needs child can result in the child's ineligibility for some public assistance.

### WHAT PUBLIC BENEFITS ARE AVAILABLE?

**Publicly Financed Education.** The Federal Individuals with Disabilities Education Act (IDEA) and related Virginia regulations provide that a free appropriate public education will be provided to all children with disabilities, aged two to 21. IDEA provides that the state must provide, at no cost, appropriate public education that meets the unique needs of disabled minors, in the least restrictive setting, which in most cases means including the child in the regular classroom. If no appropriate public facility is available, the education must be provided in a private school at no cost to the parents.

- To determine what is an appropriate for the child, the local education authority (LEA) must devise an individualized education program (IEP) for every disabled student. The parents of the disabled child are invited to participate in the formulation of the IEP.
- If the parents disagree with the IEP, they may request mediation or a due process hearing. If satisfaction is not obtained at the hearing, the parents may bring suit in state or federal court.
- When the child reaches age 18, the parent's rights to participate in the development of and implementation of the IEP and in challenging the IEP transfer to the child, unless one of the following actions is taken:
  - The adult child is declared legally incompetent by a court and a representative has been appointed by the court to make decisions for the child.
  - The adult child designates, in writing, by a power of attorney, another adult to be the student's agent to participate and make decisions concerning the child's educational program.
  - The adult student is certified as unable to provide informed consent and an educational representative is appointed.

**Supplemental Security Income (“SSI”)** is a federal welfare program that provides a minimum level of income for some needy persons. To be eligible for SSI a person must be:

- age 65 or older, blind, or disabled;
- a U.S. Citizen;
- not a resident of a public institution.

A disabled person is:

- An adult who is unable to do any substantial gainful activity because of a medically determinable physical or mental impairment. A job will constitute substantial gainful activity if the pay is more than \$940 per month after deducting the cost of impairment related work expenses.
- A child is considered disabled if suffering from a medically determinable physical or mental impairment that compares in severity to an impairment that would make an adult disabled.
- To be eligible for SSI benefits, the 2008 annual net income limit for unmarried persons is \$16,308 and for a couple is \$23,964. Deemed income is income of another attributed to the claimant. It is an issue when the child lives with an ineligible parent. Deeming stops applying in the month following the child’s 18th birthday.

Income is anything received in cash or kind that can be used for food, clothing or shelter. The following items are specifically excluded:

- The first \$20 of most income received in a month.
- The first \$65 of earnings received in a month and one half of earnings over \$65.
- The value of food stamps.
- Money someone else spends to pay expenses for items other than food, clothing, or shelter.

An unmarried individual can have no more than \$2,000 of resources. The following items are specifically excluded:

- A home owned and occupied by the person with a disability.

- A car up to \$4,500 of current value. The entire value is excluded if the car is necessary for employment or medical treatment.
- Household goods and personal effects with a total value of less than \$2,000.

Monthly SSI benefits in 2008 are \$637 per month for an individual and \$956 for a married couple.

**Medicaid** is a joint federal state program of medical assistance to an eligible needy person. Because Medicaid is operated by the states, the rules will vary from state to state. Virginia has opted for more stringent eligibility rules than SSI. However, disabled SSI recipients will generally qualify.

If an individual is eligible for both Medicare and Medicaid, Medicaid can be used to supplement the coverage provided by Medicare. For example, Medicaid will pay for expenses not covered by Medicare (i.e. prescription drugs), and the co-payments and deductibles required by Medicare.

Medicaid will cover the following services:

- Hospital or nursing home care
- Necessary medical services provided by a physician
- Prescription drugs
- In-home and/or community based care (if certain pre-screening requirements are met) i.e. Medicaid waiver services

**Medicaid Waiver Services.** Many children may not be eligible for full Medicaid due to deeming of income and resources from parents. However, Federal law authorizes states to make Medicaid benefits available to certain disabled children who would not normally be eligible for SSI because of their parents’ income. In Virginia, such benefits are available under the 1915(C) waiver which waives certain federal requirements in order to provide home and community based services to those children as an alternative to institutionalization.

In Virginia various waiver programs exist for disabled children. To qualify for a particular waiver program the child must meet certain pre-screening requirements as defined by the type of waiver program. Examples of the waiver programs include:

- Mental Health/Mental Retardation Waiver provides home and community-based services to individuals with mental retardation and individuals under the age of six at developmental risk who are determined to require the level of care provided in an Intensive Care Facility/Mental Retardation, and to individuals with related conditions currently residing in nursing facilities who require specialized services.
- Technology Assisted Individuals Waiver relates to an individual who relies on both a medical device to replace a vital body function and substantial and ongoing skilled nursing care to prevent death or further disability. The waiver services are intended to avoid placement in a hospital or nursing facility, or to shorten the stay if admission to such a facility is made.
- Developmental Disabilities Support Waiver provides home and community-based services to those with developmental disabilities but no diagnosis of mental retardation. The developmental disability must have been evident prior to age 21 and must be expected to continue indefinitely.

Financial eligibility for the individual waiver programs is basically the same in that the income limit is 300% of the current SSI payment for one person and the resource limit is \$2,000 for an unmarried individual. However, the Technology Assisted Waiver program allows the spenddown of income in excess of the SSI maximum payment for one person (i.e. the individual has medical expenses that equal or exceed the amount of her/his income), whereas the Mental Health/Mental Retardation and the Developmentally Disabled waivers do not allow for the spenddown of income in excess of 300% of the SSI Standard. In 2008, 300% of the SSI standard for one person is \$1,911.

Waiver eligible children are considered to meet the institutionalization requirements of Medicaid. This means that only the child's income and resources will be considered in determining Medicaid eligibility. The income and resources of the institutionalized child's parents are not deemed available to the child.

**Social Security Disability Income ("SSDI")** benefits may be obtained based on an individual's insured status arising from his or her own employment record. Benefits may also be available based on the record of a living (Social Security Dependent's Benefits) or deceased (Social Security Survivors' Benefits) parent. Children who became disabled before age 22 and have remained continuously disabled since age 18 may draw benefits on the record of a disabled, deceased, or retired parent as long as the child is disabled and unmarried. We often refer to such children as DAC's (disabled adult children). A DAC who marries another SSDI recipient generally will not lose benefits. The DAC should contact the local Social Security Office before marrying to determine the effect of the marriage on his or her benefits.

SSDI monthly benefits are based on the worker's primary insurance amount (PIA) which is based on the worker's indexed monthly earnings. A DAC of a worker is entitled to 50% of PIA and, if the worker is deceased, this increases to 75%. There are no resource or income limits for SSDI eligibility. However, if the child's earned income exceeds \$940 a month (after deducting the cost of impairment-related work expenses) the child will likely not be considered disabled and therefore may not be eligible for benefits.

**Medicare** is a federal health insurance program. SSDI beneficiaries are entitled to Part A Medicare benefits after 24 months (1 month for a person disabled with ALS effective 7/1/2001) of qualified disability. Part A covers inpatient hospital services, home health, and hospice benefits. It also

pays for a very limited amount of Skilled Nursing Home care but not custodial care. SSDI beneficiaries who are eligible for Part A benefits may enroll for Part B benefits but must pay a premium of \$96.40 per month in 2008. Part B benefits cover physicians' charges.

Medicare generally does not pay the entire cost of hospital stays and physicians services. In addition there are deductibles and co pays.

There are no resource or income limits for Medicare eligibility.

**Civil Service and Military Survivor Benefits** are available for an unmarried child over age 18 who is incapable of self support because of a mental or physical disability that began before age 18. The child is eligible to receive 55% of the parents' annuity after the parents' death. The child may receive the benefit even if a widow(er) is also receiving a survivor benefit. Children receiving a civil service survivor annuity are also eligible for federal employee group health benefits if the federal employee had family coverage at the date of his or her death.

### **HOW DO YOU START PLANNING YOUR ESTATE?**

Before contacting an attorney you should gather the following information:

- You must realistically assess your son's or daughter's disability and the prognosis for future development. If necessary, obtain a professional evaluation of your child's prospects and capacity to earn a living and to manage financial resources.
- You must inventory your financial assets. This inventory should include the preparation of a financial statement valuing all of your assets. You should collect copies of all deeds to real property, life insurance policies, bank and brokerage statements, stock and bond certificates, and business documents.
- You should consider the living arrangements of your son or daughter with a disability. If you or your spouse were to die or become disabled

tomorrow, where would the child live?

- You should analyze the earning potential of your special needs son or daughter. You should consider the governmental benefits that your son or daughter needs and is eligible to receive. A gift or transfer of assets to someone who is eligible for SSI or Medicaid may result in a reduction or loss of those benefits.

### **DISABILITY PLANNING**

Having decided what your child needs and what you own, you should consider with your attorney how to assist your child if you became disabled. There are three possible ways to do this:

- **General Durable Power of Attorney.** You may create a general durable power of attorney in which you appoint someone as your agent. This agent will have the authority to transact business on your behalf. Within your general durable power of attorney, you may authorize your agent to spend your funds to support your special needs child.
- **Revocable Living Trust.** You may create a revocable living trust and fund it with some or all of your assets. Within the trust document, you would appoint a trustee to act in the event of your disability. The trust agreement may provide that the trustee is authorized to spend trust funds for the support of your special needs child.
- **Standby Guardianship.** The circuit court may appoint a standby guardian of the person, or a standby conservator of the property, or both, of an incapacitated child. Such standby fiduciary is empowered to assume the duties of his office immediately upon the death or adjudication of incapacity of the last surviving parent of such incapacitated child.

### **HOW DO YOU PROVIDE FOR YOUR CHILD AT YOUR DEATH?**

There are five possible ways to provide for your special needs child after your death. Your attorney can help you choose the best option and prepare the necessary documents.

- **Disinheritance.** You can disinherit your special needs child. Virginia does not require that you leave any money to a child, whether disabled or not. If you have very little property, the best advice may be to disinherit your child and have him or her rely upon federal and state benefits after your death.
- **Outright Gift.** You can leave your special needs child an outright gift. If your child is receiving (and is expected to need) SSI or Medicaid, this gift is not a desirable course of action since the gift will be a resource in determining the child's eligibility. Additionally, if your child has a mental illness or cognitive disability, is not a good idea because the child will not be able to handle the financial responsibility of managing your gift.
- **Moral Obligations.** You may leave a gift to another child with a moral obligation and understanding to assist his or her disabled sibling. However, the gift is a moral obligation. The nondisabled child can legally ignore your wishes and do whatever he or she wants with the money. Even if there is no decision to deliberately ignore your wishes, circumstances may make it impossible for the non-disabled child to carry out your wishes. Suppose, for example, your nondisabled child suffers financial difficulties and his or her creditors seize the funds. Or, the nondisabled child may lose the funds in a divorce proceeding.
- **Support Trusts.** An obvious solution to the needs of a special needs child is to establish a trust. However, a trust that mandates the trustee to make distributions for the child's support, maintenance or medical care will cause the child to become ineligible for SSI or Medicaid. Therefore, unless the child will not require SSI or Medicaid, you should avoid a support trust.
- **Pooled Trusts.** You may contribute to a Pooled Trust (also known as a d(4)(c) trust) for the benefit of the special needs child. There are a number of non-profit associations established by families of retarded and mentally-ill adults to assist in their care. Some of these non-profit associations have established pooled trusts.

Pooled trusts are not considered an available resource for the purposes of Medicare and Medicaid. However, to the extent that there are any funds remaining in the beneficiary's account at his or her death, they must either be retained by the trust for the benefit of other beneficiaries, or used to repay the State for any medical assistance paid on behalf of the beneficiary.

- **Special Needs Trust.** You may establish a Special Needs Trust for your special needs child. For many parents with a special needs child, the use of a special needs trust is the most effective way to help that child. A special needs trust is developed to manage resources for the benefit of the special needs child while maintaining the child's eligibility for public assistance benefits. While governmental agencies recognize special needs trusts, they have imposed some very stringent rules and requirements upon them. It is vital that any family contemplating using a special needs trust consult an experienced attorney. A special needs trust is established by a trust agreement. The trust agreement must clearly show:
  - The trust is established by the family and not by the special needs child.
  - The trust is managed by a trustee other than the special needs child.
  - The trust agreement gives the trustee the absolute and uncontrolled discretion to provide whatever assistance the trustee deems advisable.
  - The trust agreement should never give the special needs child more income or resources than permitted by the government.
  - The trust agreement must be used for supplementary purposes only.
  - The trust agreement should provide instructions for the special needs child's final arrangements.
  - The trust agreement must determine who will receive the trust assets after the special needs child dies.
  - The trust agreement should provide for successor trustees.
  - The trust agreement must protect the trust assets against creditors or government agencies

trying to obtain funds to pay the debts of the special needs child.

- The trust agreement should provide for early termination if the trust jeopardizes the child's eligibility for public benefits.
- The trust agreement should authorize the trustee to amend the trust if necessary to comply with changes in the law.

A special needs trust may be created either within your will or in an inter vivos trust agreement. An inter vivos special needs trust may be either revocable or irrevocable. A revocable special needs trust is considered part of the parents' estate for estate tax purposes. If the trust is irrevocable, the creation and funding of the trust is treated as a gift for gift tax purposes.

The special needs trust must have a trustee who will manage the trust assets. The choice of the trustee is a critically important decision. In most instances, a family member will be designated as the trustee. Banks or Trust Companies are another choice. However, their fee schedules make them inappropriate for small trusts.

In addition to creating the trust document, it is extremely important that the family consider how the trust will be adequately funded. The funding of the trust must be realistic in relationship to the disabled child's needs. In the event that the family has insufficient resources to adequately fund the trust, life insurance should be considered.

### **A LETTER OF INTENT**

A letter of intent is a letter written by you or other family members that describes your special needs child's history, his or her current status, and what you hope for him or her in the future.

The letter should cover vital details for the following areas:

- General Information such as social security number, birth date, and birth place.
- Residential placement
- Education

- Employment
- Socialization
- Religion
- Medical Care
- Final Arrangements

You should write this letter today and add to it as the years go by, updating it as necessary. Even though the letter of intent is not a legal document, the courts, and the trustee of the special needs trust can rely upon the letter for guidance in understanding your special needs child and your wishes. You can continue to speak out on your child's behalf after your death or disability.

### **AN ATTORNEY CAN HELP**

An experienced Elder Law Attorney can help in planning for a special needs child. Elder Law Attorneys are familiar with public benefit laws and estate planning. They can help to create a plan that insures your special needs child's quality of life.

### **ABOUT THIS DOCUMENTS**

This document is not intended as a substitute for legal advice. It is distributed with the understanding that if you need legal advice, you will seek the services of a competent Elder Law attorney. While every precaution has been taken to make this document accurate, we assume no responsibility for errors or omissions, or for damages resulting from the use of the information in this Explanation.

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