



THE BEGLEY REPORT

PLANNING FOR SPECIAL NEEDS CHILDREN AFTER WE ARE GONE

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Planning for children with special needs is extremely important, and often completely overlooked or done haphazardly. The problem is many of our children with disabilities will be unable to take care of themselves after we are gone. As long as we are living, we will do everything necessary to see that our children live as happily and productively as possible.

THE PROBLEM

The problem begins when we are either deceased or physically unable to continue. The following items must be considered now, so that haphazard decisions are not made after we are gone.

◆**Where Will Our Children Live?** Are other family members willing and able to have our children move in with them? While we frequently think this is a great solution, in practice it seldom works. Our other children are often married and have their own families. While our children may be willing to take in a sibling with disabilities, their spouse may not be. It is good to have a conversation with family members early on to see how they really feel. Even if they are willing, are they physically and financially able to make this commitment?

◆**Who Will Take Care of Our Children?** Will our child with disabilities need to live in a group home? Is there a family member who could look in on a child with disabilities, if they do live in a group home, to be sure they are receiving the care that they require?

◆**What Will Our Child do for Money?** What will their needs actually be? It is good practice to obtain a Life Care Plan from a professional. Life Care Planners, working with the family, can determine the present and future costs associated with the individual's medical care. The Life Care Plan will address areas of the individual's life affected by the disability including medical requirements, educational requirements, medical equipment, home care (if required), transportation, architectural renovations, leisure time and recreations opportunities, the ability of the disabled child to attend school or to work, etc. The costs can be anticipated and projected over time. A determination can then be made as to how much money must be set aside in the Special Needs Trust to meet these needs.

◆**The Importance of Planning.** The Hartford made a study a few years ago indicating that 62% of parents of children with disabilities had no plan for the future. Twenty-three percent were spending \$500 per month on a child with special needs. They had no plan in place to continue funding that spending after the parent died. Sixty-five percent of parents had life insurance, but in many instances this was term insurance that probably would be insufficient to meet the needs of the child with disabilities. According to the Hartford study, 50% of parents leave money to the child with special needs, which would disqualify the child from important public benefits such as SSI, Medicaid, Food Stamps, etc. Fifty-eight percent of parents name their child with special needs as beneficiary of their life insurance, retirement accounts and/or annuities. Again, this would disqualify the child from important means-tested public benefits. Only 25% of parents of children with disabilities had a Special Needs Trust.

WHAT IS A SPECIAL NEEDS TRUST?

A special needs trust is a trust created for a person who is elderly or disabled, as a way to supplement that person's public benefits. Those public benefits may include SSI, Medicaid, Section 8 Housing, SNAP (Food Stamps), LIHEAP (utility assistance), TANF (Temporary Assistance to Needy Families), Group Homes, and other federally or state-sponsored assistance programs.

◆**Document.** The Special Needs Trust is a document. The document is prepared by a lawyer who specializes in Elder and Disability Law. It is drafted in conjunction with input from the parents of the child with disabilities.

◆**Grantor.** The grantor of the Special Needs Trust is typically the parent or parents of the child with disabilities who will eventually fund the trust on the death of the parent. The trust could be funded sooner, but usually it is not funded until the parents die.

◆**Beneficiary.** The beneficiary of the trust is the child with disabilities. Monies in the trust are used primarily for the benefit of the individual with disabilities.

◆**Trustee.** The trustee is the entity that manages the money, invests it for growth, and makes distributions for the benefit of the beneficiary. It is always wise to designate a professional trustee. Public benefit rules constantly change. If a family member is named as trustee they seldom keep up with the changes, and this often leads to problems. The problems include a loss of public benefits for the individual with disabilities. The family member serving as trustee also has a target on his or her back, because they can be sued for failing to administer the trust properly.

◆**What is Involved in Selecting a Trustee?** Selecting a trustee for a special needs trust is one of the most important steps in the planning process because, from a financial standpoint, the trustee will be empowered to manage the life of the child with special needs.

A special needs trustee should have these characteristics:

- A long-term commitment.
- A special sensitivity to the individual's disabilities.
- Active involvement in monitoring the client's services.
- The ability to be an advocate for medical and financial entitlements.

- The ability to be a prudent investor and distributor of trust funds.

While family members often want to serve as trustee, they typically don't possess all of the necessary qualifications. In addition, the law changes frequently and family members are not aware of these changes. For that reason, it is strongly recommended that families retain a professional trustee to oversee the special needs trust, with a family member named as Trust Protector.

If a family selects a professional trustee, they should be sure that the trustee has experience administering Special Needs Trusts.

Good candidates for trustee include the following:

- **Disability Organizations.** Most states have non-profit disability organizations that can serve as trustee of a Special Needs Trust. Most of these disability organizations administer Pooled Trusts for small trusts (i.e., \$25,000 to \$100,000). This means that the funds are pooled for investment purposes, but each beneficiary receives a monthly statement showing the account activity. This would show income earned by the account as well as any deposits made to the account and expenditures from the account together with the account balance. For larger trusts it is usually more practical to establish a standalone Special Needs Trust, but the disability organization can serve as trustee.
- **Bank or Brokerage Firm.** Many banks and brokerage firms are willing to serve as trustees of Special Needs Trusts. Some are not. However, experience shows that only a handful of banks and brokerage firms are really qualified and do a good job serving as trustees of Special Needs Trusts. Beneficiaries of Special Needs Trusts need a lot of attention and a lot of compassion. Not all financial institutions provide the attention that is needed. Care should be taken in selecting the proper trustee.

Families should be aware that a trustee's annual fees typically range from 1% to 1.5% of the trust assets. These annual fees are a very worthwhile investment toward the preservation of security and quality of life for a child with disabilities.

◆ **What are the Advantages of Special Needs Trusts?** A Special Needs Trust can:

- Help maintain an individual's public benefits.
- Help enrich the beneficiary's life.

◆ **What Can the Special Needs Trust Pay For?** The type of Special Needs Trust being discussed is called a "Third-Party Special Needs Trust," because it is being funded by assets of someone other than the trust beneficiary. The trust is usually funded by parents, but is often funded in whole or in part by grandparents, other family members, and even friends. If the beneficiary is receiving SSI, the SSI is intended for food and shelter. Therefore, any distribution from the trust for food or shelter will reduce the beneficiary's SSI payment. The maximum deduction is one-third of the payment plus \$20. Sometimes this reduction is unavoidable, but where possible the beneficiary should use the SSI payment for food and shelter and let the trust pay for other needs. Typically Special Needs Trusts pay for the following:

- Household goods;
- Furniture;
- Automobile;
- Durable medical equipment, such as wheelchairs;
- Television, radio and cable services;
- Computers, iPads and other forms of technology;
- Clothing and shoes;
- Telephone;
- Musical instruments;
- Recreation and entertainment;
- Medical insurance;
- Telephone bills;
- Newspaper subscriptions;
- Services of a Care Manager;
- Vacations;
- Movies;
- Tax payments;
- Medical treatment for which public funds are unavailable;

- Education;
- Cleaning supplies and paper products;
- Dental care, physical therapy, massages; support services and other medical costs not included by any benefit program;
- Home care services not covered by another program; and
- Personal services, including lawn mowing, house cleaning, grocery shopping and babysitting.

◆ **What Requirements must be met when Establishing a Special Needs Trust?** There are three key requirements:

- The trustee must be given absolute control over the distribution of the funds.
- The person with special needs cannot have the authority to revoke, amend, or terminate the trust.
- The person with special needs cannot have the power to compel a distribution from the trust.

◆ **Trust Protector.** When dealing with a professional trustee, it is wise to include in the trust document a trust protector. The trust protector has the right to remove and replace the trustee in the future. What makes trustees good trustees is the people administering the trust. If those people retire or leave, the trustee's level of service may decline. Having a family member named as trust protector enables the trust to be changed from entity to another, if necessary.

◆ **Account.** The trustee opens an account, which is invested conservatively but with an idea toward earning money over time for the individual with disabilities. At the time the trust is funded, a family member should meet with the trustee and establish a budget for the individual with disabilities. The budget would include shelter, transportation, and personal needs. A determination should also be made as to how long the trust should last. To oversimplify, there is a rule of 4%. Some commentators believe that the 4% should now be reduced to 3.3% based on economic forecasts. This means that if money is intended to last for 30 years, the trustee can only distribute 3.3% or 4% per year for the benefit of the beneficiary. For example, if \$500,000 is placed into a trust and the trust is intended to last 30 years, the trustee can only distribute \$20,000 on behalf of the beneficiary

each year. This is a concept that many people do not understand, but is it important if the trust is intended to last. There are more sophisticated ways to determine distribution levels such as Monte Carlo simulations, but the 3.3% or 4% rule is a good rule of thumb.

◆**How is Trust Accounting Handled?** The Social Security Administration requires an annual accounting of the expenditure of funds in a special needs trust. This accounting is intended to ensure that trust funds have not been mishandled, and it serves to protect the person with special needs, as well as any other beneficiaries of the trust.

Because the accounting work is fairly technical and must adhere to the rules of the Principal and Income Act, it is best handled by an accountant, who can be hired by the trustee.

TAX

Income, estate and gift taxes must all be considered in designing and drafting a Special Need Trust.

◆**Funding on Death.** In most cases the Special Needs Trust is not funded until the death of the grantor. Therefore, income tax and gift tax would not be a consideration, but federal and state estate and inheritance taxes must be considered.

◆**Lifetime Funding.**

- **Income Tax.** In order to shift income tax from the grantor to the beneficiary, trusts are sometimes funded with significant assets. Those trusts cannot be Grantor Trusts. They are Complex Trusts and any income distributed to the beneficiary is taxed to the beneficiary. Any income retained by the trust is taxed to the trust at the usually higher trust rates. These trusts must be irrevocable.
- **Gift Tax.** If an irrevocable Special Needs Trust is funded during the Grantor's lifetime and the trust is not a Grantor Trust, then gift taxes must be considered.
- **Estate Tax.** Estate and inheritance taxes must be considered in connection with Special Needs Trusts. If the trust is large enough, the grantor may elect to fund it during lifetime while the federal estate tax is high, since the IRS has indicated that there will no clawback if and when

the federal estate tax exemption is reduced (i.e., January 2026).

FEATURES OF A SPECIAL NEEDS TRUST

◆**Enriches Our Child's Life.** By establishing the Special Needs Trust, the funds in the trust can be used to enrich the child's life while at the same time maintaining important public benefits.

◆**Assets Not Countable.** The assets in the Special Needs Trust are not countable, and distributions from Special Needs Trusts are not considered income so long as distributions are not made directly to the trust beneficiary. Distributions are made to a third party who delivers goods or services to the individual with disabilities. For example, the individual with disabilities or a family member may obtain a credit card. The trustee and the individual with disabilities or family member agree on a budget. Items in the budget are charged on the credit card, and the credit card bill and receipts are sent to the trustee for payment on a monthly basis. Cash is not given to the trust beneficiary, because cash distributions to the beneficiary would reduce or eliminate public benefits.

◆**ISM.** The SSI is intended for food and shelter. Therefore, distributions from the Special Needs Trust for food or shelter for the beneficiary are considered in-kind support and maintenance (ISM) and reduce the beneficiary's SSI payment dollar-for-dollar not to exceed one-third plus \$20. To the extent possible, food and shelter should be paid for out of the SSI payment and the trust should pay for other items. This can all be covered in detail when the individual with disabilities and/or family member meet with the trustee and develop the budget.

◆**Life Insurance.** Life insurance is often a good vehicle to fund a Special Needs Trust. Unfortunately, many parents of special needs children have term insurance, because it is cheaper. The problem with this is that the parents almost always outlive the term, and the insurance disappears. It is better to have whole life insurance even if the amount is significantly less, because the need is never going to go away. A married couple can obtain something called "second to die" life insurance. This is cheaper and usually solves a good part of the funding problem.

◆**What should a Special Needs Trustee know about SSI?** The Supplemental Security Income (SSI) federal program is a minimum monthly cash payment for the

aged, blind, or disabled. To qualify for SSI, a special needs individual must meet specific SSI definitions of disability or blindness. SSI eligibility is also “needs based,” so there is a limit on income and assets. SSI should not be confused with other Social Security benefits, such as retirement, survivor, dependent or other disability benefits. SSI payments are dedicated to paying for the food and shelter of a person with a disability.

If an individual with disabilities has a Special Needs Trust, the trustee must thoroughly understand SSI rules and Medicaid laws in order to prevent any reduction in available benefits. For example, if distributions from the trust are made directly to the individual, SSI benefits will be reduced, dollar for dollar. If SSI benefits are eliminated, the individual will no longer be eligible for Medicaid.

It is the trustee’s responsibility to pay the expenses of the special needs person directly to third parties. Payments for goods and services other than food and shelter have no effect on SSI. These types of payments are called “in-kind support and maintenance” (ISM).

◆**What is the Role of a Care Manager?** A special needs trust can direct the trustee to hire a care manager. That individual specializes in making the necessary arrangements to provide the special needs individual with the level of care he or she requires. The care manager should have a social work background and related expertise, and be knowledgeable about all social service programs available to assist the beneficiary.

A good care manager will:

- Monitor the individual’s progress.
- Ensure that the individual’s needs are met.
- Coordinate nutrition and cleanliness programs.
- Make sure that exercise and physical therapy programs are maintained.
- Coordinate any socialization or psychological counseling.
- Ensure that the special needs person has assistive devices, if needed.
- Have a plan and a responsible advocate available to resolve problems in a quick and timely manner, in the event of an emergency.

◆**What is a Life Plan?** As part of the process of planning for the future of a special needs child, it is

very important for parents to prepare a Life Plan laying out their wishes for the child’s standard of living. A Life Plan provides parents with an opportunity to explain, in detail, their child’s unique life and background. The Plan helps ensure that those responsible for the child’s care in the future will see him or her as a “real,” multi-faceted person, rather than a number, statistic, or faceless subject in a legal document. The letter also serves as a vital document for the trustee, providing him or her with a greater understanding of the child, and ensuring that the family’s specific wishes, goals, and expectations can be carried out.

A typical letter of intent details the child’s:

- Unique personality traits.
- Medical history and special needs.
- Special education, past and present.
- Treatment, therapy, and daily care needs.
- Favorite foods and clothing.
- Friends, co-workers, family members, and anyone else who is close to the child.
- Favorite recreational activities and sports.
- Past vacations and those he or she hopes to take in the future.

The Plan should be accompanied by a budget and a method of funding the budget for the remainder of the child’s lifetime.

ALTERNATIVES TO SPECIAL NEEDS TRUSTS

Many public benefit programs, such as SSI, have asset limits of \$2,000. If a parent dies and leaves money in a Special Needs Trust for a child with disabilities, the money in the Special Needs Trust is not counted. Alternatives to the Special Needs Trust include the following:

◆**Disinheritance.** This is usually not a good idea, because the child with disabilities may need financial help in the future. There may be public benefits in place now to meet the child’s needs, but those public benefits may be cut back or eliminated in the future.

◆**Inheritance/Gift.** Some parents leave money to the children with disabilities who then gift it to friends or family members. If the child gifts the inheritance, there is

a loss of SSI for three years and possibly a loss of Medicaid for three to five years. Other benefits may be similarly affected.

◆**Siblings.** Often parents leave the money they want used for the child with disabilities to a sibling with the understanding that the sibling will use that money appropriately. What almost always happens is the sibling does not set aside that money in a separate account, but comingles it with his or her own money and it is not used for the benefit of the child with disabilities. If the sibling or sibling's spouse loses his or her job or falls behind in mortgage payments or other bills, the money is used for that purpose.

◆**ABLE Account.** Money can be set aside in an ABLE account for a child with disabilities. The ABLE account can be administered by the child, an agent under a Power of Attorney, or a guardian for the child. Sixteen thousand dollars per year can be deposited into the account, and so long as the total does not exceed \$100,000 it does not affect SSI. However, the maximum earned income contribution to an ABLE account by a disabled beneficiary is now \$12,880. The account requires a payback to Medicaid on death so it makes little sense to put too much in the account but having some money in the account under the control of the individual with disabilities or a family member does make sense from a control standpoint. Earnings are also tax-free, but this is a minor consideration since earnings on a small account would be minimal.

PUBLIC BENEFITS

Important public benefits that should be considered for individuals with disabilities include the following:

◆**SSI.** This is a cash assistance program. The federal benefit for 2022 is \$841.

◆**SSDI.** This is another monthly cash assistance program, but is based on the work history of the individual with disabilities. The amount varies depending on how much was paid into the account.

◆**Medicaid.** Medicaid provides medical services. Individuals receiving SSI typically receive Medicaid.

◆**Medicare.** Medicare provides medical services. Individuals receiving SSDI typically receive Medicare.

◆**Section 8 Housing.** This is federally subsidized housing.

◆**SNAP.** This is a food voucher program providing food to needy individuals and families.

◆**Veterans Benefits.** There are a number of veterans benefits available to assist veterans.

ESTATE PLANNING DOCUMENTS

◆**Parents.** Parents of a special needs children should have Wills, Living Wills, Powers of Attorney and Special Needs Trusts.

◆**Special Needs Adult Children.** Adult child with special needs who have capacity should have a Will, although they usually have little in the way of assets. It is very important that they have Living Wills and Powers of Attorney. Otherwise, if decisions have to be made on behalf of the child, a guardian must be appointed.

THE TEAM

◆**Special Needs Attorney.** Many lawyers do Estate Planning and Special Needs Trusts. However, very few lawyers have really developed an expertise in the area of Special Needs Planning. It is important to do proper research and work with a lawyer who has expertise in this field.

◆**Financial Advisor.** It is often wise for a family of child with special needs to work with a financial advisor who is familiar with the problems of special needs families.

◆**Special Education.** Children with special needs are entitled to special education. Special education is expensive and school districts are often resistant to providing the children with special needs with the education that is best suited for them. It is often important to obtain the services of a Special Education lawyer to assist in dealing with the school district.

◆**Social Work Advocate.** There are a myriad of public benefits. It is good to work with a Social Work Advocate who is familiar with navigating the disability system. Many families do not avail themselves of important public benefits, because they do not know that these benefits exist and/or that the individual or family is eligible for them.

◆**Special Schools.** While it is desirable, in many cases, to mainstream children with disabilities, it is not always possible. Special schools exist for special needs children who cannot be mainstreamed. It is important to do proper research to identify these schools.

◆**Disability Organizations.** Many disability organizations provide valuable services as well as support groups that assist parents in raising children with

disabilities. The ARC and NAMI are two examples of these organizations.

◆**Medical Care.** Special needs children often have needs that are not well met by the general medical community. St. Christopher's Hospital and Children's Hospital of Philadelphia are examples of medical facilities that specialize in working with children with special needs.

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