

ESTATE PLANNING FOR PARENTS OF CHILDREN WITH DISABILITIES

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Harry, 48, and Sally, 46, have an autistic son, Bill, age 21. Bill lives with his parents. The couple is concerned about Bill's welfare after they die. Harry and Sally always thought that Bill would live with his sister, Joan. Joan has three children and it is apparent that Joan's husband, Andy, will not be happy with Bill living in his home.

Harry and Sally have a home, retirement plans, and \$100,000 in investments. They have life insurance. Bill receives SSI and Medicaid, and he can have no more than \$2,000 of assets. Any income Bill receives will reduce his SSI benefit dollar-for-dollar, and if he loses his SSI, he loses his Medicaid. Bill would be eligible for a group home.

Like all parents of children with disabilities, the critical question in Harry and Sally's mind is, "what will happen to our child after we die?" Families are fearful that, after the parents die, there will be a loss in the quality of life of the person with disabilities. The child will lose his parents as his most effective advocates, his parents' financial resources, and the child's lifestyle in the parents' home.

From a legal and financial standpoint Harry and Sally are anxious about how to protect Bill in the future.

The Start

The first problem is finding a lawyer who specializes in estate planning for persons with special needs. Most lawyers write Wills. Very few of these lawyers have expertise in public benefits and disability law. Through *Exceptional Parent Magazine* Harry and Sally learn about the *Special Needs Alliance*. This is an organization of leading elder law and disability law

attorneys located throughout the country. These lawyers specialize in planning for persons with special needs. At www.specialneedsalliance.com Harry finds a lawyer in his state. Harry and Sally visit with the lawyer and learn about the importance of a special needs trust.

The Special Needs Trust

Special needs trusts are discretionary, spendthrift trusts created for the elderly or persons with disabilities which are intended to supplement, but not replace, any public benefits that the trust beneficiary receives.

They learn that a special needs trust is designed for persons with disabilities receiving SSI, Medicaid, Section 8 Housing and other programs. Harry and Sally's special needs trust will maintain Bill's SSI, Medicaid and potential eligibility for a group home in the future. At the same time, the trust will enable Bill to take advantage of the future inheritance that Harry and Sally will leave for his benefit. The trust fund can be used to pay for services and equipment that Medicaid would not cover. The special needs trust could purchase a home, special wheelchairs, handicap-accessible vans, mechanical beds, as well as pay for vacations, a personal attendant, and recreational and cultural experiences. This trust will be specifically tailored to enrich Bill's life.

The Special Needs Alliance attorney explains to Harry and Sally that SSI is designed to provide Bill with food, clothing and shelter. Medicaid pays Bill's medical bills. The trust funds can be used for Bill's other needs that are specifically defined in the trust document. The trust funds can be used to supplement SSI in paying for food, clothing and shelter for Bill, but this would result in a reduction of Bill's SSI benefit by approximately one-third. Bill would maintain

his Medicaid. Since SSI is rarely sufficient to pay for food, clothing and shelter, most likely the trust will be needed to pay for some of these expenses.

There are two keys to establishing a special needs trust. First, the trustee must be given absolute discretion over the distribution of the funds. If Bill can compel a distribution from the trust, the assets in the trust would be considered available to him for SSI purposes and he would lose his SSI and Medicaid. Most wills have support trusts for minor children that authorize the trustee to make distributions for the health, maintenance and support of the beneficiaries. If the trust directs the trustee to provide for a child's health, maintenance and support, the government will determine that the trust is available to the individual. This will cause the individual to be ineligible for public assistance. The trustee shall be forced to spend the trust funds on medical expenses normally covered by Medicaid. Last, Bill cannot have the authority to revoke the trust. Therefore, the trust must be carefully drafted.

Funding the Trust

Harry and Sally must decide how much money to put in the special needs trust. Parents often divide their estates equally among their children. If all of the children are healthy, this makes sense. If one child has special needs, that child may need more or less than an equal share. The best way to make that determination might be to have a life care plan designed for Bill. Harry and Sally would define the lifestyle that they want for Bill and the life care planner would estimate the cost of Bill's care over his lifetime. Harry and Sally could determine how much of their estate to leave to Bill's special needs trust. Once the life plan is analyzed, it may reveal that the assets in Harry and Sally's estate are insufficient to provide for Bill and his sister, Joan. In that case, Harry and Sally may consider buying a second-to-die life insurance policy.

On the death of the survivor of Harry and Sally the insurance proceeds would be paid in to Bill's special needs trust. Joan may then receive a larger share of the other assets.

Selecting the Trustee

A critical part of the special needs trust process is the selection of an appropriate trustee. The role of the special needs trustee requires a long term commitment, a keen sensitivity to the individual's disabilities, involvement in monitoring the individual's services, advocating for medical and financial entitlements, and prudently investing and distributing the trust funds. The trustee also has to comply with a number of very complicated laws, including the Prudent Investor Act, the Principal and Income Act, the Social Security Administration requirements concerning distributions from the trust, and the general laws pertaining to serving as trustee.

After the Special Needs Alliance attorney explains these responsibilities to Harry and Sally, they are concerned that Joan does not have the required expertise to serve as trustee. The attorney suggests that Joan be a co-trustee with a professional trustee. The professional could be a bank or an attorney experienced in serving as trustee of a special needs trust. If a bank is selected, it should be a bank with a trust department with a good track record for managing money. If an attorney is selected, he/she should either have a good track record for investing money or agree to employ a professional money manager to manage the investments. If the investments do well, Bill's lifestyle will be enriched. If the investments do poorly, Bill's standard of living will be adversely affected.

Harry and Sally hesitate on appointing a professional trustee because of the fees. Trustee's fees typically run 1-1.5% of trust assets on an annual basis. The difference between money management by a professional and money management by a family member is usually far

greater than the trustee's fee. The Special Needs Alliance attorney explains that the trustee's fee should be considered an investment rather than a cost. The trustee should be someone who (a) is responsible for managing finances, (b) understands Bill's special needs, (c) understands the rules governing Bill's public benefits programs, and (d) is someone who will be an ardent advocate for Bill's best interests.

Accountings

The Social Security Administration requires annual accountings, which report as to the expenditure of funds. If the trust has other beneficiaries, they are also entitled to accountings. Accountings must be done in accordance with the Principal and Income Act, which is fairly technical. The accountings ensure that no funds were mishandled. This protects Bill and any beneficiaries who will inherit upon Bill's death.

SSI

The Supplemental Security Income (SSI) program of the Social Security Act is a minimum monthly cash payment for "categorically" aged, blind and disabled individuals. Aged persons must be over age 65, and although the disabled and blind can be any age (including children), the individual must meet the Social Security definitions of disability or blindness. SSI eligibility is based upon limitations of income and assets. SSI should not be confused with other Social Security retirement, survivor, dependent or disability insurance benefits.

An extremely important duty of a trustee of a special needs trust is to make distributions in accordance with the requirements of the SSI program. If distributions are made directly to Bill, this will reduce or eliminate his SSI. Any cash received by Bill reduces his benefit dollar-for-dollar. If he loses his SSI, he loses his Medicaid. The Special Needs Alliance attorney

explains that the trustee arranges to pay Bill's expenses directly to third parties. Payments for goods and services other than food, clothing and shelter there have no effect on Bill's SSI payment. These payments are called "in-kind support and maintenance" (ISM).

The trustee for Bill's special needs trust must understand the SSI rules and Medicaid laws to prevent an overpayment of public benefits or a disqualification for Medicaid eligibility. Either of these events could reduce the value of the assets in the trust and ultimately the money available for Bill's lifetime.

Care Manager

Harry and Sally explain to the Special Needs Alliance attorney that they spend a considerable amount of their time caring for Bill. They are hopeful that Joan will care for Bill. The attorney explains to Harry and Sally that the trust can direct the trustee to hire a care manager. A care manager specializes in making the necessary arrangements for providing the appropriate level of care that Bill needs. The care manager would monitor Bill's progress and ensure that his needs are being met. The care manager would coordinate nutritional and cleanliness programs, exercise and physical therapy, socialization, psychological counseling, and ensure that Bill has adequate assistive devices and emergency response systems. Making arrangements for all of the necessary services for the beneficiary can be a daunting task for a trustee who does not have a background in social work and is not aware of the different services that could be made available for the beneficiary. An experienced care manager can relieve the trustee of this considerable burden, thus allowing the trustee to devote time to other trust-related tasks.

Letter of Intent

Finally, the attorney discusses the need for a Letter of Intent. This letter provides Harry and Sally with an opportunity to guide the successor trustee about making difficult decisions for Bill long after they have died. The letter can be addressed to the successor trustee and the care manager. Harry and Sally want to tell Bill's story in their letter. This letter contains his medical history and background; special education; treatments and therapies; his daily care needs; his favorite foods and clothing; important people in his life; his favorite recreation and sports activities; vacations he has taken and places he wants to visit. The letter of intent paints a picture of Bill and his unique characteristics and traits so that the trustee can see him as a human being and not a "faceless" person named in a legal document. This helps the trustee understand Harry and Sally's specific wishes and expectations as they relate to decisions about Bill's future.

Mission Accomplished

By executing their special needs trust, Harry and Sally eliminated the anxiety that had burdened them for years. They were prepared for their future and Bill's.

In retrospect, Harry and Sally discovered that the special needs trust was a thoughtful methodical process, not a legal form. This process was a journey that required them to learn. They learned about the special needs trust protections, SSI, Medicaid and how to select the best trustee for Bill. They wrote a detailed colorful picture of Bill's unique personality and character in their Letter of Intent. Their trust was truly special, because they tailored it to fit Bill and protect him for his lifetime.

Authors

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