

SPECIAL REPORT

Estate Planning for Parents of Children With Disabilities

CASE STUDY: Special needs child – public benefits retained

The Situation

John and Mary have a 21 year old son, Robert, who has autism and lives at home with them. The couple is concerned about protecting Robert's welfare after they die. They had always expected Robert to go live with his sister, Susan, who is married and has three children. But recently, they have learned that Susan's husband does not want to take on this responsibility. John and Mary now need to make alternate arrangements for their son's future.

John and Mary own a home, have retirement plans, life insurance and approximately \$500,000 in assets. Robert receives Supplemental Security Income (SSI) payments and Medi-Cal health insurance coverage and is eligible for a group home environment. By law, these benefits are available to Robert only if he has limited income and no more than \$2,000 in assets.

The Challenge

If Robert receives an inheritance from his parents, he will exceed the SSI \$2,000 asset limit and lose his benefits. If he loses SSI, he will become ineligible for Medi-Cal.

The Goal

John and Mary's greatest concern is what will happen to Robert once they die. They want to use some of their assets to ensure that Robert's housing, medical and day-to-day living needs will always be met and that he will enjoy a good quality of life, however, they must do this without jeopardizing his public benefits.

The First Step

John and Mary sought the advice of a lawyer who specializes in estate planning for individuals with special needs. That was important because, while many lawyers write wills, only those who specialize in handling cases concerning people with special needs are knowledgeable about public benefits and disabilities.

If John and Mary had not known how to find a qualified attorney, they could have contacted the Special Needs Alliance, an organization of leading special needs attorneys around the country who specialize in planning for people with special needs.
www.specialneedsalliance.com

What Families Should Know

John and Mary's attorney helped them secure their son Robert's future through careful estate planning. If you are the parent of a special needs child and have not yet put in place a plan for your child's future, it is important to seek the advice of an elder and disability law attorney. That individual will help you understand the role of Special Needs Trusts in your estate plan and guide you through many important considerations.

What Is A Special Needs Trust?

A Special Needs Trust is a discretionary, spendthrift trust created for a person who is elderly or disabled as a way to supplement the person's public benefits. Those public benefits may include SSI, Medi-Cal, Section 8 Housing and other federally or state-sponsored assistance programs.

What Are The Advantages Of A Special Needs Trust?

A Special Needs Trust can:

- Help maintain an individual's potential eligibility for a group home.
- Purchase a home for the individual.
- Pay for services that Medi-Cal does not cover including home care and such items as wheelchairs, handicap accessible vans and mechanical beds.
- Pay for a personal attendant.
- Pay for recreational and cultural experiences.
- Help enrich the beneficiary's life.

What Requirements Must Be Met When Establishing A Special Needs Trust?

There are two 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 the trust.

How Can The Amount Of Funding Required For A Special Needs Trust Be Determined?

The best way for parents to determine how much of their estate to leave to a special needs child is to obtain a life care plan from a professional Life Care Planner. That individual will estimate the cost of the child's care over a typical lifetime.

If there are insufficient funds available, parents may consider buying a life insurance policy. With one type of policy, upon the death of the second parent, the insurance proceeds are paid to the Special Needs Trust for the care of the person with special needs.

Once John and Mary understood the key issues and considerations involved in setting up a Special Needs Trust, they were ready to select a trustee.

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 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 individual's services.
- The ability to be an advocate for medical and financial entitlements.
- The ability to hire or become a prudent investor and distributor of trust funds.

While family members often want to serve as trustee, they typically do not possess all of the necessary qualifications. 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 co-trustee. Please note, however,

unless the estate is over a million dollars and the family member named as co-trustee is very intelligent and very cooperative, most professional trustees will refuse to serve with a non-professional co-trustee.

If a family selects a professional trustee from a bank, they should be sure the bank has a trust department with an excellent track record for managing money. If a family member chooses an attorney to serve as the professional trustee, they should be certain that he or she has a good track record in managing trust money, or that he or she will arrange to hire a professional money manager to oversee trust investments.

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 the security and quality of life of a child with disabilities.

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 serves to protect the person with special needs and any other beneficiaries of the trust.

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

John and Mary consider all of these issues before selecting a professional trustee and naming Robert's sister, Susan, as co-trustee.

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 also is "needs based," with 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 Medi-Cal laws in order to maximize 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 can lose Medi-Cal eligibility.

The trustee must 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. Payments for food or shelter are called "in-kind support and maintenance" or 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 with 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 social 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 “Letter Of Intent?”

As part of the process of planning for the future of a special needs child, it is very important for parents to write a “Letter of Intent” laying out their wishes for the child’s care. A “Letter of Intent” provides parents with an opportunity to explain, in detail, their child’s unique life and background. The letter 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, clothing and music.
- Friends, co-workers and family members – anyone who is close to the child.
- Favorite recreational activities and sports.
- Past vacations and those he or she hopes to take in the future.

Mission Accomplished

John and Mary were thankful for the methodical, thoughtful estate planning process their attorney helped them undertake. Setting up a Special Needs Trust and appointing a trustee as well as a family member co-trustee helped eliminate their unrelenting worry and anxiety about Robert’s future. With these decisions made, John and Mary could look forward to and enjoy their lives, knowing Robert would be provided for through both public benefits and his Special Needs Trust.

Often the home is the largest asset in the estate. The gifting and transfer of assets, especially the home, is a very complex activity and should not be approached lightly. There may be adverse tax consequences to such a gift. Without proper legal advice, the disqualification rules may be violated resulting in a failure to qualify for Medi-Cal benefits. The loss of public benefits can cause catastrophic consequences. Consider calling the Law Offices of Geraldine E. Champion or the real estate offices of Homes & Hearts, Inc., before you buy, sell, exchange or gift any real estate.

Geraldine E. Champion is one of only nine attorneys in California dually certified in Estate Planning and Elder Law. Champion is a Certified Specialist in Estate Planning, Trust, and Probate Law, by the State Bar of California Board of Legal Specialization. Nationally, Champion is a Certified Elder Law Attorney by the National Elder Law Foundation, accredited by the American Bar Association. She is a Fellow of the National Academy of Elder Law Attorneys (NAELA), served on the Board of Directors from 1992-1995 and also served as Treasurer from 1996-1998. Champion received a B.A. (*summa cum laude*) (*Phi Beta Kappa*) and an M.A. in Communications from the State University of New York at Albany, and a J.D. from Boston University Law School. She has an “A.V.” (the highest) rating by Martindale-Hubbell. Champion was honored by the Area Agency on Aging’s award for “Media Advocate of the Year” for her radio program, “Senior Focus.” Also, Champion is a licensed real estate broker and a member of the San Luis Obispo and California Association of Realtors®.