SPECIAL REPORT:
Using Self-Settled Special Needs Trusts to Protect Public Benefits
Many public benefits available to persons with disabilities, such as Supplemental Security Income (SSI) and Medicaid, place limits on income and certain types of assets. Exceeding such limits can lead individuals to lose some or all of their benefits. Therefore, individuals receiving benefits that set these kinds of limits must continually monitor their income and ensure that their “countable” assets never exceed $2,000.

If a person with disabilities expects to receive a settlement, an inheritance or any other monies that would increase his or her countable assets to more than $2,000, it is very important that the person and/or his or her family meet with an attorney who specializes in elder and disability law. The attorney can ensure that proper planning is done to protect the person's continued eligibility for public benefits.

The following case studies illustrate the difference proper planning can make to the well being of a person with a disability.

**CASE STUDY 1: A PERSONAL INJURY SETTLEMENT – PUBLIC BENEFITS LOST**

John suffered a disabling brain injury as a result of an automobile accident. Initially, he received SSI as well as Medicaid. His medical costs of approximately $7,700 a month were completely covered by Medicaid.

Upon settling his lawsuit, John received $500,000 in net proceeds. He immediately lost his SSI and Medicaid because he had more than $2,000 in countable assets. John began paying for services out of his own pocket at the rate of $7,700 per month, using up his entire $500,000 in 64 months. John then reapplied for SSI and Medicaid. He received SSI immediately, but since there were a limited number of slots for his type of Medicaid waiver, he was put on a waiting list and told that it would likely be two or three years before he received a slot. In the meantime, John’s medical services stopped.

**CASE STUDY 2: A PERSONAL INJURY SETTLEMENT – PUBLIC BENEFITS RETAINED**

Bill suffered a serious head injury in an automobile accident, which left him disabled and unable to work. He receives SSI and Medicaid. Bill settled his lawsuit for $500,000. Because he wanted to protect his public benefits, he decided to contact an elder and disability law attorney. At the advice of the attorney, Bill used the first $75,000 of his settlement to buy a handicap accessible van and pay off outstanding debts. Bill then took $100,000 as a lump sum to set aside for emergencies, and arranged to receive the remaining $375,000 as a structured settlement, which would guarantee him periodic payments over his lifetime. Based on Bill's life expectancy, which the insurance company considered to be shortened as a result of his injury, the structure gave him $2,000 a month for life with a 20-year guarantee.

Both the lump sum and the structure were paid to the trustee of a Self-Settled Special Needs Trust, which was prepared by Bill's elder and disability law attorney. As a result, Bill was able to keep his SSI and have Medicaid continue to pay for the extensive therapy he will need for maximum restoration. In addition, the monies in the
Special Needs Trust will be used to enrich Bill’s life, providing for a caregiver, travel and other goods and services he otherwise couldn’t afford.

**CASE STUDY 3: AN INHERITANCE**

Mary is 32 years old and has cerebral palsy. She has been physically disabled since birth but is mentally competent. Mary receives SSI and Medicaid and has always lived in an apartment with her mother and her sister, Joan. Mary’s mother died unexpectedly, leaving a will that named Joan as its Executor. Mary and Joan have no other siblings and the will leaves the mother’s estate to Mary and Joan equally. As a result, Mary will receive $125,000 from the estate.

Mary and Joan recognized that Mary might have a problem with her public benefits if she received the inheritance outright, so they decided to see an attorney who specializes in elder and disability law. The attorney recommended that Mary place the inherited funds into a Self-Settled Special Needs Trust, so she could benefit from them while preserving her SSI and Medicaid. The special needs attorney filed a petition with the local court to establish the Special Needs Trust with Joan as the trustee, and Mary funded the trust with the inheritance proceeds. Mary notified Social Security and Social Services that she had received an inheritance and had placed the proceeds into a Special Needs Trust. Mary retained her SSI and Medicaid and Joan, as trustee, distributes funds from the trust for items and services that Medicaid and SSI will not cover, such as Mary’s computer and Internet service, entertainment, education, trips to see her cousins, dental care and eyeglasses.

If Mary and Joan had not received the assistance of a special needs attorney, the outcome would have been very different. Mary would have received her inheritance outright and would have had to notify Social Security. Instead of retaining her SSI and Medicaid benefits, Mary would have been told that her benefits were being terminated and that she would not receive them again until her funds were reduced to below $2,000. Mary would have been responsible for covering her extensive medical expenses and other needs until the inherited funds were exhausted. Once Mary was again eligible for SSI and Medicaid, she would have had no funds left for items and services that could enhance the quality of her life.

**CASE STUDY 4: CHILD SUPPORT PAYMENTS**

Richard and Barbara have a 19-year-old Down syndrome daughter, Kathy, who is receiving SSI and Medicaid. Richard and Barbara are in the process of getting a divorce. Kathy will be living with Barbara, and Richard will be paying child support for the rest of Kathy’s life. The divorce decree specifies the amount of the monthly child support payments. When Barbara reports the child support payments to Social Security and Social Services on Kathy’s behalf, she is told that Kathy will lose both SSI and Medicaid because her monthly income is now too high to receive either benefit. Richard and Barbara will now have to pay for Kathy’s expensive medical treatment themselves.
If Richard and Barbara had known that they needed assistance because of Kathy’s disabilities, they could have consulted with an attorney who specializes in elder and disability law. The attorney would have advised Richard and Barbara that the court could establish a Self-Settled Special Needs Trust for Kathy, with Barbara as trustee, and order Richard to pay the child support payments directly to Barbara as trustee of the trust. Barbara would have reported the existence of the trust to Social Security and Social Services and would have presented both agencies with the divorce decree directing the payment of child support to the trust. Kathy’s Medicaid and SSI would have continued, and the child support payments paid to the Special Needs Trust could have been used for Kathy’s needs above and beyond those met by SSI and Medicaid.

**WHEN IS A SELF-SETTLED SPECIAL NEEDS TRUST REQUIRED?**

A Self-Settled Special Needs Trust is required if a person with disabilities currently receives – or is likely to receive in the future – SSI, Medicaid, Section 8 housing, certain types of state disability benefits or benefits under any other means-tested program, and is about to receive a settlement or other monies that will bring the person’s countable assets to more than $2,000. There are four alternatives to establishing a Self-Settled Special Needs Trust:

- **Accept the money.** The person with disabilities will lose public benefits, but if the amount is large enough or the likelihood of requiring expensive medical treatment is small enough, this could be considered.
- **Transfer the money to family members.** The transfer of the funds will disqualify the person with disabilities from receiving public benefits for a period of time, depending on the amount of the transfer. If the amount is large enough and the person does not need means-tested public benefits for the period of time for which he or she will be ineligible, this could be considered.
- **Spend the money.** If a settlement is small, this option often makes the most sense. Examples of how monies could be spent include repayment of debt or purchase of a home, car, furniture or appliances. A special needs attorney should be consulted to design a “spend-down” plan.
- **Place the money in a pooled trust.** If a settlement is small and spending down the money is not a viable option, it may be more practical to place the litigation proceeds into a pooled trust. Pooled trusts are Special Needs Trusts that house the assets of many individuals. They vary in regard to the amount of attention provided individual beneficiaries.

**WHAT ARE THE REQUIREMENTS OF A SELF-SETTLED SPECIAL NEEDS TRUST?**

- **Assets of the individual.** The trust must be funded with assets owned by the individual, such as litigation proceeds.
- **Age.** The individual must be under 65 years of age at the time the trust is funded.
- **Disability.** The individual must be disabled as defined in the Social Security Act.
- **Benefit.** The trust must be for the benefit of the individual with disabilities.
• Establishment. The trust must be established by a parent, grandparent, guardian or the court.
• Payback. The state Medicaid agency must be reimbursed upon the death of the person with disabilities.

Additionally, the trust must be irrevocable – that is, it must be permanent – and give the trustee discretionary authority to make distributions.

**WHAT PUBLIC BENEFITS ARE PROTECTED BY THE TRUST?**

The purpose of a Special Needs Trust is to preserve public benefits programs for the person with disabilities. Typically these benefits include:

• SSI. A monthly income program.
• Medicaid. A medical payment program.
• Section 8 Housing. A low-income housing program.
• State disability programs. These include group homes, vocational training, etc.

**WHAT CAN THE TRUST PAY FOR?**

The trust can pay for a very broad range of goods and services as long as payment is made directly to the provider rather than to the person with disabilities. Examples include personal effects such as furniture, appliances, computers, automobiles, rent, home improvements, pools, utilities, medical insurance, newspaper subscriptions, services of a care manager, federal and state taxes, funeral and legal fees. Payments for food and shelter are likely to reduce the SSI payment by one-third or one-third plus $20, depending on living arrangements.

Trusts can purchase homes and vehicles. While these assets are non-countable, they are considered special assets. If the trust will be used to purchase these items, there are several options that must be considered in consultation with the special needs attorney to ensure that the assets are properly titled.

Generally, funds in the Self-Settled Special Needs Trust can be used only for the benefit of the person with disabilities. Other family members or friends benefiting from the trust are usually required to pay a proportional share for their benefit. For example, if a parent lives with a disabled child in a house covered by funds from the trust, the parent must pay his or her share of expenses. Trust assets usually cannot be used by a parent as a means of meeting his or her legal obligation to support a child.
HOW MUCH OF THE SETTLEMENT SHOULD BE STRUCTURED?

Upon receiving a settlement, persons with disabilities and their families often want to purchase a new home and vehicle and take a dream vacation. They also may wish to pay off a certain amount of debt. A lump sum should be set aside for these items and to prepare for future emergencies. Only after those needs are met should the amount of the structure be determined.

Structured settlements have significant advantages, including:

- **Tax benefits.** The income, including the investment income, is tax-free to the trust beneficiary.
- **Rated age.** Many plaintiffs have a “rated age.” This means that an insurance company believes that, as a result of injuries, the person with disabilities is much older physically than in actual age and therefore has a shorter life expectancy. In this case, an annuity can be purchased to pay for the lifetime of a much older person, thereby significantly increasing the monthly payment.
- **Preservation.** The average personal injury settlement, like the average lottery winning, lasts five years. By obtaining a structured settlement, a person with disabilities can be guaranteed a monthly income for life with a fixed period guaranteed even if he or she dies prematurely.

WHAT FEATURES SHOULD BE CONSIDERED IN A STRUCTURE?

- **Cost of living.** Over time, cost-of-living increases reduce the purchasing power of a dollar. Structures can be designed to include a cost-of-living adjustment (COLA) feature. Because, historically, the cost of living has increased 3% a year, a structure with a 3% COLA, compounded, makes sense.
- **POPs.** It is usually possible to anticipate that certain events will occur during the lifetime of a person with disabilities that will require lump sums of money. The structured settlement contract can be designed to take these into consideration. POPs establish that additional lump sums will be paid out at certain stages of the disabled person’s life. For example, if the individual is likely to go to college, a significant lump sum could be paid to cover college tuition when he or she turns 18.
- **Commutation rider.** If a settlement is large, there may be federal and/or state estate tax due after the person with disabilities dies. A commutation rider in the structure ensures that monies will be available to pay these taxes, if necessary.

HOW IS THE TRUST ESTABLISHED AND FUNDED?

Federal law requires that the trust be established by a parent, grandparent, guardian or the court. The trust cannot be established by the person with disabilities. The trust is funded by having the court order the defendant to pay the lump sum by check directly to the trustee of the Self-Settled Special Needs Trust. If a structured settlement is involved, the court also must order that the monthly payments from the structure be...
paid by check directly to the trustee of the Self-Settled Special Needs Trust. Payments made to the personal injury attorney constitute “constructive receipt.” This means that public benefits agencies will consider the money in the attorney’s trust account to be available to the person with disabilities, thereby disqualifying him or her from those benefits.

**HOW SHOULD THE MONEY BE INVESTED?**

Any money placed in the Self-Settled Special Needs Trust, other than the structure, should be invested in accordance with the Uniform Prudent Investor Act. Because the assets need to last throughout the lifetime of the person with disabilities, they should be invested conservatively, with the objective of preserving principal while providing the growth necessary to outpace inflation and taxes. There should be a written Investment Policy Statement in place that specifies the acceptable level of investment risk to be taken and outlines the trust’s investment strategy.

**HOW IS A TRUSTEE SELECTED?**

Family members often want to serve as trustees of Special Needs Trusts. But, to ensure that the trust will be administered properly and continue to protect the public benefits of the person with disabilities, a trustee must have experience and expertise in the following areas, at a minimum:

- The Uniform Prudent Investment Act.
- The Principal and Income Accounting Act.
- Public benefits laws.

Since family members rarely have this expertise, a better solution is to select a professional trustee. Family members can remain involved by serving as co-trustees or trust protectors or by having a trust advisory committee appointed. The trust advisory committee, which can include a parent, a lawyer, an accountant, a social worker and even a sibling, advises the trustee with respect to distributions.

**WHAT CAN A COUNSELING SESSION ACCOMPLISH?**

When establishing a Self-Settled Special Needs Trust, it is wise to have a counseling session with the special needs attorney, the person with disabilities, the trustee and other interested family members. The person with disabilities and/or family should prepare a budget. The family and the trustee should then agree on which budget items will be paid by the trustee, which by the disabled person, and which items, if any, can be purchased through use of a credit card that ultimately will be paid by the trustee.
It also is important to run a “Monte Carlo Simulation.” This is a type of financial calculation that can be used to show how long the trust will last assuming varying conditions, such as different levels of expenses and investment returns. Once it is understood that the trust should last the lifetime of the person with disabilities and a Monte Carlo Simulation has shown how long the trust is likely to last under various scenarios, the disabled person and/or family may agree to reduce expenditures to a more appropriate level.

Finally, the counseling session is an opportunity for the special needs attorney to review with the trustee, the family and the person with disabilities the state law requirements pertaining to the administration of a Self-Settled Special Needs Trust. At the end of the session, everyone should understand the rules and a game plan should have been adopted that will enable the person with disabilities to receive maximum benefits from the trust during his or her lifetime.

**WHAT AGENCY APPROVALS ARE REQUIRED?**

- SSA. If the person with disabilities is receiving SSI, the Self-Settled Special Needs Trust should be filed with the Social Security Administration.
- Medicaid. If the person with disabilities is receiving Medicaid, the trust should be filed with the state Medicaid agency.

Filing. It is very important to file notices and copies of the trust document with the Social Security Administration and/or State Medicaid Agency. The special needs attorney generally is responsible for this. It also is important to submit a separate cover letter that shows SSA and the state Medicaid agency exactly how the trust document complies with their requirements. The agencies seldom respond with specific approval of the trust, but if they do not approve, they will respond with specific reasons.

**WHAT ESTATE PLANNING DOCUMENTS DOES THE PERSON WITH DISABILITIES NEED?**

If the individual with disabilities is a competent adult and has such non-countable assets as a home, a vehicle or personal effects, he or she should consider executing a will. The individual also should execute an Advance Medical Directive/Living Will and a Durable Power of Attorney. Advance Medical Directives/Living Wills are important for anyone wishing to avoid a Terri Schiavo type situation. A Durable Power of Attorney is extremely helpful in the event that an individual becomes incapacitated and is no longer able to take certain actions on his or her own behalf.
WHAT ESTATE PLANNING DOCUMENTS DO FAMILY MEMBERS NEED?

If the family members of an individual with disabilities intend to leave money to him or her—or for his or her benefit—they should execute a will, an Advance Medical Directive/Living Will, a Durable Power of Attorney and a Third-Party Special Needs Trust (sometimes called a Supplemental Needs Trust). Leaving money directly to a person with disabilities will jeopardize public benefits, while leaving it to a Self-Settled Special Needs Trust will trigger a Medicaid payback requirement. Placing the funds in a Third-Party Special Needs Trust can allow a family to supplement the lifestyle of the person with disabilities without loss of public benefits. Third-Party Special Needs Trusts operate in much the same way as Self-Settled Special Needs. Trusts except that there is no Medicaid payback and no Medicaid accounting requirements.

Families that wish to establish Third-Party Special Needs Trusts should consult with a special needs attorney. It also is important that the family’s beneficiary designations be reviewed to ensure that the Third-Party Special Needs Trust is the beneficiary of any funds intended for the individual with disabilities.

ABOUT THIS HANDBOOK

This guide is provided as a courtesy to help you recognize potential estate planning issues. It 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 explanation 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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