

***Consumer's Guide  
For  
Individuals with Special Needs***

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## What is a Special Needs Trust?

A *special needs trust* is set up for a person with special needs to supplement any benefits the person with special needs may receive from government programs. A properly drafted special needs trust will allow the beneficiary to receive government benefits while still receiving funds from the trust. There are three main types of special needs trusts, but first it is important to understand how a typical trust works.

A trust is really a relationship between three parties -- a donor, who supplies the funds for the trust; a trustee, who agrees to hold and administer the funds according to the donor's wishes; and a beneficiary or beneficiaries who receive the benefit of the funds. Often, but not always, the donor's wishes are spelled out in a document that gives the trustee instructions about how the Trustee should use the trust assets. Trusts have been used for estate planning for a long time, and are highly useful tools for ensuring that a donor's property is administered as he sees fit. One of the reasons trusts are so popular is that they usually survive the death of the donor, providing a low-cost way to manage the donor's assets for others when the donor is gone.

A *special needs trust* is a trust tailored to a person with special needs that is designed to manage assets for that person's benefit while not compromising access to important government benefits. There are three main types of special needs trusts: the first-party trust, the third-party trust, and the pooled trust. All three name the person with special needs as the beneficiary. A "first-party" special needs trust holds assets that belong to the person with special needs, such as an inheritance or an accident settlement. A "third-party" special needs trust holds funds belonging to other people who want to help the person with special needs. A pooled trust holds funds from many different beneficiaries with special needs.

The reason there are several different types of trusts has to do with regulations regarding Special Security Income (SSI). SSI is a government program that assists people with low incomes who have special needs. In order to qualify for SSI, an applicant or beneficiary can have only \$1,000 in his own name. If the person has more than \$1,000 in his own name, (typically because of excess savings, an inheritance or an accident settlement), the government allows him to qualify for SSI so long as he places his assets into a first-party special needs trust. The trust must be created by the beneficiary's parent or grandparent, or by a court, but it cannot be created by the beneficiary, even though his assets are going to fund the trust. While the beneficiary is living, the funds in the trust are used for his benefit, and when he dies, any assets remaining in the trust are used to reimburse the government for the cost of his medical care. These trusts are especially useful for beneficiaries who are receiving SSI and come into large amounts of money,

because the trust allows the beneficiary to retain his benefits while still being able to use his own funds when necessary.

The third-party special needs trust is most often used by parents and other family members to assist a person with special needs. These trusts can hold any kind of asset imaginable belonging to the family member or other individual, including a house, stocks and bonds, and other types of investments. The third-party trust functions like a first-party special needs trust in that the assets held in the trust do not affect an SSI beneficiary's access to benefits and the funds can be used to pay for the beneficiary's special needs beyond those covered by government benefits. But a third-party special needs trust does not contain the "payback" provision found in first-party trusts. This means that when the beneficiary with special needs dies, any funds remaining in her trust can pass to other family members, or to charity, without having to be used to reimburse the government.

A pooled trust is an alternative to the first-party special needs trust. Essentially, a charity sets up these trusts that allow beneficiaries to pool their resources for investment purposes, while still maintaining separate accounts for each beneficiary's needs. When the beneficiary dies, the funds remaining in her account reimburse the government for her care, but a portion also goes towards the non-profit organization responsible for managing the trust.

Anyone can establish a special needs trust and, if the trust is properly drafted to account for tax planning, in certain situations gifts into the trust could very well reduce the size of the donor's taxable estate. As if these are not enough reasons to create a trust, elderly people who are attempting to qualify for long-term care coverage through Medicaid can transfer their assets into a properly drafted third-party special needs trust for the sole benefit of a person with disabilities without incurring a transfer-of-assets penalty, allowing the elder to qualify for Medicaid and making sure that the person with disabilities is taken care of in the future.

## **Does Your Estate Plan Put Your Child at Risk?**

The first thing for parents to keep in mind is that they must, without a doubt, *have an estate plan*. Parents who are often so good about getting their child's plan in order can balk at creating their own estate plan for a variety of reasons. Without putting together your own plan, you are placing your child's benefits at risk. If you pass away without a valid will (known as dying intestate), your assets will be distributed according to state law. These laws will often leave a sizable portion of your estate to your children. In the case of a child with special needs, receipt of these funds could eliminate benefits that they rely upon. Therefore, it is essential that you prepare an estate plan that will take into account your child's unique circumstances.

The next thing to remember when assembling your estate plan is that, except in very limited circumstances, you should not leave anything directly to your child with special needs. Instead, your estate should flow through your own will into a special needs trust for your child's benefit. A properly drafted special needs trust will protect your child's benefits and allow your estate to be utilized as you intended without interference from outside sources.

Sometimes parents will leave their entire estate to their children without special needs with the hope that those children will take care of their sibling with special needs. You should avoid the temptation to do this. While your motives and trust in your children are well placed, this arrangement often leads to bitter family disputes and should be avoided if at all possible. Typically, the better option will be a separate trust that can hold your child with special needs' share of your estate and free up the shares for your other children to be spent as they see fit.

Another potential problem area is when parents name their children as beneficiaries of life insurance policies and retirement plans. These assets, which are not governed by the terms of your will, could easily pass to all of your children in equal shares if you are not careful about naming plan beneficiaries (this is a very common problem when your child develops a special need later in life, after you have had these policies in place for years). As you did in your will, you can place your child's share of these important assets into a properly configured special needs trust.

Finally, *your* estate plan may not be the only issue. Make sure to check with any relatives who may be leaving something for your children and make sure that they also speak with a qualified attorney before including your child with special needs in their estate plan.

## **What are 'Special Needs' in Special Needs Trusts?**

Government programs like Medicaid and Supplemental Security Income (SSI) provide essentials, such as medical care, food, clothing and shelter. Special needs trusts are designed to supplement, not replace, this kind of basic support. Such trusts pay for comforts and luxuries -- "special needs" -- that could not be paid for by public assistance funds.

What are these "special needs"? A special needs trust has been likened to a "parent's pocket" that is, it pays for the kinds of things that a parent would just reach into his or her pocket to cover.

These trusts typically pay for things like education, recreation, counseling, and medical attention beyond the simple necessities of life. (However, the trustee can use trust funds for food, clothing, and shelter if the trustee decides doing so is in

the beneficiary best interest despite a possible loss or reduction in public assistance.)

Here are some examples of expenses that a special needs trust might cover:

- Medical and dental expenses not covered elsewhere
- Special equipment like wheelchairs or specially-equipped vans
- Therapy or rehabilitation services
- Training and education
- Travel, which can include the cost of a companion
- Recreation and entertainment (summer camp, movies or social events, videos, sports equipment)
- Electronic equipment and appliances, computers
- Payments for a companion
- Legal or guardianship expenses
- Insurance
- Burial expenses

## **The Top 7 Reasons to Establish a Special Needs Trust**

Special needs trusts (SNTs) can play an important role in helping families plan for children with special needs. Here are some of the most compelling reasons to establish a SNT.

**1. Preserve public benefits while enhancing your child's lifestyle.** As adults, many individuals with significant special needs obtain basic support from Supplemental Security Income (SSI), which also is the gateway to Medicaid and other critical programs. Since SSI covers only essential expenses, most parents want to supplement their child's lifestyle. But because SSI imposes limits on income and assets, providing funds to the child directly can jeopardize benefits eligibility. Generally, the best solution is placing funds in an SNT. The Social Security Administration (SSA) does not count assets in an SNT as income for determining benefits eligibility because the assets are owned by the trust rather than the child beneficiary.

**2. Ensure assets will be used as intended.** With an SNT, distribution of assets is directed by trust documents as well as SSA and IRS guidelines. By comparison, if you leave assets to an "able-bodied" child and ask that some of the funds be used for the sibling with special needs, the child may fail to honor your request, lose the assets to creditors or die prematurely and leave the funds to his or her own children.

**3. Allow others to contribute.** If you establish the trust now, grandparents and others interested in helping your child can make annual gifts to the SNT of up to

\$13,000 (\$26,000 for a married couple) without triggering the gift tax or generation-skipping tax. Anyone interested in leaving your child money should be advised to direct bequests to the SNT.

**4.** Fund the SNT as you wish. SNTs can be funded with cash, securities or other resources. Often, a second-to-die life insurance policy offers the most affordable option, enabling a family to fund an SNT without depleting assets required for other household needs. If assets in an Individual Retirement Account (IRA) will represent a large portion of your estate, it is important to speak with an attorney about the most tax-efficient way to transfer those assets to an SNT.

**5.** Identify appropriate distributions. If you establish and fund an SNT while your child is young, you can use the trust like a checking account to pay the child's expenses. A future trustee can then refer to a record of these payments as a guide in determining necessary and appropriate distributions.

**6.** Maximize the benefits of a personal injury settlement. If your child wins a sizable settlement, having the payout (often a lump sum plus a structured settlement) directed to a self-settled SNT offers several benefits. Your child will still qualify for public benefits, can use settlement funds for nonessential expenses and may enjoy the financial security of receiving regular payments for life.

**7.** Enhance matrimonial settlements. If an adult child who receives SSI and Medicaid divorces, having a self-settled SNT drafted through the divorce decree will allow any alimony or lump-sum payment from your child's ex-spouse to be paid to the trust. With public benefits intact, it is possible your child may need less from the ex-spouse. That could help ease matrimonial negotiations while still providing your child with ample resources.

## **Choosing a Trustee for a Special Needs Trust**

Choosing a trustee is one of the most important and difficult issues in creating a special needs trust (SNT). Trustees must have the necessary expertise to manage the trust, including making proper investments, paying bills, keeping accounts, and preparing tax returns. But the SNT trustee must also have an understanding of how each distribution he or she makes will affect the beneficiary's public benefits, such as Medicaid, Supplemental Security Income (SSI) and subsidized housing. Very few people have this knowledge, so it is important to choose a trustee who can hire and supervise benefits experts.

The law isn't very strict about who may serve as your trustee, as long as the person is legally competent, meaning he or she is over 18 years of age and is capable of managing his or her own affairs. To ensure that your beneficiary's eligibility is never compromised, a trustee's knowledge of public benefit programs,

such as Social Security and Medicaid, is crucial. If no one comes to mind, a popular alternative is to select an independent trustee. This is an individual or institution who has no beneficial interest in the trust and is not related or subordinate to the trust beneficiary. Some examples include: a bank or trust company, a professional trustee, an investment advisor or manager, an investment banker, an accountant or a lawyer. Many families, recognizing the benefit of a team approach, combine these various roles like pieces of a puzzle to fit together a whole care system for the beneficiary.

For those who are uncomfortable with the idea of an outsider managing a loved one's trust, it is possible to appoint a family member and an independent trustee as co-trustees. By doing so, you can rest assured that there is a person who is familiar with the beneficiary and has her best interests at heart *and* that the public benefit programs' requirements are being met. Another option is to simultaneously appoint a trust "protector," who has the powers to review accounts and to hire and fire trustees, and a trust "advisor," who instructs the trustee on the beneficiary's needs.

If the trust fund is small, do not be surprised if some types of independent trustees, like a professional trustee or a bank, are not interested in serving in the role of trustee. Typically, a professional trustee will charge a fee equal to 1 percent of the overall trust fund. As a result, a pooled trust, which is administered by a non-profit corporation, may be a better option. But make sure that whomever you choose as trustee is financially savvy, well-organized, and, most important, ethical.

## **Choosing a Professional Trustee Involves More Than Just Taking Their Word for It**

Parents or other family members establishing a special needs trust for their child often want to name a professional -- usually a bank, trust company or attorney -- as one of the trustees of the trust in order to take advantage of that individual's experience with investments, money management and tax planning. The professional trustee can also be a great option for families looking for a "disinterested party" to provide a counterweight to a family trustee who may be much more familiar, and much more emotionally invested, in the beneficiary's day-to-day life. If your child is about to receive a large cash settlement, hiring a professional trustee may even be essential in order to preserve and manage the trust's assets for the long-term, especially if you have little investment experience.

But not every professional trustee provides the best services for trusts designed for children with special needs. Here are some questions to ask while searching for the right professional trustee for your new trust.

- *How much experience do you have working with special needs trusts?*

Special needs trusts have very complicated rules regarding distributions to and for a beneficiary with a disability. Not every bank trust department or attorney understands these rules, so it pays to look for a trustee who works with other special needs trusts and who can give you concrete examples of their expertise in this area. Remember: one mistake by a trustee could significantly compromise your child's benefits for a long time.

- *What kinds of specific services do you provide for special needs trusts?*

Unlike some trusts that merely require the trustee to pay income checks at quarterly intervals to a group of beneficiaries, special needs trusts often require a great deal of coordination and support from a trustee. Since most beneficiaries are not allowed to receive significant cash payments, the trustee often has to pay numerous bills directly to service providers, and will often have to arrange for services and care for a beneficiary who is incapable of making the proper requests himself. A good professional trustee will have a support staff or structure in place to handle these matters quickly and efficiently.

- *Do you provide tax planning and do you prepare tax returns in-house?*

Large special needs trusts usually have large tax returns. Some trustees would rather not deal with the sophisticated tax planning that goes into a well-run special needs trust. Make sure to ask how a trustee handles tax planning and annual tax filings, and what makes her qualified to do so. Just because a trustee may know everything about special needs law does not mean she is able to get the taxes right, too.

- *What do you charge and what other requirements must the trust meet in order to retain your services?*

Professional trustees will typically charge a set percentage of the trust's assets in order to manage the trust. But this may not be the only fee. Trustees often charge extra for tax planning, other time-consuming projects, and brokerage services. Sometimes, large integrated banks will require the trust to allow them to hire their own subsidiaries at market rates to perform tasks that the trustee should be doing on his own. Make sure to see a list of all fees and charges to the actual trust that a professional trustee wants to make before making a decision.

## What Are the Responsibilities of an SNT Trustee?

The trustee of a special needs trust (SNT) has all of the duties of any trustee, plus specific added responsibilities due to the special needs of the beneficiary. All trustees are responsible for:

- Appropriate investment of trust property
- Bookkeeping and accounting of trust activities
- Communication with trust beneficiaries
- Tax reporting for the trust
- Appropriate distribution of trust property to the beneficiary or beneficiaries, taking into account both current and future needs.

On top of these responsibilities, the trustee of an SNT must also:

- Inquire into the needs and welfare of the trust beneficiary
- Make certain that the beneficiary maintains her eligibility for public benefits programs
- Report to the agency or agencies administering such programs, and
- Work with the family members, teachers, social workers or others providing support for the trust beneficiary.

Due to these demands, many families find that a professional trustee is better prepared to act as trustee or as co-trustee with a family member. Professional trustees, such as banks, trust companies, and some attorneys, are equipped to handle details like establishing accounts for the management of trust assets, handling trust recordkeeping, hiring and overseeing the activities of any service providers (such as tax reporting), making distribution decisions and investing trust assets.

With regard to taxes, the trustee is responsible for notifying the IRS that the SNT has been signed and requesting an employee identification number (EIN) that will be used on tax returns. The trustee also must prepare and file annual federal and state fiduciary income tax returns, reporting any income the trust earns, whether in the form of interest, dividends or capital gains. Since tax rules vary by state and type of SNT, it is critical for the trustee to know when potential tax reductions may warrant making distributions to or for the beneficiary.

The trustee also has sole responsibility for distribution decisions. To avoid compromising public benefits eligibility, distributions generally should be made directly to providers of goods or services, rather than to the beneficiary. When the beneficiary receives an amount above the allowable monthly limit, it is considered unearned income and SSI benefits are reduced on a dollar-for-dollar basis. Similarly, distributions made for items covered by SSI (i.e., food and shelter) are considered

"in-kind" income and reduce monthly SSI benefits. The trustee must fully understand and follow SSI's distribution guidelines, which vary by state. He or she also must adhere to any distribution guidelines the Grantor outlined in the trust.

One of the most significant abilities of a trustee is often the necessity of saying "no" to a request for trust funds. While trusts may look like they hold a lot of money, often when distributed over the lifetime of the beneficiary it's not as much as is needed. Even with as much as \$1 million invested, it may well be necessary to scrimp and to use the trust funds quite sparingly. It can often be easier for an independent, professional trustee to say "no" than for a family member to do so.

Finally, the trustee has fiduciary responsibility for the management of trust assets, even if he or she chooses to hire professional investment managers to make day-to-day investment decisions. While the appropriate investment strategy depends, in part, on the beneficiary's age and needs and the amount of assets that can be invested, the trustee generally must comply with the "Prudent Investor Act," which requires that investment decisions be made responsibly and impartially. When the trust outlines specific investment guidelines, however, those take precedence over Prudent Investor Rules.

## **Funding a Special Needs Trust: How Much is Enough?**

As a parent or guardian, you want to ensure that your child with special needs will remain financially secure even when you are no longer there to provide support. Given the significant, ongoing expenses involved in your child's care and uncertainty about what needs may arise after you are gone or what public benefits may be available, determining how much a special needs trust (SNT) should hold is no small feat.

Fortunately, help in calculating your "special needs goal" is available from attorneys and financial planners with expertise in disability issues, as well as from special needs calculators, which are accessible free of charge on the Internet. Here are two such calculators:

- MetDesk Special Needs Calculator: <http://www.metlifeeasier.com/metdesk> (Available on the Special Needs Answers site at: <http://www.specialneedsanswers.com/resources/calculators.asp>)
- Merrill Lynch Special Needs Calculator: [www.totalmerrill.com/specialneeds](http://www.totalmerrill.com/specialneeds) . (Click Special Needs Calculator under "Tools and Resources".)

Using one of these calculators, either on your own or with the help of an advisor, is an excellent way to begin making concrete plans for your child's future. Based on information you provide about anticipated income and expenses, the calculators offer a realistic estimate of how much your child will need in lifetime financial

support. Financial planners suggest re-running this type of calculation periodically, particularly as your child nears adulthood, to ensure the estimate reflects the most accurate, up-to-date information about needs and circumstances.

## **Getting Started**

The first step in determining the amount you must set aside in an SNT is considering your goals and expectations for your child's future. Once you have considered the "big picture", you will need to identify your child's future income sources and living expenses. The online calculators identify relevant categories for you (e.g., public benefits income, transportation costs). For additional perspectives, take a look at the income-and-expense worksheet at [nichcy.org](http://www.nichcy.org/pubs/outprint/nd18txt.htm) (<http://www.nichcy.org/pubs/outprint/nd18txt.htm>).

Next, you will need to tackle the most arduous part of the process, placing a dollar value on each category. You can start by listing any current income or expenses likely to continue into your child's adult years. You will need to consider income from sources such as life insurance proceeds, gifts, inheritances, and legal settlements, as well as from employment and public benefits such as Supplemental Security Income and Social Security Disability Income.

On the expenses side of the column, broad categories include, but are not necessarily limited to:

- Housing: rent, a mortgage, utilities, insurance, taxes, maintenance.
- Transportation: car payments, auto insurance, fuel, repairs, public transportation costs.
- Medical care: doctor visits, therapy, prescription drugs.
- Care assistance: respite, custodial, nursing home care.
- Special equipment: wheelchairs, assistive technologies, durable medical equipment, computers, service animals.
- Personal needs: grooming, hobbies, entertainment, vacations.
- Education and employment costs: tuition, books, supplies, tutoring.
- Future asset replacement costs: for a car, major appliances, electronics, furnishings.

## **Running the Calculation**

Prior to running the calculation, you may need to indicate your child's life expectancy and the number of years remaining until your retirement. Once you have input all required data, the calculator automatically will run an analysis of your funding needs based on preset assumptions about the rate of inflation and your after-tax investment returns. Both calculators indicate the amount of annual savings required to meet your goal. The Merrill Lynch calculation includes a lump-

sum savings goal that must be met by retirement, as well as a year-by-year cash-flow analysis indicating any shortfalls or surpluses for a given year.

### **Considering “What If”**

Financial planners advise that running alternative calculations can help you plan adequately for worst- and best--case scenarios. One variable to consider is your child’s ability to earn income. For example, if he or she is able to work more than expected, earned income may cover more expenses, but SSI payments will likely be reduced. As your child’s disability advances, he or she may need to leave the workforce, potentially increasing SSI payments but also adding new expenses.

Another critical factor is the impact of higher or lower investment returns on the amount you must set aside. If your child is very young, you may plan to invest aggressively, pursuing a higher rate of return than if he were nearing adulthood. The reason “an investment rule of thumb” is that you generally can take somewhat greater risks with a longer-term investment because you have more time to recover from dips in the market. If you anticipate a lower rate of return for any reason, you will need to compensate by setting aside more in savings.

As you can see, to some extent this is more of an art than a science. You can make your best guess or work with a financial planner who specializes in this field and who can bring to bear her experience with many families in similar situations.

### **Finding the Funds**

Once you have a realistic estimate in hand, you will need to consider how to fund this need without sacrificing such financial goals as college and retirement. You may also need to balance the needs of your child with special needs with your wish to benefit other children as well as covering your current needs. You may not be able to completely fund the dollar amount resulting from the above calculations, but having a target can assist your planning.

Many families find that a second-to-die life insurance policy is the most realistic option to fund an SNT because the premiums are often lower and the trust is funded when it is most needed, after both parents have passed away. In short, how much you fund your SNT and how large an insurance policy to purchase will be a question of balance among your current needs, your retirement funding, the needs of your other children, if any, and the anticipated needs of your child with special needs.

Finally, be sure to create or update an estate plan and determine which of your assets you will leave to the SNT. Also advise relatives of the need to direct gifts

and bequests to the SNT, rather than the child, to avoid the risk of disqualifying the child from eligibility for public benefits.

## **It is Now Easier to Leave Your IRA to a Special Needs Trust**

For many parents, the majority of their savings is held in some kind of a retirement account, often an Individual Retirement Account (IRA). At age 70 ½, an IRA account holder faces the Required Beginning Date, when he or she must take mandatory distributions from the IRA. These payments are determined by the government and are known as Required Minimum Distributions.

If the parents have a child with special needs, it is often important for the parents' estate plan to direct Required Minimum Distributions following the parents' death into a special needs trust (SNT) that has been set up for the child. For income tax purposes, it is usually best to stretch these distributions out over as long a period as possible, particularly if the IRA is a large one.

The Internal Revenue Service (IRS) has ruled on two important issues involving IRAs and special needs trusts (SNTs). First, the IRS ruled that when a person dies, his or her IRA may be transferred to a child's SNT free of estate or gift taxes. Additionally, the agency said that required minimum distributions from that IRA to the SNT may be calculated based on the child's expected lifespan. This second ruling means that taxes owed on the IRA can be stretched out over the beneficiary's lifetime.

The decision comes after the IRS reviewed a specific taxpayer's case. After the taxpayer passed away, his IRA was divided among his four sons, one of whom was disabled. If the disabled son directly received the IRA, he would lose eligibility for Medicaid and other benefits. To remedy the problem, the child's mother created an SNT, to which she transferred the son's portion of the IRA. The IRS found that the transfer of the father's IRA to the SNT did not require the payment of gift and estate taxes and that any future minimum distributions from the IRA to the disabled son's SNT could be calculated based on the disabled child's estimated life expectancy.

## **Funding a Special Needs Trust With Life Insurance**

Funding a special needs trust with enough money to pay for the needs of a child with special needs can be a daunting task for many families. The costs of providing a home and care, as well as a care manager to take the place of the parents when they are no longer around, exceed the resources of most families. A solution for many parents is to fund a special needs trust with a form of life insurance. In these instances, a parent will take out a life insurance policy on his or her life to ensure

that once the parent is gone, monies will be available to care for the special needs child.

The benefits of funding an SNT with life insurance are many. Life insurance proceeds can be paid to an SNT free of taxation. Life insurance also typically pays proceeds in a short time period and so can ensure that the special needs child has the cash needed to provide for her long-term care. Further, a paid-up life insurance policy will guarantee an SNT future funding while keeping the parents' estate intact for other family members.

The various types of life insurance that can be used to fund an SNT include:

**Term Life Insurance:** Term life insurance provides coverage for a defined period of time, normally the time in which premiums are paid. After that period ends, the policyholder can choose to continue to pay for the policy or end coverage. A term policy pays a benefit should the policyholder die within the period covered under the policy. The premiums for term policies typically increase each year as the insured gets older or are level for a specified number of years, such as 20, after which the policies are typically dropped due to the steep increase in premiums at the end of the guaranteed term.

**Whole Life Insurance:** Unlike term insurance, a whole life policy lasts for the policyholder's entire lifetime and provides both death benefit protection and cash value. Part of the premium paid by the policyholder goes into a cash account which accumulates over time. The cash value tends to accumulate at a higher rate when the policyholder is younger and lessens as she ages. Further, many of these policies pay dividends, which add additional value to the policy. Policyholders may withdraw money from their whole life policy but will be charged a fee or, in the case of a loan, the holder will be obligated to pay back the borrowed amount with interest.

**Universal Life Insurance:** A universal life policy permits the policy holder to adjust death benefits and premium payment to fit any change of circumstances for the holder. Premiums can be credited to an accumulation fund from which premium costs are deducted and to which interest is credited.

**Variable Life Insurance:** The variable life insurance policy's cash value is tied to the performance of financial markets.

**Survivorship Life Insurance:** Also known as a second-to-die life insurance, this policy is taken out on the lives of two people and provides benefits only upon the death of the second insured person.

Many financial planners recommend survivorship life insurance for funding an SNT trust due to:

- The lower cost of the policy
- The funds become available upon the death of the second insured, when the funds would be most needed.
- Underwriting (i.e., the process by which an insurance company determines the insurability of the policyholder and rate of premiums) of the policy is less strict since two lives are being insured.
- Policies are available as either whole or universal life.
- Estate taxes can be delayed until both parties die.

### **Is a Survivorship Policy a Good Idea?**

For those families that have financial constraints, a survivorship policy could leave the living spouse with “significant financial hardship.” You may wish to consider purchasing term life insurance covering each spouse, with the SNT as the beneficiary. When the client, normally the parent of the special needs child, has more disposable income, he can convert coverage to a permanent policy.

Some experts believe that survivorship insurance should never be used to fund an SNT. There is no guarantee that the survivor will provide for the beneficiary. The survivor may dilute the assets, give them to another favored party and may not have the ability or inclination to set up an SNT.

### **What Expenses *Can't* a Special Needs Trust Pay For?**

If money from the trust is used for food or shelter costs on a regular basis or distributed directly to the beneficiary, such payments will count as income to the beneficiary. This can affect eligibility for government benefits like Medicaid and SSI. One of the trustee's most important jobs is to use discretion in making distributions from the trust so as not to jeopardize the beneficiary's eligibility for these government benefits.

If the beneficiary receives SSI, here are some basic expenses that should not be paid through a special needs trust without consultation with a special needs attorney.

- Cash given directly to the beneficiary for any purpose
- Food or groceries
- Restaurant meals (except if given as an occasional gift)
- Rent or mortgage payments
- Property taxes

- Homeowners or condo association dues
- Homeowners insurance if the insurance is a mortgage requirement
- Utilities such as electricity, gas, and water
- Utilities hookup or connection charges

However, many of these payments will only cause a one-third reduction in SSI benefits. The trustee may determine that the benefit of the trust making these payments far outweighs the loss of income.

## **How Special Needs Trusts Affect Eligibility**

### **For Housing Assistance**

Those with special needs often cannot get by without housing assistance from federal programs like the Section 8 Housing Choice Voucher Program. For example, while many people with special needs are on Supplemental Security Income (SSI), the average rent for a modest one-bedroom rental unit is equal to 105 percent of the monthly SSI benefit amount.

Section 8 and similar housing subsidy programs can help a lot. Tenants pay about 30 percent of their income in rent, with the government making up the difference to the building's landlord. But how do the assets in special needs trusts and the income from these trusts affect eligibility for programs like Section 8?

Unlike Medicaid and SSI, the Section 8 program focuses on a recipient's income and does not count assets in determining eligibility. So the existence of a special needs trust, by itself, should have no impact on eligibility for Section 8.

In calculating a recipient's income to determine program eligibility, the Department of Housing and Urban Development (HUD) counts pensions, annuities, alimony, certain welfare payments and Social Security and disability payments, as well as the income generated by assets in excess of \$5,000. Also, HUD will impute income to *transfers* of assets for two years after the transfer. This means that if a Section 8 recipient transfers assets into a special needs trust, for two years HUD will count a certain monthly amount as income based on the sum transferred. Depending on the amount, this could reduce or eliminate the Section 8 subsidy for a trust beneficiary.

A special needs trust set up by a third party where the beneficiary does not have the ability to access the income or principal cannot be considered income because it is not accessible. However, if a Section 8 recipient sets up a trust where the income is available to him, the income would be considered countable and accessible.

That said, infrequent income, such as gifts, medical expense reimbursements and insurance payments, are not considered countable income. This means that trusts can avoid jeopardizing a beneficiary's eligibility for Section 8 by having the trust pay sporadic or one-time expenditures and leaving regularly recurring expenses up to the trust beneficiary.

## **The Promises and Pitfalls of Home Ownership for People With Special Needs**

People with special needs often require housing that accommodates their lifestyle. In many cases, group living facilities are called for, with the group environment providing stability and support. But in other cases, a person with special needs needs a very specific type of housing, designed particularly for her. Or, it may simply make sense for a person with special needs to have a place of her own. The rental market is clearly not equipped to provide the specific accommodations many individuals with special needs require. Fortunately, there are many ways to provide private housing for a person with special needs without compromising the majority of her means-based government benefits.

The first step when thinking about purchasing a home for a person with special needs is to decide whether the home should be held in trust or given to the resident to own in her own name. Since many people with special needs are perfectly capable of managing their own property, both Supplemental Security Income (SSI) and Medicaid regulations permit beneficiaries to own their own home without it counting as an asset for purposes of qualifying for or maintaining benefits (although there may be specific limits on the value of the home a beneficiary owns, which vary by state). Home ownership also allows increased access to credit, binds a person with special needs with their community, and provides a deep sense of self-worth.

But home ownership comes with many responsibilities, and frequently families choose to place a home into a special needs trust (SNT) instead of giving it to a person with special needs. Putting the home in a trust protects the home from a trust beneficiary's creditors, who may be able to go after the equity in the home if it were owned by the beneficiary outright. Placing the home in trust also allows for flexibility if the home needs to be sold quickly, since the proceeds are retained by the trust. If a homeowner with special needs sells his own home, he would have to quickly purchase a new one for the same price or transfer the proceeds into a different kind of special needs trust (called a "first-party trust," with a government payback provision) in order to maintain access to government benefits. Finally, some people with special needs, especially those suffering from mental illnesses

that make it hard for them manage property or make them especially likely to be taken advantage of, should simply not own property in their own name.

Once the decision is made about who owns the home, the next step is determining how the home should be purchased. This decision depends on the finances of those buying the home and the government benefits being received by the resident. When a home is purchased outright (either by a trust or by a beneficiary's family, who then gives the home to the resident), SSI rules dictate that the purchase counts as in-kind support and maintenance for the month of purchase only. Under the complicated restrictions, this means that an SSI beneficiary could lose up to about \$244 (in 2010) of her benefit for one month. If the beneficiary's monthly SSI award is reduced to zero by this reduction, she could lose her benefits, and accompanying health care, for the month of the gift. She could then regain eligibility at the conclusion of the month.

On the other hand, if the home is purchased through some combination of a down payment and a mortgage being paid by the trust or by family members, then the resident's SSI award will be reduced by approximately \$244 during each month that someone other than the beneficiary pays the mortgage. However, it does not matter if the mortgage payment is very large -- the beneficiary still loses approximately \$244 monthly. While this amount usually pales in comparison to the benefits of living in a home of one's own, should a beneficiary receive an SSI award that is less than \$244 a month *before the purchase of the home*, he will lose his SSI benefit because his award is reduced to zero by the in-kind mortgage payment. Because the mortgage payments will presumably be ongoing, this loss of SSI and health care benefits could be permanent, unlike the one-time loss of benefits if the home is purchased outright. Since other sources of income can also affect an SSI award, it is extremely important that families work with a qualified special needs planner to make sure that they are not going to compromise important benefits by purchasing the home.

After the home is purchased, maintenance becomes key. Under SSI regulations, payment of many household expenses for a beneficiary counts against her SSI benefit. This applies even if a trust owns the home the beneficiary is living in. For example, if the trust pays for the home's water or electric bill, the SSA will deduct the same (up to?) \$244 from a beneficiary's award. So if a trust owns the home outright and manages to avoid paying a mortgage, the beneficiary can still incur a penalty should the trust pay for the upkeep of the home, and the same concerns regarding benefits apply. There is one important exception to these restrictions - a trust can pay for home improvements without penalty because these are not typical household expenses expected to be provided by a beneficiary.

## **Should I Have a Guardianship Over My Special Needs Child?**

Parents of children with special needs must be concerned with ensuring that medical and financial decisions will continue to be made in the child's best interest once the child reaches age 18 -- the age of legal capacity. In most states, once a child reaches age 18, he is presumed to have decision-making capacity and the parents' legal authority ends. Parents of children with special needs have various options, each with advantages and disadvantages depending on the situation, to establish a new legal authority to continue making important decisions for the child.

If the child is incapable of making personal or financial decisions once she reaches the age of majority, a parent -- or anyone else who is an adult, is not incapacitated, and does not have a significant conflict of interest -- can petition the court to be appointed the adult child's guardian or conservator (the terminology is different in different states). The downside is that guardianship and conservatorship requires a court process, which can be time-consuming, costly and emotionally trying for the person with special needs and her family. In order to protect against abuse, the individual who is the object of the guardianship or conservatorship proceeding (the "ward") will be represented by her own attorney and the court must determine if the disabled person is incapable of making her own decisions.

In cases where someone is appointed to make financial decisions, the courts requires that person to be bonded, file annual financial statements and request the court's permission before dealing with the assets of the person with special needs. This means the court must approve every dollar spent by or on behalf of the person with special needs. This is meant to increase oversight and protection, but it also decreases family control.

There are ways to avoid the time and expense of a guardianship or conservatorship process while accomplishing the same basic goals. If the person with special needs has sufficient capacity to understand, he can appoint an agent using a durable power of attorney over medical or financial matters, or both. Depending on the type of power of attorney, the agent will have the authority to make financial and property decisions or medical and personal decisions on behalf of the adult child, all without court intervention or direct oversight.

If the adult child receives either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and cannot manage the income, the Social Security Administration allows another person to receive the funds to use on the child's behalf. However this option also requires the filing of an annual report showing how the money was used.

Another option for parents to consider is establishing a special needs trust. The trust allows a person with special needs to shield assets for certain purposes while

maintaining eligibility to receive SSI and Medicaid benefits. The trustee invests and manages the trust assets, usually avoiding the need for a financial guardian or conservator.

## **Most Adults With Special Needs Require Estate Planning Documents**

Mental disabilities take many forms, and not all of them affect a person with special needs' ability to make decisions. In fact, although many, if not most, people with either mental illness or some form of cognitive disability may require significant care, they can still carry out most day-to-day activities. In most cases, people with disabilities have the capacity to create their own estate planning documents, and in some cases it is crucial that they do so.

One scenario that often arises has to do with "HIPAA" regulations. HIPAA, which stands for Health Insurance Portability and Accountability Act of 1996, is the primary federal regulation governing a patient's private medical information. HIPAA gives a patient the right to manage her medical information and regulates who can access that information. Because medical providers must follow HIPAA regulations, it is difficult for caregivers who legitimately need to access another person's medical records, often in an emergency, to do so without a health care proxy or durable power of attorney that authorizes the information's release. Under HIPAA, doctors in these situations can disclose medical information to patients' families, but they are not required to do so without a release from the patient.

Parents of children with special needs often bump into these restrictions for the first time when their child reaches 18 and obtains his own right to privacy under HIPAA. If the child is not under guardianship, either because he does not require it or because no one has obtained it, it may be hard for a parent to obtain information from a doctor or hospital without some form of HIPAA release from their child. In these cases, it is important for the child to execute a valid health care durable power of attorney, if they are able to do so.

Another case for estate planning involves adults with episodic mental illness. These adults may be perfectly functional and rational 99 percent of the time, yet they are completely disabled when their illness does strike. Having a functional health care durable power of attorney allows an "attorney-in-fact" to help a person with mental illness manage his affairs when necessary, without having to obtain an emergency guardianship when that person falls ill.

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