

# DISCOVERING SPECIAL NEEDS TRUSTS

## Estate Planning

“I want to provide for myself and my loved ones during my lifetime, and upon my incapacity or death give what I have to who I want, the way I want, when I want, and if I can, save every last fee, tax or court cost possible.”

- Robert Esperti, Loving Trust

## Our Struggle

How do you provide for your disabled child for 70 years when

- You don't know what public benefits will be available;
- You don't know what public benefits eligibility rules will be;
- You don't know what agencies will be in existence to care for the disabled child throughout his/her lifetime;
- You don't know who will best oversee the disabled child's needs.

## Tough Challenges

- Persons with disabilities are living longer;
- Public benefits are often necessary;
- There is no guarantee that public benefits will be available;
- There is no assurance that public agencies will be in existence to advocate for the disabled person over a lifetime and to provide appropriate comprehensive services.

As a result, estate planning for families with a disabled child needs to be handled with a great deal of forethought and sensitivity.



## **Common Strategies**

### 1) Disinherit The Disabled Child:

- May be appropriate in a very modest estate
- Usually not ideal

### 2) Gift to Disabled Child:

-If disabled child is receiving means-tested public benefits, an inheritance/gift directly to the child could cause those benefits to be reduced or completely eliminated;

-The disabled child may not have the requisite skills to manage money appropriately;

-The disabled child might be vulnerable to unscrupulous individuals willing to take advantage;

-Dying without a will or trust will usually result in a portion of your estate to the disabled child by default;

-Naming your disabled child as a beneficiary of a life insurance policy, a retirement account or a payable-on-death account will have the same result.

### 3) Distribution to Sibling:

-Even if the sibling is a trustworthy person, this can be a risky proposition. These assets would be exposed to the creditors of the sibling, could be claimed in a divorce action by the sibling's spouse and if the sibling spends more than \$13,000 per year for the benefit of the disabled child, the sibling could potentially be exposed to gift tax.

-There is no guarantee that the sibling will not mismanage or misappropriate the gift.

#### 4) Distribution to a Special Needs Trust:

-The purpose of a special needs trust is to preserve public benefits for the trust beneficiary while supplementing the beneficiary's lifestyle with private funds.

-Special needs trusts are generally used to achieve the following goals:

- protect public benefits;

- manage money;

- control distributions;

- avoid cost-of-care reimbursement claims;

- provide for the disabled beneficiary if public benefits are curtailed or eliminated in the future.

-A special needs trust is designed so the funds are not considered “available” to the beneficiary.

-The beneficiary cannot compel distribution.

-By establishing a special needs trust, parents ensure proper management of the assets by a qualified trustee.

#### Testamentary or Inter Vivos (During Lifetime)?

-The advantage of an inter vivos special needs trust is that if other family members want to provide for the disabled child, they may do so through the already existing special needs trust.

-If an individual is to serve as successor trustee the individual can gain some experience acting as a co-trustee during the parent's lifetime under the watchful eye and supervision of the parent.

-The inter vivos trust can be a standby trust that remains unfunded until the death of the parent when the will/trust of the parent would simply pour the intended

portion of the parent's estate into the trust.

-The disadvantage of the inter vivos trust is the cost of creation and ongoing administration of the trust.

### Revocable or Irrevocable?

-The tax objectives of the parent usually determine whether an inter vivos special needs trust is revocable or irrevocable.

-A parent who intends to utilize the trust to save estate or gift taxes might establish the trust as irrevocable from its creation.

-If a parent is not concerned about federal estate taxes and gift taxes and wishes to maintain maximum control over the trust, the trust can be revocable until the death of the parent.

### Types of Special Needs Trusts

- 1) Third party trusts
- 2) Medi-Cal Payback (d)(4)(a) trusts (First Party or Self Settled)
- 3) Pooled (d)(4)(c) trusts (First Party or Self Settled)

### Third-Party Special Needs Trusts

A trust is a form of ownership of property, whether real estate or investments, where one person (or entity) - the trustee, manages such property for the benefit of someone else - the beneficiary. The instructions are set out in the trust agreement as to how to spend trust funds on the beneficiary's behalf - whether and when to distribute the trust income and principal - and the trustee must follow these instructions.

- Each situation and each benefit program has its own rules which affect the drafting, funding and administration of special needs trusts.

-In general, if a parent creates a trust for the benefit of a disabled child, and the trust is drafted to give the trustee complete discretion as to whether and when to

make a distribution on behalf of a disabled child, the trust funds will not be considered as "available" when considering the disabled child's eligibility for public benefits.

-However, complications could arise when trust funds are actually used for the disabled child. Cash given directly to the disabled child will reduce his/her SSI benefit dollar for dollar. Trust funds used on the disabled child's behalf might also cause a reduction in SSI benefits. Thus, while the existence of a properly drafted trust will not affect eligibility for benefits, the use of the trust funds could impact eligibility if care is not taken.

-This is why choice of the trustee who will be administering the special needs trust is such an important decision.

### Choice of Trustee

-The appointment of a proper trustee and the drafting of removal powers are of critical importance in this type of trust.

-The trustee of a special needs trust must be able to fulfill all of the normal functions of a trustee - accounting, investments, tax returns and distributions - and also be able to meet the needs of the disabled child. This must include an understanding of various public benefit programs, knowledge of services that may be available and sensitivity to the needs of the disabled child.

-Family members often consider the money belongs to the family rather than to the disabled child.

-The appointment of an independent trustee prevents a family trustee from being caught up in an endless series of conflicts of interest.

-If a family member serves as co-trustee, the trust document should clearly delineate the responsibilities of each of the trustees.

-Professional trustees - banks, trust companies - are usually skilled in financial management and often have expertise in public benefits law, but may not be familiar with the family and the family's specific goals for the disabled child. This

problem can be minimized by a clear letter of intent from the parent to the institution and/or the hiring of a care manager. A family member might be appointed as a co-trustee. Professional trustees, however, generally require a minimum amount of funds in the trust. Otherwise, their fees become unreasonable in relation to the size of the trust.

-In situations where the size of trust is insufficient to justify hiring a professional trustee, a parent might establish a trust advisory committee consisting of several individuals who know and care for the disabled child, such as a family member, social worker, care manager, accountant, nurse, etc. to advise a family trustee. Of course, a trust advisory committee could certainly be used with a professional trustee as well.

-Another option which might be used in cases where funds are insufficient to hire a professional trustee is a pooled trust. Certain non-profit organizations that advocate for disabled persons have pooled trusts. Banks or trust companies usually manage these funds. Separate accounts are maintained for each beneficiary and an accounting can be made from each subaccount. Not all non-profits are as well run as others so care must be taken in making these choices. The pooled trust cannot be specifically tailored to the needs of an individual beneficiary, and pooled trusts often require that a large portion of the trust assets remaining at the death of the disabled beneficiary be paid to the non-profit organization.

-A trust protector is another device to protect the disabled child and to make the family feel more comfortable in dealing with a professional trustee. A trust protector is given authority to review the actions of the trustee and to remove and replace the trustee where appropriate.

-Whether or not bonding of the trustee should be required is dependent on who is selected as trustee. A bond is unnecessary where there is a financially sound corporate trustee.

### Funding the Trust

- How much will your disabled child require over his/her lifetime?
- Should you leave the same portion of your estate to all of your children, regardless of need?

- How will you assure that there is enough money?
  - It is better to err on the side of more money rather than less. Current programs may not continue for the child's lifetime; thus, paying for such services should be factored in to the calculations.
- How will your other children feel if they receive less than their pro rata share?
- Is your estate already smaller than it would be otherwise due to the time and money you spent providing for your disabled child?
- Have your other children received less of your attention growing up than they would have otherwise had there not been a disabled child in the family?

-Life insurance may be one solution to the question of fairness and to the challenge of assuring that there are enough funds, particularly second-to-the policies.

#### Determining Amounts:

1. Calculate estimated costs yourself based on life style desired, inflation factors, potential for lost benefits, expenses and estimated returns.
2. Web calculators:  
eg: <http://askmerrill.ml.com/specialneeds>
3. International Academy of Life Care Planners  
114 NW Fifth Street, Suite 103  
Ankeny, Iowa 50021  
(800) 531-5146  
[www.internationalacademyoflifecareplanners.com](http://www.internationalacademyoflifecareplanners.com)

#### Housing Needs

What circumstances do you consider acceptable or unacceptable?

Do you want the beneficiary to own a home?



If so, how will expenses on the home be paid?

### Health Needs

Is your child presently covered under your insurance? If so, what happens if your insurance is no longer available?

What medical services does your child need that are not presently covered by any public benefit program?

If the public benefit program that presently covers your child's medical care were no longer available, what medical expenses would need to be paid by the trust?

Does your child have a progressive illness which is likely to demand more medical care and services as time passes?

### Social Needs

What social activities do you wish your trustee to encourage?

Are there any activities your disabled child particularly enjoys or hates?

### Family Relationships

Do you wish the trust to contain provisions encouraging family contact?

Would you like your disabled child to be able to remember family members with gifts at birthdays and holidays?

Are there certain other expenditures you would approve in order to make ongoing family contact possible?

### General

The special needs trust should state your intent in your establishing such a trust so it will be clear to a future trustee, who might not know you, what you expect.

The trust should outline broad principles and instructions that are not likely to change. The memorandum of intent can be more detailed and kept current as the details change over time.

The trust should state where you wish to give any remaining trust assets in the event of the death of the disabled child.

### Review and Update

The special needs plan should be reviewed periodically to ensure it reflects any changes in your economic situation, in the beneficiary's condition, in benefit eligibility and service availability. The trustee and members of the trust advisory committee should be people with whom you still feel confident. In addition, all assets should be in the name of the trust or the trust should be the named beneficiary.

### Medi-Cal Payback (d)(4)(A) Trusts (First Party or Self Settled)

This type of trust is funded with the disabled child's own funds; thus, it is sometimes called a "self-settled" trust. It is usually created with personal injury settlement funds or when a child receives an inheritance from someone who did not use a third party special needs trust. Medi-Cal and SSI have very strict rules as to what type of trusts are allowed in these circumstances. The (d)(4)(A) trust is a "safe-harbor" trust that is permitted by Medi-Cal and SSI for those beneficiaries under the age of 65. It must be established by either the parent, grandparent, conservator of the disabled child or the court. Its major provision is that the trust must "pay back" the state for any Medi-Cal expenditures made on the beneficiary's behalf at the time of the beneficiary's death.

### Pooled (d)(4)(c) Trusts (First Party or Self Settled)

This is another safe-harbor trust allowed by Medi-Cal. It is a pooled disability trust that must be managed by a non-profit association. It can be created for beneficiaries of any age (not limited to under age 65) and can be established by the beneficiary herself/himself. However, there may be a penalty for those over age 65 who make transfers into the pooled trust. Upon the beneficiary's death, Medi-Cal does not need to be reimbursed as long as the funds are retained in the pooled trust for the benefit of other disabled beneficiaries.

