THOMPSON WILDHACK, plc
ATTORNEYS AT LAW

PLANNING FOR INDIVIDUALS WITH SPECIAL NEEDS

by
Kelly A. Thompson
kelly@twplc.com
Member, Special Needs Alliance
www.specialneedsalliance.com

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I. INTRODUCTION

Planning for persons with disabilities is usually referred to as "special needs planning". The estate planner is frequently called upon to recommend trust or other shelter options for clients who wish to protect the intended inheritance to a family member with a disability. The concern may be the beneficiary's ability to manage the assets. There is also frequently a concern for the public benefits eligibility of the beneficiary.

The estate planner may also be consulted when a person with a disability receives an inheritance for which no planning has been done, is going to receive a tort settlement of some kind, or is divorcing and desires to maintain both public benefits eligibility and the alimony or property settlement anticipated.

"Cost of care" is a term often used in conjunction with planning for the needs of a disabled individual. It is a term of art rather than a specifically defined "cost" established by statutes or regulation. In general the term refers to the overall cost of providing the care a disabled individual may require throughout their life. Most planning is done to

avoid “cost of care”. That is to say that parents will want their assets to be used to provide for the special or supplemental needs of their disabled child when the “cost of care” can be provided through public programs such as SSI, Medicaid and Section 8 housing.

To determine what kind of planning should be done, the estate planner should be familiar with the benefits potentially available to a person with a disability. Some are based on financial need and some are entitlement programs - Social Security disability benefits, Supplemental Security Income (SSI), Medicare, Medicaid, Section 8 housing grants, Civil Service and military survivor and dependent benefits, etc.

II. THIRD PARTY TRUSTS

a. In this case, the grantor of the trust is concerned with management of assets for a person with a disability and, usually, preservation of the beneficiary’s eligibility for public benefits programs. Such trusts are usually established by a parent or family member of a person with a disability. A trust can be established for a third party with a disability by inter vivos agreement or by testamentary means. Generally, a separate inter vivos trust is used for the special needs trust to allow other family members to utilize the trust in their estate plans.

b. The issue is whether the trust will be considered a “resource” to the beneficiary for public benefits purposes. In general, a trust is not a resource if the trustee is not required to distribute sums for the beneficiary’s support. The inclusion of standards such as “the beneficiary’s maintenance, support and comfort” have enabled courts to focus on the standard as establishing a right to income or principal in the beneficiary. However, even when the language of the trust is purely discretionary, some states (such as New York and Ohio) will consider the trust to be an available resource to the beneficiary even when distributions are not being made.

c. Aside from the many standard provisions of a trust the "Special Needs" trust should contain the following provisions:

(1) Purpose Clause. Sets out Parents' (grantors) desire that the trust assets have been set aside to provide for special, supplemental and/or emergency

needs. Distinguishes the purpose of trust from standard "support, maintenance and health" trusts. Parent should avoid language which evidences a desire to meet "support, maintenance and health" needs as this leaves open a judicial interpretation requiring the trust to pay for those services which otherwise would be provided through public programs.[1]

(2) Non-reduction clause. Establishes that the Trustee is to use the Trust Estate to promote the happiness, welfare and development of the Beneficiary without in any way reducing the services or financial assistance in basic maintenance, support, residential, medical or dental care that the Beneficiary may receive in his own right from any local, state or federal government or agency or department thereof, and without using any portion of the Trust Estate, income or principal, to reimburse any local, state or federal government or agency or department thereof, or private agency or department thereof for basic maintenance, support, medical and dental care received by the Beneficiary, in his own right.

(3) Emergency Clause. Allows the Trustee to contravene "non-reduction" principal that Trust assets should not be used if they would cause loss of public benefits. The trustee is given discretion to determine the existence of an "emergency" which loosely defined would arise when available public resources were so inadequate that the primary needs of the Beneficiary could not be met without the intervention of the Trustee. Eg., Beneficiary receives $564.00 in SSI but receives no housing subsidy and must secure housing at fair market rental. To meet emergency housing need Trustee chooses to secure apartment for beneficiary and allow him to live there rent free causing one-third reduction of SSI benefits.

(4) Authority to rent property to Beneficiary. Permits trustee to charge rent (or not) to the beneficiary property owned or leased by Trust (e.g. condo). This may allow beneficiary to qualify for rental subsidies or avoid reduction in SSI payments.

(5) Spendthrift Clause. Eliminates the ability of the beneficiary to encumber or alienate the trust estate and protects the trust estate from claims of the Commonwealth of Virginia which has provided the beneficiary with care and/or welfare benefits.

6. Discretion. Permits trustee to use its discretion with respect to use of income and or principal to meet special needs of beneficiary. So long as the Trustee has complete discretion to determine if, when and how disbursement from the trust will be made, the assets in trust will not be counted as a resource of the beneficiary and will allow the beneficiary to remain eligible for programs such as SSI and Medicaid which are "resource" sensitive.

(7) Termination clause. Permits Trustee to terminate trust in favor of other family members if and when the Trust Estate becomes liable for services which otherwise would be provided through public programs. Only exercised if Trustee determines Trust would no longer provide benefits to beneficiary and funds would be wasted. E.g., Beneficiary is hospitalized in state facility at no cost but changes in state laws would require that trust pay for "cost of care". Given the high cost of state care, the Trustee determines that trust principal would be expended within two years with no expectation that the beneficiary would be able to leave facility or benefit from the trust. Trustee concludes the trust purposes are no longer viable and terminates the trust in favor of the remaindermen.

(8) Amendment clause. Permits the Trustee to amend the trust to insure that the trust will not disqualify the beneficiary for public benefits. This clause can be very helpful to protect the trust estate if there are changes in the applicable laws or regulations.

D. Inter Vivos Trust. In general, the use of a Revocable Living "Special Needs" Trust offers the most flexibility for the parent. The trust is an entity which can be named in the estate plans of other family members as the receptacle for bequests to the family member with a disability. This also permits parents to fund trust with assets prior to their death which will be immediately available to the Trustee upon death of Grantors. In Virginia, it also allows the parents to name family members residing outside of Virginia as Trustees without concern about bonding expense.

v. Irrevocable trusts. While irrevocable trust may be advantageous to the parent for estate tax planning purposes they obviously limit the ability of the Grantor to amend and or revoke the trust to respond to changes in the rules and regulations governing public benefits. Use of "Crummey" provision may interfere with

beneficiary's eligibility for public benefits. The sum subject to the withdrawal power will be a countable resource to beneficiary during 30-60 day “present-interest” window.

vi. Letter of Intent

1. Purpose. While the Special Needs Trust will contain the language necessary to protect the trust assets from cost of care claims, it is not the place to detail the many private thoughts and desires that parents or other grantors will want to communicate to their Trustee. The "Letter of Intent" is the vehicle through which the parent can communicate their intentions and desires for the future of their disabled beneficiary.

2. Non Legal Document. While there are many approaches, forms and schedules which have developed to facilitate the formulation of a "letter of intent", it is a non-legal document and may be as simple as a hand written letter from the parent to the Trustee and other family members.

3. Importance of Letter of Intent. Most often parents will have been the primary provider of care for their disabled child and will know the most intimate details of the child's history and needs and how best these needs can be met. In other words what has worked and what hasn't. It is essential that this information be reduced to writing and shared with those persons charged with caring for or overseeing the care of the disabled child.

4. Contents of Letter. The letter should contain essential information such as Social Security Numbers and birth dates of immediate family members including parents.

a. Names, addresses and telephone numbers of important family members, professionals and other caring persons who have been involved in the disabled person's life.

b. History of disability, treatment and successful or unsuccessful strategies which have been used.

c. Relevant information pertaining to housing or residential care,

education, employment, behavior management, social environment and religious issues.

d. Personal feelings of parents concerning what they want for their child's future.

5. Share Letter of Intent. Once the letter is completed it may be shared with Trustees and other family members. At the very least parents must make the appropriate people aware that it has been prepared and where it can be found.

6. Preparing and updating letter. It is suggested that the letter be updated on an annual basis. Encourage the client to pick a non-important but distinctive annual event on which to sit down and update letter, i.e. Groundhog Day. The point is to pick a day which will be noticeable but will not be complicated with other duties such as birthdays and holidays.

7. Use of professionals in drafting letter. While the letter can be prepared without the assistance of professionals there are organizations such as the Personal Support Network in Northern Virginia which, for a fee, will assist the parent in developing a personalized plan to meet the needs of the child after the parent has passed away. The use of such an organization will facilitate the writing of a comprehensive document which can be referred to by family members and trustees for guidance.

G. Tax Considerations

A. A special needs trust is frequently made the beneficiary of a qualified retirement plan. This creates some drafting challenges, just as when any trust is made the beneficiary of a qualified plan. To gain maximum tax benefit the drafting attorney will usually wants the trust to qualify as a designated beneficiary and that can be accomplished by naming the remainder beneficiaries and making certain they are all identifiable individuals. [2] This allows the qualified plan balance to be distributed over a longer period of time, thus deferring taxes. As the usual special needs trust gives the trustee complete discretion over income, it is possible that the qualified plan distributions will be retained in the trust and subjected

to a higher tax bracket. The trustee must be very cautious in weighing the tax consequences of the retention of income against the public benefits impact of income distribution.

B. Some practitioners have recommended the use of a charitable remainder trust as beneficiary of the qualified plan, thus permitting tax-free withdrawals from the qualified plan. The charitable remainder trust then makes its annual payment to the special needs trust. The payments from the charitable remainder trust to the special needs trust are treated as payments to an individual under IRC Section 664 and the charitable remainder trust is treated as a designated beneficiary of the qualified plan. This plan could work very well when a large qualified plan is the primary funding source for an inheritance to a person with special needs.

III. SELF-FUNDED TRUSTS.

These are trusts created by a Medicaid/SSI beneficiary or applicant to allow the person to shelter assets and also receive public benefits. They are commonly referred to as "d4a" trusts or "d4c" trusts, depending on variety.

A. Medicaid Rules

1. An applicant for Medicaid is generally disqualified when the applicant has created an inter vivos trust where (a) distributions from the trust are discretionary in the trustee; and (b) where the distributions may be used to benefit the applicant and/or the applicant's spouse.

2. The Omnibus Budget Reconciliation Act of 1993, Public Law 103-66 (OBRA-93) outlines certain types of trusts which will not be considered as resources and/or income to Medicaid applicants and applies to trusts created after August 10, 1993.

3. OBRA-93 sets a special category of trusts for disabled persons who have not yet reached age 65:

A trust containing the assets of an individual under age 65 who is disabled (as defined in section 1614(a)(3)) [3] *and which is established for the benefit of such individual by a parent, grandparent, legal guardian, or a court if*

the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a State plan under this title. [4]

Such a trust will not disqualify the applicant for Medicaid purposes. Applications of the rule vary from state to state. For example, in Colorado the trust can be established only with assets received from a personal injury settlement. In Virginia there are no such restrictions and d4a trusts are commonly used to restructure unexpected unplanned inheritances, personal injury or other tort settlements, and sometimes alimony or property settlements.

4. A d4a may be funded only by a person under age 65 and such a trust cannot be added to or otherwise augmented after the individual reaches age 65. However, in some states, including Virginia, a d4c pooled trust can be created by a Medicaid recipient age 65 or older. The trust will not exempt resources for an SSI recipient over age 65. [5]

B. SSI Rules

1. The Foster Care Independence Act of 1999 essentially applied the Medicaid trust rules to SSI benefits. [6] Rules concerning trusts for SSI recipients are found in the Program Operations Manual (POMS) published by the Social Security Administration and the POMS sections dealing with trusts have been greatly expanded in recent years. To determine if a trust meets SSI criteria, the POMS provides a set of qualification criteria

C. Pooled Trusts. OBRA 93 also provides for a pooled asset trust variety of self-funded special needs trust sometimes referred to as a "d4c" trust. [7] The statutory requirements for a d4c trust are:

B. The trust is established and managed by a non-profit association;

C. A separate account is maintained for each beneficiary of the trust, but, for purposes of investment and management of the trust, the trust pools the accounts;

D. Accounts in the trust are established solely for the benefit of individuals who are disabled (as defined in section 1614(a)(3)) by the parent,

grandparent, or legal guardian of such individuals, by such individuals, or by a court;

E. To the extent that amounts remaining in the beneficiary's account upon his or her death are not retained by the trust, the trust pays to the State an amount equal to the total amount of medical assistance paid on behalf of the beneficiary.

F. Advantages: They differ from the Medicaid payback trust in that the disabled individual may create the trust himself or herself. This can be a very important element to a competent person with a disability. The pooled trust also allows the grantor to leave assets for the benefit of other members of the pool, rather than have all assets go to repay Medicaid.

G. Other advantages are very practical in that many beneficiaries with a disability do not have a family member capable of serving as trustee. The assets may also be too little to warrant the services of a corporate fiduciary.

The following pooled trust programs are currently operating in Virginia:

1. Personal Support Trusts
98 N. Washington Street, Falls Church, VA 22046
Tel: 703-532-3214

2. Commonwealth Community Trust
P.O. Box 29408, Richmond, VA 23242-0408
Tel: 804-740-6930

IV. OTHER ISSUES IN PLANNING FOR PERSONS WITH SPECIAL NEEDS

A. Guardianship While many parents act as surrogate decision-makers for their adult disabled children, at the age of 18, absent a court finding of incompetence or incapacity, the child becomes an adult legally empowered to act independently. Without a guardianship order, parents are not the legal guardians of adult disabled children. This may never be challenged during the lifetime of the parents, but it fails to provide a plan for the delegation of the decision-making authority after the

death of the parents. Since the implementation of HIPAA in 2003, implementing extensive medical privacy rules, it is more difficult for parents to continue as de facto guardians for their children. There also seems to be an increase in instances of school and vocational service providers using the parent's lack of guardianship to ignore the parent's attempts to advocate for their child.

1. When an individual has the capacity to execute self-directed substitute decision-making instruments, guardianship is an overly restrictive supervisory arrangement which can and should be avoided. If circumstances dictate guardianship, it can be tailored to provide necessary support and supervision without unnecessarily restricting the rights of the person under a disability. The 1998 revisions to the Virginia guardianship law specifically anticipate limited guardianships.

2. Virginia law allows a parent or legal guardian of an incapacitated child to petition the court to name a standby guardian who would become guardian after the death or incapacity of the last surviving parent or legal guardian. This provides a smooth transition at the loss of a parent.

3. Parents may also wish to make a statement in their Will that states a preference as to who should be appointed as Guardian for an adult child with a disability.

B. <u>Representative Payee</u> The program is designed to provide a custodian for federal benefits (Social Security or Civil Service) payable to recipients who are minors, incompetent, incapable of managing their affairs, or who receive SSI benefits and are drug addicts or alcoholics. Its use is limited to federal benefits.

1. Anyone may apply to become "rep payee", but there is an order of preference when there are competing applicants. By Social Security regulation, rep payees may not be compensated.

2. Social Security requires the rep payee to render a summary annual account of what amounts were expended for the beneficiary, how much was spent on items other than food and shelter, and how much was not spent.

3. Generally the rep payee system is used to supplement a trust or durable

power of attorney but is not enough to manage the affairs of a disabled person.

4. Rep payees should be aware that there is potential personal liability for failure to report, overpayments etc.

C. Trustee

1. Many of the planning opportunities described herein require the use of a trust. While we spend a great deal of time choosing and drafting the individual trust, often more time and attention needs to be spent in selecting the trustee and successor trustees who will act for the benefit of the disabled child for his or her lifetime. Some questions should be considered:

   a. Will the trust have assets which require special expertise?
   b. Are there assets in more than one jurisdiction?
   c. Is the named trustee going to outlive the trust term?
   d. Are there family circumstances which will effect the fiduciary's decisions? (i.e. second marriages, estranged children, sibling rivalry)
   e. Are there tax considerations necessitating an "independent fiduciary"?

2. A good special needs trustee possesses the following attributes:
   a. Competence
   b. Ability to serve
   c. Willingness to serve
   d. Investment, accounting and tax experience or the ability to hire competent professional help in these areas
   e. Knowledge of and sensitivity to the beneficiary and their needs and public benefits requirements
   f. Integrity and loyalty
   g. Flexibility to meet changing circumstances

3. Clients may select a family member, friend, attorney, professional advisor,

or bank trust department to serve as trustee. Many families with a special needs trust have no family member suitable to serve as a Trustee and limited assets (below the size to entice a professional fiduciary). There are four organizations in Virginia that provide pooled trusts for family funded special needs trusts:

a. Personal Support Trusts - The Arc of Northern Virginia
98 N. Washington Street, Falls Church, VA 22046
Tel: 703-532-3214

b. Commonwealth Community Trust
P.O. Box 29408, Richmond, VA 23242-0408
Tel: 804-740-6930

ENDNOTES

1. See Chenot v. Bordeleau, 561 A.2nd 891 (1989) Appendix 1

2. Treasury Regulation Section 1.401(a)(9)

3. The determination of disability need not be made prior to the creation of the trust. POMS 01150.121

4. 42 U.S.C. Sec 1396p(d)(4)(a)

5. POMS SI 01120.203B.1.b. If the trust was established and qualified prior to age 65, then it will continue to do so after age 65.

6. Pub. L. No. 106-169, §§§§ 206 (enacted Dec. 14, 1999)

7. 42 U.S.C. §1396p(d)(4)(c) as amended by OBRA 93 §13611(b)