

PLANNING FOR INDIVIDUALS WITH SPECIAL NEEDS

by

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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.

II. BENEFITS

A. Social Security

1. Workers may be eligible for disability benefits based on their own insured status. Generally, a worker must have 20 Quarters of Coverage (“QC’s”). A QC is earned for any calendar quarter in which a worker had earnings subject to FICA and in excess of a threshold amount.
2. If a disabled person does not have sufficient Quarters of Coverage on his or her own work record, he or she may still qualify on the work record of a parent. Workers’ children are entitled to benefits if dependent upon the worker; unmarried; and under the age of 18, or over the age of 18 and disabled with a disability that began before age 22. A child may be biological, adopted, illegitimate and acknowledged, or a stepchild. The disabled child will become eligible at the disability, retirement or death of the parent/worker.
3. Monthly benefits are based on the worker’s primary insurance amount (“PIA”) which is currently based on the worker’s average indexed monthly earnings. This calculation is available from Social Security. The eligible child of a worker is entitled to 50% of the PIA. If the worker is dead, this increases to 75%. If the child is entitled to benefits based on more than one worker’s record, the benefits will be based on the largest PIA.
4. There are no resource or income limits for Social Security Disability benefits eligibility. However, if the disabled individual’s earned income exceeds \$980 per month (2009), the person will likely not be considered to be disabled and therefore not eligible for benefits.

5. The Social Security law can be found at 42 USC §§ 401_433. The Social Security Administration has a very helpful web site at www.ssa.gov.

B. Medicare

1. Persons under age 65 who are entitled to receive Social Security benefits are also entitled to Part A Medicare benefits after 24 months of qualified disability. There is a shorter waiting period for persons with ALS or renal failure. Part A covers inpatient hospital services, post-hospital extended care services, home health and hospice services. Psychiatric hospital stays are limited to 190 days in the beneficiary's lifetime. Skilled nursing facility stays are limited to 100 days and are 100% covered for the first 20 days only. For days 21-100, the patient is liable for a copay of \$133.50 (2009) per day. There may also be substantial deductibles and copays for Medicare services.
2. "Custodial care" is not covered. This is care that could be given safely and reasonably by a person who is not medically skilled and that is given mainly to help the patient with daily living such as walking, bathing and dressing. There is no coverage for custodial care even if performed in a skilled nursing facility or home health care environment.
3. Medicare Part B covers physicians, diagnostic tests, medical equipment, ambulances, and outpatient physical and speech therapy. Any person eligible for Part A may enroll and pay the premium for Part B coverage. The 2009 premium is \$96.40 per month (unchanged from 2008).
4. The Medicare Prescription Drug Benefit went into effect in 2004, with a preliminary discount card program. The full benefit went into

effect in 2006. The monthly premium for the coverage averages \$37. In 2009, after a deductible of \$295, Medicare will pay 75% of costs between \$295 and \$2700, and 95% of costs above \$4350 annually. There is a gap in coverage (“doughnut hole”) for costs between \$2,700 and \$4,350. There are some enhanced benefits for low income individuals.

5. There are no resource or income limits for Medicare eligibility.
6. The Medicare regulations are in 42 CFR parts 405 _ 424. The Medicare statute begins at 42 USC § 1395.

C. Civil Service and Military Survivor Benefits

1. Civil Service survivor benefits are available if the employee dies after electing a reduced survivorship pension or dies before retirement. They are available to an unmarried child age 18 or over and incapable of self-support because of a mental or physical disability that began before age 18. The disabled child receives a payment of approximately \$450 per month.
2. Guidelines for determination of the disability are less clear than under Social Security guidelines, but the applicant must provide a physician’s report of the disability, including the date it started, degree of impairment, probable length of the disability, and an educational and employment history.
3. Payments to a disabled child stop at the end of the month before the one in which the child marries, dies, recovers from the disability, or becomes capable of self-support.
4. Children receiving a civil service survivor annuity are also eligible for federal employee group health benefits if the federal employee had family coverage at the date of his or her death.

5. Under the Military Survivor Benefit system, the military retiree must have elected coverage for the child at the time of his or her retirement and the election at retirement is irrevocable. A maximum of 55% of the retired service member's retirement pay can be obtained for a disabled child. The retiring member can elect a smaller "base amount" if desired. Most service members elect a benefit for both spouse and child, so that a survivor benefit is paid for the lifetime of the spouse and then for the child's subsequent lifetime. This benefit is essentially insurance and a premium is paid by the retiree but it is very reasonable. If the disabled child is receiving a survivor benefit, then he or she will also be eligible for military health care benefits under TRICARE.
6. These civil service and military benefits can be substantial and are a planning challenge as, for high ranking officers, the benefit can disqualify their child from Medicaid or Medicaid waiver benefits. Most group home and day support services are funded through Medicaid waiver benefits and an applicant with more than 300% of the SSI amount (\$2,022 per month in 2009) is not eligible for these services. An individual with income of more than \$2,022 per month but less than the \$7-8,000 per month needed to private pay are left with out options. Civil service and military survivor benefits are not currently assignable to a special needs trust.

D. Supplemental Security Income (SSI)

1. SSI is a federal welfare program providing a minimum level of income to certain categories of needy persons. Eligibility is not based on a person's employment record, a person's relationship to an insured worker, or employment taxes paid. A person may be eligible for both Social Security and SSI. Eligibility for SSI may make a person eligible for other benefits such as food stamps, housing subsidy or Medicaid.
2. To be eligible for SSI a person must meet the following criteria:
 - a. age 65 or older, blind, or disabled;

- b. U.S. citizen or certain qualified documented immigrants;
 - c. not a resident of a public institution.
3. A disabled person is defined as:
- a. An adult (18 years or older) who is unable to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months.
 - b. A child under 18 is considered disabled if suffering from a medically determinable physical or mental impairment(s) which compare in severity to an impairment that would make an adult disabled.
 - c. Persons diagnosed as addicted to alcohol or drugs will be found to be disabled only if the disability is based on symptoms, signs, and laboratory findings independent of the addiction itself. If the drug addiction or alcoholism is found to be a contributing factor to the disability the person is required to participate in free treatment, if available, to maintain their eligibility.
4. Residents of public institutions are not eligible for SSI. Public institutions are those operated or controlled by a government entity that provide treatment or services in addition to food and shelter to four or more persons. Exceptions are persons who live in such institutions to receive vocational or educational training, persons who live in group homes or community residences with no more than 16 residents.
5. To be eligible for SSI benefits, the annual net income limit for an unmarried person in 2009 is \$8,088 (\$74 monthly). Married persons are entitled to benefits if combined annual income is less than \$12,132 (\$1,011 monthly). Income includes anything received in cash or in kind that can be used to meet the person's needs for food or shelter. Some non-

income items are:

- a. medical care and services;
 - b. social services;
 - c. proceeds of sale of a resource;
 - d. income tax refunds;
 - e. payments from credit life or credit disability policies;
 - f. proceeds of a loan (including reverse mortgage payments);
 - g. bills for items which are not food or shelter paid by
 - h. \$400 per month of earned income (maximum \$1,620 per calendar
 - i. \$20 per month of unearned income;
 - j. \$65 per month of earned income;
 - k. one third of support payments made to or for a child by an absent
 - l. in kind assistance provided by a non-profit organization;
 - m. the value of plane, train, bus tickets received as a gift.
6. Deemed income is income of another attributed to the claimant. Generally, it is an issue when the claimant lives with an ineligible spouse or parent. "Deeming" stops applying in the month following a claimant's 18th birthday.
7. An individual may have no more than \$2,000 (married couple \$3,000) in resources to be eligible for SSI. Resource determinations are made as of the first moment of the month. Items received in one month are counted as income and, if retained, become a resource as of the first of the next month. Proceeds of sale of a resource are not income, but continue to be a resource. Countable resources are anything that the individual owns, has an independent legal right to negotiate, can be converted to cash, and is usable for food or shelter. Some excluded resources are:
- a. the value of the person's home and appurtenant land, as long as
 - b. the value of household goods and personal effects up to \$2,000;
 - c. wedding and engagement rings and special equipment related to
 - d. the value of an automobile (limit of \$4500 was abolished in early

2005);

- e. life insurance policies with face value up to \$1,500;
 - f. burial spaces up to \$1,500 and irrevocable funeral and burial arrangements of any value.
8. Monthly SSI benefits are \$674 for an individual or \$1,011 for a married couple. An eligible spouse in a health care facility receives \$40 per month. Some states provide a supplement to this amount or to certain categories of disabled persons. Virginia supplements SSI only for recipients who live in licensed homes for adults. This supplement is known as a Medicaid Auxiliary Grant.
9. Transfers of resources for less than fair market value within 36 months of an application for SSI may result in the imposition of a period of ineligibility of up to 36 months determined by dividing the uncompensated value of the amount transferred by the SSI benefit rate. This penalty was implemented by the Foster Care Independence Act of 1999.¹

E. Medicaid

- 1. Medicaid is a joint federal-state program of medical assistance to eligible needy persons. SSI and TANF (Temporary Assistance to Needy Families), recipients are usually eligible for Medicaid, but states have the option to apply more or less restrictive guidelines and are known as Section 209(b) states. Virginia is a Section 209(b) state and has opted for more stringent guidelines.
- 2. To be eligible for Medicaid, a person must meet the following general criteria:
 - a. citizen or resident alien;
 - b. resident of the state providing the benefit;
 - c. disabled, blind or aged, and eligible for SSI, or, in some states (including Virginia), qualified under special Medicaid criteria, or; the parent of a dependent child who qualifies for TANF;

- d. financially needy under state criteria.
3. Individuals may have \$2,000 in countable resources (\$3,000 for a married couple if both apply). Exempt resources are:
 - a. personal effects;
 - b. household furnishings;
 - c. one automobile;
 - d. term life insurance;
 - e. life insurance with a face value up to \$1,500. (If face value is over \$1,500, cash value is counted);
 - f. burial funds (see separate paragraph);
 - g. burial plots (NOTE: SSI limit is still \$1500);
 - h. life estates in real estate (may soon change).
 4. The home (1 acre or minimum zoning requirement) and up to \$5,000 of adjacent contiguous property are exempt while the applicant/recipient, the spouse or a disabled child reside there. There is a six-month exemption when the owner is institutionalized, then the exemption ends unless a specified relative continues to reside in the home.
 5. Virginia Medicaid will exempt some funds set aside for burial expense. A \$3,500 restriction applies primarily to the cost of “services” associated with the disposition of remains. The limitation does not apply to the value of items classified as "burial space items", which include a casket, urn, vault and/or marker as well as the cost of opening and closing the grave. These items are not subject to any cost restriction. The \$3,500 set aside must be reduced by:
 - a. face value of life insurance not counted as a resource;
 - b. burial insurance - if the policy is designated for burial;
 - c. irrevocable burial arrangements;
 - d. funds in a revocable burial arrangement.

Applicants may spend-down resources by pre-planning funerals. Although

you cannot irrevocably pre-pay the funeral home, you may contract with the funeral home and place the cost of the contract into an irrevocable burial trust. This irrevocable trust is not subject to a specific dollar limit, but it cannot exceed contract cost of "services", which are subject to the \$3,500 limit, and burial space items.

4. The Virginia Medicaid regulations can be found in Title 12 Part 30 of the Virginia Administrative Code (12VAC30). Advocates should also consult the Virginia Medicaid Manual concerning Virginia's Medicaid policy. It can now be found online at www.dss.state.va.us/benefit/medicaid_manual.html.

F. Housing Choice Voucher Program ("Section 8")

1. Section 8 is a federal housing subsidy. The household pays a portion of the monthly housing cost - usually 30 percent of the household income.
2. Income limits to receive Section 8 housing assistance vary by area of the country and are based on median income for that area.
3. Section 8 applicants and recipients must report all income earned on assets except those assets in a special needs trust. However, transfers of assets into a special needs trust other than by court order will result in a period of ineligibility of up to 2 years.ⁱⁱ

III. THIRD PARTY TRUSTS

- 3.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.

3.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.

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

A.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.ⁱⁱⁱ

A.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.

- A.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 \$674 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.
- A.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.
- A.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.

¶55.1-19 of the Virginia Code provides that the Commonwealth of Virginia may seek reimbursement for "cost of care" expenditures from standard "spendthrift trusts" unless the Beneficiary is an "individual who has a medically determined physical or mental disability that substantially impairs his ability to provided for his "care or custody and constitutes a substantial handicap." While no case law defines the terms "care or custody" and "substantial" as used in this statute, the statue is likely to encompass most disabled individuals who are collecting disability benefits such as SSI. This statute provides a clear and unambiguous legislative intent to permit the use of "special needs"

trusts.

- A.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.

- A.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.

- A.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.

- A.9 Avoid these provisions. Many drafters insert a provision that "no part of the principal or income of this trust may be distributed for food, clothing or shelter, or to replace any public assistance benefits for which the beneficiary may be eligible." This provision is mistakenly thought to be necessary to maintain SSI eligibility. A second commonly utilized provision is one requiring the Trustee to seek support and resources for

the beneficiary from all public benefits programs. While well-meaning, this provision places liability on the Trustee for a role she cannot fulfill unless she also serves as a Guardian or Conservator for the beneficiary.

- 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.
- A.E 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.
- A.F 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. Special Rules for Trust for Surviving Spouse. In Virginia, a trust created for the benefit of a surviving spouse who is receiving or may receive Medicaid benefits must be a testamentary trust. Virginia Medicaid will not allow a Medicaid recipient to be disinherited by his or her spouse. The Medicaid recipient spouse will be required to pursue his or her augmented estate rights. If the Medicaid recipient spouse does not pursue augmented estate rights, then the Medicaid recipient will be deemed to have made gift of the augmented estate share, resulting in a period of ineligibility for Medicaid. The augmented estate share may be satisfied by use of (1) an outright distribution of 34% to the spouse; (2) a distribution of 34% to a testamentary trust, allowing distribution of income and principal to the spouse ; or (3) a distribution of the full estate to an “income only” testamentary trust for the surviving spouse.

A.H Trusts Established by a Medicaid Applicant for Benefit of a Person with a Disability.

1. Trusts are sometimes established by a Medicaid applicant for the benefit of a disabled child or any disabled individual under the age of 65. The transfer of assets to such a trust does not result in any penalty or period of ineligibility to the Medicaid applicant. This is particularly helpful when an older parent in a nursing home must spend down to Medicaid eligibility but would like to provide for the need of a disabled child.

Spenddown may be accomplished instantly by funding such a trust. The Omnibus Budget and Reconciliation Act of 1993 (OBRA 93) authorized this type of transfer but placed certain requirements on this type of trust. The trust must be solely for the benefit of the disabled person.

H.2 “Sole benefit” rule. A transfer is considered to be for the sole benefit of a disabled child, or a disabled individual if the transfer is arranged in such a way that no individual or entity except the disabled child or disabled individual can benefit from the assets transferred in any way, whether at the time of the transfer or at any time in the future. . . . However, the trust may provide for reasonable compensation, as defined by the State, for a trustee or trustees to manage the trust, as well as for reasonable costs associated with investment or otherwise managing the funds or property in the trust (without violating the concept of sole benefit).^{iv}

H.3 The sole benefit rule may be met if (1) the disbursement of the fund will be exhausted over the actuarial lifetime of the beneficiary, or (2) the fund contains a payback requirement to Medicaid.

IV. 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

A.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))^v 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.^{vi}

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.^{vii}

B. SSI Rules

- A.1 The Foster Care Independence Act of 1999 essentially applied the Medicaid trust rules to SSI benefits.^{viii} 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:

Was the trust established with the assets of an individual under the age of 65? If no, the trust does not qualify. If yes, go to the next question.

Was the trust established with the assets of a disabled individual? If no, the trust does not qualify. If yes, go to the next question.

Is the disabled individual the beneficiary of the trust? If no, the trust does not qualify. If yes, go to the next question.

Did a parent, grandparent, legal guardian or a court establish the trust? If no, the trust does not qualify. If yes, go to the next question.

Does the trust provide specific language to reimburse the state for medical assistance paid upon the individual's death? If no, the trust does not qualify. If yes, go to the next question.

Does the trust meet the special needs trust exception to the extent that the assets of the individual were put in the trust prior to the individual attaining the age of 65? Any assets placed in the trust after the individual attained age 65 are not subject to this exception.

Is the trust irrevocable? If no, the trust does not qualify.

2. SSI rules also require that the trust limit expenses that may be paid at the individual's death to
 - (1) taxes due to the federal or state government due to the death of the beneficiary; and
 - (2) reasonable administration expenses associated with the termination of the trust.Noteworthy is the requirement that the trust not allow payment of funeral expenses or debts due to third parties prior to the reimbursement of Medicaid. ^x

3. An area of much discussion in SSI rules is the issue of legal authority to act with respect to the assets of the disabled individual. While federal law specifically states that the trust

may be created by a parent or grandparent of the beneficiary, SSI decisions have recently taken issue with the authority of that parent or grandparent to establish the trust. There is no issue if the person under a disability is not competent to transfer assets to the trust. In those cases the common practice is to have the court establish the trust and authorize the transfer of assets to the trust.^{xi} However, if the person with a disability has the competence to transfer assets, SSI has not been allowing the disabled person to do so. The Philadelphia region of the Social Security Administration has recently been allowing the parent to establish the trust and “seed” it with a nominal sum and then allow the competent beneficiary to transfer assets to the trust.

A.4 SSI rules also look to the state’s trust laws regarding irrevocability. Essentially, they look at provisions that pass the remainder interest to the grantor’s heirs and look to state law to determine whether the Doctrine of Worthier Title applies in that state, thus creating an automatic reversion or revocable trust. Virginia Code Section 55-14 seems to repeal the Doctrine of Worthier Title, providing that whenever a person by writing takes a life estate and in the same writing grants a remainder in the person’s heirs, the word “heirs” creates a remainder in the person’s heirs. However, as pointed out by Andrew Hook in the September 19, 2003 issue of his firm’s newsletter, Elder Law News, the headline to the statute refers only to abolition of the rule in Shelley’s case. While Virginia Code Section 1-13.9 provides that statute headlines are not a part of the code section, the Virginia Supreme Court has held that the title of a code section is entitled to a due share of consideration. Section 55-14 would therefore seem less than clear as to whether the Doctrine of Worthier Title applies to special needs trusts in Virginia.

1.1 Some states place additional restrictions on these d4a trusts. For example, Maryland has extensive restrictions - requiring that the trust prohibit compensation by the trust of the beneficiary’s family members as trustee, caregiver, travel companion etc.^{xii}

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.^{xiii} The statutory requirements for a d4c trust are:

- 3.1 The trust is established and managed by a non-profit association;
- 3.2 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;
- 3.3 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;
- 3.4 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.
- 3.5 Advantages: In Virginia, these trusts can be established for or by a disabled person of any age. They also 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.
- 3.6 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: 703-532-3303

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

V. 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. Va. Code 37.1-128.2 allows a parent or legal guardian of a mentally ill or mentally retarded 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.

3. The caregiver (individual or institution) becomes the de facto guardian in the absence of other arrangement

B. Representative Payee 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.

D. 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
- a.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

98 N. Washington Street, Falls Church, VA 22046
Tel: 703-532-3303

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

- c. Virginia Beach Community Trust
Pembroke Six, Suite 218, Virginia Beach, VA 23462
Tel: 757-437-5778

- d. Norfolk Community Trust
248 W. Bute Street, Norfolk, VA 23510
Tel: 757-441-5300

ENDNOTES

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- i. The SSI statute can be found at 42 USC §§1381 et seq and the regulations at 20 CFR §416.
 - ii. HUD Handbook 4350.3 REV-1, Section 5-7
 - iii. See Chenot v. Bordeleau, 561 A.2nd 891 (1989) Appendix 1
 - iv. Transmittal 64 at §§3259.1.A.4 and 3259.3 and 4
 - v. The determination of disability need not be made prior to the creation of the trust. POMS 01150.121
 - vi. 42 U.S.C. Sec 1396p(d)(4)(a)
 - vii. 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.
 - viii. Pub. L. No. 106-169, §§§§ 206 (enacted Dec. 14, 1999)
 - ix. POMS S1 01 120.203
 - x. POMS 01120.203 B.3
 - xi. Note that the court should “establish” rather than “create” the trust according to POMS SI 01120.203B.1.a.
 - xii. COMAR Section 10.09.24
 - xiii. 42 U.S.C. §1396p(d)(4)(c) as amended by OBRA 93 §13611(b)