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Special Needs Trusts For Disabled Children

I. Introduction

If assets and income are “available” for basic needs, a disabled person is required to exhaust such resources before seeking means-tested government assistance. In 1993, both Congress and New York passed significant legislation affecting qualification for government programs. The federal legislation addressed Medicaid and codified an exception for self-settled trusts established by a disabled child for his or her own benefit. The New York legislation, EPTL § 7-1.2, codified a Court of Appeals decision sanctioning disability trusts, and creating clear rules for their use.

The primary focus of the Medicaid legislation was an attempt by Congress to hinder the affluent elderly from transferring assets into self-settled ““Medicaid” trusts by imposing a 60 month “lookback” period. However, Congress also created an exception for disability trusts created for disabled persons under the age of 65 funded with the disabled person’s own assets.

In exchange for the promise that Medicaid would be paid back for benefits paid during the life of the disabled child after the trust terminated — usually when the child died — these self-settled disability trusts could be used by disabled persons under 65 to shelter their own assets and thereby qualify for Medicaid. These statutory “first party” trusts are much more restrictive than comparable “third party” trusts, which evolved under common law and which are typically funded by parents’ or family members’ assets.

Third party trusts are less restrictive

since those trusts are not motivated by a desire of the parent to qualify for Medicaid. Rather, they trusts are funded to benefit their disabled child. Third party disability trusts are superior to first party trusts not only because they are less restrictive, but also because they need not contain a Medicaid “payback” provision. Nevertheless, the only option for funding a child’s disability trust may at times be a first party trust.

Also in 1993 New York codified *Matter of Escher*, 52 NY2d 1086 (1981), a Court of Appeals decision involving a testamentary trust created for a disabled child. In *Escher*, the New York Department of Mental Hygiene sought reimbursement for care provided to the decedent’s daughter in a psychiatric facility for 30 years. The Surrogate found that the trust contained in *Escher*’s will expressed his clear intent to leave assets to the daughter’s distributees. Finding for the estate, the Surrogate reasoned that if the corpus were paid to New York in 1978, that would leave nothing for those distributees. This would conflict with the clearly stated intent of the testator.

Affirming the decision of the Surrogates Court rejecting the claim, the Surrogate concluded that the desire of a parent to supplement the standard of living of a disabled child was not dependent upon the benevolence of the law, and that the government entitlement is a floor, rather than a ceiling. New York appealed the case to the Court of Appeals, which affirmed the Surrogate in a landmark decision. Against the backdrop of *Escher* and the federal changes, New York enacted EPTL § 7-1.12, under which disability trusts have gained prominence.

Sheltering Assets to Qualify Qualify For Medicare and SSI

Enabling the disabled child to receive means-tested government benefit programs

requires that trust assets not be considered “available” assets for government benefit programs. Special needs trusts (“SNTs”) shelter assets and render those assets an “unavailable resource” for purposes of applying eligibility rules for disabled persons receiving health care coverage under Medicaid, or income support under Supplemental Security Income (SSI).

Medicaid provides direct payments to providers for health related costs, whereas SSI provides income directly to disabled persons. In New York and most States, qualification under SSI will automatically entitle the disabled person to Medicaid. The loss of SSI benefits may result in the loss of Medicaid. SSI is federal program that provides monthly payments to people with limited income and few resources.

[New York is among the states that make “State Supplemental Payments (SSPs). Some states’ supplemental payments are administered by the Social Security Administration (SSA). Those 12 states include CA, DE, NJ, PA, RI and VT. New York is among the 33 states that pay and administer their own SSPs. Six states do not offer SSPs: AZ, AR, MS, ND, TN, and WV.]

While SSI is a federal program of income assistance, Medicaid is a joint federal-state program of medical assistance, administered by the states. States determine Medicaid eligibility and the scope of health services offered pursuant to federal requirements. The legal authority for Medicaid is found in the Social Security Act, 42 USC § 1396 et seq. Unlike SSI, Medicaid makes payments only to third parties. Like SSI, Medicaid is need-based. Medicaid is actually a group of programs, with differing benefits, rules, and eligibility requirements.

Medicare and Social Security Distinguished

As an aside, Medicare and Social Security are examples of government programs that are not means-tested. Social Security, funded by payroll tax, is based on one’s earnings record, and is available to persons age 62 or over, or to those who are disabled or blind. Medicare is age-based, and is available to citizens or permanent legal residents age 65 or over.

Objective of Special Needs Trust

The choice of a trust by Congress to accomplish its objective was judicious, since a trust provides flexibility to serve the needs of the disabled person. EPTL § 7-1.12 governs Special Needs Trusts in New York, and provides helpful trust language intended to make compliance with means-tested government and private programs more predictable. Special needs trusts are also referred to as “Supplemental” Needs Trusts, using the same acronym.

An SNT improves the quality of life of the disabled child by paying for enhanced medical care, such as premium health insurance, health services and medical equipment. The trust may also help the child become independent by purchasing a residence or by funding more comfortable housing. The trusts also serve a myriad of other purposes, one of which is to ensure continued care after family members are deceased. (A “letter of intent,” or a “future care plan” is important when family members are gone and will be discussed later.) The assets of a special needs trust, when not used for shelter or food, will not “count” for purposes of SSI or Medicaid, and can thus be utilized to improve the living standard of the disabled child.

Special needs trusts are particularly useful in providing for items that are not provided by means-based government programs or by private insurance. These may include transportation, vocational training, computers, personal care givers, vacations, and many other items.

The special needs trust, like any trust, is not a legal entity. Rather, a special needs trust is a relationship wherein the trustee holds property for the benefit the disabled person, or cestui que trust. A division of ownership occurs between the trustee, who holds legal title, and the disabled beneficiary, who holds equitable title. Trusts evolved in England because of the inherent limitations of law courts to provide equitable relief.

Special needs trusts appear to be a hybrid form of several different types of trust. An SNT generally contains an anti-alienation provision, a feature of spendthrift trusts. An SNT also bears some resemblance to a discretionary trust, since the trustee alone decides when to distribute income or principal. The discretionary element of an SNT is tempered by the limitation imposed on the trustee not to exercise this discretion in a manner that would jeopardize the beneficiary's eligibility for publicly or privately funded benefits.

An SNT differs from a support trust in that the trust must carefully circumscribe the benefits the trust may provide without becoming an "available resource" which would preclude means-tested government assistance. To avoid being an available resource, an SNT must also be irrevocable. However, the trust may contain provisions allowing amendment or modification if circumstances warrant. For example, modification might be necessary in order to become eligible for a means-tested benefit program whose requirements have changed. A court might also allow modification where the

law has changed.

Improving the life of the disabled person, most often a child, without affecting eligibility for public benefits requires an understanding of public benefit programs available to the child. Each program may have different eligibility rules. The objective of a properly drafted SNT is to be treated as "exempt" by government agencies providing means-tested benefits. A special needs trust must be skillfully administered by the trustee since an improper distribution could entail the loss of benefits to the child.

Several distinguishing characteristics are present in all special needs trusts: First, they must be irrevocable. Revocable trusts will be considered an available asset and will render the trust defective for SNT purposes. Second, the person must be under the age of 65 and "disabled" within the meaning of the Social Security laws. (Persons over 65 receive governmental benefits by reason of their age). Third, with respect to first party trusts, which are funded by the disabled child, the trust must include a Medicaid "payback" provision. This provision requires that the trust reimburse Medicaid for the cost of Medicaid services provided. After Medicaid has been reimbursed, remaining trust assets may be distributed to contingent remainder beneficiaries. First party trust are also subject to other unique requirements, discussed later.

A testamentary special needs trust takes effect upon the death of the grantor (settlor). It may be a separate document or a provision in the testator's will. An inter vivos SNT is separate legal document, executed during the grantor's lifetime. It is usually funded during the grantor's lifetime, but may also be funded at the grantor's death. One reason to implement an SNT for a minor child is to facilitate lifetime gifts or testamentary bequests from grandparents or other family members. Without an SNT in existence (and

without a potential benefactor knowing of its existence) the funds might be left outright to the disabled child. This would limit the child to establishing an inferior first party special needs trust. First party trusts may also be the only option if the child must take legal possession of substantial assets, such as when the child receives a tort settlement.

An inter vivos SNT may be appropriate for a parent or parents who wish to purchase an insurance policy during the child's adolescence. The policy would be owned by the trust and premiums could be gifted by parents to the trust. A second-to-die policy owned by the trust could provide substantial benefits to the child without affecting means-tested government benefits. Such an arrangement would also prevent a "lag" period during which the SNT could not provide assistance to the child following the passing of the surviving parent.

Whether a special needs trust is appropriate for a disabled child depends on (i) whether the child is receiving means-tested government benefits or whether such benefits may be sought in the future; or (ii) whether the disabled child might receive bequests from family members other than parents. If the trust is implemented to hold an insurance policy, or if the child may receive non-means-tested ("waivered") benefits, the SNT may be an appropriate choice. The child may not be eligible for means-tested benefits during child's minority, which ceases when the child turns 18 due to the parents' legal obligation to support the child during minority.

If the disabled child does not require a special needs trust, it may be prudent to consider a less restrictive discretionary support trust, which provides for many of the benefits of the special needs trust, such as management of trust assets and asset protection. Since government benefits will likely not be sought, the distribution standard

could be far more permissive, perhaps employing the familiar "health, education, maintenance and support" (HEMS) standard.

Family wealth may also obviate the need for means-tested government benefits, in which case a discretionary trust might also be appropriate. Not all government benefits are means-tested, although most are.

II. EPTL § 7-1.12

EPTL §7-1.12 was enacted in 1993 to facilitate the creation of disability trusts for disabled children by family members. It provides clear guidance in establishing a "statutory" special needs trust. Under the model statutory language for third party trusts, a trustee's discretion is limited only when the distribution would adversely affect the beneficiary's benefit eligibility. For first party trusts, the trustee's discretion is significantly more limited. EPTL §7-1.12 requires that the trust be restrictive in order to prevent assets from becoming "available" assets.

The trust should always include language indicating that the intent of the settlor is to establish a trust fund for the benefit of the disabled child. The trust should also contain the following or similar language restricting expenditures that could affect government benefits:

None of the income or principal of this trust shall be applied in such a manner as to supplant, impair, or diminish benefits or assistance of any federal, state, county, city or other governmental entity for which the beneficiary may otherwise be eligible or which the beneficiary may be receiving.

The trust should also state that the beneficiary has no power to assign, encumber, direct, distribute, or authorize distributions from the

trust. The trust must include language prohibiting the trustee from taking any action that would impair the eligibility of the disabled child for receiving public benefits.

Any person may establish a testamentary trust for the benefit of a disabled person, not only a parent. The statute at first blush appears to preclude a parent from establishing a disability trust for a child under the age of 18, since the parent has a legal obligation of support. However, if the trust does not affect the parents' legal obligation of support, there appears to be no reason why a parent of a child under 18 not seeking government assistance could not establish a third party special needs trust to accomplish other important objectives.

The more sensible interpretation of the statute is that the support prohibition should not apply to children who either receive either no government benefits or only receive benefits under a "waivered" program. In those cases there would be no rationale for including a Medicaid payback provision in the trust. On the other hand, if the child is receiving means-tested government benefits as a minor, the child must be 18 or older before a no-payback special needs trust can be established due to the parental obligation of support.

Granting the Trustee Flexibility to Forego Government Benefits

Following the suggested language in EPTL § 7-1.12 might conflict with the trustee's judgment as to what is in the child's best interest. The required language might preclude distributions of food, clothing, shelter, or medical care covered by a benefit program. The prohibition would reduce the risk of noncompliance with the benefit program, but paradoxically might not always be in the best interest of the child.

The trustee might reasonably and

conclude the benefit of a distribution would exceed the loss of government benefits in a particular case. For example, the trustee might wish to subsidize the beneficiary's rent so that the child could be placed into a more commodious living arrangement. This would reduce the monthly Supplemental Security Income (SSI) benefit by a maximum of 1/3. Since the distribution would adversely impact a government benefit it would be prohibited under the most restrictive trust language found in EPTL § 7-1.2.

EPTL § 7-1.12 provides a solution, which is addressed by including trust language authorizing the trustee to deviate from the prohibition against reducing government benefits if the trustee believes that the distribution, despite impacting government benefits, would be in the best interest of the child. Suggested language also appears in EPTL § 7-1.12.

However, a governmental agency might later decide that program eligibility will be adversely affected if the trust provides that the trustee may make discretionary distributions despite the loss of government benefits. Here, additional suggested language also sanctioned under the statute could be included, allowing the trustee to "opt-out" of the trust provision allowing distributions even though such distributions would adversely affect eligibility for government programs. In essence, the relationship of the trust to the agencies providing benefits becomes a "cat and mouse" game if the two optional provisions are included in the trust.

It could be argued that this "togglng" feature actually undermines the restrictive nature of the trust, and makes the trust tilt more toward the discretionary spectrum, which might be regarded as against the public policy of the statute. However, since the additional language does have the imprimatur of the New York legislature, an agency

providing benefits might be somewhat more reluctant to challenge a trust benefitting from trust language allowing what amounts to built-in modification. When one weighs the benefit to the child versus the risk (cost) to the agency providing the benefits, the provision of benefits to the child may outweigh the gatekeeping function of the agency.

There is another important policy reason for the language allowing the trustee to forego government benefits in the best interest of the child: It recognizes the possibility that the beneficiary at some future time might not participate in a government program. If that were the case the child would be best served by allowing the trustee greater discretion.

Interestingly, it is not entirely clear that discretionary support trusts not meeting the requirements of EPTL § 7-1.12 would necessarily result in ineligibility for means-tested government benefits. For example, the Social Security Administration does not treat discretionary support trusts as “countable” assets if the beneficiary cannot compel distributions. POMS SI 01120.200. However, it is clear that a trust which grants the trustee unlimited discretion to provide for general support of the beneficiary would jeopardize qualification under Medicaid, SSI and other means-tested government benefit programs.

Distribution Standard Under EPTL §7-1.12

The distribution standard for special needs trusts suggested by EPTL § 7-1.12 range from extremely restrictive, to less restrictive, to an option to “toggle” between the two. If an SNT is deemed too restrictive, then the parent might instead consider a discretionary support trust. While the least restrictive option, this type of trust would might not achieve eligibility for means-tested government benefits.

Twin objectives of the SNT are to (i) employ the least restrictive distribution standard necessary to maintain compliance with eligibility criteria for means-tested government benefits now and in the future; while at the same time (ii) making maximum use of trust assets to improve the child’s quality of life. Since future eligibility requirements cannot be predicted, and even if they could be predicted, the child might not need a particular benefit, the trust should be capable of being amended or modified.

Whatever the distribution standard chosen, in interpreting the trust, under Escher and EPTL §7-1.12(a)(5)(i), courts will likely examine the parents’ clearly stated intent. Therefore, a clearly stated intent to preserve government benefits coupled with the beneficiary’s inability to directly or indirectly control distributions should allow for a more flexible distribution standard that would pass judicial scrutiny.

The strict distribution standard refers to the limitations placed on the trustee in making distributions that would curtail means-tested government benefits. What the statute forbids are distributions for “basic needs,” which consist of food and shelter (or distributions that would imperil government benefits). The trust must also prohibit the distribution of cash to the child. However, a trust can provide for a multitude of “special needs” that are not “basic needs.”

Thus, the trust might allow the trustee to make distributions for internet, cable television, or even a vacation. There are virtually limitless other permitted expenditures. To refine the point, the trust may prohibit distributions for basic needs such as food and shelter, and cash, but could expressly permit distributions for virtually anything else that has no impact on means-tested government programs.

If a flexible distribution standard is

employed, then distributions even for basic needs may be allowed if the distribution is in the best interest of the disabled child. When drafting the trust, it seems appropriate to enumerate expenses that the trustee may incur for the child, even though the list may be stated as being “illustrative,” rather than “exhaustive.” This would enable the trustee to make expenditures without having concern as to their propriety, aside from restrictions imposed by the statute.

For example, the child may have enjoyed a previous vacation to Disneyland in Anaheim. An explicit provision allowing a vacation there might also impliedly justify expenditures for other vacation destinations. Moreover, though such an expenditure would in all likelihood be appropriate without the provision, if the expense were substantial — as it likely would be — having the explicit provision in the trust would facilitate a decision of the trustee to allow the expenditure. If parents accompanied the child, it is conceivable that the trust could cover the entire vacation expense.

Early Termination

If the trust no longer serves its intended purpose, it may be desirable to terminate the trust. The trust might provide for termination if the beneficiary became employed for a continuous period of two years or otherwise loses eligibility for government entitlements; that a physician familiar with the beneficiary certifies that the disability no longer limits him or her from being gainfully employed; or that the trustee in his sole discretion determines that the facts warrant early termination. If the requirements for termination are clearly stated in the trust, the risk of a contingent beneficiary objecting to the termination appear low. In a case of a first party trust, Medicaid would presumably

require repayment of benefits paid until the time of trust termination.

III. Third Party Special Needs Trusts

Most special needs trusts are third party trusts funded by persons other than the disabled child — usually parents and grandparents. They are superior to first party trusts, but are not possible if the trust is to be funded by the disabled child himself. Unlike first party trusts, third party trusts need not contain a Medicaid payback provision, and their terms need be far less restrictive than their first party trust counterpart.

A third party trust may provide lifetime benefits to the child (assuming the disability lasts that long) with trust assets passing to remainder beneficiaries named in the trust. Third party special needs trusts effectively shelter assets so that they are “unavailable” and therefore will not impact eligibility for means-based government programs.

To be effective for their intended purpose, trust language must comply with EPTL § 7-1.12. Failure to so comply will not invalidate the trust per se, but it will most likely render the trust ineffective in obtaining SSI benefits, and will likely adversely impact eligibility for means-tested government benefits. The trust will still operate, but will not provide the benefits of a special needs trust. It will be internally contradictory, difficult to administer, and might require court involvement.

A third party special needs trust is typically funded either during the lifetime of the parents or at their death. Once funded, the trustee will have control over the assets distributed to the disabled child. Funding the trust during the parents’ lifetime will ensure that the trust is in effect when both parents are no longer alive. Lifetime funding may also reduce potential estate tax liability of the

parents by removing an appreciating asset from the parents' taxable estates.

Other tax benefits can also be achieved with proper tax planning. As noted, special issues arise when implanting a third party trust for a minor if means-tested government benefits are being sought, since parents have a legal obligation to support their child until the age of 18.

IV. First Party Special Needs Trusts

New York and most other jurisdictions bar a settlor from creating a self-settled, asset-protected trust in which the settlor is also the only beneficiary. EPTL § 7.3.1(a) provides that “[a] disposition in trust for the use of the creator is void as against the existing or subsequent creditors of the creator.” Accordingly, first party special needs trusts did not exist under the common law. However, as a result of the 1993 federal Medicaid legislation, first-party self-settled special needs trusts were sanctioned. Since federal law trumps state law under the “preemption doctrine,” New York then enacted a limited exception for self-settled trusts in the context of those which qualify under federal law. That exception was included in the language EPTL § 7-1.12.

Under federal Medicaid law, a disabled beneficiary may “self-settle” a special needs trust with assets owned by the disabled child himself. The assets might derive from a tort settlement, an inheritance, or a gift. The common thread is that the assets legally belong to the disabled child. However, first party trusts—in contrast to third party trusts—must contain a provision requiring the trustee, upon the death of the child, to reimburse Medicaid to the extent of remaining trust assets, for all amounts paid for the child during his or her life. Any trust assets remaining will pass to residuary beneficiaries

named in the trust.

Since a first party special needs trust is an exception to the doctrine barring self-settled trusts, permissible distributions from a first party special needs trust are circumscribed, and much more restrictive than distributions from third party trusts. The exception traces its lineage to the federal Medicaid statute revised in 1993. In addition, several eligibility requirements are exclusive to first party special needs trusts.

The Medicaid statute enumerates those requirements: First, the assets must come from an individual under the age of 65; second, the person must be “disabled” as defined under the Social Security law; third, the trust must be “established” by a parent, grandparent, legal guardian, or court; and fourth, there must be a “payback” provision in favor of Medicaid when the beneficiary dies.

The enabling statute, 42 U.S.C. §1396p(d)(4)(A) provides:

“[there shall be no transfer penalty to] a trust containing the assets of an individual under age 65 who is disabled . . . and which is established for the benefit of such individual by a parent, grandparent, legal guardian of the individual, or a court if the state will receive all amounts remaining in the trust upon the death of such individual up to [the total Medicaid outlay]. (Emphasis added).

Although the disabled child will be contributing his or her own assets to the trust, he or she may not “establish” the trust. The trust must be established by a parent, grandparent, legal guardian, or court. Creation of the trust by a parent or grandparent is optimal because that will in most cases obviate the need for court approval. However,

if the child is a minor or lacks capacity, a guardian ad litem may be need to be appointed. In that case, court involvement would be required.

In permitting first party special needs trusts, Congress has given special dispensation to disabled persons wishing to create trusts for their own benefit which will not impair government assistance. The disabled person is sheltering assets when transferring those assets to the trust. Yet for purposes of Medicaid and SSI, such transfers are not penalized and the assets will be respected as sheltered for purposes of Medicaid and SSI. The transfer will not affect benefit program eligibility, and the principal and income of the trust will continue to be exempt. (Whether the assets would be sheltered from claims of other creditors of the child is an interesting question.)

The inferiority of first party special needs trusts when compared to third party trusts reflects an attempt to reconcile the exception for first party SNTs with the general rule in New York prohibiting self-settled trusts. Since the federal Medicaid statute contains a carve-out allowing self-settled first party special needs trusts, the NYS Department of Health issued regulations which require the trustee to notify the local Social Services district of the creation and funding of a special needs trust established for the benefit of the applicant for Medicaid when the trust is funded with the applicant's own assets.

V. Deeming Rules and Parental Obligation of Support

SSI considers income and assets of parents of minor disabled children as "available" and countable for eligibility purposes. Disabled children under the age of 18 may therefore not qualify for public benefit

programs because their parents' income is "deemed" available to them. Parental deeming ceases once the child reaches age 18. At that time, the child may well qualify for SSI, Medicaid and other government and private benefits.

Some means-tested government benefit programs contain "waivers." If so "waivered," the income of parents is not relevant in determining the child's qualification for the benefit. This may occur, for example, where a severely disabled minor child returns home from an institution.

Interestingly, there appears to be no bar to a grandparent not under a legal obligation to support the minor disabled child from making a bequest to a no Medicaid payback supplemental needs trust before the child reaches the age of 18. However, the trustee would in most cases be precluded from applying for means-tested benefits by virtue of the "deeming" rules.

Although a bequest made to a special needs trust by a grandparent for the disabled child during his or her period of minority could not benefit the child with respect to means-tested benefits until the child attained the age of majority, once the child does reach age 18, and becomes eligible for means-based benefit programs, the previously funded SNT would presumably be sheltered for purposes of SSI and Medicaid, and could provide significant benefits.

In contrast, if no SNT exists for the child during the period of the child's minority, a grandparent wishing to make a bequest could only make the bequest directly to the child. This would limit the child to implementing an inferior first party trust. Therefore, by the expedient of having even an unfunded third party trust in place to act as a receptacle for gifts from grandparents and others, a third party trust established during a period of minority either by a parent or by a

grandparent to enable the child to qualify for government benefits when the child reaches the age of 18, would seem to not require a Medicaid payback provision.

A third party trust were created for a minor child should be named as the legal entity receiving any bequest from a parent or grandparent. It would defeat the purpose of the third party trust for a bequest to be paid to the child directly, because that would limit the child to creating a first party trust. The mistake of not making the gift to the trust would be difficult to correct. Once the bequest is “accepted” by the child, legal title to the assets pass to the child by operation of law. Retitling the asset into the name of an existing SNT will not be equivalent to the grandparent or relative having made a bequest directly to the SNT. Only a first party SNT could be considered.

Curiously, there may be one solution to a gift or bequest made by a grandparent to the child directly when a third party trust is in existence. That solution involves the child disclaiming the bequest. However, for this possible solution to be considered, several facts must be established: First, the disclaimed property must pass to the parents; second, the child must not have accepted any benefits; and third, the disclaimer must be effective.

If the bequest is made by will, then the disclaimed property must pass by operation of law to the parents. If this is not the case, then disclaiming the property would not be an option. However, if the disclaimed property were to pass to a parent, then the child must not have accepted any benefits of the disclaimed property. This requirement will likely have been met. Merely transferring the property to the bank account of the child would not be considered as the child having received benefits to disqualify a disclaimer.

Finally, the disclaimer must be effective, which means that it must be consummated

within 9 months of the bequest. The disclaimer would likely require court involvement, and might take more than 9 months to effectuate. A guardian ad litem would need to be appointed. There is also the problem of the bequest passing to the parent, who would then not be under a legal obligation to fund the third party trust either now, or more likely, when the child turned 18. However, a Court might approve a parent taking legal title to the bequest if the funds were held in escrow.

VI. Supplemental Security Income and Resource Rules

Supplemental Security Income (SSI) is a federal monthly cash income benefit provided to people with very low income and resources who are either aged (65 and over), blind or disabled. It is administered by the Social Security Administration (SSA). SSI eligibility depends on age, disability and need, but not work history. Qualification for SSI usually results in automatic qualification for Medicaid. The legal authority for SSI derives from the Social Security Act. 42 USC § 1381 et. seq. Policy guidelines are found in the Program Operations Manual System (POMS) on the Social Security Administration website. SI 00500.000 et. seq. The POMS sections relating to special needs trusts were revised effective April 30, 2018.

Although in New York and other States, qualifying for SSI will result in automatic qualification under Medicaid, the converse is not true: Not all Medicaid recipients qualify for SSI. This is significant, because many means-tested programs reference SSI and not Medicaid in determining eligibility.

In New York, SSI recipients receive two deposits: one from the federal Social Security Administration (SSA), and one from the New York State Office of Temporary and Disability

Assistance (OTDA) for the State Supplemental Payment (SSP) portion of the benefit. In New York, SSI recipients who live alone automatically get SNAP (Supplemental Nutrition Assistance Program) through NYSNIP (New York State Nutrition Assistance Project). Monthly cash income is typically direct-deposited into a recipient's bank account.

SSI eligibility references income and assets. A person must have no more than \$2,000 in available resources and little or no income. Some assets are not "countable" as resources: Those assets include the beneficiary's home, one automobile, household furnishings, prepaid burial expenses, tools of the beneficiary's trade, and several other items.

Money received in a given month is income. Any money remaining at the start of the next month becomes an asset. "Countable" income is used to determine SSI eligibility; "excluded" income is not counted. "Unearned" income refers to income received without the performance of work. Gifts and investment income constitute unearned income.

Unearned income reduces SSI benefits dollar-for-dollar. Earned income is treated more favorably. However, since an SSI recipient is a person with a disability rendering him or her "unable to perform any substantial gainful activity," a significant amount of earned income might cause a termination of SSI benefits.

Special Needs Trusts Not a Resource If Properly Drafted

Given that the purpose of special needs trusts is to ensure that assets owned by the beneficiary are not available resources for purposes of means-tested government programs such as SSI and Medicaid, a

properly drafted SNT should comply with the requirements of both the Medicaid statute and the rules for SSI as found in POMS.

With respect to Medicaid, the special needs trust must be drafted to comply with the Federal Medicaid Statute found in 42 U.S.C. §1396(d)(4). The situation with POMS (for SSI purposes) is more complicated: POMS provides that compliance with the federal Medicaid statute is necessary but not sufficient. The trust must still be evaluated to determine whether it is an available resource.

In New York, a trust in which the grantor is also the sole beneficiary is deemed to be revocable, even if the trust provides that it is irrevocable. Under SSI, a revocable trust is considered a countable resource. This would seem to disqualify a first party special needs trust, because the disabled child is both the grantor and beneficiary. However POMS provides in a section applicable only to New York and New Jersey that a trust will not be deemed revocable if residuary beneficiaries consist of (i) a named living person, (ii) "issue" (if living, and the grantor's issue), or (iii) the State of New York.

Receipt of lump sums may be problematic and are addressed in POMS. A court order directing a lump sum be paid directly to a trust may result in the payment being deemed irrevocable and thus not countable income. This could apply to a tort settlement, alimony, or child support. Some payments such as Social Security, federal or state pensions, and veterans benefits, are not assignable. There is no transfer penalty for transfers into a special needs trust for a disabled individual under age 65.

In-Kind Support and Maintenance

In-kind distributions by parents of food or shelter reduce SSI payments by a maximum of 1/3. In-kind payments of items other than

goods and services will not reduce SSI payments. Medicaid does not track in-kind distributions. Medicaid is only concerned with income and resources actually available to the disabled child.

Payments for food and shelter are considered “necessities of life,” and when made by parents to a third party will be treated as “countable” income. However, the amount of countable income for SSI purposes is not the amount actually paid to the provider. Rather, the SSI monthly benefit is reduced by the lesser of

- (i) the value of the items provided; or
- (ii) 1/3 of the SSI benefit.

For 2023, the federal SSI benefit for a single person is \$914; the New York supplemental benefit is \$87.

Illustration. John is disabled due to a serious physical or mental illness and is receiving federal SSI benefits of \$914 per month. Father gives John \$700. The income is “countable” and reduces the SSI benefit dollar-for-dollar to \$214, regardless of how John spends the money. Now assume Father buys John \$700 of food. The \$700 is still “countable,” since it was used to buy food or shelter, which are “necessities of life.” One-third of the SSI benefit is \$305. Since \$305 is less than \$700, John’s monthly federal SSI benefit is reduced by \$305, to \$409.

Now assume Father gives John \$500 to buy food. John’s monthly SSI benefit is reduced dollar-for-dollar by \$500, to \$214. If John had instead used the \$500 to buy a bicycle, his SSI would also be reduced by \$500. If John’s father had instead purchased the bicycle for John, John’s SSI benefit would be unchanged since a bicycle is not a

“necessity of life,” which is limited to food or shelter. Finally, assume Father buys John an iPhone for \$1,500. Since the in-kind distribution was not for food or shelter, it is also not “countable.” John’s SSI benefit would be unaffected. If Father had given John \$1,500 to purchase the iPhone, John’s SSI benefit would be reduced to 0.

Parents of a disabled child receiving SSI might elect to pay the rent of their child at an adult care facility. That that payment, being a “necessity of life,” would reduce the SSI benefit by 1/3, regardless of the amount of the rental payment. Therefore, if parents made a monthly rental payment of \$2,000 for their disabled child receiving monthly SSI of \$914, the SSI benefit would be reduced by \$305, to \$609. This might be an acceptable trade off, and the trustee might deem the reduction in SSI benefits for the improved living arrangement in the best interest of the child.

The discretion of the trustee of an SNT to make this payment — that is, to forego the full SSI payment in order to improve the life of the child — is an important feature of the optional language suggested in EPTL §7-1.12. Since Medicaid eligibility references SSI eligibility in New York, loss of Medicaid would appear not to be problematic.

The drafter of a third party SNT has two basic options at the outset: The trustee may be prohibited from making any payments or distributions to the child for “necessary expenses” or expenses that could undermine eligibility for government benefits. This route is safest, since violation of intricate rules governing Medicaid and SSI are unlikely to be violated. Although safest, this is not necessarily the preferred option.

Most settlors would choose to confer upon the trustee discretion with respect to in-kind distributions of food or shelter even though such distributions that might reduce SSI benefits. No special concern exists for in-

kind distributions of items other than food or shelter, since those in-kind distributions will not affect SSI benefits.

When making an in-kind distribution for housing, it is important that the distribution not violate any of the highly technical rules governing public benefit programs. Failure to adhere precisely to those rules could conceivably cause a termination of SSI benefits. Since Medicaid is tied to SSI, losing SSI would also possibly cause a loss of Medicaid benefits. Therefore, one must tread lightly employing a more flexible standard when drafting the trust. The trustee must tread even more lightly when actually making such an in-kind distribution pursuant to trustee discretion.

VII. Trustee Considerations

The parent may be a suitable, even preferred trustee of an SNT. The parent serving as trustee should be familiar with the government benefits the child receives or is likely to receive. The parent may enlist the help of an attorney in this regard. A financial advisor can also be retained. Tax advisors will also be necessary to timely file fiduciary tax returns. Many special needs trusts require that the trustee be bonded by a commercial surety company.

Matter of J.P. Morgan Chase

Matter of the Accounting of *J.P. Morgan Chase Bank, N.A.*, 956 NYS 2nd 856 (N.Y. Surr. Ct., 2012) examined the extent to which a fiduciary has an affirmative duty to ensure that the needs of the beneficiary of a special needs trust are met. The case illustrates that the grant of “full discretion” may require the trustee to invest more time and attention to a disabled child.

Mark, who was autistic, had a well-

funded trust that had implemented by his mother. Both parents became deceased. Mark was living in a Medicaid-funded residential program for individuals with autism. It was the responsibility of *J.P. Morgan* to determine how private dollars should be spent to supplement the care Mark was receiving. The Surrogates Court in reviewing the account of the trustees determined that while the bank took commissions and fees, practically nothing was spent on Mark until the Court intervened. The trust sat “dormant” for years. The Court determined that J.P. Morgan was not entitled to compensation because it failed to be proactive in identifying the needs of the beneficiary:

It was not sufficient for the trustees merely to prudently invest the trust corpus. . . . The trustees here were affirmatively charged with applying trust assets to Mark’s benefit. . . . Both case law and basic principles of trust administration and fiduciary obligation require the trustees To keep abreast of Mark’s condition, needs, and quality of life, and utilize trust assets for his actual benefit.

J.P. Morgan ultimately retained a private social worker to determine how Mark’s life could be improved through the prudent use of trust funds. As a result, Mark’s life in fact improved greatly. The case illustrates the need for even an institutional trustee to engage other professionals who can assist in managing the needs of the disabled child, especially in situations where the parents are gone and there are no other persons who could fill the void in advising the trustee of the child’s needs. The case also underscores the need for an effective and comprehensive letter of intent, discussed below.

VIII. Tax Considerations

A first party special needs trust would typically be a grantor trust for income tax purposes since the child contributes the trust assets and remains the beneficiary. First party SNTs are usually funded with the proceeds of a tort litigation or from an outright inheritance. Since this trust is authorized by the Medicaid statute, 42 U.S.C. § 1396p(d)(4)(A), it is sometimes referred to as a (d)(4)(A) trust.

Although the child retains the right to income and principal of the trust, the child's interest is restricted since the trustee has full discretion with respect to distributions, and can only make distributions that will not impair benefits the child receives from governmental programs.

Since grantor trusts are ignored for federal income tax purposes, income from a first party trust will be taxed to the disabled child, who will typically be in a low income tax bracket and may have large medical expenses that will be deductible.

In some circumstances it may be prudent to seek to have the trust taxed as a nongrantor trust for income tax purposes. This can be accomplished by the trustee relinquishing certain powers. In that case, the trust would be a separate taxable entity.

Third party SNTs are usually funded by parents or grandparents of a disabled child. If created during the parents' lifetime, the trust would be a separate document. If created at death, it would typically be incorporated into a will. To be effective, the trust must be irrevocable. Although a will may be revoked, if it contains a testamentary SNT, the irrevocability requirement is satisfied, since the trust will become irrevocable when the parent dies.

If the third party SNT is created during

a parent's lifetime, the trust can be structured to be either a grantor or a nongrantor trust. In general, grantor trust status is preferable, since the trust corpus will continue to grow tax-free without the imposition of income tax. The status of a trust as a grantor trust created by a parent would terminate at the death of the parent. At that point, the trust would become a non-grantor trust.

If the third party SNT were drafted as a nongrantor trust, the trust would report income, file its own tax return, and pay taxes from trust income or principal. The trust would be subject to the compressed trust tax rates, so accumulated income would be taxed at a higher rate than if the trust were a grantor trust.

IX. Letter of Intent

During the life of the disabled child, the parents will be able to best assess the progress of the child and attend to his or her needs. However, the child may outlive both parents, and the trust may continue to operate. It is apparent that the terms of even a well-drafted trust that served the child well during the life of the parents would then be insufficient alone.

Filling this void is an issue which should be addressed during the life of the parents. As a first step, the parents will have typically named a guardian to make legal decisions outside the ambit of the trustee. If a parent were serving as trustee and has continued in that fiduciary capacity until death, it would be extremely helpful if the new trustee had a document which contained important information about the child.

To assist the new trustee, as well as a relative or family friend who may participate in the care of the child, a "letter of intent" could prove to be an invaluable resource to the new persons or entities now charged with not

only administering the trust, but helping the disabled person deal with the loss of parents and the child's new life challenges. The letter need not be drafted all at once. It can be prepared throughout the child's life, and supplemented with important medical or other documents as necessity dictates.

The letter of intent should be thorough and contain financial and other information helpful to a new trustee, be it an individual or institution. Other relevant information, such as the child's medical situation, personal preferences for food and recreation, and important contacts might be included. While preparing a letter of intent plan is possible after the parents are gone, the quality of a letter drafted by another family member, or even another person with knowledge of the child's circumstances would not approach that prepared by the parent or parents.

In situations where the special needs trust appears in a testamentary document, most likely as a provision in a will, it is even more important that the letter be comprehensive. Here, the trust will be nascent and trust provisions are likely to be much less detailed than if the trust had been operating as a separate instrument during the parents' lives.

The loss of both the child's parents will undoubtedly be very difficult for the child to cope with. Anything which helps the new caregivers deal with the child's loss — pictures and mementos — will make it easier for the child to deal with his or her grief.

X. ABLE Accounts

An ABLE account allows individuals with disabilities and their families to save for qualified disability-related expenses on a tax-free basis without adversely affecting the child's ability to benefit from Supplemental Security Income, Medicaid, and other means-

tested government benefit programs now or in the future. Since the ABLE account does not affect these eligibility for these government benefit programs, an account may be used either as a stand-alone substitute or in conjunction with a special needs trust. ABLE stands for "Achieving a Better Life Experience Act of 2014."

NY ABLE is intended to qualify under IRC Sec. 529A. The program is managed by Ascensus Broker Dealer Services, LLC. Ascensus has responsibility for day-to-day operations, including investment advisory, recordkeeping, and administrative services. Except to the extent of FDIC insurance provided for the checking option, neither New York or its agencies, nor Ascensus or its affiliates, guarantees the principal deposited or any investment returns.

A parent or legal guardian, or a disabled person him or herself under the age of 26 may open an account if the person (i) is either entitled to SSI or (ii) meets special criteria for disability. Proof of eligibility is not required to open an ABLE account; it is nevertheless advisable that the parent maintain a benefits verification letter, a record of diagnosis, or other proof of eligibility. An account may be opened online for \$15, or by paper application for \$25.

The maximum contribution to an ABLE account in 2023 is \$17,000 from all sources. Each State sets its own maximum account limits. In New York, the limit is \$100,000 for persons receiving SSI. For persons not receiving SSI, the maximum account balance is \$520,000.

Account balances grow tax-free. Amounts paid for qualified disability expenses are not taxed, and will not adversely affect Medicaid or SSI benefits. Amounts withdrawn and not used for qualified disability expenses are taxed as income, and will be subject to a 10 percent federal tax penalty. Withdrawals

can be made by phone, online, with a NY ABLE debit card or by check.

Funds may be used for disability-related expenses that assist the beneficiary in improving or maintaining health, independence, or quality of life. Qualified disability expenses include expenses related to education, health and wellness, housing, transportation, legal fees, financial management, employment training, assistive technology, personal support services and oversight and monitoring.

Funds derived from the beneficiary's assets, or from the receipt of gifts deposited into an ABLE account are exempt as income and resources under NYCRR § 352. Such transfers will shelter the beneficiary's assets for Medicaid and SSI purposes. However, monthly income of the beneficiary deposited into an ABLE account is not "exempt" for Medicaid or SSI purposes.

One useful feature of an ABLE account relates to payment of rent. The payment by parent (or trustee) for rent of the child will reduce the SSI payment by up to one-third. If the payment originates from an ABLE account, the SSI benefit would be unaffected. A parent wishing to utilize this technique could either make deposits into an ABLE account which would then make the qualified expenditure, or make a transfer to the SNT, which could then make a transfer to the ABLE account. Funds transferred from the SNT to the ABLE account will not count as income to the child. Social Security Administration's POMS SI 01130.740.

At death, the ABLE account must pay back to Medicaid an amount equal to the costs incurred by Medicaid since the ABLE account was established. This rule is more favorable than the payback rule for first party trusts which requires reimbursement for all costs paid by Medicaid during the lifetime of the disabled child.

XI. Conclusion

Third party special needs trusts enable parents and relatives to fund trusts which shelter assets so that their disabled child can qualify for Medicaid, SSI and means-tested governmental benefit programs without exhausting trust assets. Those trust assets can improve the child's quality of life by providing funds which can be used to pay for almost any expense other than food, shelter or an expense that would impair qualification for a government benefit.

When the child dies, remaining trust assets will benefit named trust beneficiaries. Care must be taken when implementing a third party trust for a minor, since the parent still has a legal obligation of support during the period of child's minority. Even so, the third party trust can likely serve other important purposes during the period when the child is under 18, one of which is being a receptacle for bequest made by perhaps grandparents, another of which relates to "waivered" government benefit programs that would not require Medicaid payback.

First party special needs trusts are a fallback, and may be used when a third party trust is not possible. This would be the case where the child has assets from a settled tort claim, or receives a direct bequest. First party trusts are funded not by parents or relatives but by the child himself. Since New York and nearly all other States do not permit a person to create an irrevocable, creditor-protected trust for his or her own benefit, a first party trust is possible only by virtue of the federal Medicaid statute which creates an exception for such trusts. The requirements for first party SNTs are more stringent than for third party SNTs, and the distribution requirements are more rigid. First party trusts must also "pay back" to Medicaid all funds expended by

Medicaid during the child's lifetime when the trust terminates.

Both first and third party SNTs benefit from EPTL §7-1.2, which contains suggested language ensuring that the trust qualifies as a special needs trust. Various distribution options available only for third party trusts provide give added flexibility to the trustee with regard to discretionary distributions.

Special needs trusts in New York draw directly from the principles articulated by the Bronx Surrogates Court and affirmed by the Court of Appeals in *Matter of Escher*, a landmark case decided nearly fifty years ago, which held that a disabled person should not be required to exhaust his or her own assets before qualifying for government assistance:

It is the conclusion of this court that the rigidity of any possible public policy requiring an invasion of trust corpus to the burdens of a publicly funded program is subject to dilution, if it extends at all, in situations where the expenditure involved is the current astronomical cost of institutional care where the application of the total corpus to these charges would summarily render meaningless, a testamentary scheme, carefully designed to carry out an intent to retain some portion of a trust corpus for the ongoing needs of the life beneficiary, with a remainder for the benefit of other surviving issue. A contrary conclusion would, for almost all testators, except the most affluent, totally vitiate the viability of testamentary trusts as a device for bequeathing a remainder should the vicissitudes of life lead to an aged life beneficiary requiring extended institutional care.

Matter of Escher, 94 Misc.2d 952 (Surr.Ct.,

Bronx Cty 1978), *aff'd* 75 AD2d 531 (1st Dept. 1980). *aff'd* 52 NY2d 1006.