Estate Planning for a Family with a **Special Needs Child**

By Sebastian V. Grassi Jr.

This article is a general overview of issues that a lawyer may need to address when preparing an estate plan for a family with a special needs child.

For purposes of this article, "special needs child" refers to a child who, at birth or because of a subsequent illness or injury, is mentally, physically, or emotionally disabled, and because of the severity of the disability is, or may be, eligible for means-tested government benefits. "Means-tested" government benefits are public programs with limitations on the amount of income and assets/resources a recipient can own. Such programs include Supplemental Security Income and Medicaid.

Typical special needs children include those born with cerebral palsy, autism, Fragile X syndrome, Down syndrome, mental impairment, and so on. See Thomas D. Begley Jr. & Angela E. Canellos, *Special Needs Trust Handbook* (2009); chapter 17 of Lawrence A. Frolik & Melissa C. Brown, *Advising the Elderly or Disabled Client* (2d ed. supp. 2008); and Sterling L. Ross Jr., *The Special Needs Trust: A New Wrinkle No More*, 36th Heckerling Inst. on Est. Plan. ch. 16 (Jan. 2002), at 15-i, for detailed information on special needs planning.

Overview of Critical Government Benefit Programs

The most important means-tested government benefit programs concerning a special needs child are:

- Supplemental Security Income (SSI), 42 U.S.C. § 1381 et seq., 20 C.F.R. Part 416, which provides a minimum level of monthly income to aged, blind, and disabled individuals who meet certain eligibility requirements and are indigent. In most states, the receipt of SSI benefits automatically entitles or includes the receipt of Medicaid benefits. The two benefits are linked together. If the special needs child loses his or her SSI benefits, the child may also lose his or her Medicaid benefits.
- Medicaid, 42 U.S.C. § 1396 et seq., 40 C.F.R. Parts 430, 431, and 435, which is a medical payment program (and not a health insurance program) for the aged, blind, and disabled who meet certain eligibility requirements and are indigent. In addition to paying for medical services, Medicaid pays for a host of ancillary services that are essential for a special needs child, such as personal care attendants, housing, and so on. Consequently, preserving the special needs child's Medicaid eligibility is typically of paramount concern.

Special Needs Challenges and Responses

In addition to the usual hurdles that parents face when preparing an estate plan (for example, who should be the guardian, trustee, executor, and so on), the parents of a special needs child are faced with five unique estate planning challenges:

1. how to provide for *all* of their loved ones without jeopardizing the special needs child's current (or potential) eligibility for means-tested government benefits such as SSI and Medicaid;
2. how to design an estate plan that supplements the special needs child's means-tested government benefits and enhances the quality of the special needs child's life;
3. how to treat the other children equitably while providing for the special needs child;
4. how to make sure sufficient funds are available at a parent's death to care for the special needs child; and
5. how to provide for the proper supervision, management, and distribution of an inheritance for the special needs child through a third-party created and funded special needs trust (SNT).

Of these five unique estate planning challenges, items (4) and (5) typically prove to be the most difficult to implement. This is especially true if most of the parents' estate is composed of retirement benefits, if there is no trustee in the parents'/special needs child's vicinity who is experienced in administering SNTs, or if there is an experienced trustee

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available (typically a corporate trustee) but its minimum fee is too high relative to the proposed size of the SNT.

Practice Point: In the client estate planning questionnaire/intake form, ask if any family members are disabled, incapacitated, or have special needs.

At a minimum, the parents of a special needs child should typically have the following five estate planning documents prepared:

1. A last will and testament.
2. A general durable power of attorney for financial affairs (GDPA). The parent's GDPA should permit the agent to make discretionary nonsupport distributions to or for the benefit of the special needs child and to establish a third-party created and funded SNT for the benefit of the special needs child.
3. A durable medical power of attorney.
4. A revocable living trust. During a parent's period of incapacity, the parent's revocable living trust should contain language that permits the trustee to make discretionary nonsupport distributions to or for the benefit of the special needs child. On the parent's death, the special needs child's inheritance should be distributed to a third-party created and funded SNT previously established by the parent.
5. A third-party created and funded SNT, which is discussed below.

Five estate planning options are available to parents concerning their special needs child:

1. Distributing assets outright to the special needs child (not recommended because the assets may disqualify the child from receiving means-tested government benefits);
2. Disinheriting the special needs child (generally not recommended because the child will have no "safety net" if government benefits are subsequently reduced or eliminated);
3. Leaving property to another family member with the "understanding" that the property will be used for the benefit of the special needs child (generally not recommended because the arrangement is not legally enforceable and the sibling's creditors (including a potential ex-spouse) may be able to seize the assets);
4. Establishing a third-party discretionary support trust for the special needs child (generally not recommended because the trust will, in many states, disqualify the child from receiving means-tested government benefits); and
5. Establishing a third-party created and funded SNT for the special needs child (highly recommended because the trust will not disqualify the child from receiving means-tested government benefits).

An SNT established by and wholly with the assets of someone other than the special needs child is considered to be a "third-party" trust.

The Third-Party Created and Funded Special Needs Trust

Of these five options, practitioners generally prefer that parents establish an inter-vivos stand-alone, third-party created and funded SNT. An alternative to a stand-alone, third-party created and funded SNT is to have the parents' last will and testament or their revocable living trust contain third-party created and funded SNT provisions.

An SNT established by and wholly funded with the assets of someone other than the special needs child (or the special needs child's spouse) is considered to be a "third-party" trust. Under existing applicable law, assets contained in a properly drafted and administered third-party created and funded SNT are not considered to be "available" to the special needs child for determining the child's (financial) eligibility for means-tested government benefits, such as SSI and Medicaid, *and there is no requirement that Medicaid be repaid from the third-party created and funded SNT when the special needs child dies or if the trust terminates during the special needs child's lifetime.*

A typical third-party created and funded SNT is one established by the parents or grandparents of the special needs child that is funded with the parents' or grandparents' assets (and not with the assets of the special needs child) *and* such trust is not created under 42 U.S.C. § 1396p(c)(2)(B)(iii) to make the trustmaker (for example, the parent or grandparent) eligible for Medicaid paid nursing home care. A trust established with the special needs child's assets (such as an inheritance, gift, bequest, alimony, or lawsuit settlement received by or payable to the special needs child) is considered to be a "first-party" or "self-settled" trust. First-party special needs trusts are discussed below.

Caution: *Never, ever* include a Medicaid payback provision in a third-party created and funded SNT. This point cannot be overemphasized.

Practice Point: If an irrevocable inter-vivos third-party created and funded SNT is established by the parents or grandparents, the parents' (or grandparents') wills should specify the

source for the payment of any death taxes attributable to the trust if any part of the third-party created and funded SNT is includable in the parents' (or grandparents') gross estate. Should the death taxes be apportioned against the third-party created and funded SNT, or against the residue of the parents' (or grandparents') estate?

Trustee Selection

Because the trustee of a third-party created and funded SNT is given complete discretion in making distributions to or for the benefit of the special needs child, who should serve as the trustee of a third-party created and funded SNT is important. The selection of the trustee involves many considerations, including the trustee's ability to understand and respond to the needs of the special needs child; the trustee's knowledge of government benefit programs and the effect that trust distributions will have on the special needs child's government benefits; the trustee's health, integrity, reliability, and financial acumen; the trustee's potential for a conflict of interest if the trustee is a current or remainder beneficiary of the trust; and the potential for adverse income and transfer tax consequences if a family member serves as a trustee and is also a current or remainder beneficiary of the trust.

Caution: Because of SSI and Medicaid rules and for various tax reasons, neither the special needs child nor his or her spouse should serve as trustee of either a third-party or first-party SNT.

A Maximum Flexibility

Because a third-party created and funded SNT is a discretionary nonsupport trust with spendthrift provisions (a very important element under common law and the Uniform Trust Code (UTC)—see UTC §§ 501 and 502), the trustee has maximum flexibility to meet the beneficiary's needs and maintain the beneficiary's eligibility for government benefits, all of which underscores the need to select the right person to serve as trustee.

As previously mentioned, such a trust, if properly drafted and administered, does not disqualify a special needs child from receiving means-tested government benefits. A third-party created and funded SNT is well suited to deal with possible changes in the amount of government benefits that may be available in the future because of changes in SSI or Medicaid funding, budget cuts, eligibility requirements, and so on.

The principal purpose of a third-party created and funded SNT is to provide an inheritance for the special needs child without risking the loss of important means-tested government benefits such as SSI, Medicaid, and so on.

Even if the special needs child does not receive means-tested government benefits such as SSI or Medicaid and instead receives entitlement-based government benefits such as Social Security Disability Income and Medicare, a third-party created and funded SNT will always protect the special needs child from his or her inabilities, disabilities, predators, and creditors. A third-party created and funded SNT can, at the same time, be both flexible and protective.

Contingent Provisions

Anyone can become a special needs child (or severely disabled) in just a matter of seconds. An auto accident or sporting injury can change a person's life forever. To plan for the possibility that a child (or beneficiary under a trust or will) becomes severely disabled at a later date, the testator/trustmaker should include a provision in the governing instrument that permits the fiduciary to establish a third-party created and funded SNT and fund the trust with the property that would otherwise be paid outright to the (now) severely disabled beneficiary. See sample drafting language on the following page.

Coordination with Other Relatives' Estate Plans

The principal purpose of a third-party created and funded SNT is to provide an inheritance for the special needs child without risking the loss of important means-tested government benefits such as SSI, Medicaid, and so on. Consequently, it is important that grandparents and other relatives (including the siblings of the special needs child) do not leave an inheritance outright to a special needs loved one.

Fortunately a parent's stand-alone inter-vivos third-party created and funded SNT can be structured to receive gifts, bequests, and inheritances from grandparents' (and other relatives'/friends') for the benefit of the special needs child. This avoids the grandparents (or other relatives/friends) having to prepare a separate third-party created and funded SNT.

Review of All the Parents' Assets

A corollary to the need to coordinate a special needs child's inheritance with other relatives is the need to review all possible ways a special needs child could receive property, an inheritance, or a gift. For example, the following common assets and applicable beneficiary designations should be reviewed to make sure they will not be paid (or given) directly to the special needs child:

- IRA, 401(k), and other retirement benefits, see section 6.3.11 of Natalie B. Choate, *Life and Death Planning for Retirement Benefits* (6th ed. 2006), www.ataxplan.com;

Sample (contingency) language for inclusion in a relative's trust or will [use "Executor"] in the event a beneficiary subsequently becomes disabled and needs public assistance benefits. The author makes no warranties or representations concerning the tax implications or efficacy of the sample language.

Power to Establish a Special Needs Trust, and to Amend or Reform a Trust. If an individual beneficiary-devisee has applied for or is receiving government assistance that is based on financial eligibility requirements, or if Trustee [Executor] reasonably anticipates that a beneficiary-devisee may need such government assistance in the foreseeable future, Trustee [Executor] may in its sole, absolute and uncontrolled discretion withhold the trust [estate] property otherwise distributable to such beneficiary-devisee and establish a third-party created and funded discretionary non-support spendthrift special needs trust; or if that is not possible or practicable, establish by court order a first-party (i.e., a self-settled) discretionary non-support spendthrift special needs trust (such as a self- settled special needs trust permitted under 42 U.S.C. 1396p(d)(4)(A) or 42 U.S.C. 1396p(d)(4)(C)). Trustee [Executor] shall then fund the special needs trust with the property that would otherwise be distributed to the beneficiary-devisee. In establishing a special needs trust, Trustee [Executor] may select a trustee and successor trustees (other than the beneficiary-devisee or the beneficiary-devisee's spouse), establish accounting requirements, and shall include all provisions determined to be reasonable and necessary by Trustee [Executor] after consultation with a qualified attorney. It is my intent that any special needs trust established pursuant to this provision be drafted and administered so as to provide the maximum benefit to the beneficiary-devisee and that the assets of the special needs trust not be available to the beneficiary-devisee for determining the beneficiary-devisee's income or assets under rules by which any government agency determines eligibility for need-based services or financial services (such as SSI and Medicaid). To the extent required by law, the special needs trust shall be for the sole benefit of the beneficiary-devisee during his or her lifetime. To the extent not prohibited by law, distributions from the special needs trust shall be made in the sole, absolute, and uncontrolled discretion of the special needs trustee to or for the benefit of the beneficiary-devisee. In making such distributions, the special needs trustee shall consider the effect such distributions may have on the beneficiary-devisee's said government assistance benefits. The special needs trust (or joinder agreement as concerns a special needs trust established pursuant to 42 U.S.C. 1396p(d)(4)(C)) shall provide (to the extent possible) that upon the beneficiary-devisee's death and after all proper reimbursements and payment of expenses have been made (to the extent such reimbursements and payment of expenses are required by law), the special needs trustee shall distribute the remaining trust property (if any) to such of my descendants (other than the beneficiary-devisee, the beneficiary-devisee's estate or the creditors of either) as the beneficiary-devisee shall appoint by the beneficiary-devisee's last will and testament that makes specific reference to this testamentary limited power of appointment. Any unappointed trust property shall be distributed to the then living descendants of the beneficiary-devisee, by right of representation, or if there are no then living descendants of the beneficiary-devisee, the unappointed trust property shall instead be distributed: (i) to my descendants by right of representation, or (ii) to such remainder beneficiaries as may be determined by a court of competent jurisdiction at the time of Trustee's [Executor's] establishment of the special needs trust. Trustee [Executor] shall neither possess nor exercise its authority hereunder in a manner that would impair or prevent a beneficiary's unexercised right of withdrawal that has not yet lapsed, or prevent an existing bequest from qualifying for the marital or charitable deduction, or impair the status or qualification of a trust that holds shares of stock in a Subchapter S corporation, or prevent a trust from qualifying as a Look-Through Trust with a Designated Beneficiary (or Beneficiaries).

After my death, Trustee [Executor] may obtain an order from a court of competent jurisdiction to amend or reform any trust (or any trust created or to be created) under this instrument to the minimum extent necessary to comply with my intent and to comply with applicable federal and state laws or regulations, including those pertaining to special needs trusts. Trustee's [Executor's] authority hereunder is to be exercised only in fiduciary capacity and may not be used to enlarge or shift any beneficial interest except as an incidental consequence of the discharge of fiduciary duties, and in no event shall any amendment or reformation increase the class of beneficiaries. No Trustee [Executor] (or court) shall have the power to amend or reform this instrument in a manner that would thwart my intent, impair or prevent a beneficiary's unexercised right of withdrawal that has not yet lapsed, or prevent an existing bequest from qualifying for the marital or charitable deduction, or impair the status or qualification of a trust that holds shares of stock in a Subchapter S corporation, or prevent a trust from qualifying as a Look-Through Trust with a Designated Beneficiary (or Beneficiaries). In no event shall this power of amendment or reformation be construed or exercised in a manner so as to bestow upon Trustee [Executor] a general power of appointment (as that term is defined under the Internal Revenue Code). ■

- life insurance (including employer-provided life insurance) benefits;
- accidental death and travel insurance benefits provided through credit cards when a person purchases a plane ticket, and so on, using that credit card;
- annuities;
- savings bonds;
- any property not subject to the parents' will or trust;
- UGMA or UTMA accounts;
- "transfer on death" (TOD), "pay on death" (POD), "in trust for" (ITF) designations on accounts, savings bonds, or securities;
- inheritances, gifts, or bequests through another person's will or trust (if not paid to a third-party created and funded SNT);
- deeds;
- joint accounts;
- jointly owned property, including jointly owned real estate;
- final paycheck (including unused vacation and sick pay);
- collectibles, antiques, and family heirlooms;
- personal injury and wrongful death proceeds payable to a deceased parent's estate; and
- homestead laws that give the surviving spouse a life estate and the minor children a vested remainder interest (as does Florida law in certain instances).

Caution: This list is not exhaustive.

Managing Assets Already Owned by a Special Needs Child

If a special needs child who is disabled (as defined by Social Security under 42 U.S.C. § 1382c(a)(3)) has received (or has a vested noncontingent right to receive) an inheritance, gift, bequest, lawsuit award or settlement, child support, alimony, or divorce property settlement, the special needs child's receipt of these assets can result in the disqualification of means-tested government benefits such as SSI and Medicaid. See Thomas D. Begley Jr. & Andrew H. Hook, *Using Self-Settled Special Needs Trusts to Facilitate Matrimonial Settlements*, 34 Est. Plan. 42 (Apr. 2007).

To preserve these government benefits, the special needs child's disqualifying assets should be converted into exempt (or noncountable) assets or be transferred to a first-party self-settled SNT that is government approved.

The (d)(4)(A) SNT

The first type of safe harbor first-party self-settled SNT is an inter-vivos irrevocable trust established under 42 U.S.C. § 1396p(d)(4)(A), commonly referred to as a "(d)(4)(A) SNT" or a "(d)(4)(A) Medicaid payback trust." A (d)(4)(A) SNT is best suited for a significant amount of resources that can sustain a professional trustee's minimum fee schedule. Generally, a corporate fiduciary requires the trust to contain at least $100,000 in marketable assets. By statute, a (d)(4)(A) SNT must contain a Medicaid payback provision on the death of the special needs child (or in some instances, if the trust terminates during the lifetime of the special needs child)—hence the name, "Medicaid payback trust."

Practice Point: As previously mentioned, a third-party created and funded SNT is *not* required to contain a Medicaid payback provision and should *never* contain a Medicaid payback provision.

The (d)(4)(C) SNT

The second type of safe harbor first-party self-settled SNT is an inter-vivos "pooled account trust" established under 42 U.S.C. § 1396p(d)(4)(C), commonly referred to as a "(d)(4)(C) SNT" or a "(d)(4)(C) pooled account trust." A (d)(4)(C) SNT is administered by a nonprofit charitable association, which also acts as the trustee. The special needs child's disqualifying assets are transferred into the master trust, and a separate trust account (also known as a "sub-trust account") is established by the nonprofit charitable association for the sole benefit of the special needs child. For purposes of investment and management of funds, however, the master trust pools all the separate trust accounts—hence the name, "pooled account trust." A (d)(4)(C) pooled account trust is best suited for the situation in which the amount of non-exempt assets owned by the special needs child is not large enough to justify the cost of establishing and administering a (d)(4)(A) SNT or when the parents or child want to ultimately benefit the mission of the nonprofit association on the death of the special needs child.

Practice Point: Not all states have (d)(4)(C) pooled account trusts.

The transfer of a special needs child's assets to a properly drafted and administered OBRA '93 SNT does not penalize the special needs child for purposes of qualifying for means-tested government benefits.

OBRA 1993 Special Needs Trusts

Collectively, (d)(4)(A) SNTs and (d)(4)(C) SNTs are referred to as "OBRA 1993 special needs trusts" ("OBRA '93 SNTs") in reference to the law (the Omnibus Budget Reconciliation Act of 1993) that established the use of these trusts to preserve Medicaid eligibility, which was subsequently clarified in the Foster Care Independence Act of 1999, 42 U.S.C. § 1382b, to preserve SSI eligibility. See 42 U.S.C. § 1382b(e)(5), which

authorizes the use of (d)(4)(A) and (d)(4)(C) SNTs to preserve SSI benefits for a special needs child.

The transfer of a special needs child's assets to a properly drafted and administered OBRA '93 SNT does not penalize the special needs child for purposes of qualifying for means-tested government benefits, and the child's assets held in a properly drafted and administered OBRA '93 SNT are not considered to be "available" to the special needs child for determining the child's financial eligibility for means-tested government benefits.

Practice Point: To avoid the special needs child making a completed gift to the OBRA '93 trust remainder beneficiaries on funding the trust, the special needs child should be granted a testamentary limited power of appointment over the trust assets. Treas. Reg. § 25.2511-2(c).

Medical Treatment and the Adult Special Needs Child

Under the privacy rules of the federal Health Insurance Portability and Accountability Act (HIPAA), 42 U.S.C. § 1320d, 45 C.F.R. Parts 160–164, which went into effect in April 2003, medical personnel (such as doctors and hospitals) are not allowed to talk freely about a patient's medical condition, and they can be fined or jailed for dissemination of any private health information without the patient's consent. This applies to all patients over the age of 18, including patients with special needs. Although the HIPAA privacy rules are well-intentioned, they can have horrendous implications for the medical care of an *adult* special needs child if he or she is unable to give informed consent and knowingly participate in his or her own medical treatment.

If an adult special needs child lacks the ability to make informed medical or mental health decisions or to give consent to the release of confidential medical information, parents should consider these options:

- if the special needs child is mentally competent under applicable state law, have an estate planning attorney prepare a durable medical power of attorney that includes HIPAA release information and names each parent as a "personal representative" under the HIPAA rules so that the parent can legally request and receive confidential medical information; or
- if the special needs child is mentally incompetent, obtain a guardianship over the special needs child for medical treatment purposes.

Once the child becomes an adult, a parent's right to know, monitor, advocate, and intercede in the special needs child's affairs may be limited or prohibited absent the child's consent, a court order (such as a guardianship), or a GDPA.

Assisting the Adult Special Needs Child in Financial, Educational, and Daily Living Matters

General Durable Power of Attorney

If an adult special needs child is mentally competent under applicable state law, he or she should have a GDPA prepared by an estate planning attorney. The GDPA for the special needs child should authorize the child's agent to transfer the child's assets into a first-party SNT.

Practice Point: Under federal law, a GDPA cannot be used by the special needs child's agent to establish a (d)(4)(A) SNT for the benefit of the special needs child; however, an agent under a GDPA can transfer the special needs child's assets into an existing (d)(4)(A) SNT. An agent under a GDPA, however, can execute a joinder agreement for a (d)(4)(C) pooled account trust and transfer the child's assets into the (d)(4)(C) pooled account trust. See Andrew H. Hook, 859 T.M., *Durable Powers of Attorney*, for a discussion of GDPAs and sample forms.

Once the child becomes an adult, a parent's right to know, monitor, advocate, and intercede in the special needs child's affairs may be limited or prohibited absent the child's consent, a court order (such as a guardianship), or a GDPA. A GDPA will permit the person named as the power of attorney to assist the special needs child in his or her financial affairs. The GDPA is highly recommended because it is the least costly and least intrusive method for assisting the adult child in his or her nonmedical affairs. When the special needs child dies, the authority given the person named as power of attorney under the GDPA automatically expires.

Parent as Representative Payee

In addition, a parent may become the "representative payee" of the special needs child's SSI, SSDI, and Social Security benefits, thus avoiding a court-appointed "guardian of the estate" or conservatorship. 20 C.F.R. Parts 404.2001–404.2065. A representative payee is the SSA's version of a

conservator/guardian of the estate (as concerns the benefits in question), and the appointment of a representative payee preempts the authority of a court-appointed guardian or conservator concerning the benefits in question. As with a conservatorship or guardian of the estate, however, an annual report must be filed with the SSA documenting how the funds were used for the benefit of the special needs child.

Durable Power of Attorney for Education Matters

If an adult special needs child is mentally competent under applicable state law, he or she also should have a durable power of attorney for education matters prepared. Such a document can name the parents as the child's agent and advocate concerning educational matters. Assisting the child in education-related matters once the child turns 18 is especially important if the child is intimidated by authority figures, such as teachers and school administrators, and needs a third party to advocate on the child's behalf. In most instances, the parents are the natural and preferred choice to serve as the child's advocate. See Judith C. Saltzman & Barbara S. Hughes, *Planning with Special Needs Youth upon Reaching Majority: Education and Other Powers of Attorney*, 1 NAELA J. 41 (2005).

Conclusion

Estate planning for the special needs family is the first of many steps that needs to be taken by parents in their journey of caring for all their loved ones. Financial planning, retirement planning, housing issues, caretakers, personal assistants, advocates, and so on, also need to be considered, especially as pertains to a special needs child. Estate planning is a starting point, not the end all. Competent legal counsel along with other professionals can guide the parents along the way. "It takes a team to plan for a special needs child." See Abraham J. Perlstein, *Comprehensive Future Care Planning for Disabled Beneficiaries*, 27 Est. Plan. 358 (Oct. 2000). ■