

Chapter 9

Special Needs Requires Special Attention: Estate Planning for a Family With a Special Needs Child*

SEBASTIAN V. GRASSI, JR.**

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** **Sebastian V. Grassi, Jr., Esq.:** Sebastian V. Grassi, Jr. of Grassi & Toering, PLC, located in the Detroit suburb of Troy, Michigan, is a member of the Christian Legal Society, where he served on its national board of directors. Listed in *The Best Lawyers in America*, and in *Michigan Super Lawyers*, Sebastian is a Fellow of the American College of Trust and Estate Counsel (“ACTEC”), and has served as a member of the Michigan Probate and Estate Planning Council. The Council advises the Michigan legislature on changes in probate and trust law.

Sebastian’s practice emphasizes business law, business succession planning, estate planning and probate (including estate planning for special needs families), special tax counsel to trustees and executors concerning complex tax issues, and related real estate matters.

Sebastian has published over 100 articles on business law, estate planning, estate planning for special needs families, and tax matters in *Probate & Property*; *ACTEC Journal*; *Estate Planning*; *Journal of Practical Estate Planning*; *The Journal of Taxation*; *The Journal of Taxation of Estates and Trusts*; *Michigan Bar Journal*; *Michigan Probate & Estate Planning Journal*; *Michigan Tax Lawyer*; *Probate Practice Reporter*; *Tax Management Estates, Gifts and Trusts Journal*; *Wealth Strategies Journal*; *Practical Tax Strategies*; *The Practical Lawyer*; *The Practical Tax Lawyer*; and *Tax Ideas*. Sebastian is also a winner of the American Bar Association’s *Probate & Property* “Probate & Trust Excellence in Writing Award for Best Practical Use Article.”

Sebastian is a frequent lecturer for the State Bar of Michigan’s Institute of Continuing Legal Education. He also serves on the Institute’s Estate Planning Advisory Board, and has served on the Estate Planning Advisory Board of the American Law Institute - American Bar Association (“ALI-ABA”). Sebastian has lived in China, and lectured at the Electronics Industry Management College, Beijing, Peoples Republic of China. Elsewhere, Sebastian has lectured at various ACTEC meetings, at various Probate and Estate Planning Bar Associations, The Washington, D.C. Estate Planning Council, The Michigan Probate Registers Annual Conference, The Annual Great Plains Federal Tax Institute, The Annual Minnesota Probate and Trust Law Section Conference, The Annual Notre Dame Tax and Estate Planning Institute, The National College of Probate Judges, the ALI-ABA, The Heckerling Institute, as well as at the University of Michigan Law School.

Sebastian is the author of three books on estate planning and tax matters: *A Practical Guide to Drafting Irrevocable Life Insurance Trusts (With Checklists and Sample Forms) - Second Edition* (www.ali-aba.org/aliaba/BK45), *A Practical Guide to Drafting Marital Deduction Trusts (With Checklists and Sample Forms)* (www.ali-aba.org/aliaba/BK36), and *A Practical Guide to Drafting Irrevocable Life Insurance Trusts (With Checklists and Sample Forms)*. All are published by the ALI-ABA, (800)

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253-6397. He is also the author of *Understanding Your Eternal Estate Plan* (www.probateandtrusts.com/eternal).

Sebastian and his wife, Elizabeth, have three children, Laura, Stephen, and Carolyn. Laura is an adult special needs child with cerebral palsy. Sebastian and Elizabeth are lifetime members of The ARC of Oakland County, Inc. (www.thearcoakland.org).

Sebastian can be reached at www.probateandtrusts.com, svgjr@aol.com, or (248) 269-2020.

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¶ 900**2009 INSTITUTE ON ESTATE PLANNING****9-4****¶ 918 Attachment A: Special Needs Planning: It Is More Than Drafting a Trust****¶ 900 Introduction**

This article is a general overview of issues an estate planner may need to address when preparing an estate plan for a family with a special need child. The article assumes that the estate planner is knowledgeable about general estate planning matters (wills, trusts, powers of attorney, advanced medical directives, etc.), but is not a specialist or expert in special needs planning.

For purposes of this article, “special needs child” refers to a child who (at birth or due to 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, such as Supplemental Security Income and Medicaid. *See*, ¶ 903, below, concerning means-tested government benefits.

Typical special needs children include those born with developmental disabilities, such as, mental retardation, cerebral palsy, autism, and epilepsy. Such a child is legally referred to as a “developmentally disabled” individual.

¶ 901 Statistics Reveal That It’s Not Your Father’s Neighborhood Anymore**¶ 901.1 Special Needs Does Not Discriminate – It Is 100% Unbiased**

Because special needs children are found in all nationalities, religions, race and economic categories, special needs is non-discriminatory and unbiased. Thus, no parent is immune from their child being born (or becoming) a special needs child. Examples of notable parents of a special needs child include, U.S. Senator Ted Kennedy (oldest sister, Rosemarie was mentally impaired and died in January 2005), columnist George Will (adult son, Jon, has Down syndrome), Alaska Governor Sarah Palin (young son, Trig, has Down syndrome), etc.

¶ 901.2 U.S. Census Statistics Concerning Special Needs

According to “Disability and American Families: 2000,” *US Census Bureau, July 2005 Report*:

- Out of 72.3 million families included in the 2000 Census, about 2 in every 7 families (or 28% of American families) have at least one family member with a disability.
- An estimated 2.8 million families (or 3.9% of American families) are raising at least one child aged 5 to 17 with a disability.
- Among the 2.8 million families with a disabled child, 367,000 families (or 13% of America’s 2.8 million families who have a disabled child) are raising two or more children with a disability.

¶ 901.3 MetLife Survey Concerning Special Needs

According to a 2005 MetLife survey of special needs families, *The Torn Security Blanket: Children With Special Needs and the Planning Gap* (April 2005) <http://www.metlife.com/WPSAssets/77629443601199477298V1FTornSecurityBlanketexp0309.pdf>):

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- 88% of parents with a special needs child (or 2.5 million American families) have not established a trust to preserve the special needs child's eligibility for SSI and Medicaid. *See*, ¶ 907, below.
- 84% of parents with a special needs child (or 2.3 million American families) have not written a letter of intent outlining an agreement for the future care of their special needs child. *See*, ¶ 907.8.B, below.
- 72% of parents with a special needs child (or 2 million American families) have not named a trustee to handle their special needs child's finances. *See*, ¶ 907.3, below.
- 53% of parents with a special needs child (or 1.5 million American families) have not named a guardian for their special needs child. *See*, ¶ 912 and ¶ 913, below.
- 32% of parents with a special needs child (or 896,000 American families) spend more than 40 hours per week with their special needs child, which puts tremendous strain on a marriage and other family relationships. Because special needs families operate under a high level of stress, it is helpful to have an understanding of the general dynamics of a special needs family. *See*, "This Family Is Different," contained in pages 58 - 61 of Sebastian V. Grassi, Jr., "Special Planning Is Needed for Families with a Special-Needs Child," *10 Journal of Practical Estate Planning* 53 (June-July 2008); and "Parenting a Child with Special Needs - 3rd Edition," *National Dissemination Center for Children with Disabilities* (Washington, DC 2003) (www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/nd20.pdf) for a discussion of the emotional, physical, psychological and financial strains on a family raising a special needs child.
- Parents with a special needs child spend an average of \$326 per month, or just under \$4,000 per year, on out-of-pocket medical expenses on their special-needs child. Many parents spend even more, especially for educational and social activity related expenses for their special needs child. *See*, "An Estate Plan Built for Special Needs," *Wall Street Journal* (October 9, 2008) (http://online.wsj.com/article_email/SB122351155944317491-1MyQjAxMDI4MjAzOTUwMTkxWj.html).

¶ 901.4 Author's Personal Observations Corroborate U.S. Census Statistics and MetLife Survey

The author's personal observations corroborate both the 2000 Census and the MetLife survey statistics. For example, in the author's neighborhood there are three special needs children: (i) the author's adult daughter who has severe cerebral palsy, (ii) an adult child who is severely autistic (and whose adult brother has dwarfism), and (iii) the author's daughter's 18 year old girl friend who is mentally impaired.

Welcome to, "*Estate Planning For The Special Needs Family Down The Street: It's Not Mister Rogers' Neighborhood, Anymore.*"

¶ 902.1**2009 INSTITUTE ON ESTATE PLANNING****9-6****¶ 902 Learning to Navigate in the Twilight Zone****¶ 902.1 Special Needs Planning – A Parallel Universe for Estate Planners**

Special needs planning for most estate planners is akin to entering the Twilight Zone: *“It is another dimension, beyond that which is known to the typical estate planner. It is a dimension as vast as the world itself, yet as close as one’s neighborhood. It a parallel universe of reality where few dare to venture, but many live. It is the middle ground between the known and the unknown, the seen and the unseen. It is right before your eyes, yet it is shrouded in mystery and steeped in complexity. It is the dimension of special needs. It is an area that parents of a special needs child call the ‘Twilight Zone.’ ”* (With apologies to Rod Serling.)

¶ 902.2 Demystifying Special Needs Planning

This article will attempt to demystify the “Twilight Zone” of special needs planning, remove the shroud that obscures the estate planner’s vision concerning special needs families, and provide the estate planner with the necessary reference tools to become comfortable in preparing an estate plan for America’s 2.8 million special needs families - all of whom need an estate plan to protect their disabled child.

“[The Twilight Zone of special needs planning with all its] obstacles cause many to shy away from providing special needs counsel. However, the need for effective planning is great and growing. If you are considering a special needs planning practice, your reward can be significant personal and professional gratification resulting from the help you provide to improve the lives of individuals with disabilities and their families.” Sanford J. Mall, “Drafting Special Needs Trusts: Safeguarding Government Benefits,” 23-2, *48th Annual Probate and Estate Planning Institute* (ICLE, Ann Arbor, MI 2008).

¶ 902.3 Focus of This Article

The focus of this article is *not how to* draft a special needs trust (“SNT”). Rather, the focus of this article is *where to* obtain information about special needs planning (and SNTs) so that the general estate planner can become more familiar and comfortable with preparing an estate plan for a special needs family. *See, Attachment A* by Andrew H. Hook, “Special Needs Planning: It Is More Than Drafting a Trust,” for a detailed overview of special needs planning and drafting SNTs.

¶ 903 Overview of Four Critical Government Benefit Programs Available to Special Needs Families**¶ 903.1 Overview of Two Important Government Benefit Means-Tested Programs for Special Needs Families**

The starting point for estate planning for a special needs family is to become familiar with two important government benefit programs: (i) Supplemental Security Income (“SSI”), 42 U.S.C. § 1381 *et. seq.*; 20 C.F.R. Part 416, and (ii) Medicaid, 42 U.S.C. § 1396 *et. seq.*; 42 C.F.R. Parts 430, 431 and 435. Both are means-tested government benefit programs, which means these programs have restrictions and limitations on the amount of income and assets that the special needs child-recipient can own in order to receive benefits.

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General (public) information about SSI can be found at: (http://www.ssa.gov/pgm/links_ssi.htm).

See, Chapter 2 of Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009); and Chapters 5 and 14 of Lawrence A. Frolik and Melissa C. Brown, *Advising the Elderly or Disabled Client - 2nd Edition* (RIA/Warren, Gorham & Lamont, Boston, MA, Supp. 2008) for detailed information on SSI and Medicaid.

¶ 903.2 Supplemental Security Income

Generally speaking, the first and most important means-tested government benefit program for a special needs child is SSI, which is a federal income supplement program administered by the Social Security Administration (“SSA”) and is funded by general tax revenues (not by Social Security or Self-Employment taxes).

SSI is designed to help aged, blind, and disabled individuals who are indigent, i.e., have limited income and limited resources. SSI provides a modest monthly stipend, which most states supplement, to meet basic needs for the individual’s food and shelter. In 2009 the SSI amount (a.k.a. the “Federal Benefit Rate”) for a single person is \$674 per month, with a resource limit of \$2,000 of non-exempt assets owned by the special needs child. SSI does not pay for the costs of medical care (Medicaid or Medicare does that, *see*, below). *See*, John J. Campbell, “Basic Strategies For SSI Planning,” 1 *NAELA Journal* 311 (2005).

A. SSI Generally Results in Automatic Receipt of Medicaid Benefits (Except in Eleven States)

The reason why SSI is generally the most important means-tested government benefit program for a special needs child is because in thirty-nine states and the District of Columbia, the receipt of SSI automatically qualifies the SSI recipient for Medicaid benefits. (However, in seven of the thirty-nine states, to wit, Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon and Utah, the SSI recipient must also file a separate Medicaid application). For individuals living in D.C. and these thirty-nine states, SSI and Medicaid are “categorically” linked together, and if the special needs child loses his or her SSI benefits, the child may also lose his or her Medicaid benefits.

Maintaining SSI eligibility is critical since SSI opens the door to Medicaid, and Medicaid is the portal to health care benefits and many other programs that provide a multitude of ancillary services that benefit a special needs child. Therefore, it is important that the special needs child’s SSI benefits generally not be reduced below \$1, since just \$1 of SSI benefits results in 100% of Medicaid benefits, but \$0 of SSI will (with some exceptions) generally result in 0% of Medicaid benefits. *But see*, ¶ 907.8, below, concerning when to intentionally reduce or eliminate a special needs child’s SSI (and Medicaid) benefits.

Practice Point: In the eleven remaining states (Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia, which are known as “209(b) states”), the receipt of SSI does not automatically result in the receipt of Medicaid benefits. These states use criteria

¶ 903.3**2009 INSTITUTE ON ESTATE PLANNING****9-8**

for Medicaid eligibility that is more restrictive than current SSI criteria (but the criteria that these eleven 209(b) states use may not be more restrictive than that state's Medicaid rules that were in effect on January 1, 1972). In these eleven states, SSI and Medicaid are not categorically linked together. In 209(b) states, SSI eligibility may not result in eligibility for Medicaid, and the loss of SSI in a 209(b) state may not necessarily result in the loss of Medicaid benefits.

¶ 903.3 Medicaid

The second important means-tested government benefit program for a special needs child is Medicaid. (Actually, Medicaid is THE most important means-tested government benefit program; however, it is SSI eligibility that generally makes Medicaid coverage available in the first instance.)

It has been said that "Medicaid is the best health 'insurance' that money cannot buy."

Medicaid is joint federal-state funded medical payment program (and not actually a "health insurance" program) for the aged, blind, and disabled who are indigent, (i.e., have limited income and resources), and meet certain eligibility requirements.

Although the federal government provides substantial funding for Medicaid and establishes general (minimum) guidelines for the Medicaid program, each state sets its own guidelines regarding eligibility and services, which can be broader but not more restrictive (except in 209(b) states) than the federal (minimum) guidelines. Consequently, "Medicaid [is] a complex and irrationally coordinated body of law comparable to the Internal Revenue Code in complexity, yet daunting because many Medicaid regulations either are unpublished or are found in policy handbooks at the state level." David J. Correia, "Interaction of Estate Planning and Medicaid Planning Strategies," *27 Estate Planning* 425 (November 2000) (citation omitted).

Some states offer more Medicaid benefits and coverage than other states. However, because Medicaid is a state administered program, eligibility for Medicaid benefits depends on the individual's state of residency.

General (public) information about Medicaid can be found at: (<http://www.cms.hhs.gov/>).

¶ 903.4 Two Important Government Benefit "Social Insurance" Programs for Special Needs Families: Social Security and Medicare

Social Security ("SS"), 42 U.S.C. § 401 *et. seq.*; 20 C.F.R. Part 401 *et. seq.* [including Social Security Disability Insurance ("SSDI"), 42 U.S.C. §§ 420 - 425; 20 C.F.R. Part 404], and Medicare, 42 U.S.C. § 1395 *et. seq.*, 42 C.F.R. Part 400 *et. seq.*, are neither means-tested nor need-based government benefit programs. Rather, they are "entitlement-based" government benefit "insurance" programs based on a worker's past earnings record. They are "social insurance" programs based on (payroll tax and self-employment tax) contributions made by a worker. Eligibility for Medicare is tied to eligibility for SS Benefits or Railroad Retirement Benefits.

In the case of a dependent special needs child who is disabled (under SS's definition of disability) before age 22 and is not a worker, the special needs child can receive

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SSDI benefits based on his or her parent's past earnings record, provided the parent is disabled, retired or deceased. If the dependent special need's child parent is receiving SS, it is possible for the disabled special needs child to receive SSI, SSDI, Medicaid and Medicare benefits all at the same time.

A disabled individual who receives both SSI and SSDI is referred to as "concurrent recipient." An individual who receives both Medicaid and Medicare, and/or both SSDI based on their own work record and SSDI based on their parents' work record, is referred to as "dual eligible" recipient.

When a special needs child is a "concurrent recipient," care must be taken to avoid inadvertently causing the child's SSI to drop below \$1 and possibly causing the child to lose his or her Medicaid benefits.

See, ¶ 13.07 of Lawrence A. Frolik and Melissa C. Brown, *Advising the Elderly or Disabled Client - 2nd Edition* (RIA/Warren, Gorham & Lamont, Boston, MA, Supp. 2008); §§ 3.102 - 3.103 of Thomas Beltran, "Public Benefits for Persons With Disabilities," *Special Needs Trusts - Drafting and Administration*, Chapter 3 (California CEB, Oakland, CA Supp. 2009); and Andrew H. Hook and Thomas D. Begley, Jr., "Lawyering for Older Clients: A New Paradigm - Part 1," *32 Estate Planning* 48 (April 2005) concerning concurrent recipient and dual eligible recipient issues.

A discussion of SS, SSDI, Medicare, and other government benefit programs for special needs families are beyond the scope of this article.

General (public) information about SS can be found at: (<http://www.ssa.gov/>). General (public) information about SSDI can be found at: (http://www.ssa.gov/pgm/links_disability.htm).

General (public) information about Medicare can be found at: (<http://www.cms.hhs.gov/>).

See, Chapters 4 and 13 of Lawrence A. Frolik and Melissa C. Brown, *Advising the Elderly or Disabled Client - 2nd Edition* (RIA/Warren, Gorham & Lamont, Boston, MA, Supp. 2008) for detailed information on SS and Medicare. See, Chapter 2 of Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009) for a discussion of public benefit programs for special needs families.

Caution: Although this article generally cites national treatises and articles, the practitioner should be aware that state laws, rules, and regulations explain or modify many of the federal-government-based programs for special needs children.

Practice Point: Although government benefits such as SSI and Medicaid are federal programs, they are implemented at the state level, and the administration and rules of eligibility may vary from state to state. Thus, this article, all treatises, articles and sample forms cited in this article, and the below sample drafting language must be read, interpreted, and adapted to applicable federal and state law, rules, and regulations. For example, some states have statutes that expressly permit third-party created and funded SNTs (e.g., Ohio, Wisconsin, California,

¶ 904.1**2009 INSTITUTE ON ESTATE PLANNING****9-10**

Missouri, Illinois, Texas, New York, and Kansas). In other states, such as Michigan, third-party created and funded SNTs are creatures of common (case) law. *See, e.g., Carol Miller v. Department of Mental Health*, 432 Mich. 426, 479 N.W. 2d 617 (1989). *See*, ¶ 907, below, concerning third-party created and funded SNTs.

¶ 904 Special Needs Parents Face Five Unique Estate Planning Challenges**¶ 904.1 Five Unique Estate Planning Challenges for Special Needs Parents**

In addition to the usual hurdles that parents face when preparing an estate plan (e.g., who should be the guardian, trustee, executor, etc.), 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 adequately providing for the special needs child;
- (4) How to make sure there are sufficient funds 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 SNT. *See*, ¶ 907, below.

Of these five unique estate planning challenges, above items 4 (sufficient funds) and 5 (proper supervision and management of the funds) typically prove to be the most difficult to implement. This is especially true: (i) if the majority of the parents' estate is composed of retirement benefits (*see*, ¶ 909, below, concerning retirement benefits), (ii) if the proposed trustee is inexperienced in administering SNTs, or (iii) if there is an experienced trustee available that is knowledgeable about special needs (typically a corporate or professional trustee), its minimum annual fee is too high relative to the proposed size of the SNT.

See, ¶ 907.3, below, concerning trustee matters. *See*, Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009); Chapter 17 of Lawrence A. Frolik and Melissa C. Brown, *Advising the Elderly or Disabled Client - 2nd Edition* (RIA/Warren, Gorham & Lamont, Boston, MA, Supp. 2008); and Sterling L. Ross, Jr., "The Special Needs Trust: A New Wrinkle No More," *36 Heckerling Institute on Estate Planning*, Chapter 16, (Matthew Bender/Lexis-Nexis, Newark, NJ, 2002) for detailed information on special needs planning. *See also*, William L. E. Dussault, "Planning for Disability," *33 ACTEC Journal* 42 (Summer 2007) for an excellent overview of special needs and disability planning, as well as an easy to understand flowchart that shows how Social

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Security interacts with Medicare and how SSI interacts with Medicaid.

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

¶ 905 Basic Estate Planning Issues for Special Needs Families**¶ 905.1 Everyone Has an Estate Plan – But Is It the Correct Plan?**

Every individual has an estate plan—either one he or she has purposely created, or one that the government has created. The government’s plan involves probate (i.e., intestacy), is expensive, is time consuming, favors the government concerning a special needs child’s inheritance (i.e., a “spend down” of the child’s inheritance and/or reimbursement of Medicaid benefits), favors the Internal Revenue Service concerning estate taxes (i.e., includes no death tax minimization planning), and relies upon a judge (and not the parents) to select a guardian to care for the special needs child. Left to its own devices, the government’s plan may be summarized, “Heads the government wins, tails the special needs family loses.” In other words, the maxim “if you fail to plan, you have planned to fail,” readily applies those who rely on an estate plan created by the government.

¶ 905.2 Five Essential Estate Planning Documents for a Special Needs Family

At the minimum, a special needs child deserves a parent’s continued stewardship and guidance, even though the parent may be incapacitated or deceased. Therefore, the parents of a special needs child should typically have the following five estate planning documents prepared:

- (1) Last will and testament.
- (2) General durable power of attorney for financial affairs (“GDPA”). The parent’s GDPA should permit the agent to make discretionary non-support 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. *See, Exhibit 1* for sample drafting language.
- (3) Durable medical power of attorney.
- (4) 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 non-support distributions to or for the benefit of the special needs child. Upon 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. *See, Exhibit 2* for sample drafting language.
- (5) Third-party created and funded SNT. *See, ¶ 907, below.*

¶ 906.1**2009 INSTITUTE ON ESTATE PLANNING****9-12****¶ 906 Tax Planning****¶ 906.1 Tax Planning for a Special Needs Family Should Not Be Overlooked**

Tax planning should not be ignored when preparing an estate plan that involves a special needs child.

There is a general (and incorrect) assumption among some estate planners that taxes are of little or no concern to families of special needs children. In fact, it is the author's experience that some practitioners who prepare estate plans for special needs families do not always have a comprehensive background in income and transfer tax law. This is unfortunate.

Income taxes, estate taxes, gift taxes, and the confiscatory generation-skipping transfer ("GST") tax should all be considered and dealt with when preparing an estate plan. Equally important are the income and transfer tax consequences of a special needs trust.

See, Acker, 852-2nd T.M., Income Taxation of Trusts and Estates; and Zaritsky, 858-2nd T.M., Grantor Trusts: Sections 671-679 for a discussion of the income tax issues concerning trusts. See also, Section VI, F of Moore and Landsman, 816 T.M., Planning for Disability; and Robert B. Fleming, "Taxation of Special Needs Trusts," Thirty-third Notre Dame Tax & Estate Planning Institute (October 2008) for an overview of common income tax issues concerning a special needs child, and SNTs.

¶ 907 Estate Planning Options Available to Special Needs Families**¶ 907.1 Five Estate Planning Options Available to Special Needs Families**

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

- (1) Distributing assets outright to the special needs child (not recommended since the assets may disqualify the child from receiving means-tested government benefits);
- (2) Disinheriting the special needs child (generally not recommended since 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 since 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 since 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 since the trust will not disqualify the child from

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receiving means-tested government benefits).

¶ 907.2 The Stand Alone Third-Party Created and Funded Special Needs Trust

Of these five options, generally practitioners prefer that parents establish an inter-vivos stand alone third-party created and funded SNT because of its benefits and flexibility.

A SNT established by and wholly 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 state law and section SI 01120.200 of the SSA's Programs Operations Manual System ("POMS"), assets contained in properly drafted and administered third-party 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. 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). *But see*, ¶ 911.2, below, concerning a parent establishing and nominally funding (with "seed" money) a first-party (d)(4)(A) SNT.

An inter-vivos third-party created and funded SNT can be either revocable or irrevocable. However, when the parents (or grandparents) die, a revocable inter-vivos third-party created and funded SNT must become irrevocable.

See, Dennis M. Sandoval, "Tax-Efficient Funding of a Lifetime Special Needs Trust," 32 *Estate Planning* 10 (October 2005) for a discussion of sophisticated funding techniques for an inter-vivos third-party created and funded SNT. *See also*, Thomas D. Begley, Jr. and Andrew H. Hook, "Special Needs Trust Administration: Special Assets," 35 *Estate Planning* 44 (April 2008).

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?

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, even though the trust is established by a third-party pursuant to 42 U.S.C. § 1396p(d)(4)(A) or 42 U.S.C. § 1396p(d)(4)(C) and/or the trust is and nominally funded with "seed" money by the parents. *See*, ¶ 911, below.

See, Chapter 5 of Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009); ¶ 16.01 of Thomas D. Begley, Jr. and Andrew H. Hook, *Representing the Elderly or Disabled Client: Forms and Checklists with Commentary* (RIA/Warren, Gorham &

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Lamont, Boston, MA, Supp. 2008); and Chapter 3 and Illustration 3-B of Clifton B. Kruse, Jr., *Third-Party and Self-Created Trusts: Planning for the Elderly and Disabled Client - 3rd Ed.* (American Bar Association, Chicago, IL, 2002) for sample third-party created and funded SNT forms, all of which need to be tailored to the specific needs of the special needs child and need to comply with applicable federal and state laws, rules and regulations governing such trusts.

¶ 907.3 Selecting the Right Trustee for a Third-Party Created and Funded Special Needs Trust Is Important

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. Thus, 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; 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, etc.

See, Chapters 9 and 10 of Sebastian V. Grassi, Jr., *A Practical Guide to Drafting Marital Deduction Trusts (with Sample Forms and Checklists)* (ALI-ABA, Philadelphia, PA, 2004 & Supp. 2008) (www.ali-aba.org/aliaba/BK36) ("Grassi, *Drafting Marital Deduction Trusts*") for a discussion of trustee selection and related tax issues. See also, Sebastian V. Grassi, Jr., "Checklist of Trustee Duties and Common Mistakes Made by Trustees," 31 *Tax Management Estates, Gifts and Trusts Journal* 239 (November 9, 2006); and Keith Bradoc Gallant, "The SNT Trap," 144 *Trusts & Estates* 50 (March 2005) for examples of trustee "nightmares" in the administration of SNTs. See generally, Rounds and Rounds, *Loring: A Trustee's Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, 2009).

Caution: Due to 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.

¶ 907.4 Appoint a Trust Protector for a Third-Party Created and Funded Special Needs Trust

A third-party created and funded SNT can have a trust protector. At a minimum, the trust protector should can have the power to: (i) direct the trustee's actions; (ii) receive financial-investment statements and accountings; (iii) terminate the third-party created and funded SNT (and have the assets be distributed to the remainder beneficiaries), (iv) remove and replace a trustee, and (v) direct or approve the reformation or amendment of the trust to reflect changes in the law and in order to comply with the trustmaker's intent and purpose. See, Uniform Trust Code ("UTC") section 808 (<http://www.law.upenn.edu/bll/archives/ulc/uta/2005final.htm>).

For tax reasons, a trust protector should not be "related or subordinate" to the settlor

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or the trust beneficiaries, within the meaning of IRC section 672(c). *See*, Revenue Ruling 2004-64, 2004-27 I.R.B. 7. *See*, Alexander A. Bove, Jr., "Trust Protectors," 144 *Trusts & Estates* 28 (November 2005).

¶ 907.5 A Third-Party Created and Funded Special Needs Trust Provides Maximum Flexibility

Because a third-party created and funded SNT is a discretionary non-support trust with spendthrift provisions (a very important element under common law and the UTC - *see*, UTC sections 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. *See*, Kevin D. Millard, "Rights of a Trust Beneficiary's Creditors Under the Uniform Trust Code," 34 *ACTEC Journal* 58 (Fall 2008).

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 also well suited to deal with possible changes in the amount of government benefits that may be available in the future due to changes in SSI or Medicaid funding, budget cuts, eligibility requirements, etc.

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 SSDI 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.

¶ 907.6 Alternatives to a Stand Alone Inter-Vivos Third-Party Created and Funded Special Needs Trust

An alternative to a stand alone inter-vivos 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.

¶ 907.7 The Thirteen Benefits of an Inter-Vivos Stand Alone Third-Party Created and Funded Special Needs Trust

The thirteen benefits of an inter-vivos stand alone third-party created and funded SNT are:

- (1) The trust can be established by the parents (or by any third party, such as the grandparents) for the benefit of the special needs child.
- (2) The trust provides for the investment and management of the special needs child's inheritance by a third party - the trustee.
- (3) The persons establishing the trust (such as the parents or grandparents) decide the terms and conditions of the special needs child's inheritance and who is to receive the balance of the trust funds when the special needs child dies - rather than having to reimburse the government for Medicaid and/or

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“cost of care” benefits provided to the special needs child. *See* Section V-IB-2 of Moore and Landsman, 816 T.M., *Planning for Disability*.

Practice Point: One of the significant differences between a between a third-party created and funded SNT and a first-party SNT is that there is *no* Medicaid payback requirement for a third-party created and funded SNT, and a third-party created and funded SNT should *not* contain a Medicaid payback provision.

- (4) The trust does not have to be for the “sole benefit” of the special needs child; other children of the parents can be current beneficiaries (although it is generally recommended that the special needs child be the preferred beneficiary vis-a-vis the other current beneficiaries).
- (5) The persons establishing the trust can name who should serve as the initial trustee and as the successor trustees, thereby avoiding the risk of the probate court appointing a “stranger” as a trustee.
- (6) The trust avoids family conflict, since the trust spells out who gets what, when, how, and why.
- (7) The trust avoids a probate court guardianship for the special needs child’s inheritance.
- (8) The trust (if properly drafted and administered) maintains the special needs child’s eligibility for government benefits (assuming the child is otherwise qualified to receive government benefits). *See*, Chapter 9 of Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009); and Chapters 14 and 15 of *Special Needs Trusts - Drafting and Administration* (California CEB, Oakland, CA Supp. 2009) for how to administer a SNT.
- (9) The trust coordinates government benefits and trust assets to meet the special needs child’s lifetime needs.
- (10) The special needs child can be any age (i.e., the trust is not limited to a special needs child under age 65).
- (11) The trust can provide for the appointment of an independent advocate for the special needs child, regardless of whether the child has a guardian, as well as a Trust Advisory Committee to advise the trustee concerning distributions for the benefit and well being of the special needs child.
- (12) The trust protects the special needs child’s inheritance from being seized by his or her creditors, and avoids the imposition of a Medicaid lien.
- (13) The trust agreement can be “short and simple” or “long and sophisticated,” depending on the amount and type of assets that are used to fund the trust. For example, if the trust is funded with S corporation stock, the trust agreement will probably be “long and sophisticated,” and an Electing Small Business Trust (“ESBT”) (IRC section 1361(e)) will have to be used to hold the S corporation stock for the benefit of the special needs child. A

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discussion of ESBTs and their tax consequences is beyond the scope of this article.

Practice Point: Note that many of these benefits also apply to third-party created and funded SNT provisions that are contained in the parents' revocable living trust, their irrevocable life insurance trust ("ILIT"), or their will (in the form of a testamentary trust).

Caution: If an ILIT is used to provide an inheritance to a special needs child, practitioners generally prefer to exclude the special needs child from having a *Crummey* withdrawal right. Not providing a *Crummey* withdrawal right to the special needs child obviates the government's potential argument that the special needs child has an "available" asset (to wit, the amount of the *Crummey* withdrawal right) and that the special needs child's lapse of his or her *Crummey* withdrawal right constitutes a first-party self-settled trust by the special needs child (and not a third-party created and funded SNT). See, ¶ 911 below concerning first-party self-settled trusts.

¶ 907.8 Two Ways to Design a Third-Party Created and Funded Special Needs Trust

Subject to applicable state law, a third-party created and funded SNT can generally be designed in two ways.

The first (and more traditional) way to design a third-party created and funded SNT is for the trust to be a discretionary non-support spendthrift trust that expressly prohibits the trustee from making any distributions that would disqualify the special needs child from means-tested government benefits.

The trust expressly states that trust distributions are to supplement but not supplant or replace public assistance benefits available to the special needs child, to wit, the trust's income and principal cannot be used to provide basic support (such as food and shelter) for the special needs child or for medical care that is paid for by Medicaid. Also, the trust expressly prohibits the trustee from paying any money directly to the special needs child; instead, trust funds must be distributed to third parties to pay for goods and services on behalf of the special needs child.

The second (and more flexible) way (to the extent permitted by applicable state law), is to design a third-party created and funded SNT as a pure discretionary non-support spendthrift trust without any express restrictions on the trustee's payment of income and principal to or for the benefit of the special needs child. This approach permits the trustee, in its sole, absolute, and uncontrolled discretion to make disqualifying transfers and distributions to or for the benefit of the special needs child if the trustee determines such transfers and distributions are in the best interests of the special needs child (even though such transfers and distributions may result in a diminishment or elimination of means-tested government benefits for the special needs child).

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A. Trustee Will Act as the Gatekeeper

The trustee of the third-party created and funded SNT will act as a gatekeeper of the special needs child's inheritance.

The trustee will typically distribute money for permissible "extra" quality of life items and services not provided for by means-tested government benefits. These distributions will not jeopardize the special needs child's receipt of (or qualification for) SSI and Medicaid. Thus, the trustee "supplements" the benefits provided by the government.

The trustee should generally avoid making distributions that will reduce SSI benefits or result in a loss of Medicaid coverage. (But see the preceding discussion of permitting the trustee to make discretionary transfers and distributions that would reduce or eliminate the special needs child's means-tested government benefits.)

Trust distributions for basic shelter and food, and direct payment of cash to the special needs child will reduce or eliminate the child's SSI benefits, and may result in a loss of Medicaid coverage.

Caution: When making distributions from the third-party created and funded SNT, the trustee needs to be aware of the impact the distributions may have on the child's continued eligibility for means-tested government benefits, such as SSI and Medicaid.

B. Provide the Trustee With a Letter of Intent

To assist the trustee of the third-party created and funded SNT, a letter of intent should be prepared by the parents.

The letter of intent serves as a blueprint that provides valuable information concerning the daily life and health care needs of the special needs child. This is especially important when a new caregiver has to step in and manage the child's day-to-day activities. The letter of intent also provides information concerning the unique likes, dislikes, needs, preferences, and other critical information concerning the special needs child - all of which is helpful to the trustee and the child's caregiver.

The letter of intent should not cause any adverse transfer tax consequences to the grantor(s). *See*, Jonathan C. Lurie and William R. Burford, "Drafting Flexible Irrevocable Trusts," 33 *ACTEC Journal* 86, 90 (Summer 2007).

See, Peggy R. Hoyt and Candace M. Pollock, *Special People, Special Planning (Creating a Safe Legal Haven for Families with Special Needs)* (Legacy Planning Partners, 251 Plaza Drive, Suite B, Oviedo, Florida 32765, (407) 977-8080, 2003, (www.specialpeoplespecialplanning.com) for a sample letter of intent. *See also*, Alexander A. Bove, Jr., "Letter of Wishes," 145 *Trusts & Estates* 46 (January 2006).

¶ 907.9 Income Taxation of a Third-Party Created and Funded Special Needs Trust

A third-party created and funded SNT can be taxed as a grantor trust under IRC sections 671 - 679, as a non-grantor trust under IRC sections 641 - 668, or as a qualified disability trust under IRC section 642(b)(2)(C).

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The income tax consequences of a third-party created and funded SNT is beyond the scope of this article.

See, Dennis M. Sandoval, "Special Needs Trust Taxation," *Special Needs Trusts - Drafting and Administration*, Chapter 13 (California CEB, Oakland, CA Supp. 2009); and Robert B. Fleming, "Taxation of Special Needs Trusts," *Thirty-third Notre Dame Tax & Estate Planning Institute* (October 2008) for an overview of tax issues concerning third-party created and funded SNTs. See also, Caryl Shortridge Peters and Roy W. Froemming, "Minimizing Income Taxes With 'Qualified' Supplemental Needs Trusts," 1 *NAELA Journal* 87 (2005).

¶ 907.10 Special (Contingent) Estate Planning Provisions to Deal With the Possibility of Special Needs or Severe Disability

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, as it did for author and disability advocate Joni Eareckson Tada at age 17, and (now deceased) Superman actor, Christopher Reeve at age 42.

In order to plan for the possibility that a child (or beneficiary under a trust or will) could become 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, **Exhibit 3** for sample drafting language.

A possible alternative to the sample drafting language contained in **Exhibit 3** is to give a trustee a power to appoint (i.e., decant) the trust assets to another trust that will preserve the disabled beneficiary's eligibility for means-tested government benefits. See, Alan S. Halperin and Lindsay N. O'Donnell, "Modifying Irrevocable Trusts: State Law and Tax Considerations in Trust Decanting," 42 *Heckerling Institute on Estate Planning* Chapter 13 (Matthew Bender/Lexis-Nexis, Newark, NJ 2008).

¶ 908 Coordination of the Special Needs Family's Estate Plan With Other Relatives' Estate Plans**¶ 908.1 Coordinate Other Relatives' Estate Planning Documents With the Parent's Third-Party Created and Funded Special Needs Trust**

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, etc. Consequently, it is important that grandparents and other relatives (including the siblings of the special needs child) 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. See, **Exhibit 4** for sample drafting language.

¶ 908.2**2009 INSTITUTE ON ESTATE PLANNING****9-20****¶ 908.2 There Are Many Ways a Special Needs Child Can Receive an Outright Inheritance and Lose Means-Tested Government Benefits**

A special needs child can receive an outright inheritance in indirect ways. For example, if the grandparent's will leaves his or her estate to "my descendants, by right of representation," and the parent of the special needs child predeceases the grandparent, actually or presumptively under the requirement for survival (typically 120 hours (or 90 days for GST tax purposes)), a portion of the deceased parent's share of the grandparent's estate will pass outright to special needs child, and possibly disqualify the child from receiving certain government benefits.

Another way, that is not so obvious for a special needs child to receive an outright inheritance, is when an unmarried adult sibling dies without children and leaves his or her estate to his or her "heirs" and the decedent's parents are also deceased. In such instance, the decedent's special needs sibling (as an heir of the decedent) will receive an inheritance. *See*, ¶ 911, below, on how to preserve means-tested government benefits when a special needs child receives an outright gift or inheritance.

¶ 909 Undertake a Thorough Review of All the Parent's Assets**¶ 909.1 Review All of the Parent's Assets and Beneficiary Designations**

A corollary to the need to coordinate a special needs child's inheritance with the 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 sixteen 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:

- (1) IRA, 401(k) and other retirement benefits. *See*, Section 6.3.11 of Natalie B. Choate, *Life and Death Planning for Retirement Benefits—6th Edition* (Ataxplan Publications, Boston, MA 2006), www.ataxplan.com.
- (2) Life insurance (including employer-provided life insurance) benefits.
- (3) Accidental death and travel insurance benefits provided through credit cards when a person purchases a plane ticket, etc. using that credit card.
- (4) Annuities.
- (5) Savings Bonds.
- (6) Any property not subject to the parents' will or trust.
- (7) Uniform Gifts to Minors Act ("UGMA") or Uniform Transfers to Minors Act ("UTMA") accounts.
- (8) Transfer On Death ("TOD"), Pay On Death ("POD"), In Trust For ("ITF") designations on accounts, savings bonds, or securities.
- (9) Inheritances, gifts, or bequests through another person's will or trust (if not paid to a third-party created and funded SNT).

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- (10) Deeds.
- (11) Joint accounts.
- (12) Jointly owned property, including jointly owned real estate.
- (13) Final paycheck (including unused vacation and sick pay).
- (14) Collectibles, antiques and family heirlooms.
- (15) Personal injury and wrongful death proceeds payable to a deceased parent's estate.
- (16) 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.

¶ 910 Financial Planning Issues for Special Needs Families**¶ 910.1 Integrate Financial Planning With the Parent's Special Needs Planning**

Financial planning for a special needs family's future should be considered as a part of the overall estate planning process, and should be undertaken when the parents know the extent of their child's disability - if not sooner.

See, Minoti H. Rajput, CFP, "Planning for Families of Children with Disabilities," *Journal of Financial Planning* (August 2001) (<http://spwfe.fpanet.org:10005/public/Unclassified%20Records/FPA%20Journal%20August%202001%20-%20Planning%20for%20Families%20of%20Children%20with%20Disabilities.pdf>); Ronald T. Staebell, "Securing The Future Of A Child With A Disability," 139 *Trusts & Estates* 43 (August 2000); MetLife MetDESK (www.metlife.com/desk); and MassMutual SpecialCare (www.massmutual.com/specialcare) for a general overview of the financial planning aspects for a family with a special needs child.

¶ 910.2 The Important Role of Life Insurance in Special Needs Planning

Life insurance (typically other than term life insurance) may be one of the most cost effective (and least expensive) ways to ensure that the special needs child will receive an inheritance - as administered through a third-party created and funded SNT.

On the other hand, 401(k), IRA and other types of retirement benefits (possibly other than income tax-free Roth IRA, Designated Roth 401(k) and Designated Roth 403(b) retirement benefits), if paid to a third-party created and funded SNT, may be an inefficient and (income) tax-expensive method of providing an inheritance for the special needs child, since retirement benefits constitute income in respect of a decedent (IRC section 691) and are subject to both estate and income taxation.

A competent financial planner who is experienced in working with special needs families can be of great help and provide valuable assistance in planning for both the family and the special needs child's future.

A. Use Term Life Insurance to Replace Lost Income

Term life insurance is an inexpensive way to replace lost income due to the

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premature death of a wage earner (such as a father), or provide income to pay for the cost of a replacement caregiver if the primary caregiver (such as a mother) dies prematurely. However, term life insurance becomes more expensive as the insured ages. For annual renewable term life insurance, the premium amount increases each year. For term life insurance for a fixed number of years (such as a 20- or 30-year level term life insurance policy), the premiums will increase dramatically at the end of the 20- or 30-year period, and the insurance cost generally becomes prohibitive.

B. Use Permanent Life Insurance to Provide an Inheritance

Term life insurance is designed for a specified term of years - it is not designed to provide an inheritance. Permanent life insurance that can build up cash value, such as whole life, universal life, or variable universal life is, however, designed to replace lost income *and* to provide an inheritance for a special needs child. Therefore, permanent cash value life insurance should be considered as the cornerstone for a special needs family's financial plan.

See, Chapter 16 of Sebastian V. Grassi, Jr., *A Practical Guide to Drafting Irrevocable Life Insurance Trusts (with Sample Forms and Checklists) - Second Edition* (ALI-ABA, Philadelphia, PA, 2007) (www.ali-aba.org/aliaba/BK45) (“Grassi, *Drafting ILITs*”) for an overview of life insurance policies.

C. Blend Permanent Life Insurance With Term Life Insurance for Lower Premiums

The “best of both worlds” for life insurance coverage may be for a parent to purchase a blended permanent/term policy. Blended permanent/term insurance is a combination of permanent life insurance (the “base”) and term life insurance. Blending is used to reduce the total premiums required to maintain a desired amount of death benefit, permanently. The less base and the more term, the lower the initial premium.

In a blended policy, the total death benefit is comprised of the guaranteed death benefit from the permanent life, paid-up additions, and the term insurance. Thus, the blended product is designed so that dividends or interest paid on the permanent life base will be used to buy paid up additions (additional blocks or units of paid up permanent life insurance) that will ultimately replace the term insurance component. Consequently, dividend/interest performance on the permanent life base is extremely important. *See*, Section 16.3 of Grassi, *Drafting ILITs* for further discussion of blending permanent life insurance with term life insurance, and the issues associated with blending.

¶ 911 Managing Assets Already Owned by a Special Needs Child**¶ 911.1 Protecting a Special Needs Child's Existing Assets by Using a First-Party Self-Settled Special Needs Trust**

If a special needs child who is disabled (as defined by Social Security pursuant to 42 U.S.C. § 1382c(a)(3)) has received (or has a vested non-contingent right to receive) an inheritance, gift, bequest, lawsuit award or settlement, child support, alimony, or divorce property settlement, the special need's child's receipt of these assets may result in the disqualification of means-tested government benefits such as SSI and

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Medicaid. *See*, Thomas D. Begley, Jr., and Andrew H. Hook, “Using Self-Settled Special Needs Trusts to Facilitate Matrimonial Settlements,” 34 *Estate Planning* 42 (April 2007).

To preserve these government benefits, the special needs child’s disqualifying assets should be converted into exempt (or non-countable) assets or be transferred to a first-party self-settled SNT.

For purposes of this discussion, there are only two types of government approved (safe harbor) first-party self-settled SNTs.

The first type of safe harbor first-party self-settled SNT is an inter-vivos irrevocable trust established pursuant to 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.”

The second type of first-party self-settled SNT is an inter-vivos “Pooled Account Trust” established pursuant to 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.”

(d)(4)(A) SNTs and (d)(4)(C) SNTs are collectively 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, and 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 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 eligibility for means-tested government benefits.

Practice Point: In order to avoid the special needs child making a completed gift to the OBRA’93 Trust remainder beneficiaries upon 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).

See, Bernard A. Krooks and Andrew H. Hook, “What Attorneys Need To Know About Special Needs Trusts,” 11 *ALI-ABA Estate Planning Course Material Journal* 5 (October 2005); Thomas D. Begley, Jr., and Andrew H. Hook, “Drafting Issues in Self-Settled Special Needs Trusts,” 31 *Estate Planning* 510 (October 2004); Thomas D. Begley, Jr., and Andrew H. Hook, “When Is an Irrevocable Special Needs Trust Considered to Be Revocable?,” 31 *Estate Planning* 205 (April 2004); and Andrew H. Hook, “What the Trust and Estates Lawyer Needs to Know about d(4)(A) Special Needs Trusts,” 29 *ACTEC Journal* 192 (Winter 2003).

¶ 911.2 Using a (d)(4)(A) Special Needs Trust to Protect a Special Needs Child’s Existing Assets

In the case of the (d)(4)(A) SNT, the special needs child’s parents, grandparents, legal guardian, or the court establishes the trust, which must be irrevocable and be for

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the sole benefit of the special needs child during his or her lifetime. A (d)(4)(A) SNT cannot be established by the special needs child's spouse or siblings (in their sole capacity as such).

A (d)(4)(A) SNT may only be established if the special needs child: (i) is disabled pursuant to the Social Security definition of "disability" (42 U.S.C. § 1382c(a)(3)); and (ii) is under the age of 65 at the time the trust is established and funded. Also, no contributions to the trust can occur after the child reaches age 65, the trust must be for the sole benefit of the special needs child during his or her lifetime, the trust assets must be unavailable to the special needs child directly (i.e., the child cannot have the power to demand a distribution or exercise any control over the trust), the trust must be irrevocable and cannot be terminated or revoked during the child's lifetime (although the trust may be amended or reformed to comport with changes in the SSI and Medicaid rules), and the trust must contain a spendthrift clause that prohibits both involuntary and voluntary transfers of the special needs child's interest in the trust income or principal. *See*, Chapter 6 of Thomas D. Begley, Jr. and Angela E. Canellos, *Special Needs Trust Handbook* (Wolters Kluwer/Aspen Publishers, Frederick, MD, Supp. 2009) for a sample form of (d)(4)(A) SNT. *See*, Illustration 3-C of Clifton B. Kruse, Jr., *Third-Party and Self-Created Trusts: Planning for the Elderly and Disabled Client - 3rd Ed.* (American Bar Association, 2002) for a sample form of a court-created (d)(4)(A) SNT.

After the (d)(4)(A) SNT is established, the special needs child's disqualifying assets are transferred into the trust by the child (if competent), the child's agent under a durable power of attorney, the child's guardian or by court order. *See*, William L. E. Dussault, "Planning for Disability," 33 *ACTEC Journal* 42, 61 (Summer 2007).

Practice Point: If a parent or grandparent establishes the trust without nominally "seeding" the (d)(4)(A) SNT with their own assets or without a prior court order, they may want to consider obtaining a *nunc pro tunc* court order authorizing (and not merely "approving") the parent or grandparent to establish the trust, thereby avoiding the government subsequently challenging the trust's validity.

Practice Point: According to Kenneth A. Brown of the Social Security Administration ("SSA"), it is the position of the SSA (which position has been clarified in the January 2009 amendments to the SSA's POMS) that "In the case of a legally-competent, disabled adult, a parent or grandparent may establish a 'seed' [(d)(4)(A)] trust using a nominal amount of their own money, or if State law allows, an empty or dry trust. After the seed [(d)(4)(A)] trust is established, the legally competent adult may transfer his or her own assets to the [(d)(4)(A)] trust or another individual with legal authority such as a DPA agent may transfer the individual's assets into the [(d)(4)(A)] trust. In the case of a [(d)(4)(A)] trust established by a court, the [(d)(4)(A)] trust must actually be established by a court order. Approval of a [(d)(4)(A)] trust by a court is not sufficient." Page 6 of Kenneth J. Brown, "Trusts and Supplemental Security Income Program," *Stetson University College of Law Special Needs Trusts IX* (October 2007). *See*, POMS SI 01120.203B.1.f (amended January 2009).

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Because the (d)(4)(A) SNT is funded solely with the special needs child's assets (ignoring any nominal "seed" funding of the trust by a parent), the trust is considered to be a "first-party" or "self-settled" trust. Consequently, under common law and most state's creditors rights statutes, the special needs child's assets will not be protected from the reach of his or her general creditors, except where the (d)(4)(A) SNT is established as a domestic asset protection trust ("DAPT") in a state that permits DAPTs, such as Delaware, Alaska, etc. Restatement (Second) Trusts § 156; Restatement (Third) Trusts § 58(2); and UTC section 505(a)(2). *See*, Robert F. Collins, "The Greater Asset Protection Self Settled Special Needs Trust (or GAPSNT)," 1 *NAELA Journal* 111 (2005); and Richard E. Davis and Stanley C. Kent, "The Impact Of The Uniform Trust Code On Special Needs Trusts," 1 *NAELA Journal* 235 (2005).

The estate, gift, generation skipping, and income tax consequences of a "first-party" self-settled trust are beyond the scope of this article. *See*, Dennis M. Sandoval, "Special Needs Trust Taxation," *Special Needs Trusts - Drafting and Administration*, Chapter 13 (California CEB, Oakland, CA Supp. 2009); Section VI, F of Moore and Landsman, 816 T.M., *Planning for Disability*; and Robert B. Fleming, "Taxation of Special Needs Trusts," *Thirty-third Notre Dame Tax & Estate Planning Institute* (October 2008) for an overview of tax issues concerning SNTs.

The trustee of the (d)(4)(A) SNT is authorized to pay for the permitted supplemental needs of the child. With proper planning, a family member (depending on state law, and depending on the HUD Section 8 Housing rules concerning OBRA '93 SNTs) may be able to serve as the trustee (or co-trustee) of the (d)(4)(A) SNT. Therefore, the (d)(4)(A) SNT should be drafted to minimize potential adverse tax consequences and conflicts of interest when a family member serves as a trustee or co-trustee. *See*, ¶ 907.3, above, concerning trustee issues - which issues are also applicable to a (d)(4)(A) SNT.

Upon the death of the special needs child, the (d)(4)(A) SNT Trust must first reimburse the government for medical benefits provided by any state's Medicaid (but not SSI) program to the special needs child before the trust residue is distributed to the trust's "remainder" beneficiaries (usually the special needs child's then living descendants (if any), or the special needs child's then living siblings) - hence the nickname "(d)(4)(A) Medicaid Payback Trust."

Practice Point: A (d)(4)(A) SNT must contain a Medicaid payback provision.

This is one of the significant differences between a first-party self-settled SNT and a third-party created and funded SNT. A third-party created and funded SNT is not required to contain a Medicaid payback provision, and should *not* contain a Medicaid payback provision!

¶ 911.3 Using a (d)(4)(C) Pooled Account Trust to Protect a Special Needs Child's Existing Assets

In the case of a (d)(4)(C) Pooled Account Trust, a nonprofit charitable association establishes and manages a master trust. *See*, Illustration 3-E of Clifton B. Kruse, Jr., *Third-Party and Self-Created Trusts: Planning for the Elderly and Disabled Client* -

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3rd Ed. (American Bar Association 2002) for a master form of (d)(4)(C) Pooled Account Trust.

The child (if competent), the child's agent acting under a GDPA that authorizes the agent to take the action necessary to join a (d)(4)(C) Pooled Account Trust, the child's parents, grandparents, legal guardian, or the court establishes a trust account (within the master trust) solely for the benefit of the special needs child, who must be disabled pursuant to the SSA's definition of "disability." 42 U.S.C. § 1382c(a)(3).

The special needs child generally can be of any age to use a (d)(4)(C) Pooled Account Trust, although some states penalize a child (to wit, reduces or suspends the special needs child's means-tested government benefits) if he or she makes contributions to the trust after the child reaches age 65.

Practice Point: In January 2009 the Social Security Administration amended its SSI POMS to clarify that a transfer on or after age 65 by a special needs child to a (d)(4)(C) Pooled Account Trust may result in a divestment by the special needs child and a period of ineligibility for SSI benefits. *See*, POMS SI 01120.203B.2.a (amended January 2009).

The special needs child's disqualifying assets are then transferred into the master trust, and a separate trust account (also known as a "sub-trust account") is established by the nonprofit association for the sole benefit of the special needs child. However, for purposes of investment and management of funds, the master trust pools all the separate trust accounts – hence the name "Pooled Account Trust."

The tax issues surrounding a (d)(C)(C) Pooled account Trust are beyond the scope of this article. *See*, Robert B. Fleming, "Taxation of Special Needs Trusts," *Thirty-third Notre Dame Tax & Estate Planning Institute* (October 2008) for an overview of tax issues concerning (d)(4)(C) Pooled Account Trusts.)

The nonprofit association, as trustee, administers the child's trust account and uses it to pay for the permitted supplemental needs of the child. Family members or friends can act as "advisors" to the trustee-nonprofit association concerning the needs of the child.

Depending on the terms of the master trust and the joinder agreement that establishes the special needs child's separate trust account under the master trust agreement, any funds remaining in the child's separate trust account at the child's death will be either (i) kept by the nonprofit association (and not be used to reimburse the government for medical benefits provided by any state's Medicaid program to the special needs child); or (ii) used to first reimburse the government for medical benefits provided by any state's Medicaid (but not SSI) program to the special needs child, and the remaining amount of the special needs child's separate trust account will then be distributed (a) pursuant to the court's order that established the child's trust account, (b) pursuant to the child's exercise of a testamentary limited power of appointment (which limited power of appointment could be contained in the child's will, a court's order or the joinder agreement), (c) pursuant to the child's will, or (d) pursuant to the laws of intestacy.

A (d)(4)(C) Pooled Account Trust is best suited where the amount of non-exempt

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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 where the parents or child want to ultimately benefit the mission of the nonprofit association upon the death of the special needs child.

Practice Point: Not all states have (d)(4)(C) Pooled Account Trusts.

¶ 912 Medical Treatment and the Adult Special Needs Child**¶ 912.1 HIPAA Rules and the Adult Special Needs Child**

Under the federal Health Insurance Portability and Accountability Act, 42 U.S.C. § 1320d; 45 C.F.R. Parts 160 - 164 (“HIPAA”) privacy rules, 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 eighteen (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.

¶ 912.2 Two Options Concerning HIPAA Rules and the Adult Special Needs Child

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 two options:

- (1) 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 a parent can legally request and receive confidential medical information; or
- (2) If the special needs child is mentally incompetent, obtain a guardianship over the special needs child for medical treatment purposes.

¶ 913 Assisting the Adult Special Needs Child in Financial, Educational and Daily Living Expenses**¶ 913.1 General Durable Power of Attorney for a Competent Adult Special Needs Child**

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. (As previously mentioned in ¶ 911.2, above, although 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, an agent under a GDPA can transfer the special needs

¶ 913.2**2009 INSTITUTE ON ESTATE PLANNING****9-28**

child's assets into an existing (d)(4)(A) SNT.) However, as previously mentioned in ¶ 911.3, above, an agent under a GDPA 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 of assisting the adult child in his or her non-medical affairs. When the special needs child dies, the authority given the person named as power of attorney under the GDPA automatically expires.

¶ 913.2 Parent as Representative Payee of a Special Needs Child

Additionally, 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 pre-empts the authority of a court-appointed guardian or conservator concerning the benefits in question. However, as with a conservatorship or guardian of the estate, an annual report must be filed with the SSA documenting how the funds were used for the benefit of the special needs child.

¶ 913.3 Durable Power of Attorney Concerning Education Matters for a Competent Adult Special Needs Child

If an adult special needs child is mentally competent under applicable state law, he or she should also 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 and Barbara S. Hughes, "Planning With Special Needs Youth Upon Reaching Majority: Education And Other Powers Of Attorney," 1 *NAELA Journal* 41 (2005).

¶ 914 Premature Death of the Special Needs Child**¶ 914.1 Parents May Incur Additional Financial Strain When a Special Needs Child Dies Prematurely**

In addition to the normal grief associated with the death of a child, a special needs family may need a source of additional finances to assist in the transition following the death of their child.

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Besides the obvious expense of a funeral, the family may no longer have need for the (expensive) adaptive vehicle they recently purchased (on an installment loan basis). Typically such vehicles depreciate more rapidly than non-customized vehicles, and are difficult to sell. A piece of durable medical equipment that became a fixture in the family home may need to be removed, and the house may need to be remodeled to make it more attractive for re-sale.

The best approach to provide for these potential expenses is for the parents to purchase a rider to their life insurance policy that also insures the life of the special needs child. Or, if a rider is not available, the parents may be able to purchase a life insurance policy on the life of their special needs child. Since the special needs child is not the owner of the policy and would not be the beneficiary of the policy, there would be no SSI or Medicaid disqualification (or asset cap/income issues) concerning the life insurance policy. If the life insurance policy pays dividends, the policy owner may be able to use the dividends to purchase paid up additional coverage without proof of the special needs child's insurability, thereby providing a larger death benefit amount. *See*, Section 2.15 of Grassi, *Drafting ILITs* for a discussion of the income taxation of life insurance policy dividends.

¶ 915 What If the Special Needs Child's Parents Need to Qualify for Medicaid?**¶ 915.1 Providing an Inheritance for a Special Needs Child if the Parents or Grandparents Need Medicaid Paid Nursing Home Care**

As the parents of the special needs child age, one or both of the parents may need Medicaid assistance for nursing home care. *See*, Lawrence A. Frolik, "Basic Medicaid: Paying For Nursing Home Care," 13 *ALI-ABA Estate Planning Course Materials Journal* 11 (April 2007). If that should occur, what can be done to qualify the parent for Medicaid while preserving an "inheritance" for their special needs child? Fortunately there are several special exceptions to the Medicaid divestment rules if the parent's assets are transferred to a special needs child. *See*, Matthew J. Marcus, "Many Effective Medicaid Planning Strategies Still Exist After the DRA," 35 *Estate Planning* 24 (October 2008).

For example, a Medicaid applicant-parent can transfer assets of any nature outright to a blind or disabled child (42 U.S.C. §§ 1832c(a)(2) and (3)), regardless of the child's age or marital status. 42 U.S.C. § 1396p(c)(2)(B)(iii). Such a transfer may be appropriate where the special needs child is not receiving means-tested government benefits. A Medicaid applicant-parent can also transfer his or her homestead to a blind or disabled child. 42 U.S.C. § 1396p(c)(2)(A)(ii)(II).

A Medicaid applicant-parent can transfer assets of any nature to a trust for the sole benefit of a blind or disabled child (such as a (d)(4)(A) SNT or a (d)(4)(C) Pooled Account Trust) regardless of the child's age or marital status. 42 U.S.C. § 1396p(c)(2)(B)(iii); HCFA Transmittal 64 §§ 3257.6 and 3259.7. Such a trust would be appropriate if the special needs child is receiving means-tested government benefits. *See*, Exhibit 1 for sample language to permit a parent's agent under a durable power of attorney to create a trust under 42 U.S.C. § 1396p(c)(2)(B)(iii).

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Any Medicaid applicant (not just a Medicaid applicant-parent), such as a grandparent, aunt, uncle, sibling or friend, can transfer assets of any nature to a trust for the sole benefit of any disabled individual (such as a special needs grandchild, special needs niece or nephew, special needs sibling or special needs friend) who is under the age of 65. 42 U.S.C. § 1396p(c)(2)(B)(iii); HCFA Transmittal 64 § 3257(B)(6). The trust can be a (d)(4)(A) SNT or a (d)(4)(C) Pooled Account Trust. However, some states require that payments from a “sole benefit” trust must be paid out annually based on the special needs beneficiary’s life expectancy.

None of the above transfers to the special needs child (or to a trust for the sole benefit of the special needs individual) are considered an impermissible divestment by the Medicaid applicant.

¶ 916 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, etc. 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 *Estate Planning* 358 (October 2000).

¶ 917 Exhibits

¶ 917.1 Exhibit 1

Sample language for inclusion in a parent’s general durable power of attorney for financial affairs. The author makes no warranties or representations concerning the tax implications or efficacy of the sample language.

Power of Agent Concerning Supplemental Non-Support Distributions for the Benefit of a Disabled Child. If a child of mine is disabled and is receiving Medicaid, SSI, or other government benefits (or would otherwise be eligible for such benefits), my Agent shall have the power to pay to or apply for the benefit of such child such amounts as my Agent, in my Agent’s sole, absolute, and uncontrolled discretion, may from time to time determine concerning such child’s special needs (and not for my disabled child’s support and maintenance). My Agent shall have the absolute right to refuse to make any payment to or for the benefit of such child, and neither the child nor any representative of the child shall have the right to demand any such distribution from my Agent. Such payments by my Agent shall supplement (and not supplant) such government benefits received by my disabled child. My Agent may also establish and fund with my assets: (i) a trust permitted under 42 U.S.C. § 1396p(c)(2)(B)(iii) for the sole benefit of my disabled child, and/or (ii) an inter-vivos third-party discretionary non-support special needs trust with spendthrift provisions for the benefit of my disabled child during such child’s lifetime, and upon the death of my disabled child, the trust residue shall be distributed to my then living descendants by right of representa-

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tion. In no event shall my disabled child serve as my Agent, nor shall my Agent delegate any of my Agent's powers to such child. If it is determined by a court or administrative agency that the existence of the foregoing powers granted to my Agent renders my disabled child ineligible to receive SSI, Medicaid, or similar governmental benefits, or if by reasons of the grant of such powers, my income or assets are found by a court or an administrative agency to be subject to garnishment, attachment, execution or bankruptcy proceedings by any creditor of such child, then the special powers granted to provide benefits for such child herein shall terminate and thereafter be null and void.

¶ 917.2 Exhibit 2

Sample language for inclusion in a parent's revocable living trust. The author makes no warranties or representations concerning the tax implications or efficacy of the sample language.

Power of Trustee Concerning Supplemental Non-Support Distributions for the Benefit of a Disabled Child. During any period which I, Jane Anderson Doe, am incapacitated or incompetent, if a child of mine is disabled and is receiving Medicaid, SSI, or other government benefits (or would otherwise be eligible for such benefits), Trustee may, in its sole, absolute, and uncontrolled discretion, distribute to or apply for the benefit of my disabled child such amounts of the trust's income and principal as Trustee shall determine. Trustee shall have the absolute right to refuse to make any distribution to or for the benefit of my disabled child, and neither the child nor any representative of the child shall have the right to demand any such distribution from Trustee. Such distributions by Trustee shall supplement (and not supplant) such government benefits received by my disabled child. In no event shall my disabled child serve as a trustee, nor shall Trustee delegate any of Trustee's powers to such child.

Transfer of Trust Estate Residue to Third Party Created and Funded Special Needs Trust. Upon my death and after the proper administration of the trust estate, Trustee shall distribute the residue of the trust estate to the then acting trustee of The Jane Anderson Doe Third Party Special Needs Trust FBO [name of special needs child], dated December 1, 2008, to be held, administered, and distributed in accordance with the terms of said special needs trust.

¶ 917.3 Exhibit 3

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,

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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 un-appointed 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 un-appointed trust property shall instead be distributed: (i) to my then living 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 would impair the status or qualification of a trust that holds shares of stock in a Subchapter S

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corporation, or would 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 would impair the status or qualification of a trust that holds shares of stock in a Subchapter S corporation, or would 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).

¶ 917.4 Exhibit 4

Sample pour-over language for inclusion in a relative's will or trust when a bequest or inheritance would otherwise be payable outright to a special needs relative. The author makes no warranties or representations concerning the tax implications or efficacy of the sample language.

Special Provisions Concerning Distribution of Property to a Disabled Relative. If any property would otherwise be distributable to my [nephew, niece, grandchild, etc.] whose name is [name of disabled relative], my fiduciary shall not distribute the property to the aforesaid individual (or to that individual's guardian or conservator) but shall instead distribute the property to the then acting trustee of The Jane Anderson Doe Third Party Special Needs Trust FBO [name of disabled relative], dated December 1, 2008, to be held, administered, and distributed in accordance with the terms of said special needs trust.