



Helping Parents Plan for Children with Special Needs

The authors offer drafting suggestions and other tips to help parents plan, financially and otherwise, for their special needs child.

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A disabled or “special needs” child’s parents face important planning issues. They need to find necessary care and services, foster the development of independent living skills, and protect their child from harm. They also should maximize financial resources for present and future expenses, which will allow the highest possible quality of life for the child and other family members.

Planning must assure appropriate management of finances and personal decisions in the event of disability or death of both parents and avoid future problems. Parents might also need to continue making decisions for a severely disabled child during adulthood, provide for future residential needs, and find someone to care for the child when they are no longer able.

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They typically seek help from knowledgeable professionals, and they often contact an attorney first. Although some parents are aware of the array of legal issues they must confront, most arrive at the lawyer's office concerned only about what will happen on their deaths and perhaps wondering about a "special needs" trust. These are discretionary trusts drafted so that the income and assets are not counted as resources of the disabled beneficiary for purposes of establishing eligibility for "means-tested" benefits, i.e., those that are reduced or denied when income or assets rise above specified limits.

Parents may be unaware that their minor disabled child will automatically inherit from them unless they execute estate planning documents,¹ which could in turn result in estate guardianship and court supervision over the minor's estate. Attorneys should educate parents about the other important legal issues they must address and the decisions they must make when choosing among various legal options. This article and the accompanying checklists describe the information you must acquire and the relevant topics you must discuss with your clients.

Reviewing the child's needs

As counselor, you must carefully explore the child's unique situation so you can design an appropriate planning strategy. You should gather detailed information about the nature, extent, and expected duration of the child's disability (or other "special needs"), as well as about available financial resources and treatment, services, and benefits that are now or will become necessary. (See sidebars for planning checklists.)

At the initial consultation, parents may understand the extent of their child's disability but not its likely impact on his or her ability to function as an adult. Further, parents may not be familiar with relevant programs, services, and benefits, particularly those needed in adulthood.

Since legal options will be driven by choices relating to future care, services, programs, and governmental benefits, and these are in turn driven by the child's disabilities, you should recommend a comprehensive professional evaluation of the child's physical, medical, social, emotional, educational, and services needs, if one has not been done. Refer

parents to professionals for these evaluations.

You might also refer them to case managers, agencies that serve children with the particular disability in question,² and qualified financial planners. The National Endowment for Financial Education publishes a pair of informational booklets that may be helpful to parents.³

When reviewing the child's need for means-tested governmental benefits, take care to distinguish between Supplemental Security Income (SSI) benefits and Social Security Insurance benefits⁴ and also between Medicaid and Medicare.⁵ Unearned income and ownership of assets do not affect eligibility for Social Security and Medicare benefits,⁶ but they do for SSI and Medicaid.⁷ SSI eligibility is affected not only by cash and checks paid to a recipient but by in-kind income in the form of goods and services purchased by third parties.⁸ These differences dictate the provisions you should include in planning documents.

You must also help with planning for assets held in the name of a child who requires means-tested benefits, including future assets likely to be received by the child. The goal is to assure that the child is not disqualified by assets placed in his or her name.

If possible, parents should spend the child's assets before the child attains age

18. They should also discourage others from transferring additional assets to the child. If the child's assets cannot be spent down, consider creating a self-settled special needs trust (see the discussion below).

Special needs trusts

Typically, parents include a testamentary trust in their estate plan for the benefit of their minor children. Generally

1. 755 ILCS 5/2-1(a).

2. Some national organizations devoted to the interests of disabled individuals and their families include: Alexander Graham Bell Association for the Deaf and Hard of Hearing, American Association on Mental Retardation, CHADD, Council for Exceptional Children, Easter Seals, Epilepsy Foundation, Lighthouse International, Muscular Dystrophy Family Foundation, Inc., National Alliance of the Disabled, National Center for Learning Disabilities, National Down Syndrome Society, and United Cerebral Palsy.

3. *With Open Arms* (2002), Easter Seals, 230 W. Monroe, Suite 1800, Chicago, IL 60606. *Making Plans* (2003), National Down Syndrome Society at (800) 221-4602 or info@ndss.org.

4. SSI is a federal income program for indigent persons who are aged, blind or disabled. Social Security is a federal program which pays income to retired or disabled workers who have paid required Social Security contributions and have worked a specified number of quarters in covered employment, as well as to certain of their dependants and survivors. See 42 USC §1381 et seq. See also 42 USC §401 et seq.

5. Medicaid is a joint federal-state medical insurance program for indigent persons. Medicare is a federal medical insurance program for Social Security income recipients. See 42 USC §1396. See also 42 USC §1395.

6. 42 USC §401 et seq and 42 USC §1395.

7. 42 USC §1381 et seq and 42 USC §1396.

8. 20 CFR 1101.1003.

Special-needs planning checklist

- Ascertain nature and value of parents' assets
- Plan for managing parents' estate upon their disability or death
- Plan for paying expenses if child will remain in family home
- Plan for parents' health care decisions in event of their disability
- Plan for care for child in event of parents' disability or death
- Plan for gifts during parents' lifetime
- Ascertain nature and expected duration of child's disability or special needs
- Ascertain nature and value of income and assets owned by special needs child
- Determine income and assets which may be received by special needs child in future
- Ascertain present medical insurance coverage and plans for future medical insurance
- Determine child's present and future need for means-tested benefits, including Supplemental Security Income (SSI)/Social Security Benefits, Medicaid/Medicare, food stamps, community integrated living arrangements, independent living programs, home services, in-patient or out-patient mental health services, or residential services
- Plan for managing child's personal and financial decisions after age 18 (does child have capacity to make personal and financial decisions or execute POA or will?)

these are "support" trusts⁹ that terminate when the children are deemed to be able to manage the funds independently. This may be when they turn 21 or later. Some support trusts continue for the life of the child.

If a child needs – and qualifies for – means-tested benefits, a support trust will make him or her ineligible.¹⁰ Property held in a properly drafted discretionary "special needs" or "supplemental needs" trust, on the other hand, will not affect the disabled child's eligibility.¹¹ The income and assets of a trust can thus be devoted to improving his or her quality of life.

A discretionary special needs trust may be established by any competent adult. The trust document must clearly state that the purpose of the trust is to supplement, not to replace, funds available from governmental and other benefit programs and that the trustee has complete discretion to use the funds in any way for the beneficiary.¹² The beneficiary must not have any legal right to access trust income or assets.¹³

The trust may prohibit the trustee from making any payments directly to the beneficiary and from using trust assets to pay expenses covered by available public or other benefits. Trust protectors, grantors, or trustees should be empowered to amend the trust if necessary to address changes in laws or rules affecting the trust's purpose. Parents may also

wish to give the trust protector power to remove the trustee.

Each trustee of a discretionary special needs trust must be willing and able to advance and protect the best interests of the disabled person, even where such interests conflict with the trustee's own interests. The trustee must also understand the laws and rules governing the public benefits programs affecting the disabled beneficiary and maintain complete and accurate records of all trust distributions for the benefit of the child.

The trustee must carefully plan trust distributions to avoid an unintentional reduction or termination of benefits. For example, payments to any account held in the child's name (outside the trust) will cause a reduction in benefits under most means-tested programs.¹⁴ Therefore, the trustee must avoid trust distributions to a bank or debit-card account.

Similarly, in-kind income from payments to third parties for basic food or shelter of an SSI recipient will cause a reduction in SSI benefits.¹⁵ Unless the trust agreement is drafted to allow payments for these expenses, the trustee is prohibited from paying them, even where the SSI benefits are inadequate to pay for food and proper housing.

Third-party special needs trusts

Discretionary special needs trusts established by someone other than the disabled child, or the disabled child's

If possible, parents should spend the child's assets before the child attains age 18. They should also discourage others from transferring additional assets to the child.

agent or legal representative, and funded with assets belonging to someone other than the disabled child, are customarily known in Illinois as "third party special needs" or "Phillips" trusts.¹⁶

A third-party special needs trust may be created by parents or any other individual for the benefit of the child. The trust may include any other persons, as well as such entities as lifetime or remainder beneficiaries. It may offer creditor protection for the beneficiary.

There is no requirement that the beneficiary be either disabled or eligible for means-tested benefits. However, restrictions on the types of distributions that can be made by the trustee might make a different type of trust a better choice if the intended beneficiary does not qualify for means-tested benefits.

A testamentary trust can be used where gifts to the trust will not be made until the death of the parents. Where parents, or other family members and friends, will make gifts to the trust before death, the trust can be established immediately, as an inter vivos¹⁷ trust. In this

Care and protection of special needs child

- Short-term guardianship
- Guardianship for minor child upon disability or death of parents (designation of guardian, stand-by guardian)
- Powers of attorneys (health care and property) for child when he or she reaches age 18
- Guardianship for adult disabled child (physician's report and procedures, stand-by guardian, successor agents or guardians)

Lifetime gifts for child

- Gift and estate tax issues
- Avoiding disqualification for means-tested benefits

Management of parents' estates

- Property and healthcare powers of attorney
- Gifts to special-needs child
- Power to create and fund special needs trust for parent
- Trust for special needs child (support v special needs trust, third-party v self-settled trust, inter vivos v testamentary trust, revocable v irrevocable trust, trustee qualifications and conflict of interest issues, funding trust and tax considerations, coordination with benefits eligibility rules and beneficiary designations)

9. A support trust is one which is intended by the settlor to pay the beneficiary's basic support needs.

10. See *Department of Mental Health and Developmental Disabilities v Phillips*, 133 Ill App 3d 337, 478 NE2d 1052 (1st D 1985), rev'd in part and aff'd in part, 114 Ill 2d 85, 500 NE2d 29 (1986) for a discussion of the elements of support trusts and special needs trusts.

11. *Id.*

12. *Id.*

13. *Id.*

14. See, for example, 42 USC §1382a(a)(2) and 89 Ill Adm Code 120.330.

15. See 20 CFR 416.1131 and 416.1140.

16. See James Zartman, *Discretionary Trusts for Disabled Beneficiaries*, 81 Ill B J 517 (1993), for an in-depth discussion of the background and development of these trusts.

17. An inter vivos trust is one which is funded and administered during the lifetime of the settlor/grantor.

case, parents should make provisions for future funding of the trust in the event of their incapacity, as well as upon death.

Although a revocable trust will permit the parents to make changes at any time, other donors may be disinclined to make gifts to a revocable trust. Also, since gifts to a revocable trust will be included in the parents' estate,¹⁸ you must address potential estate tax liability.

If a child qualifies for means-tested benefits, a support trust will make him or her ineligible; property held in a discretionary "special needs" or "supplemental needs" trust will not.

If you must include Crummey withdrawal rights because of gift tax rules,¹⁹ take care that no such rights are granted to the disabled child, because this will result in loss of benefits eligibility. Where the trust will be "complex"²⁰ and is unlikely to distribute all income for the benefit of the child, potential donors may wish to explore other gifting alternatives, such as 529 educational accounts and direct payments for goods and services to benefit the disabled child, to minimize tax on income generated by

donated assets.

Self-settled special needs trusts

A discretionary special needs trust established by the parents but funded with assets belonging to the special-needs child is not a third-party trust. It is a "self settled" trust.

The Omnibus Budget Reconciliation Act of 1993 (OBRA '93)²¹ authorizes the use of self-settled "OBRA '93 pay back trusts" to shelter assets owned by a disabled child and preserve the child's eligibility for Medicaid benefits. These trusts have also been used for SSI recipients²² and children who receive benefits from other programs, even some that do not specifically exempt these trusts.²³

The key difference between a third-party special needs trust and an OBRA '93 pay back trust is the "pay back" requirement. On the death of the trust beneficiary, or upon earlier termination of the trust, the trustee of an OBRA '93 trust must "pay back" the state for any governmental benefits expended on behalf of the disabled person during his or her lifetime.²⁴ Funeral expenses, claims against the trust estate, and residuary beneficiaries of the trust cannot be paid until the state has been fully reimbursed. However, trust administration expenses may be paid

before the state is reimbursed.²⁵

Federal law limits the use of OBRA '93 pay back trusts to persons who qualify as "disabled" under the definition set forth in the Social Security Act.²⁶ The trust beneficiary need not be mentally incompetent or adjudicated a "disabled person" under Illinois guardianship laws.

Although federal law authorizes parents to establish this type of trust on behalf of their disabled adult children,²⁷ SSI requires them to fund the trust ini-

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18. 26 USC §671(a)
19. 26 USC §2503. *Crummey v Commissioner*, 397 F2d 82 (9th Cir 1968).

20. 26 CFR §1.661(a)-1.

21. 42 USC §1396p et seq.

22. 42 USC §1382b(e).

23. For a comprehensive discussion of OBRA '93 pay back trusts, see A. Margot Gordon and Howard S. Berk, *Medicaid Planning for the Disabled: The Use of OBRA '93 Pay-Back Trusts*, 86 Ill B J 16 (1998).

24. 42 USC §§1396p(d)(4)(A), 1396p(d)(4)(C).

25. Social Security Administration Program Operations Manual System (POMS) SI 01120.203(B). In a letter from the Assistant Regional Commissioner of Social Security Administration Region V to the District Manager of Chicago, Illinois, dated February 7, 2006, this provision was interpreted to allow payment of "state and federal taxes due from the trust because of the beneficiary's death and reasonable fees for administration of the trust estate, such as an accounting of the trust to a court, completion and filing of documents, or other required actions associated [with] termination or wrapping up of the trust."

26. 42 USC §1382c (a)(3)(A) provides that "an individual shall be considered to be disabled ...if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months."

27. *Id.*

OBRA '93 pay back trusts

Comparison	(d)(4)(A) Individual Trust	(d)(4)(C) Pooled Trust
Who may establish trust?	Parent, grandparent, guardian, or court	Parent, grandparent, guardian, court, disabled person, or agent
Who may serve as trustee?	Any qualified individual or corporation	Not-for-profit corporation
Age limits	Only for disabled beneficiaries under age 65	Disabled beneficiaries of any age
Investments	Trust assets segregated from all other assets	Sub-trust assets pooled with assets of other beneficiaries
Additional assets	May receive assets until beneficiary reaches age 65	May receive assets at any age
Pay back requirements	Must pay back state before payment to any other person or entity	Option to have pooled trust retain funds in lieu of repayment to state

tially with their own assets, based on its interpretation of what is meant by "establishment" of the trust.²⁸ This initial funding can be a minimal amount, such as \$10, so long as it is \$10 belonging to the parent and not to the trust beneficiary. Thereafter, the remaining assets contributed to the trust are owned by the trust beneficiary.

An OBRA '93 pay back trust must be irrevocable and created for the sole benefit of one disabled person.²⁹ The Social Security Administration will not consider an Illinois trust to be "irrevocable" unless the trust designates one or more specific remainder beneficiaries, either by name or classification (i.e., descendants, children, parents) and not simply the "estate" of the beneficiary.³⁰

Remainder beneficiaries for a minor or incapacitated adult beneficiary with no estate plan should be those persons who would inherit under Illinois' intestate succession statute.³¹ The trust should also authorize the trustee or a trust protector to amend the administrative terms of the trust if necessary to accommodate changes in laws or regulations. The "sole benefit" requirement has been interpreted to require only one lifetime beneficiary but to allow any number of remainder beneficiaries.³²

Assets of any value may be sheltered by an OBRA '93 pay back trust. It is important to distinguish between assets and income, because income paid to a recipient of a means-tested benefit will likely count as a resource and operate to reduce or terminate the person's benefits. SSI will usually consider money to be "income" based upon the name on the check.³³

For example, money from a property sale, or personal injury award, may not be "income" to an SSI recipient if the check is payable to the trustee of the OBRA '93 pay back trust. In contrast, annuity benefits paid to the trust beneficiary are considered income, even if deposited directly into an OBRA '93 pay back trust. A beneficiary may irrevocably assign annuities or other benefits to the OBRA '93 pay back trust, to avoid having payments result in a reduction of SSI benefits.³⁴ However, certain payments, such as Social Security, ERISA pensions, and Veteran's benefits, are non-assignable under law, and will always count as "income" for SSI eligibility purposes.³⁵

Two types of OBRA '93 pay back

trusts are used in Illinois: "(d)(4)(A)" trusts³⁶ ("individual OBRA '93 pay back trusts"), and "(d)(4)(C)" trusts³⁷ ("OBRA '93 pooled pay back trusts"). These names relate to the sections of OBRA '93 that authorize them. (See sidebar for a description of their key features.³⁸)

Illinois not-for-profit organizations operating pooled OBRA '93 trusts are usually associated with banking institutions. We know of three pooled OBRA '93 trusts operating in Illinois.³⁹ In contrast, individual OBRA '93 trusts may designate any corporate or individual trustee, including a parent or other relative.

Pooled OBRA '93 trusts offer improved investment options from pooling of assets and professional trust administration, even for relatively small trust estates. They are the only OBRA '93 trust option for disabled individuals who are 65 or older. They may be preferable for disabled persons who are nearing age 65 or likely to receive assets after reaching age 65, to shelter assets received after age 65 without having to create a new trust. Since they also may be established by a competent disabled person or the person's duly empowered agent, they are particularly useful where there is no parent or grandparent available to create the trust, thus avoiding the need for court involvement and supervision necessary for creation of an individual OBRA '93 pay back trust.

Individual OBRA '93 trusts offer more flexibility in selection of trustee. They are appropriate where the grantor desires to appoint a trustee who is a

family member or other individual, or a corporate trustee which does not operate a pooled OBRA '93 trust. When the trustee is a non-professional individual, it may be wise to establish the trust through guardianship proceedings, so that the court may supervise administration of the trust.

Conclusion

Attorneys can help parents of special-needs children create wills and trusts, but they can also point them to sources of information, help them identify other professional resources, and assure that all relevant issues are addressed. Planning for disability of the parents, for the child's own assets, and for care of the child and administration of his or her inheritance after the parents' deaths, will help parents avoid serious problems and promote the best interests of the child and the family.⁴⁰ ■

28. POMS SI 01120.203.B.1.e.

29. 42 USC §§1396p(d)(4)(A), 1396p(d)(4)(C).

30. POMS SI 01120.203 and SI 01120.200.D.3. See also Region V Office Guidelines.

31. 755 ILCS 5/2-1.

32. POMS SI 01120.203.B.3.

33. 42 USC §§1381a, 1382a(a).

34. POMS SI 01120.200.

35. POMS SI 01120.200.G.1.c.

36. 42 USC §1396p(d)(4)(A).

37. 42 USC §1396p(d)(4)(C).

38. 42 USC §§1396p(d)(4)(A), 1396p(d)(4)(C).

39. Illinois Disability Pooled Trust, (312) 332-4622; Life's Plan Special Needs Trust, (630) 628-2355; Options for Living OBRA Pay Back Trust, (630) 584-0043.

40. For further reading see Clifton B. Kruse, Jr., *Third Party and Self Created Trusts: Planning for the Elderly and Disabled Client* (ABA 3d ed 2004) and Margolis, H., *The Tax Implications of the OBRA '93 Disability Trust*, *The Elder Law Rep*, Vol VI, N 10 (May 1995).

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ing either party should first determine if the nonparent has standing and, if so, whether it can be contested. Without the authority to proceed, even the best intentioned nonparents will be denied an opportunity to present the merits of their case. From the parent's perspective, demonstrating nonparents' lack of standing provides a quick end to the litigation and saves time, expense, and stress on the family.

Practitioners should also know the facts of their case to determine if a guard-

ianship petition under the Probate Act or a custody petition under the IMDMA would fulfill their client's goal. Each avenue presents distinct obstacles and benefits. Because *R.L.S.* has drastically changed the way in which these proceedings are governed, the determination of what and where to file is even more important.⁸⁵ ■

85. I would like to acknowledge the assistance of Kassandra Wagner, our intern, who assisted in the research for this article.