



Special Needs Planning For Special Family Situations

By Richard A. Courtney, CELA

According to the 2000 census, there were more than 49.7 million persons over age 5 with disabilities in the United States and 607,570 such persons in Mississippi. Advances in medical treatment and technology have led to increased survival rates and longer life expectancies for children and adults with disabilities. New breakthroughs in treatment for mental illness have also had an effect on both quality of life and life expectancies. According to a report released in April 2004 by the National Alliance for Caregiving and AARP, one out of five U.S. residents provides unpaid caregiving services to an adult.

The family of a person with a disability desires to maximize the financial resources available to pay for living expenses and medical care for their disabled spouse, child or parent, including after the deaths of the caregiving family members. Many persons with disabilities have no medical insurance coverage and no real hope of obtaining it. For those who qualify, the Medicaid program will pay their basic medical expenses (including nursing home care), and the Supplemental Security Income (SSI) program of the Social Security Administration will assist with the costs of basic food, clothing and shelter. These public benefits are available only if the individual with a disability meets the income and asset criteria of the programs. Current and future eligibility for these programs can only be assured by proper planning to maintain such benefits as well as other private resources. Consider the following scenarios:

Scenario 1: Mrs. Client has an adult son, John, who has a brain injury and lives

in her home. Mrs. Client's income is limited, and John has been declared eligible to receive Supplemental Security Income (SSI) payments by reason of his disability. John's grandmother has indicated her desire to give him a generous gift in her will or possibly before her death. Mrs. Client is concerned about how John can retain his disability benefits and how he will be able to meet all his needs after her death. She and John's grandmother are considering several planning options: (a) Mrs. Client (or grandmother) may leave a specific gift of assets to John in her will. This will ensure that assets will be available to meet John's needs, and no guardian will be required (unless John has been determined legally incapacitated and a conservator has been appointed). However, these assets would make John ineligible for his existing SSI and Medicaid benefits, and he could misuse funds or be exploited financially by others trying to get the funds. (b) Mrs. Client could disinherit John in her will and leave nothing to him. While he would continue to be eligible for all government benefits and there would be no danger of financial misuse by John or exploitation by others, this option is emotionally difficult for Mrs. Client, and there are no assurances that John's needs will be met after her death, since funds are going to others. (c) Mrs. Client (or grandmother) can make a "morally obligated" gift of all assets to another child or individual and ask him or her to use them for John's benefit and support. John could continue receiving government benefits as funds would not be in his name, and extra funds

Continued on next page

Special Needs Planning For Special Family Situations

would be available to meet his needs without trust fees, accountings or guardianship expenses. However, such an informal agreement cannot be legally enforced to compel the recipient to use funds for John, the money would be exposed to the divorce, judgments, bankruptcy and creditors of the recipient, or the recipient may die and the funds may be distributed to other individuals. (d) Mrs. Client (or grandmother) may have a trust drafted in her will (or outside her will) which requires that the funds left in that trust be

used for the "health, education, support and maintenance" of John. Such a trust could provide monetary support for John after his mother's death, with financial control by the trustee, but it will cause John to become ineligible for his government benefits. None of these options ensure **both** use of the funds for the disabled child's benefit and retention of his public benefits through SSI and Medicaid.

Scenario 2: Mr. Smith's wife, Martha, has a progressive dementia condition, and Mr. Smith is uncertain whether he can con-

tinue to care for his wife at home due to his own health condition. He is worried about having enough money to pay her nursing home costs, his living expenses, and pass some inheritance to his grandchildren. Through some elder law planning, it will be possible to qualify Martha for Medicaid to help pay her nursing home costs. They own their home and 150 acre farm as joint tenants with rights of survivorship. (a) Mr. Smith has heard (and believes) that he can just leave the home in joint ownership and effectuate his estate planning goals. However, if he predeceases Martha, Medicaid will have a claim against the home and farm at her death for repayment of all nursing home and medical costs paid by Medicaid, and could cause the sale of the residence. (b) Mr. Smith's current will leaves everything to Martha at his death. Again, if he dies first, the financial assets he leaves to Martha will disqualify her for nursing home Medicaid until all those assets are expended on her care, and a court-supervised conservatorship may be required if she lacks capacity to manage those assets. (Medicaid considers assets in a guardianship or conservatorship to be the assets of the ward for eligibility purposes.)

Scenario 3: Mary H. is the single mother of 15-year-old Alan H., who was seriously and permanently injured two years ago in a vehicular collision with a commercial truck. Alan is now a quadriplegic wheelchair user who requires assistance with dressing, toileting and feeding and whose medications cost at least \$250 per month. He is to obtain prescribed physical and occupational therapies several times each week for what will likely be an extended period of time. He will also see his neurologist, urologist, orthopedist, gastroenterologist and other doctors three to four times a year in the near future and will require additional orthopedic surgeries to correct injury-related conditions. His power wheelchair with custom seating costs approximately \$15,000 and will dictate that Mary purchase a modified van. Alan will need daytime attendant care to enable Mary to continue her work. Mary would like to move from their small rented house into a home with modifications for the wheelchair and modified bath accommodations. After two years of litigation, Mary's lawyer has been able to settle the case for the \$500,000 commercial policy limits, with \$100,000 to go to Medicaid in

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Special Needs Planning For Special Family Situations

settlement of its lien for medical expenses paid for Alan. (a) Mary has learned that, upon receiving the settlement funds, Alan will lose the Medicaid which has paid his medical expenses since the injury. Mary will have to place the settlement funds in a guardianship account and, subject to periodic court approval, use Alan's settlement funds to pay all the costs mentioned above, even to the point of depletion of the money with none left for his needs in later life. She desperately wonders if there is a way to preserve the Medicaid benefits for Alan.

The Special Needs Trust Solution

For each of these scenarios, there is a better solution – one that will achieve the clients' goals of preservation of public benefits and the retention and proper management of private resources for the benefit of the person with a disability in the future. This solution is the Special Needs Trust. A trust is an arrangement in which someone (the "grantor") transfers ownership and control of certain money and property (the trust "corpus" or "principal") to a person or financial institution (a "trustee"), who is legally responsible for

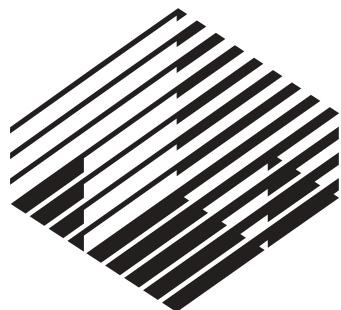
investing, managing and distributing trust assets for the benefit of another person (the "beneficiary"). Trusts may be created in two ways: a "testamentary" trust is established in the grantor's last will and testament and will take effect only at the grantor's death, while an "inter vivos" trust is created by a grantor to take effect immediately or prior to the grantor's death. A trust may be "revocable" (meaning the grantor retains the right to revoke the trust or require that the trust property be distributed to the grantor) or "irrevocable" (meaning the grantor gives up the right to "undo" the trust and take back the trust assets).

Many trusts used in estate planning to provide for spouses, children or grandchildren require the trustee to spend trust funds for the "support and maintenance" of the beneficiary. These are called "support" trusts, and the beneficiary can legally enforce payments from the trust to pay for food, clothing, shelter and other basic support needs. However, a trust may give the trustee "sole and absolute discretion" to determine whether expenditures will be made from the trust, for what purposes and

in what amounts. This is called a "discretionary" trust, and the beneficiary generally cannot compel the trustee to spend trust funds for particular purposes. Every trustee has a "fiduciary" responsibility, which is a legal requirement to exercise the highest degree of care and utmost good faith in handling the trust assets for the benefit of the beneficiary, in keeping with the grantor's directions as set forth in the trust document.

"Special needs trust" is the term commonly used to refer to any trust established to hold and manage funds for a person with a disability. The primary purposes of such a trust are (1) to prevent the trust assets and disbursements from disqualifying the disabled beneficiary for Medicaid and/or SSI benefits, and (2) to provide effective management of the trust assets so as to best meet the needs of the beneficiary. The trustee who administers the trust will be responsive to the needs of the beneficiary as communicated through other responsible family members as parents, guardians or conservators. The special

Continued on next page



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needs trust will provide funds that can be used to supplement the basic support and medical coverage furnished by the public benefit programs. The types of items and services a special needs trust can purchase and provide for the beneficiary include supplemental medical and dental care, training, education, treatment and rehabilitation programs, eye glasses, hearing aids, transportation (including vehicle purchase), maintenance, insurance, purchase or modification of housing, psychological support services, recreation, travel, entertainment, electronic equipment (such as radios, television sets, audio and video devices, and computer equipment), supplemental attendant and custodial care, and any other care or services that would enhance the quality of life of the beneficiary and which would not be paid for by private insurance or government entitlements.

Summary of Disability Benefit Programs

Most of the rules governing special needs trusts are found in the laws and regulations of the Medicaid and SSI programs. *See* 42 USC §1396p(d). However, administrative and judicial interpretations of the laws and regulations about these programs change frequently, and it is imperative that any special needs trust be drafted by an experienced attorney and administered under the guidance of an attorney and/or trustee who has some expertise in these benefit programs. There is great popular confusion regarding public benefit program rules and eligibility. In order to know whether a trust will help a person with a disability obtain or retain eligibility for a particular benefit program, it is crucial that the specific program be identified. Eligibility for the SSI and Medicaid programs is dependent upon the recipient's income (earned and unearned) and assets, while eligibility for Social Security Retirement, Social Security Disability Income, Social Security Survivor's Benefits and Medicare is not.

An SSI recipient may have "countable" monthly income of no more than \$564 (2004) or \$846 for a married couple, and "countable" resources (assets) not exceeding \$2,000 (2004) or \$3,000 for a married couple. "Countable income" for SSI purposes is generally calculated by subtracting from the individual's total monthly

earned and unearned income: up to \$20/month, first against unearned income then earned income; the next \$65 of earned income; earned income used to pay impairment-related work expenses; and one-half of the remaining earned income. Income from non-eligible family members can be "deemed" available to the SSI applicant. Food, clothing and shelter expenses paid for by another is considered "in-kind support and maintenance" (ISM) and will result in a partial reduction (generally up to one-third) of the recipient's monthly SSI payment. For purposes of the SSI resources test, certain assets are considered "exempt" resources and will not be counted in determining eligibility. The following resources, among others, are not counted for eligibility purposes: entire value of individual's home and land adjacent to it; current market value of household goods and furnishings, personal property up to \$2,000; wedding/engagement rings and disability-related equipment regardless of value; current value (wholesale) of an automobile up to \$4,500 and a second car if needed for employment or medical treatment or if modified for a disabled person; trade or business assets necessary for claimant's self-support; cash value of all life insurance if the total face value is \$1,500 or less; value of burial spaces for claimant or entire family; and up to \$1,500 for an individual (\$3,000 for a couple) of burial expense fund.

Medicaid provides payment of medical expenses for persons age 65 or over or disabled (in accordance with Social Security disability definitions), who also qualify in terms of limited assets and income. Medicaid is administered by state agencies under a federally approved medical assistance plan. For many disabled individuals who cannot obtain other medical insurance, Medicaid provides the only safety net for health care. Medicaid pays for many more services than Medicare, including prescription drugs and nursing home care. In Mississippi, any SSI recipient is automatically entitled to receive Medicaid benefits. If the beneficiary receives income or has assets that are in excess of the SSI limits, s/he is likely to lose his or her SSI eligibility – and the automatic Medicaid coverage along with it. The loss of Medicaid coverage can be a more serious problem than the loss of SSI benefits, especially if alternative medical insurance

is not readily available. In addition, persons who do not receive SSI but meet the income and asset guidelines of other "Medicaid-only" programs can receive Medicaid benefits. Medicaid coverage is dependent upon income and assets. The SSI and Medicaid programs treat assets held in a special needs trust as exempt resources. There are two basic types of special needs trusts based on who is placing assets in the trust.

Third Party Special Needs Trust.

Mrs. Client (and/or grandmother) can establish, and gift or bequeath assets to, a testamentary or inter vivos special needs trust which gives the selected trustee the discretion to use the funds conveyed to that trust for John's "supplemental needs" – that is, his needs which are not met by his SSI or Medicaid benefits. No guardianship will be required for management of those funds. Similarly, Mr. Smith can place all marital assets in his sole ownership and establish a testamentary special needs trust for Martha's future benefit with those assets. If he predeceases his wife, the trust will not terminate her nursing home Medicaid eligibility and the trustee can manage the principal (avoiding a conservatorship) and provide for her supplemental needs. An inter vivos special needs trust may be created by the spouse, parents, grandparents or anyone else who wishes to establish a fund that can later receive money or assets for the disabled beneficiary by lifetime gift(s) or by last will and testament bequests. The assets in this type trust will be used for the disabled beneficiary's needs during his/her lifetime, and the assets remaining in the trust at the death of the beneficiary will be distributed to the persons and in the manner prescribed in the trust (such as to other children or family, non-profit groups, etc.). This trust, called a "third party" trust, will not provide for any recovery by Medicaid, thus permitting all the trust assets to be distributed to the designated remainder beneficiaries at the death of the disabled primary beneficiary.

Self-Settled Special Needs Trust.

A special needs trust created to hold the assets already owned by the beneficiary, or that the beneficiary is entitled to receive through a lawsuit settlement, inheritance or life insurance settlement, is called a "self-settled" trust. Federal law (42 USC §1396p(d)(4)(A)) states that the assets of a

Special Needs Planning For Special Family Situations

disabled person placed in an irrevocable trust for that person's benefit are exempt from the application of these trust rules if the trust is:

(A) A trust containing the assets of an individual under age 65 who is disabled (as defined in section 1614(a)(3)) and which is established for the benefit of such individual by a parent, grandparent, legal guardian of the individual, or a court if the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a state plan under this title.

Thus, the essential elements of such a trust are: age of the beneficiary; disability; a single beneficiary; a qualified creator of the trust; and repayment to Medicaid upon the beneficiary's death. The beneficiary whose money or assets are being used to fund the trust must be under age 65 when the trust is established. Under current Medicaid policy, the trust assets retain their exempt status after the beneficiary reaches age 65, but the person's right to contribute additional assets to the trust terminates at that time. Such a self-settled trust must be created (that is, the trust document signed) by the beneficiary's parent, grandparent, legal guardian or a court. The individual cannot establish his/her own trust. If there is no parent or grandparent available to set up the trust, the individual may seek access to a court for appointment of a legal guardian or for establishment of the trust by the court as settlor. At the beneficiary's death, Medicaid must be first in line to recover from the trust assets the amount Medicaid has paid for the beneficiary's medical care. Any remaining balance in the SNT can be paid to those persons designated by the creator of the trust (the "remainder beneficiaries").

Thus, in the scenarios above, the special needs trust will provide the following advantages: provides funds for extras above and beyond basic Medicaid or SSI support; when drafted and administered correctly, will preserve eligibility for government benefits for spouse or child with disability; in third-party trust, assets escape Medicaid pay-back for cost of care by health care system; provides manage-

ment and flexibility regarding distribution and investment of funds; assets placed in inter vivos trust can avoid probate process; assets in the trust will be secure against predatory exploitation and the debts or liabilities of the disabled person; and ultimate distribution of trust remainder to other beneficiaries (after Medicaid pay-back in self-settled trust). It is necessary to choose a reliable trustee, who can work with the individual with a disability and other family members.

Conclusion

The third-party special needs trust is a necessary part of a family's plan to protect Medicaid and SSI benefits of a disabled child or adult from being accidentally terminated. These benefits can provide a huge source of financial assistance over time. In addition, the special needs trust will provide numerous advantages in management and care for the disabled beneficiary.

The self-settled special needs trust is the preferred method for (1) settling personal injury cases for plaintiffs who have or may need Medicaid and/or SSI benefits,

and (2) qualifying a disabled person who owns excess resources for Medicaid and SSI. The trust can be established by or for any person under age 65 with a disability, to hold that person's resources, and thereby establish or continue eligibility for these benefits. ■

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