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ESTATE PLANNING

for Clients with Modest Means and Disabled Children

By **JOHN E. DONALDSON**

Parents of severely disabled children have unique estate planning needs. To adequately serve those needs, an attorney requires a familiarity with fundamental estate planning techniques, an understanding of the child's particular disability and capabilities, present and future, an awareness of the likelihood of the need for institutional care, and a knowledge of the assets and resources that can be utilized in conjunction with the plan. Most parents of disabled children have only modest wealth. For many, a crucial financial resource that must be carefully considered in the planning process is the disabled child's actual or potential eligibility for a variety of federal, state and local assistance programs. The planner thus requires a familiarity with a number of social programs that normally is possessed only by attorneys who specialize in social service law.

There is, of course, no "model" estate plan for the client with a severely disabled child. Arrangements that might be suitable for a client with substantial means and only a disabled child as the beneficiary of his estate, would be inappropriate for the client of modest means with several young children, only one of whom is disabled. For the latter, it is often important to the success of the estate plan that the disabled child not lose eligibility for entitlement programs and that family assets be

protected from claims of public agencies and institutions that may provide care to the child following the death of the parents.

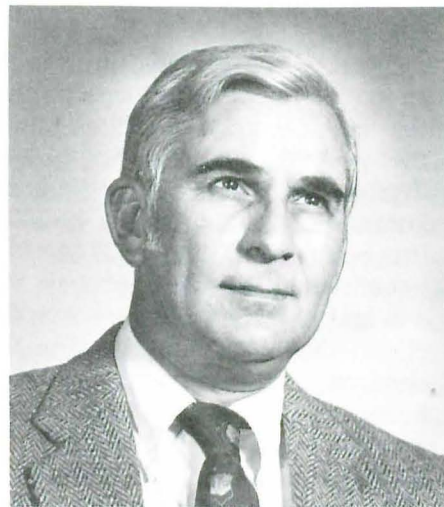
The purpose of this article is to assist the practitioner in providing estate planning services to clients of modest means who have severely disabled children. Because of limitations of space, important topics such as the necessity or desirability of guardianships and considerations in the selection of trustees are not covered.¹ The key features of the more important entitlement programs will be discussed and several planning techniques will be examined. The services available through a new organization, the Planned Lifetime Assistance Network, will also be noted.

Entitlement Programs for the Disabled

The Social Security System provides survivor benefits without regard to need or disability to minor children (up to age 22 if in college) of covered parents.² More importantly for our purposes, those benefits are extended to the severely disabled adult child whose disability began before age 22 and who remains unmarried.³ The benefit can be as high as 75% of the parent's primary insurance benefit. Because

of limits on maximum family benefits, the disabled individual's entitlement will be less if other dependent children are drawing on the same account. The level of benefits is not affected by the assets or unearned income of the disabled child.

Medicare also provides health benefits to disabled persons who have received social security payments for more than two years.⁴ Supplemental "Part B" Medicare



John E. Donaldson

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coverage is also provided unless the disabled individual elects not to have his social security benefits reduced to pay the premium. Among other things, Medicare does not cover long-term hospitalization or private duty nursing care. Medicare coverage is unaffected by the level of income or assets of the disabled individual.

Unlike Social Security and Medicare, which are administered without regard to a "need" standard, other entitlement programs extend benefits only if certain "income" and "asset" requirements are met. The first of these to be discussed, the Supplemental Security Income (SSI) program, is designed to provide a minimum guaranteed income, currently \$336, through cash payments to or for the benefit of the blind, aged or disabled.⁵ It is not an insurance program of the social security variety and is funded from general tax revenues rather than payroll contributions. It is strictly a poverty relief program. The recipient of SSI benefits must be essentially a pauper.

SSI is of considerable importance to the client who anticipates that the level of social security benefits that will be payable to a surviving disabled child will be less than the guaranteed amount under SSI. To the extent that the social security benefit and other income is less, SSI will make up the difference. For the client who has a number of minor children, or whose earnings have been subject to social security withholding for only a short time, or whose earnings are less than the maximum subject to withholding, social security survivor benefits available to a disabled child may be significantly less than the SSI guaranteed minimum income.

Where the disabled child upon the death of parents is potentially eligible for SSI, retention of that eligibility should be carefully considered in the estate planning process. Attention to the "need" standard is of particular importance. SSI benefits are not available if the

"assets" test is not met. Although there are exemptions for residential real estate and other items, generally, if the disabled child has assets exceeding \$1,500, SSI will not be available until the assets are "spent down." Furthermore, because SSI is a minimum income maintenance program, benefits can be reduced dollar for dollar for social security payments and other income payable to or for the benefit of the disabled child. "Income" for this purpose is broadly defined and with limited exceptions anything that the disabled person receives in cash or in kind that he may use to meet needs for "food, clothing or shelter" is considered income. Special rules apply to nominal amounts of earned income.

A practical consequence of the "need" standard underlying SSI is that outright bequests to severely disabled children, as well as trust arrangements requiring distributions of income or payments for support, may cause loss of eligibility for SSI payments. To the extent that such loss occurs, the bequest or trust arrangement is essentially for the benefit of the federal and state governments and not for the benefit of the client's family.

Another important "needs based" program available for disabled individuals is Medicaid, which is administered by the state under guidelines of the Department of Health and Human Services.⁶ Medicaid provides a number of hospital, physician and nursing care services including those of "intermediate care facilities for the mentally retarded." Medicaid is closely coordinated with SSI. Generally, eligibility for SSI equates with eligibility for Medicaid. Also, SSI payments may be reduced to \$25 per month plus a possible nominal state supplement if the disabled individual is in an institution where the bills are paid by Medicaid. Some persons whose income and assets exceed the need standard for SSI may qualify for Medicaid as medically needy per-

sons. The estate planner should be mindful that bequests and trust arrangements requiring the payment of income or support to a disabled beneficiary may cause disqualification for Medicaid.

The foregoing description of entitlement programs is at best a summary of major relevant features. The client who has a severely disabled child is likely to be in contact with local social service agencies and will know or can determine whether the child's disability is such that he may potentially qualify for entitlements. The client may also be a member of the Association for Retarded Citizens (ARC) or a similar support organization and may have available extensive information regarding entitlement programs and other services. Literature on entitlement programs is usually available through local social services offices. Those offices can also supply information regarding food stamps and Aid to Dependent Children (ADC) programs, which though relevant to disabled individuals, are of less importance in the formulation of estate plans.

For many parents of severely disabled children an important factor in overall estate planning is the possibility or certainty that some form of institutional care will be needed after their deaths. Private institutional care may be prohibitive in cost. The only feasible option may be care in a state hospital or mental care facility. If that is the case, the estate planner must be especially mindful that statutes make the disabled individual liable for the costs of care and any assets or income right to which the disabled person is entitled may be reached by the state in its capacity as creditor.⁷ Even where a sibling may be initially willing to provide care for the disabled child upon death of parents, the prospect of ultimate institutional care should not be lightly disregarded. State agencies are deemphasizing institutionalization of the handicapped. Group homes and other ar-

rangements are increasingly utilized in conjunction with SSI, Medicaid and housing subsidies.

Planning Options

The estate plan of a client of modest means with a severely disabled child should be formulated with a proper regard to the entitlement programs which have been discussed. For most families, the primary focus of the estate plan as it relates to the disabled child will be after the death of both parents. Depending upon the circumstances of the client, the disabled child and the family as a whole, the optimal plan as it relates to the disabled child in relation to overall objectives can take several forms.

For many clients, economic considerations and family needs may dictate that the best plan is one that simply disinherits the disabled child. Necessity is the author of the plan. When the parents are young, have other minor children and limited financial resources, there may be no practical alternative to disinheritance. Any intestate portion or legacy for the disabled child would deprive nondisabled children of needed resources and could reduce public entitlements and services that would otherwise have been provided to the disabled child. A decision to disinherit a disabled child is psychologically and humanly difficult, but given the need to maximize resources, it is often the only realistic option.

A second option that is suitable for certain clients, but which should be used with caution, is sometimes referred to as an "informal" trust. Where the client has adult children in addition to the disabled child, a bequest of a disproportionate share to an adult child, coupled with complete or virtual disinheritance of the disabled child, may be made in the expectation that the adult child will provide financial and other assistance to the disabled. Precatory language, rather than language giving the disabled child

enforceable rights as a trust beneficiary, is used. Such an arrangement should not impair the disabled child's eligibility for need-based entitlement programs. However, should the child reside with the adult sibling and receive free room and shelter, SSI benefits may be reduced by a third.⁸

There are risks in the use of informal trusts that should be carefully assessed. Among these are the possibility that the adult child may have unanticipated greed, may become indifferent to the needs of his sibling, may suffer financial reverses, or may die prematurely. The estate planner, before recommending the informal trust device, should consider whether a discretionary "luxury" trust discussed next is more feasible.

A third option, which to a large extent is an alternative to the informal trust, is the discretionary luxury trust. Such a trust could be a fully funded revocable trust for the benefit of the client and spouse while alive and for the benefit of the disabled child upon the death of the survivor. It may also take the form of a nominally-funded revocable trust designed to be enlarged by a testamentary power over, or it may be a testamentary trust under, the will of the surviving parent.

The key object of the trust would be to supplement rather than supplant need based entitlement programs otherwise available to meet basic needs of the disabled child. To accomplish that object, it is essential that the child have no enforceable rights to income or corpus. To the extent that such rights may be created, eligibility for SSI and Medicaid may be curtailed and income and corpus may be subject to state claims for reimbursement of the cost of institutional or other care.⁹

Careful drafting is essential if the discretionary luxury trust is to be effective. The instrument should contain language expressing the intent of the settler that the trust fund

be used only to promote the happiness and welfare of the disabled child in ways that do not reduce the services and financial assistance for support and medical care to which the disabled child would otherwise be entitled without charge from any federal, state or local government agency. A spendthrift clause should be included with language that expressly prohibits the payment of income or principal to reimburse any governmental agency for basic support, maintenance or medical care.¹⁰ The powers of the trustee should be exercisable in their sole and absolute discretion, and such powers should include authorization to expend funds to provide the disabled child with such "luxuries" as vacations, trips to visit relatives, attendance at movies, television sets, extra clothing and so on. The instrument should, of course, provide for the disposition of the trust fund to remaindermen upon the death of the disabled child. As "boiler plate," the trust document should also require termination upon a determination by the trustees that the existence of the trust causes the child to be ineligible for SSI or Medicaid or that the trust income or corpus may be subject to claims by creditors of the child, including the state. The duties given the trustee can include the duty of serving as an advocate of the interests of the child with express authorization to spend trust funds for the services of attorneys and others in securing the full benefit of entitlements and opportunities available.

The suggested spendthrift language and termination provisions should discourage, but may not prevent, the state from seeking to reach trust income for reimbursement of the costs of public assistance programs which benefit the disabled beneficiary. A 1981 statute¹¹ authorizes circuit court proceedings to "reform" trusts for recipients of welfare benefits. The statute is rather vague. However, it does provide that where the trust

benefits more than one person any "order of reformation shall require the trustees to expend only so much of the income of the trust and to dispose of only so much of the trust res to which the beneficiary, which has received the public assistance, would be entitled in accordance with the provisions of the trust." Furthermore, the court is not to "affect any income or trust res to which the beneficiary. . . has no legal or equitable entitlement whatsoever." It permits the court to "direct the exercise of such discretion" where the trustee has discretionary powers. Importantly, the statute prohibits the invasion of corpus of a spendthrift trust.

Planned Lifetime Assistance Network

For many parents of disabled children, a major concern is assuring that someone will be diligent in promoting the interests of the disabled child after they are no longer able to do so. Should the child be denied a training opportunity or other benefit or service to which he is entitled, or receive inadequate care, they want an advocate to protect the interests of the child.

Attorneys in Virginia should become aware of the important role that is now being played by a new organization dedicated to promoting the interests of the disabled. Planned Lifetime Assistance Network (PLAN), based in Charlottesville but with offices in other areas of the state, is now assisting parents of disabled children with a variety of services. It has developed useful forms which can be used in preparing trust arrangements. Very importantly, it has developed a lifetime advocacy trust arrangement under which it will function on behalf of participating parents in providing advocacy services on behalf of disabled children. Attorneys may contact PLAN at P.O. Box 344, Charlottesville, VA 22902, or by calling (804) 295-0653.

Attorneys with clients living in the city of Virginia Beach should also consider opportunities under the Virginia Beach Community Trust arrangement developed by its Office of Mental Retardation Developmental Disabilities Programs. The arrangement involves a master trust already in place which is prepared to administer contributed funds on behalf of disabled beneficiaries.

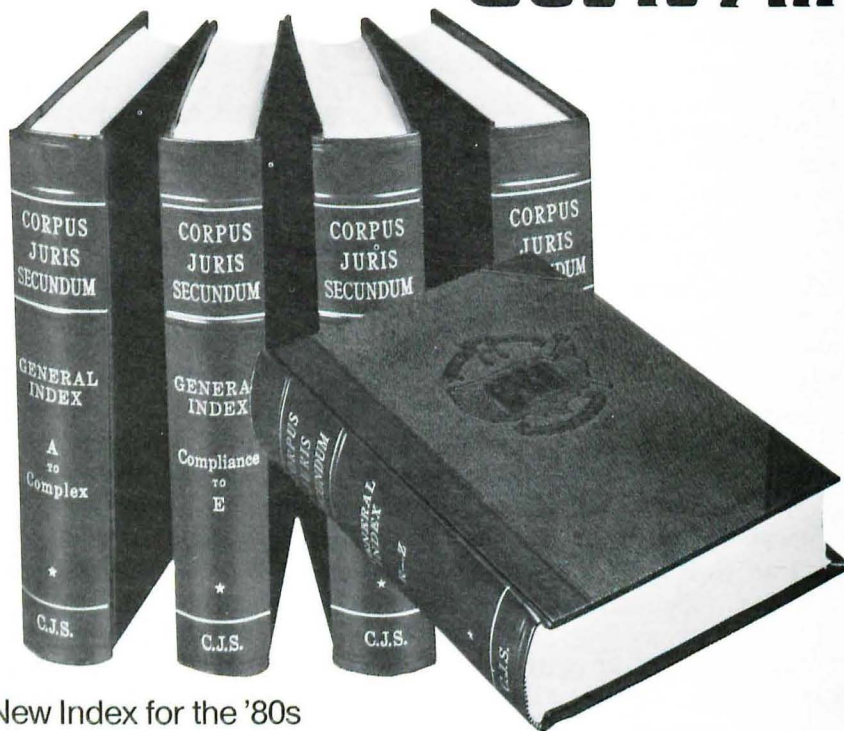
Conclusion

Attorneys providing estate planning services to clients with disabled children should do so with due regard for the benefits available under entitlement programs. Planning options that do not impair eligibility for entitlements should be carefully considered. The estate

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planner should not ignore the potential need for an advocate to protect the interests and oversee the quality of care received by the disabled child.

FOOTNOTES

1. For more extensive treatment, see "How to Provide For Their Future," a thorough pamphlet issued by the Association for Retarded Citizens and available by writing ARC, P.O. Box 6109, Arlington, TX 76011. See also Frolik, "Estate Planning for Parents of Mentally Disabled Children," 40 U. of Pitt. Law Rev. 305 (1979).
2. 42 U.S.C. §§401 *et seq.* "Disability" for social security and SSI purposes means inability to engage in substantial gainful activity by reason of a medically determinable physical or mental impairment. 20 C.F.R. 404.1508-1509.
3. 42 U.S.C. §§423 *et seq.*
4. 42 U.S.C. §1395.
5. 42 U.S.C. §§1381 *et seq.*; 20 C.F.R. Part 416.
6. 42 U.S.C. §1396. Detailed rules are found in the *Medicaid Manual* for Virginia which is available through the Virginia Department for Social Services.
7. Va. Code §§37.1-105 *et seq.*
8. 42 U.S.C. §382.
9. Va. Code §§37.1-105 *et seq.* See also Va. Code §55-19.1.
10. Spendthrift trusts are valid under Va. Code §55-19 but may be affected by Va. Code §55-19.1.
11. Va. Code §55-19.1.

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