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Planning for a Disabled Child

Estate planning must be handled with care to ensure that the disabled child is adequately provided with financial resources and personal assistance throughout his or her life span. This article examines many means for doing so without jeopardizing the child’s chances for receiving government assistance.

By Judith G. McMullen

In the ordinary course of things, parents expect their children to become increasingly independent as years go by. After many years of nurturing and educating, the offspring leave the nest and go on to support themselves and form families of their own. Hopefully, affectionate ties will continue and deepen. Well-to-do elders may institute gift-giving programs for their children and grandchildren. Family businesses will often absorb workers from the younger generations. However, there is usually an expectation that children will be more or less personally and economically self-sufficient.

Parents of disabled children thus find themselves outside of the ordinary course of things. Depending on the nature of a child’s disability, he may never be totally self-sufficient in either his personal life or his economic situation. Parents of disabled children may work doubly hard at educating and caring for their offspring, in the hopes of allowing them to achieve whatever health, fulfillment, and independence is possible. Yet, the parents are plagued by a nagging question: “What will happen to my child when I can no longer care for him?”

People who have extensive financial resources may be able to craft trust and guardianship arrangements to adequately provide for the disabled family member. Persons having more modest resources, however, must be especially careful to allocate resources in a way that will at best leave the disabled child with a better quality of life and at worst not jeopardize the quality of life the child already has. Many disabled children are eligible for state and federal assistance programs, and well-intentioned but poorly planned gifts or bequests could eliminate their eligibility without making an appreciable difference in their lives.

This article provides an overview of the options open to parents in this difficult situation. It is my intention to provide a basic analysis of the issues involved in planning for the disabled child, along with general suggestions about how best to address those issues. Obviously, an attorney planning for a particular family will need to do specific research concerning the rules of the state of the family’s residence, the characteristics of the specific disability, the complicated regulations governing the state or

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federal public assistance programs for which the disabled child might be eligible, and other specific issues. This article is meant to be a starting point.

Summary of Traditional Approaches

Objectives of Planning for Disabled Children

Parents of children hope to provide support and education for them, to protect their resources from creditors or the unscrupulous, and to treat them as equally as possible. Parents of a disabled child may have the additional objective of preserving any eligibility their child may have for available government or private programs. All parents hope to achieve these objectives within a structure that provides flexibility to address changes in circumstances.

First and foremost, with disabled children and healthy children alike, the parent's main objective is to ensure that each child has adequate support and will be educated in a manner that enables the child to achieve his full potential. With nondisabled children, this can usually be accomplished by the nomination of a guardian for minor children and a trust to cover educational and support needs during minority or for a short period thereafter. For a disabled child, the picture is more complicated. Longer-term, hands-on care and financial support are typically required, although resources may be limited.

Another typical parental concern, that the child receive benefits that will not be diminished by his or her squandering or by the opportunism of others, becomes especially poignant in the case of the disabled child. For one thing, with certain types of disability, the hoped-for progression to good money management skills may not happen for a particular child. For another thing, care providers, including government agencies, may aggressively pursue any money that becomes available to a disabled child.

Treating children equally is frequently impossible. At the very least, any property must be given to the disabled child in a form different from that given to the nondisabled. In many cases, the disabled and nondisabled children cannot as a practical matter receive the same amount of property. Frequently, the nondisabled child must assume responsibilities for the personal or financial care of a disabled sibling, because no viable alternative exists. Parents may anguish over these inequities.

Perhaps the most important planning consideration for middle-class parents is to provide for the disabled child in a way that preserves whatever eligibility the child may have for assistance programs. This planning can be tricky, and it is more easily done in some states than in others.

Finally, parents want the trustees, guardians, or others who will ultimately implement their plan to have enough flexibility in their powers that they can deal with changes in the law, changes in the child's condition, or other unforeseen eventualities. Here again, the planner faces some tough choices.

Traditional Approaches

Outright Gifts

Parents with small to moderate-sized estates typically leave money or property in trust or guardianship accounts for minor children but give outright gifts to children who are past the age of majority or have completed their education. Very large estates are more likely to be left in trust, but substantial payments of income or principal may be paid to adult children from the trust.

If the disabled child has reached the age of majority, has a disability that does not and will not affect her ability to manage assets, and does not need public benefits (nor will ever be likely to), this approach may still be viable. However, for most disabled adult children, outright gifts are not a good idea.

First of all, outright gifts necessitate money management skills and wise spending habits. Many disabilities, such as developmental disabilities, mental disabilities, or substance abuse problems, leave the child without these capabilities. Secondly, outright gifts of any size may disqualify the recipient from any public benefit programs for which she would otherwise be eligible, such as Supplemental Security Income (SSI) or Medicaid, which are only available if a recipient has few resources and minuscule income. Moreover, “eligibility for such benefits cannot be restored by simply disclaiming the inheritance,” because many federal and state programs treat disclaimers as disqualifying transfers. Thirdly, the gift may be claimed by the state as reimbursement for public services that have previously been provided. In these last two instances, the disabled child would receive no benefit from the gift, and might actually experience a drop in his standard of living.
As far as planning goes, it is not enough for parents to eliminate outright bequests to the disabled child. It is important to ensure that no significant distributions of money or property occur from any source. Thus, trustees should not be authorized to give many typical trust distributions directly to the child, nor should insurance policies or other plans having survivor benefits name the child as a beneficiary. In addition, parents need to inform grandparents, siblings, or other relatives who might make inter vivos or testamentary gifts to the disabled child that an outright gift would be problematic for the child. This planning requires great attention to detail, because many such gifts may be contingent. For example, a grandparent’s will might leave property in equal shares to her children who are living, with the share of any deceased child going to his children. If a disabled child’s parent predeceases both him and the grandparent, this could result in an unanticipated outright bequest to the disabled child. This is particularly worrisome because contingent bequests such as the one in this example are frequently automatically included in simple wills. The grandparents’ lawyers need to be informed of the condition of the grandchild in order to deal with the issue.

Disinheritance
Some parents, especially those with modest estates, choose to disinherit the disabled child altogether. The usual approach would be to give the estate to the disabled child’s siblings (or to other family members, if there are no siblings) with the express or implied expectation that the recipients will use some of the property for the benefit of the disabled child when the parents are gone. Once again, this is not generally the best approach, but it may work well in certain limited circumstances. For example, if the siblings receiving the property are both well off and solicitous about the disabled child’s welfare, this method may work.

However, there are some foreseeable dangers. The persons receiving money from the parent’s estate are not legally obligated to spend any of it on the disabled child. A sibling may feel a keen moral obligation to share the inheritance, but if her own family falls on medical or financial hard times, the pressure will be very great to give priority to her own family. She may not have a choice. Since the property is legally hers, any of her creditors can pursue it. If the sibling to whom the inheritance is given fails, intentionally or unintentionally, to use some of it for the benefit of the disabled child, that child will have no extra resources. If the disabled child has no resources other than public benefits, his standard of living is likely to be at the poverty line or worse, since government benefit programs are geared to the barest subsistence level. This is the very situation that parents seek to avoid by careful planning.

Trusts
Many parents create inter vivos or testamentary trusts for gifts to children who are minors, have not completed their education, or are poor money managers. The best approach is generally a trust authorizing distributions of income and principal as needed for the support, health care, education, and welfare of the beneficiaries. Once the beneficiaries have reached the age of majority, the trustee is generally allowed to make direct distributions. Remaining principal is usually distributed to the beneficiaries in one or two payments once a certain age is reached or all education has been completed. Often, a spendthrift clause is included.

If the parents are in the position to put a very substantial sum of money into a trust, this approach may work for a disabled child. The amount must be sufficient to pay out income and principal to cover all costs of support, medical care, shelter, clothing will count as income that will disqualify the beneficiary from need-based benefit programs such as SSDI, Medicaid, or housing subsidies. The trust itself may be regarded as a disqualifying resource. Unless the trust can provide at least as much support as the benefit programs, the disabled child could end up worse off than if no trust were provided. Furthermore, if the trustee is authorized to pay out for the disabled child’s support and medical care, the state’s ability to pursue the trust income and principal as reimbursement for past services provided to the child is limited.

Given the circumstances, the best approach is generally a trust authorizing distributions of income and principal as needed for the support, health care, education, and welfare of the beneficiaries. Once the beneficiaries have reached the age of majority, the trustee is generally allowed to make direct distributions. Remaining principal is usually distributed to the beneficiaries in one or two payments once a certain age is reached or all education has been completed. Often, a spendthrift clause is included.

However, in most situations, particularly those involving middle-class families, a support trust will simply not provide adequate protection for a disabled child. The reasons for this have been extensively analyzed in the literature. The basic problem is that trust distributions or provision of food, shelter, or clothing will count as income that will disqualify the beneficiary from need-based benefit programs such as SSDI, Medicaid, or housing subsidies. The trust itself may be regarded as a disqualifying resource. Unless the trust can provide at least as much support as the benefit programs, the disabled child could end up worse off than if no trust were provided. Furthermore, if the trustee is authorized to pay out for the disabled child’s support and medical care, the state may successfully pursue the trust income and principal as reimbursement for past services provided to the child. Although other creditors can normally be staved off with a spendthrift clause, courts have held that denying the state
reimbursement is contrary to public policy when the disabled child is the beneficiary of a support trust.12

The approach that is usually recommended is the creation of a trust that authorizes, but does not require, the trustee to make distributions for the benefit of the disabled beneficiary.13 These trusts have been variously referred to as discretionary trusts, luxury trusts, special needs trusts, and special use trusts. Successful trusts of this type share several characteristics.

First, the trustee has absolute discretion to distribute, or to withhold, trust income or principal. Since a beneficiary cannot compel the trustee to make a distribution, creditors of the beneficiary cannot claim the trust assets. This is because of a settled rule of trusts, which states that creditors of a beneficiary can only reach trust assets to the same extent that the beneficiary can reach the assets.14

Second, the trust document specifically states that it is the intention of the grantor (or of the testator, if the trust is testamentary) that no trust distribution be made that would disqualify the disabled beneficiary from any public benefits to which he would otherwise be entitled. It should be made clear that this intention is meant to control in the event of any other conflicting provisions within the document. While there continues to be discussion about the policy of allowing a trust beneficiary to continue to collect public benefits, in general a provision like this will be upheld because of strong precedent for freedom of testamentation, and for freedom to make or withhold whatever gifts a donor wishes.15

In utilizing a trust of this kind, it is very important that the trustee's discretion be absolute and not qualified by descriptions that can be interpreted as making the trust a de facto support trust. To illustrate, consider the following: A discretionary trust can be created by use of language such as “the trustee may in his absolute discretion, distribute or withhold principal or income to the beneficiary.” The trust can retain its character as a discretionary trust if additional direction is given to the trustee about the grantor's intentions, as long as that direction does not restrict the unlimited discretion to pay or withhold funds from the trust. An example of this sort of language would be a clause such as “the trustee may in his absolute discretion distribute or withhold trust income or principal for travel expenses, entertainment, or other expenses not covered by public benefit programs for which the beneficiary is otherwise eligible.” However, an apparently slight difference in wording could result in the inadvertent creation of a support trust rather than the intended discretionary trust. If, for example, the clause reads “the trustee may, in his absolute discretion, pay income or principal for the support and welfare of the beneficiary,” most courts would interpret this to require that the trustee pay out for the reasonable costs of the beneficiary's support. The trust might even become available for payment to creditors who have provided support to the beneficiary in the past.16 In addition, the trustee may be compelled to pay out to support the beneficiary under those terms, thereby disqualifying him from any benefit programs for which he might have otherwise been eligible. It should be noted that the appropriate language for a totally discretionary trust does not require the trustee to pay out for the support of the disabled child, nor does it forbid him to do so, except where such payment would interfere with benefit eligibility.17 Thus, in the event the child's benefit programs are cut or eliminated, the trust could provide a safety net, at least until it is used up.18

Parents sometimes express concerns that trusts will be too costly to manage. This concern is exaggerated. While trusts do tend to generate expenses, such as the cost of preparing separate income tax returns, these expenses can be kept to a minimum if individual rather than corporate trustees are utilized. A bigger problem is finding a qualified and willing individual trustee. Siblings, other relatives, or friends of the family who are familiar with the disabled child are the usual choices. Appointing co-trustees may lessen the burden on each trustee and may make family members and friends more willing to take on the responsibility of trusteeship.

Discretionary, or “special use,” trusts have been used successfully for some years, and they have been authorized by statute in some states.19 They are clearly the best option available to parents who wish to contribute to their disabled child's quality of life but whose estates are not sufficient to completely support the child. However, it should be explained to clients that there is no 100 percent guarantee that such trusts will be upheld forever. There is some uncertainty because of dissension about public policy that allows a person who may benefit from a trust to continue to receive money from need-based programs, thereby decreasing the
total pool available to all benefit recipients, including those who have no other source of support.

Community Trusts
Still another option is a community trust, if the disabled child lives in a region that has one.

These trusts are pooled funds whereby upon payment of a certain amount of money, the disabled child will join the group of trust beneficiaries for the duration of his or her life. Payments will be made on that child’s behalf, or services will be provided to her according to previously agreed-upon terms. These payments typically continue even if the disabled child’s expenses exceed the contribution that was made on her behalf. Thus it provides security in the event of unforeseen circumstances such as higher-than-expected increases in expenses or a longer-than-average life span. Another advantage is that contributions can be made to the fund by any relative or friend interested in the disabled child’s welfare. Funds contributed “may not be considered when determining a beneficiary’s eligibility for needs-based government benefits and may not be reached by the beneficiary’s creditors.”

Enrollment may require a minimum contribution on behalf of the child, but some programs supplement the trust with charitable contributions, which are used to provide services for disabled persons whose families are too poor to enroll them under the usual terms. However, upon the disabled child’s death, any contribution made on her behalf that has not been used up remains in the trust for the benefit of the other disabled participants. This is a disadvantage if the parents would prefer to leave any remaining funds to their other heirs.

Options During a Parent’s Incapacity
While most of the literature and planning advice focus on planning for a situation in which the parents both predecease the disabled child, there is another scenario that should be considered. What will happen to the disabled child if the survivor of his parents becomes incapacitated and no longer has the physical or mental ability to provide services or stipends to the child?

The usual advice to persons wishing to protect themselves in the event of incapacity is to execute a durable power of attorney, which authorizes the agent to stand in the shoes of the principal in collecting and managing bills and paying bills and obligations. However, costs associated with the disabled child are only bills or obligations of the parent if the parent is legally responsible for the support of that child. Under current law, that situation normally occurs only when the child is still a minor. So an agent could not pay out funds from the principal’s estate for the benefit of an adult disabled child. It should be noted that there is precedent, at least in some states, for holding parents liable for the support of unemancipated adult disabled children, so the attorney should be especially alert to local developments.

In the likely case that the parent is not legally responsible for the support of a disabled adult child, a distribution of funds by the agent to the disabled child will be considered a gift. Most states require the principal to specifically confer the power to make gifts upon the agent, and will not imply a power to make gifts from an ordinary durable power of attorney. Any such delegation must be drafted with federal tax rules in mind.

The other option frequently utilized by persons fearing incapacity is a living trust. A revocable trust can be set up and funded with some or all of the grantor’s assets. The grantor acts as the initial trustee, if desired, and upon death or incapacity a successor trustee steps in. A living trust could be utilized to give the trustee unlimited discretion to pay out (or withhold) funds from the trust for the benefit of a disabled child, consistent with that child retaining eligibility for benefit programs. In the event of the grantor’s incapacity, then, the successor trustee would have discretion to use trust benefits for the child’s benefit. This arrangement operates in the same way as discretionary trusts created to operate after the grantor’s death, with the exception that here the primary beneficiary is the grantor. In any case, other children, grandchildren, or other objects of the grantor’s bounty can also be included as trust beneficiaries, subject to whatever terms and conditions deemed appropriate by the grantor.

Personal Assistance
Many parents of disabled children provide them with many personal services such as transportation, handling of business transactions, and researching and pursuing appropriate educational or entertainment opportunities. When a parent is no longer there to provide these services, financial planning alone cannot replace them. Parents need to carefully select and consult with substitute ser-
vice providers. If the plan includes a trust, selection of a trustee who is familiar with the child’s needs and abilities, and has the child’s best interests at heart, is essential.

Setting up a caring support network to provide a myriad of other services is more problematic. Hopefully, there will be caring family members who already have a close relationship with the disabled child. Some services, such as transportation, can be contracted for and obtained for a fee. Social service agencies may have caseworkers available in some cases. Another option is to contract for the services of a visiting nurse. Since it is difficult to accurately predict specific needs far in advance, clients who use a discretionary trust may wish to list some of these services as some of the “extras” for which the trustee may make discretionary distributions. Families who utilize community trust programs will likely have certain services provided to the child under the terms of the trust.

Considerations in Choosing an Option
Any one, or several, of the above options may be appropriate for a given family, depending on the circumstances. The attorney and the clients need to have a frank discussion about several issues before coming to a decision. These issues include the nature of the child’s disability, the amount of money likely to be in the parents’ estates, the abilities and inclinations of the persons who could potentially perform fiduciary duties or provide personal care for the disabled child, the parents’ and the child’s attitudes about utilizing public assistance programs, and the type of public and private assistance available in the community. The lawyer, obviously, must carefully consider any state statutes or cases that are on point, since states may vary in or change their approaches.

The Nature of the Disability
Discussions of this issue may be painful, but chances are that circumstances have already forced all but the newest parents of disabled children to come to a realistic appraisal of the child’s abilities and prognosis. In addition to ascertaining the exact nature and extent of the disability from the parents, the lawyer should do some independent research on the condition to obtain a better understanding of possible complications. Both a best-case and a worst-case scenario should be discussed in terms of the likely progression of the disability and its effects on physical and mental functioning and upon life span. It should be recognized that some disabilities, such as some developmental disabilities or blindness, are fairly stable over time. Other disabilities, such as substance abuse disorders or mental illnesses, may fluctuate. Still others may have the potential of being cured, if research advances rapidly enough. Planning should offer as much flexibility as possible for the best outcome while preserving a safety net if that outcome is not achieved.

The Size of the Estate
While money may not buy happiness, more money provides more options to parents of a disabled child. The current costs of providing for the child should be compared to the size of the potential estate available for that use, keeping in mind that the costs are likely to escalate. Parents with an estate of several million dollars may be able to plan so as to virtually guarantee complete lifetime support of the child. Parents with significant assets, which are nonetheless insufficient to provide complete support, are the most likely candidates for a discretionary trust or a community trust. Parents likely to have very small estates may be better off disinheriting the child in favor of siblings or other concerned family members who could informally provide extras for the child. Family dynamics and the parents’ feelings about leaving equal shares to their children are important factors in this discussion.

The Abilities of Potential Fiduciaries
The ideal planning situation is a family in which the disabled child has one or more adult, educated, and willing siblings or other same-generation relatives to provide personal and financial guidance. Even where this situation apparently exists, all parties need to understand that conflicts of interest may arise between the provider’s obligation to the disabled child and obligations to the provider’s spouse, children, or employer.

Where no family members are able or willing to act, professional fiduciaries and care providers can be employed. However, this is more expensive and thus not a viable option for many families. Also, as a practical matter, a person is needed to obtain and oversee the various services needed by the child over time. This is not a likely service to be provided by a corporate fiduciary; however, there may be
other alternatives, if a family member is not willing or able to act in an overseeing or counseling role. Some communities have volunteer advocates or guardians. Churches, or associations geared to a particular disability, may provide other avenues for assistance.

**Attitudes Toward Acceptance of Public Benefits**

Some people view it as personally or morally unacceptable to accept public benefits if there is any possible alternative. Others view acceptance of public aid as their entitlement after years of tax burdens. Either way, the plan should be tailored to address these concerns insofar as possible. As numerous commentators have pointed out, government programs have limited resources, and it may be unfair to expect government support to go to people who, in fact, have other resources. Should it do so, potentially benefits might be reduced that would otherwise have been available to persons who have nothing. On the other hand, one cannot fault a parent for wanting to provide a child with a quality of life better than mere subsistence. As has been discussed above, so far the law has rewarded parents and others who plan carefully to provide for their disabled children, and a client need have no scruples about receiving this assistance.

**Available Community Services**

Finally, plans must be created to coordinate with whatever resources are available in the community in which the disabled child resides. Once again, the family and the lawyer may long for a crystal ball, because just as it is impossible to flawlessly predict future needs of the child or future requirements of the law, it is impossible to predict what services will be available in the future. In general, larger communities are likely to have a larger variety of services, although resources may be spread thinner and individualized assistance may be more difficult to get. Smaller communities may have fewer programs, but the overall atmosphere may be safer and more accessible to a vulnerable person needing services. The size and character of a community, its economic climate, and its social and educational priorities may all change over time. In fact, where discretionary trusts are utilized, it may be a good idea to give the trustee the discretion to finance the disabled child’s relocation to a more hospitable city or state.

However, even though programs and services may change, giving fiduciaries instructions and discretion with respect to certain programs, or other similar programs, will provide essential guidance and knowledge about the parent’s intentions.

**Conclusion**

It is impossible to answer with certainty the wrenching question, “What will happen to my child when I can no longer care for him?” But careful planning can achieve a great deal of security for the child and peace of mind for the parents. I have attempted in this article to highlight the main areas for concern in the process of planning for a disabled child. Hopefully, through discussions with the parents and child, and careful additional research, the attorney will be able to recommend and draft a plan that will achieve the best possible quality of life for the disabled child.

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**Endnotes**

1. Throughout this article, I will use the terms “child” and “children” to include both minors and adults who are the objects of the estate planning efforts of an older generation. While I generally refer to the planning generation as the “parents,” the planning advice is also relevant to grandparents, aunts, and uncles or to any other person who is planning to give benefits to a disabled person.

2. Several articles cited herein provide detailed planning advice of the sort that is beyond the scope of this article. See, e.g., Lawrence A. Frolik, *Discretionary Trusts for a Disabled Beneficiary: A Solution or a Trap for the Unwary?* 46 U. Pitt. L. Rev. 335 (1985); see also, Debra L. Stetter, *Planning for Life: Guidelines for When Children Are Involved*, TRUSTS & ESTATES, Sept. 1997.

3. Of course, this undesirable outcome is not limited to persons with mental or developmental disabilities. A child who is a confirmed spendthrift may not develop into a good money manager either. However, as will be explained later in the article, a support trust with a spendthrift clause may solve the problem for the nondisabled child but will not be appropriate in most cases involving disabled children.


5. Stetter, supra note 2, at 59 (citation omitted).

6. See id.

7. “An institutionalized adult is normally liable for reimbursement to the state for the cost of the institutionalization. . . . [I]f the institutionalized individual is a trust beneficiary, the state may contend that the trustee should use the trust assets to reimburse the state for the costs of institutionalization.” [Frolik, supra note 2, at 343 (citations omitted)].

8. Even where the bequest includes precatory language, there is no legal obligation to carry out the request. [See George Gleason Bogert, Law of Trusts § 19 (5th ed. 1973)].

9. See Stetter, supra note 2, at 60.

10. It is difficult to estimate these costs, even for a particular disability. However, they include potentially astronomical expenses such as hospitalization, nursing home care, professional consultations, and medications. Besides being expensive to begin with, many of these costs have escalated at a rate far outpacing inflation, and they may continue to do so. Stetter suggests $500,000 to $1 million segregated for the disabled child alone as a bare minimum for avoidance of government program dependence [Stetter, supra note 2, at 58 (citing Betty Booker, Who Will Care For Them? Making Provisions for Disabled Children, Richmond Times-Dispatch, Feb. 26, 1996)].

11. See, e.g., Frolik, supra note 2; McMullen, supra note 4; Stetter, supra note 2.

12. See, e.g., Department of Mental Health & Dev. Disabilities v. First Nat'l Bank of Chicago, 432 N.E.2d 1086, 1088–89 (Ill. App. 1982) (taking the position in dicta that persons having any sort of interest in a trust are not the needy for whom cost-free care should be provided).

13. See generally, Frolik, supra note 2; McMullen, supra note 4; Stetter, supra note 2.


15. See Hyatt, supra note 4, at 14–16.


17. But see Stetter, supra note 2, at 61 (citation omitted). Stetter indicates that some commentators advise language authorizing distributions for the support of the disabled child if the trustee, in his sole discretion, determines that the level of support is inadequate. In my view, this is too risky.

18. This may seem like a remote eventuality, but then, who would have predicted 20 years ago that welfare programs in this country would be virtually eliminated?


20. Stetter, supra note 2, at 61.

21. See, e.g., the Illinois self-sufficiency trust, discussed in McMullen, supra note 4, at 455–56; Stetter, supra note 2, at 63 n.26.


25. See, e.g., McMullen, supra note 4, at 461–62; Shaffer & Mooney, supra note 24, at 258–59 (the authors question whether the lawyer should raise this as a moral dilemma if the client does not raise it first).