Estate Planning For Families With Sons or Daughters with Special Needs[1]

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Many special considerations must be taken into account in estate planning by parents of a son or daughter with special needs severe or multiple enough to interfere significantly with personal, economic, and social functioning as an adult. Such persons are more likely than others to be dependent upon special services, yet given limited income potential they are less likely to be able to pay for such services themselves. Some services are available without regard to financial factors, like Medicare and Social Security Disability benefits. Many others, including long-term health and residential care, are available only privately or to persons who meet technical "means" test, making the services available only to persons with limited income and resources. However, the means tests are typically so restrictive as to require the total impoverishment of the individual, depriving the individual, and often the family, of the capacity to meet other current or future needs as they arise. Given the financial and personal burdens of raising such children, their parents are themselves less likely to be able to accumulate sufficient resources to provide privately for their care over a lifetime. Finances aside, planning must take into account personal and family considerations, since implementation in most cases will require the voluntary participation of other family members in a variety of potential roles. Lastly, the individual himself should, for practical as well as legal reasons, to the extent of his or her capacity, be involved in decision-making on his or her own behalf. In sum, effective planning requires figuring out how to mobilize and coordinate all potential resources on the individual's behalf – the individual's own strengths, the commitment of other family members, the family's own financial resources, as well as potential government benefits, to bear on the need to enhance the quality of life of the individual of concern.

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1 By Donald N. Freedman. Updated 12/01/11.

1. Estate planning for families with a son or daughter with special needs must itself be special.

Traditionally, and still today in many other contexts, estate planning is essentially an aspect of tax law. The planner's task was to find ways to transmit property to the next generation, with minimal loss from estate taxation and costs of estate administration. Planning focused simply on getting property to the beneficiaries, and keeping it safe until the beneficiaries reached adulthood, when, the parents assumed, they could and would handle it independently.

While tax and administrative considerations must be taken into account in estate planning for a family with a son or daughter with special needs, more personal considerations should often be given priority. Where is she to live? Who is to be responsible for decisions relating to his education? Medical treatment? Special day and, if necessary, residential programming? Who will have responsibility for the investment and management of assets set aside for her? Even more importantly, who is to have responsibility for decisions on how the assets are to be used? What kind of guidance can and should be given to help ensure that the decisions are right, in the sense of being truly responsive to his special needs? How, overall, can the estate plan be structured so as to make the most of every resource potentially available to the child, including family members, family assets, and governmental entitlement programs?

2. Traditional advice has often been to exclude the son or daughter with special needs from the parents' estates. Instead, the plan would involve gifts only to other children, with the expectation that they would "take care of" the family member with special needs. This option carries significant risks, and is in our view seldom appropriate.

This notion resulted from two beliefs: that governmental medical, social, and income programs for persons with disabilities were sufficient to ensure an adequate standard of living and support; and that bequests on behalf of the disabled child would necessarily interfere with eligibility. Neither assumption is valid.

Governmental entitlement programs for the disabled are not sufficient, in themselves, to provide even a minimally acceptable quality of life. Examples are legion. At its inception in 1972, Supplemental Security Income constituted a theoretical attempt to set a national subsistence floor of income for the aged, blind, and disabled. The floor was far below the national poverty level then, and cost-of-living adjustments since have fallen far short of coping with inflation. Upward adjustments in the asset and income limitations on eligibility have been minimal. As a result, an individual has to be much more (in terms of effective buying power) today then in years past to qualify for assistance. Medicaid (called MassHealth in Massachusetts) has encountered a similar history. Financial eligibility requirements are, in effect, far more restrictive today than in earlier years, and the number of services covered, as well as the number of available providers, continues to shrink. Rental housing subsidy programs can play a critical role in making a comprehensive program of home- and community based supports financially viable. However, a freeze on the number of available vouchers in the most important such programs has resulted in long waiting lists, even for people meeting all eligibility criteria. In short, governmental entitlement programs will certainly continue to be <u>necessary</u> to assure the welfare of many persons with special needs, but they certainly are not <u>sufficient</u> in themselves to achieve this purpose.

The second common assumption – that making provision for an individual with special needs will necessarily interfere with benefits – is similarly incorrect. The problem of avoiding or at least minimizing conflicts between program eligibility and supplemental support through a trust or other estate plan vehicle is not simple. What may be most effective for one program may be problematical for another. Careful assessment, planning and drafting is critical. However, giving other family members resources with the expectation that they will use it for the individual with special needs also creates risks. As discussed in more detail below, even with the best of intentions, any number of problems can arise that may interfere with the ability to use the resources on behalf of the person in need – death, divorce, business failure, unemployment, threatened foreclosure, bankruptcy, etc.

3. The traditional function of wills and trusts is the transmission of property upon death. However, parents can also use wills and trusts to communicate personal information and perspectives on the child, including hopes, expectations, and priorities for care and services. Use of estate planning instruments in this manner may help ensure that family resources are used appropriately to benefit the child.

The situation encountered by the persons such as guardians and trustees who are charged with making personal and financial decisions for the individual in need, after the death or incapacity of the parents, is vastly different from that encountered by guardians and trustees in less special circumstances. The plain and common sense that one might think to apply, based on more typical parenting experiences, may be just wrong. Given the choice between a community and institutional training program, the first being more normal but the second being more intensive, for which should the guardian advocate? Should the guardian approve a work attempt, knowing that the person may lose Supplemental Security Income as a result of a successful, though part-time, work experience? Given the possibility of embarrassment for the individual, and others, resulting from participation in normal community or religious activities, should the child attend? Parents of disabled children make these hard decisions every day, and may well have developed clear and effective, if not always explicit, approaches to dealing with such issues. Instruments such as wills and trusts stand as certainly the last, if not necessarily the best, opportunity for the parents to give guidance on the importance and priority they feel would be appropriate in such matters.

Facing the uncertainty of future personal and financial arrangements for the disabled child is often terrifying for parents in these circumstances. Legal counseling, and the instruments which will be its tangible product, must be sensitive to these issues for the matter to be of real benefit to the individual in need.

4. A trust is often the planning tool of choice in these circumstances, even for small estates.

A trust is an arrangement in which a person (or persons), called the "settlor" or "grantor" enters an agreement with a second person or financial institution, called the "trustee," to hold, manage, and use identified assets, called "trust principal and income," for the benefit of a third person, the "beneficiary." The trust instrument itself spells out the principles and rules that are to guide the trustee in making decisions about the investment and use of trust property.

Initially, this seems too complicated for many. Why not simply leave funds to other family members, with the expectation and understanding that they will use an appropriate portion for the sibling's supplemental support?

This approach is seldom satisfactory and is fraught with risk. Even assuming utmost good faith on the part of the relatives (not an assumption which should be comfortably made, unfortunately), the property, held by the relatives without legal restriction, is subject to risks of loss beyond the relative's control. Divorce, death, disability, business failure, legal liability, bankruptcy, or other circumstances beyond the relative's control may deprive the relative of the power to use the property for the benefit of the disabled sibling, regardless of best intentions. The temptation to "borrow" the funds for personal use, during periods when it may not be needed by the disabled sibling, may be too great to bear, especially if the relative encounters a financial emergency or "opportunity" of his own, or feels pressure from his own immediate family to use the funds.

Why should a family consider a trust as a vehicle for long-term financial planning for a disabled son or daughter, rather than guardianship?

The private contractual nature of a trust permits tailoring to the individual needs of the beneficiary. This is in sharp contrast to guardianship, where legal rules limit discretion, and court involvement is often necessary. Also, appointment of a trustee is not dependent upon the legal incompetence of the beneficiary. You can use a trust in a situation where the individual has a diminished capacity to function independently, even though the individual is not so incapacitated to justify a court declaration of incompetence. Lastly, one can write a trust so that the beneficiary will be able to benefit from the trust while retaining eligibility for means-sensitive entitlements.

Property held by a guardian, however, is generally counted when an eligibility determination is made.

The circumstances of the family and the beneficiary influence what type of trust, from among many alternatives, is most appropriate.

A "living trust" is a trust that is established during the lifetime of the settlor. A trust may be a living trust whether or not assets are actually placed in the trust during the settlor's lifetime.

A "testamentary trust" is a trust that is established and funded in the individual's will. It thus does not go into effect until the individual's death.

A "revocable trust" can be cancelled or amended by the settlor at any time during his or her lifetime, providing a measure of flexibility, whereas an "irrevocable trust" generally cannot, providing a measure of security. Also, an irrevocable trust is usually more appropriate in cases where persons other than the parents – such as grandparents -- may make transfers to the trust, either through lifetime gifts or in their wills.

A "crummy trust" may be appropriate to permit lifetime transfers to the trust to qualify for the federal annual gift tax exclusion, currently $13,000 per donee.

A "special needs trust" or "pooled trust" may be drafted to comply with federal and state requirements for Medicaid and Supplemental Security Income eligibility in very specific circumstances. Often, the circumstances relate to the need to protect assets that the beneficiary may himself have acquired, through inheritance or settlement of a lawsuit. However, such trusts may also be appropriate protective vehicles for relatives of a disabled individual, where the relative himself has assets blocking his own Medicaid eligibility.

Whatever technical tax and benefit provisions may need to be included, it is important for the trust instrument to provide guidance to the trustee on appropriate utilization of the trust for the beneficiary. A section on trust "purposes" should be included which reflects the values and priorities that parents want the trustee to assume in making decisions on how the trust is to be used. Do not lose sight of the ultimate purpose of the trust, in enhancing the life of the beneficiary. Minimizing conflicts with government benefits is only a means to that end, and not an end in itself.

5. How are trusts funded? That is, how do we put property into a trust?

Property can be added to a trust in essentially five ways, by (1) buying property or setting up accounts in the name of the trustee; (2) transferring property or accounts into the name of the trustee; (3) naming the trustee to receive bequests in a will and the wills of other family members; (4) naming the trustee as the beneficiary of life insurance policies, pension plans, annuities, or other arrangements where beneficiaries may be designated; or (5) naming the trust as the beneficiary under a Will – sometimes referred to as a "pour-over" arrangement.

6. How much property should parents set aside in the trust for a family member with special needs?

This question usually arises in the context of conflicting parental impulses and the needs of other family members. On the one hand, parents most frequently wish to make equal gifts to their children, to avoid an appearance of favoritism and the jealousies that could result. On the other hand, making equal gifts just to be "fair" may leave the child with special needs at special risk, since his or her financial needs may be greater than those of his siblings, while his or her capacity to earn his or her own may be much more limited.

One approach to consider is to attempt to allocate on the basis of need. Relative need for assistance from the trust is difficult to gauge with precision. It varies over time, as the individual's needs change, and as the scope and nature of disability services develop. Also, that special needs may not presently exist for other family members is certainly no guarantee of the future.

Ironically, sometimes the more severe the individual's disability the less the need for supplemental assistance through the family's estate plan. For example, Medicaid eligibility will meet most of the basic needs of a very severely and multiply handicapped child residing in a pediatric nursing home. However, Medicaid eligibility will do little to support the same child in the home of a family member. Therefore, if the child is dependent solely on Medicaid eligibility, there may be no practical alternative to institutional care. Similarly, an individual with more severe disabilities may be entitled to priority support from state agencies like the Massachusetts Department of Developmental Services (formerly the Department of Mental Retardation), whereas persons who qualify for services but whose disabilities are less severe may only be wait-listed for services.

Sometimes it is the less-severely disabled individual who is more at risk financially and therefore more potentially in need of trust assistance. This is so because disability standards for many federal and state programs are unrealistically narrow and strict. Under the rules for Supplemental Security Income, Medicaid, and Social Security Disability Insurance benefits, for example, an individual is eligible for benefits only if he or she is "unable to engage in any substantial gainful activity by reason of a severe impairment." Work activity, even part-time or at minimum wage, may lead to disqualification. Persons with mild mental retardation, long-term if not severe mental illness, some forms of autism, epilepsy, cerebral palsy, and learning disabilities often are extremely vulnerable to inappropriate loss of benefits. Less-severely disabled persons are often the last to be hired, and the first to be fired, particularly in difficult economic times. For these individuals, supplementary family assistance through the vehicle of a trust may well be essential.

No future is predictable. No two circumstances are the same. Yet projections of need can be estimated, at least on the basis of the individual's needs today, his current and projected financial and other entitlements, current rates of return on investments, and conservative projections of future trends. On the other hand, depending on their own lifetime needs, parents may have significantly less (or more) resources available to distribute at death than they currently estimate. Sometimes, we use a formula to address this uncertainty, in preference to a straight equal division, to better ensure that the child will have at least a minimally appropriate level of support, e.g., "one-third but not less than $_____________."

Creativity in planning will often be required to take into account such financial and personal considerations in a way appropriately balanced to family needs and preferences. For example, parents who wish to make equal provision for their children in their basic estate plans may nonetheless make supplemental arrangements for a child with special needs by other means – by lifetime gifts, for example, or designating a trust for the child as the beneficiary of a life insurance policy.

7. You must select trustees and assign their responsibilities in a manner that reflects the long-term and problematical nature of the role.

The trustees will in most cases be taking on responsibilities for life. The role will require a sensitivity to the particular needs of the individual, involvement in the provision and monitoring of services, advocacy regarding personal and financial entitlements, and care in spending so as to avoid or minimize entitlement conflicts.

In our experience, family members are often in the best position to take on these roles. They know the beneficiary best, and may bring a level of personal commitment to the role that cannot be replicated by any friend or professional.

On the other hand, if the family member is both a trustee and a "remainderman," standing to inherit whatever is left in the trust at the death of the lifetime beneficiary, the relationship poses a classical conflict of interest. Every dollar spent by the trust on the beneficiary is a dollar less available for distribution at the beneficiary's death. Even the appearance of such a conflict of interest can create distrust and adversely affect relationships among the family members involved.

Also, a family member may be inappropriate to serve as a trustee if he has serious financial, personal, marital or business problems of his own.

Immediate family members may live far away, or may be preoccupied with their own family circumstances. They may fear they are not able to take on the responsibilities of trustee.

Sometimes, there is concern that having a sibling assume the role and authority of a trustee may work at cross-purposes with a normal sibling relationship with the beneficiary.

If the potential trustee is concerned about assuming responsibility and potential financial liability, this may be addressed in the trust itself, by explicitly insulating a family member trustee (although not a bank or professional trustee) from any possible claim of negligence, as long as they act in good faith. If family member trustees lack technical expertise regarding the investment, accounting, and benefits-related spending aspects of the trustees' role, they can be assured that paying for investment or legal advice is a valid use of the trust itself.

Families consider professional fiduciaries often in the absence of other available and appropriate family resources. These may include attorneys, accountants, banks, trust companies, and non-profit trust agencies. In exploring the possibility of a professional serving as trustee, or co-trustee with a family member, make sure you understand exactly how fees are to be assessed. And certainly ask questions to ascertain the extent to which the professional has the experience and sensitivity to function effectively in this context.

I have mentioned the possibility of "co-trustees." Trustees can share their responsibilities. This might lessen the risk of burnout from one person attempting too much. It will also provide a degree of mutual oversight and assistance. Sharing can be accomplished informally by the unadorned designation of two people as co-trustees. A further elaboration of roles is possible, given enough volunteers. One co-trustee (the "financial trustee") might have primary responsibility for investment, accounting, and tax management of the trust. The other co-trustee (the "personal trustee") would have primary responsibility for deciding on how the trust is to be used to benefit the beneficiary. This approach is particularly useful with larger trusts, where a financially unsophisticated family member who knows the beneficiary best may be unwilling to assume full responsibility as trustee, including tax, accounting, and investment issues. A second family member, or a professional, could perhaps handle the financial issues, despite living at a distance or being unfamiliar with the day-to-day needs of the beneficiary. It thus may be possible to tailor long-term responsibilities to the special talents and interests of different family members.

Where family members are just not able or willing to assume direct responsibility as trustees, there may nevertheless be other roles that they can play. The family members (usually brothers or sisters) can be assigned the role as advisors to the trustee, particularly in matters involving how the trust is to be used. Similarly, they can be named to receive notification by the trustee of planned trust actions, and copies of trust accounts and tax returns. They may even be given the power to monitor and replace an independent trustee. These kinds of involvement give the family members both the right and the encouragement to stay involved over time, but without creating responsibilities or expectations they cannot realistically meet.

8. Are trustees compensated? How?

The decision on whether to compensate the trustees is made by the settlor, and is usually reflected in the trust instrument itself. Trustees are generally entitled to what the law calls "reasonable compensation" as well as reimbursement for expenses incurred in the performance of their duties. What is reasonable depends on the circumstances, the nature of the particular task, the presence of special time constraints, the complexity of the trust property and time and skill required to manage it, the complexity of the special needs of the beneficiary and the demands on the trustee created by those needs, and so forth. In contemplating the appointment of a professional trustee, the trustee will be able to provide a formal schedule of fees and reimbursable costs.

The trust can indicate that the trustee is not to receive any compensation. This will of course not work with a professional trustee, who will simply refuse to accept appointment, or resign. We generally do not recommend this approach, even for family members, since it may create hard feelings, given the time demands of the job. One alternative approach may be to give a family member other assets in consideration of accepting responsibility as trustee, without further compensation. Some people prefer a clause providing compensation to family member trustees on the basis of so many dollars per year, or of a percentage of income or principal. This eliminates the need to keep time records or justify particular activities, and should avoid possible disputes about the reasonableness of any compensation taken.

9. To permit the trust to exist without counting as an asset or resource for entitlements purposes, it must not permit the beneficiary (or anyone else other than the trustee) any right, power or authority to control trust expenditures or distributions, directly or indirectly. The trust must also be clearly "supplemental" in intent.

Distribution of trust property must be at the <u>discretion of the trustee</u>. The beneficiary cannot have any right, power or authority to make distributions from the trust to himself or for his benefit.

The trust must be explicitly supplemental in intent. It is not necessary that the trust prohibit any expenditure for goods or services that could potentially be available through a public source. This would be overkill. It could force the trustee to rely on public services alone, even if inadequate in quality and quantity for the beneficiaries needs. It is enough that the trustee take into account the potential availability of public benefits, together with many other factors, in deciding how best to use the trust for the benefit of the individual of concern. On the other hand, be careful of language that might be construed as creating implied obligations in the trustee to make payments, or giving the beneficiary implied rights to income or principal. Even if payments are "solely within the discretion of the trustee," some courts have held that refusal of a trustee to make payments for basic food, clothing and shelter under a general grant of authority is an "abuse of discretion," rendering trust principal countable for benefits purposes.

10. Even if trust principal is not counted in determining the beneficiary's eligibility, trust payments and distributions may be counted as income to the beneficiary. This could reduce the level benefit in income-sensitive programs. The trust should contain language to target this concern, to make certain that the trustee is aware of the potential problem.

Approaches to using a trust effectively vary from one entitlements program to another. However, the example of Supplemental Security Income (SSI) is instructive. Supplemental Security Income rules permit a recipient to receive only $60 of unearned income in any calendar <u>quarter</u>. That's only $20 per month. Any additional cash from a trust or other source other than work earnings, which are subject to their own rules) reduces benefits on a dollar-for-dollar basis. There are, however, ways to minimize, if not eliminate altogether, this undesirable effect of trust use on SSI.

- To the extent feasible, direct cash payments to the beneficiary should be avoided or minimized, since they have the most direct impact on level of benefits.

- Recognize that certain kinds of payments by a trustee, such as payments directly to a provider for medical care and services, do not cause eligibility problems. If the beneficiary needs supplemental assistance, these payments should be made first, if appropriate. Even room and board during medical confinement is within the exception, as is arguably psychiatric care, including residential care in a facility like a halfway house. Similarly, payments for social services generally are excluded. For payments for medical care or social services not to count as income to the beneficiary <u>they must, however, be paid directly to the provider</u>.

- Similarly, trustee payments directly to a vendor for goods or services which are not directly related to food or shelter, and which cannot be converted by the beneficiary to cash, are not counted as income to the beneficiary. For example, there should be no reduction in benefits as a result of trustee payments of bills for such items as transportation, recreation, appliances, furniture, furnishings, legal services, household maintenance and personal services.

- Durable goods or other property with significant resale value cannot ordinarily be purchased and given to the recipient without having their value counted as "in-kind income" to the recipient. However, if the trustee retains ownership of the property, and the beneficiary is allowed merely the use of the property, then the property should not be countable as income. This is so because the beneficiary does not have the legal right to sell the property to convert it to cash to use for his or her basic needs. Examples could include furniture, or airline tickets charged on a credit or debit card in the name of the trustee.

- Money borrowed by the beneficiary from the trustee as a loan for short-term use is not counted as income (although loan proceeds held beyond the month of receipt may then be counted as a resource). A loan exists if there is an understanding between the parties that is recognized as an enforceable contract under state law. It should not matter that the loan is made by friends or relatives (or presumably by a trustee), at little or no interest.

- If the trustee has used all of the foregoing means of providing assistance to the beneficiary, but the beneficiary still has unmet basic needs relating to food, clothing, and shelter, the trustee should make payments directly to the vendors rather than giving cash to the beneficiary to pay these costs. Cash payments made directly to the beneficiary would essentially cause a dollar-for-dollar reduction in benefits, whereas payments directly to the vendor are considered "in-kind" contributions subject to a special rule limiting the benefit reduction to one-third of the benefit level.

The rules governing the effect on eligibility of spending from a trust vary from program to program, and may change over time. The specific rules discussed above are presented for illustration purposes only, and may not apply to the particular programs relevant to the needs of your child, or at the particular time that the trust is in effect. For example, state and federal rent subsidy programs distinguish between trustees that have or do not have family members as trustees, and between "regular" and "sporadic" distributions from the trust in terms of impact on rent. It is, therefore, imperative that the trustee establish and maintain a close working relationship with an attorney or social worker who is intimately familiar with eligibility regulations, in order to obtain timely guidance on trust utilization.

11. In light of the possibility of changes in the law involving eligibility for many programs, some form of "safety valve" provision should be included in irrevocable trusts, allowing the trustee to terminate or to amend the trust in specified ways, so as to avoid unanticipated and needless depletion.

This is not a merely academic concern, as recent law changes affecting the use of irrevocable trusts for the elderly make clear. Unless the trust provides for this possibility, trust principal or income may make an individual ineligible for necessary services. This would necessitate either foregoing the service, or paying for it privately.

If the service is not vital to the individual, or is not costly, the impact of such a conflict may be slight. If the service were vital, and expensive, all but the largest trusts would quickly be depleted. The trust must give the trustee alternatives to deal with such a conflict.

In conclusion, a properly drawn trust can serve as a dynamic organizing vehicle to marshal family personal and financial resources on behalf of a family member with disabilities, in full coordination with public benefits and other resources.