

## ***FAMILIES WITH SPECIAL NEEDS CHILDREN: A FINANCIAL GUIDE FOR THE PERPLEXED PART II***

This is part two of the special commentary co-authored with Herbert D. Hinkle, an attorney who practices in Lawrenceville and Marlton, New Jersey and in Yardley, Pennsylvania. Herb has represented people with disabilities and their families since 1974.

In the first part, we focused on the economic problems faced by those who support physically, mentally, or emotionally disabled persons, and the importance of assessing and quantifying the resources available to solve those problems. In this issue, we will concentrate on the latest tools and techniques that can be used to solve those problems and on practical solutions that supplement available government assistance and enhance existing financial security.

### **THIS CLIENT IS DIFFERENT**

Before implementing the various tools and techniques for parents of a special needs child, it is essential to keep in mind the incredible emotional strain and the physical drain on the persons before you. The never-ending tasks which they must face daily and the crucial decisions which they must make for as long as they and their disabled child live make your empathy, understanding, patience, and commitment even more important than in most other cases. They are acutely aware that planning for children who cannot take care of themselves is not an option, and they are deeply concerned about what will happen to their children when they are no longer here.

Parents of special needs children devote almost all of their time, energy, and resources in their efforts to provide and caring for these children. They often have healthy children who, like themselves, have been to some extent (or feel they have been) emotionally or financially neglected. The point is, as you read our comments about planning for those with special needs, it is essential that you incorporate that effort with conscious consideration of other family members' needs – including the needs of the caregivers.

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## GUARDIANSHIP ISSUES

When a person is unable to make responsible decisions pertaining to his or her medical, legal, and financial needs or manage day-to-day affairs, a guardian is necessary. At times, such as when a significant sum of money or other property and an incompetent are involved, the courts will insist that a second "guardian of the property" be appointed – in addition to the "guardian of the person" – who is authorized to separately supervise the investment and management of the incompetent's assets. So, one of the first and most important decisions that must be made by the parents or relatives of an incompetent is, "Who should be nominated as the guardians of the person and of the property of the person, and who should be named as back-ups?" (Normally, we suggest at least two back-ups. But in the case of special needs children, if there are others that could and would serve, consider naming them as well.)

Of course, until a child reaches the age of majority (generally at 21 or, in some states, as early as age 18), the parents have the right to act on behalf of their children. But from that age on, unless a child is declared otherwise by a formal adjudication of legal incompetency, a child is considered by the law to be a competent adult. At that point, without court approval, parents no longer have the legal right to act on their child's behalf.

The major advantage of guardianship is that it formally establishes who may speak and act for an individual with a legal disability. This legal authority takes on greater importance after the incompetent's parents are deceased. Many states allow (and the authors strongly encourage) the naming of multiple successor guardians in the wills of parents in order to avoid the bothersome and costly process of petitioning the court for the appointment of a new guardian (if the originally named person dies, becomes disabled, refuses to serve, or for any reason resigns).

There is a wide range of responsibilities that must be shouldered by a guardian (typically a spouse, parent, or other close adult family member nominated by will and/or formally appointed by the court) of a physically, mentally, or emotionally incompetent. A guardian may be called upon to act as an advocate for the person with the disability, consult with physicians on the appropriate form and type of medical treatment, and monitor the care provided in day care facilities and residential programs. In other words, the guardians sometimes must shoulder awesome and almost always long-term responsibilities. The guardianship process itself is relatively expensive to create and maintain since the guardian is forced – in many cases – to seek court approval and submit regular accounting for even relatively small amounts of expenditures, and report even relatively small amounts of income.

## GIFTS

To give or not to give? That is the question. Many parents and other relatives of disabled persons (who may or may not be legally incompetent) often ponder the pros and cons of making outright gifts to them. Often, the major problem is legal; if the donee is legally incompetent, he or she will

have no right to make a will, create or change an estate plan, or make gifts or otherwise dispose of property once it has been received. So in most cases, it does not make sense to make outright gifts of significant amount (or value) to disabled individuals.

But you should not make the assumption that because someone is disabled, he or she is not able to handle property. In fact, many individuals who are physically handicapped are legally competent and quite intellectually capable of making mature and intelligent investment and property management decisions.

Even those whose financial abilities are impaired can often handle relatively smaller fixed sums of weekly income. For such individuals, the gift of an annuity (with a lifetime payout) can provide a simple and relatively inexpensive means of assuring income as well as dignity, and will not require any investment expertise or the approval of another person or a court. But in most cases, this approach should not be used if the recipient is receiving SSI or Medicaid or is expected to require governmental services. A potential loss of government benefits should always be considered before providing a disabled person with either assets or income in any form.

Some parents feel that an "end-around" approach to provide for the financial needs of an incompetent makes sense. For example, parents may make a lifetime or testamentary gift with the proviso that, "I leave \$100,000 to my daughter, Mary, with the understanding that my desire is for her to use whatever portion of it she feels is appropriate or necessary to care for the needs of her brother Peter."

But is such a gift to a healthy child, made on the assumption that he or she will use it to provide care for the disabled child, a wise decision? On the plus side, such an outright gift to a third party is simple and inexpensive, and may be the only practical approach in certain situations. Clearly, a gift to one child who is morally charged with using the gift on behalf of a sibling will not cause the loss of governmental benefits, since the disabled child has no legal right to the gifted property or its income. This technique may be quite viable – or perhaps the only logical choice – where the estate in question is small and human and financial resources are limited.

Unfortunately, there are many disadvantages associated with this "morally obligated gift." Income earned on the gifted assets is taxable to the healthy child (who is probably in a much higher income tax bracket) rather than the intended recipient, the disabled child (who is likely to be subject to relatively lower income tax rates). Second, the asset will be included in the estate of the actual donee if the healthy child dies before using (or exhausting) it on behalf of the disabled sibling. Third, to the extent the donor-parents' annual exclusions are used to shelter their gift intended for the disabled child but actually made to a healthy child, they will not be available for other gifts to the healthy child.

Aside from the numerous adverse tax implications, there are many practical problems. For example, what happens if the healthy child dies, becomes disabled, loses the money gambling, invests poorly, becomes bankrupt, absconds, or embezzles the gifted assets/funds, or becomes divorced? The healthy

child has no legal responsibility and there are no guarantees that any of the money will actually be paid to, or used on behalf of, the disabled sibling. Neither the parent nor the disabled child has any legal recourse if the healthy child decides to keep or spend the money.

Parents can easily overestimate the ability or willingness of a healthy child to shoulder the physical, emotional, or financial task of caring for a disabled sibling. It is quite possible, if available financial resources are exceeded by costs, that a healthy child may sacrifice his or her own interests – or that of their own family members – in order to provide care for a disabled sibling. In some cases, the healthy child is faced with a choice between walking away from the responsibility – or submitting to severe emotional, physical, and financial strains that could injure his or her own health and financial well-being.

## DISINHERITANCE

To bequest or not to bequest? This is yet another question parents and relatives of a disabled person must face. It is, of course, legally possible in most states to disinherit a child. Few states require that a parent make provision in a will to continue the support of a child after the parent's death. The key issue is a very personal one; is the parent willing to totally omit a disabled child from his or her will? The question is most easily answered when the person is profoundly disabled and incapable of understanding the parent's action, or when the parents have limited resources and must provide support for other children.

Outright bequests of income-producing assets to disabled individuals are seldom practical and, as noted in the first of this two-part series, can easily result in blocking receipt of supplemental social security income or Medicaid benefits. Bequests, particularly those of relatives other than parents, may be appropriated by governmental institutions as payment for the services rendered by state welfare departments. On the other hand, "disabled" does not mean a person is without dignity or feelings, and the authors have found that many individuals will at the least want to provide mementos and token gifts of sentimental value in their wills for the disabled family members or relatives.

## POWER OF ATTORNEY

A power of attorney is one of the first and most important of all the estate planning tools that can be used both by a disabled person and his or her parents. It is a legal document that appoints and authorizes an individual ("agent") to take certain actions on behalf of another person ("principal"). The person to whom the power is given is called an "attorney-in-fact" and can be any competent adult. This person is typically, but not necessarily, a family member who meets state law requirements, and in whom the principal (maker of the power) has full confidence. Because of the length (or amount) of time and possible degree (or complexity) of services required when the maker of a power has become legally incompetent, he or she may want to consider a side agreement stating that the attorney-in-fact will be compensated (at a given rate or under a specified formula) for the time and effort taken under the power to help or represent the interests of the maker of the power.

The power of attorney is an invaluable supplement to a revocable or irrevocable trust. But where the assets in question are too small in value to warrant the expense of a trust, the power of attorney is a highly useful device on its own. It provides a practical, inexpensive, and simple means of providing assistance for those who are unable to take care of their assets, or those who may become unable to do so at some future date. The document can be quickly drafted, it is typically inexpensive, and does not require assets to be either transferred or re-titled.

Planners should consider a power of attorney for almost all clients. But such powers are particularly indicated whenever a person's physical, mental, or emotional condition begins to deteriorate and someone will be required to act on that person's behalf. Powers of attorney are essential not only for the disabled individual (where legally possible), but also for the healthy parents or other persons who provide the care of, and decision-making for, a disabled person.

Generally, mere physical disability of an individual does not preclude his or her execution of a valid power of attorney. But if the signer is mentally incompetent (i.e., does not have the requisite capacity to understand the nature and significance of what he or she is signing), the power will not be accepted as valid. Note, however, that psychiatric disorder does not automatically equate to mental incompetence. For example, if there are intervals of time during which the maker is competent, the execution will not be considered invalid if it was signed at such a time. This makes it important to obtain as much evidence as possible (for example through audio- or video tape and independent witnesses) at that time with respect to the maker's competency.

A power of attorney should only be drafted by a competent lawyer who is able to inter-relate state law requirements with the specific needs and objectives of the client. It is a highly flexible document that can be drafted as broadly (or narrowly) as circumstances require (or as the client desires). It can be revoked at any time until the client's death or legal incompetency. Unlike a guardianship, a power of attorney does not require a judicial declaration of incompetency and preserves certain rights (such as the right to contract or vote) that would be lost in a guardianship situation.

Typically, a power of attorney should be "durable." This preserves its utility even if the client becomes legally or otherwise incompetent. It may be immediately effective (and physically retained by the attorney who drafts it) but held in confidence until needed. Alternatively, it may be a "springing" power that comes into legal effect only if, and when, the client becomes disabled. In this case, a mechanism must be provided in the document to define what is meant by "disabled" and to specify who will make that determination. Durable powers continue until there is evidence that the maker of the power has revoked it, or the maker has died. A disabled person's power of attorney may, in some states, be amended or revoked by a guardian.

As noted above, the attorney-in-fact should be given authority in the document to take whatever actions are necessary with respect to the power-giver's financial interests and personal needs. The following powers are among those that should be considered. The power to:

- authorize admission to a medical, nursing, or residential facility or hospice, group residence, or similar facility;
- authorize any medical or surgical procedure;
- fund a revocable trust (which may obviate the appointment of a guardian of the property for the disabled person and could also avoid an ancillary administration of property located in another state);
- contract for care, custody, and control of the physical well-being of any family member;
- establish residency in a nursing home or other facility;
- make funeral and burial arrangements;
- make decisions and obtain information affecting health care such as the right to obtain and disclose medical records, employ or discharge health care professionals, or consent, or refuse to consent, to medical treatment;
- permit irrevocable transfers to family members and to charity; (This will enable estate planning to continue after incapacity, but on the other hand, it might lead to an unintended depletion of the estate.)
- provide that third parties can rely conclusively on the power;
- authorize the attorney-in-fact to sue any party who does not honor the power if that refusal results in injury or lost opportunity;
- deal with the IRS and state authorities in all tax return preparation and litigation matters; (The attorney-in-fact must obtain IRS Power of Attorney form 2848.)
- access safe-deposit boxes; and
- deal with life insurance, annuities, and retirement plans.

It is important to ensure that there are "back-up" power holders; if the person given the power dies or becomes disabled, or for some other reason cannot or will not serve, there should be (assuming state law permits) a joint or substitute attorney-in-fact nominated in the document.

Planners must also consider and discuss with their clients the downsides of the power of attorney. For instance, some banks, hospitals, and tax authorities will insist on the use of their own power of attorney documents and may not recognize the power of attorney drafted by the client's attorney. Likewise, the extent of the power given may not be readily accepted. For example, a hospital may balk at accepting a power of attorney that gives the attorney-in-fact the power to authorize surgery. The authors suggest clients personally discuss with banks and hospital officials what documents will be accepted or required.

Powers of attorney may grow "stale." Even though it was intended to be effective for many years after it was drawn, an institution may refuse to honor an "old" document. It is best, therefore, for clients to execute a new power of attorney at least every three to five years.

There are other potential problems that must be considered with respect to powers of attorney. One is that a state other than the one in which the power was executed may not recognize the validity of the power, perhaps because it does not comply with statutory requirements of the new state. The authors suggest that these execution, witnessing, and notarization issues be considered before the power is drafted. Typically, the use of three competent adult witnesses, unrelated to the maker, who sign in each other's presence and in the presence of an unrelated notary should meet all states' requirements. If there is any issue as to the maker's mental competency, it is essential to take the same precautions as in making a will.

Even a valid power of attorney has certain limitations. For example, a power of attorney cannot be used to help a disabled person obtain a divorce, vote in formal incompetency hearings, or exercise other "personal" rights. Nor can a power be used to make or revoke a disabled person's will, or to create or revoke a trust.

## JOINT ACCOUNTS

Under these arrangements, parents and/or grandparents give an asset to their children and/or grandchildren jointly. Although a joint tenancy between the disabled person and one or more healthy siblings (or others) appears at first to be a useful tool – assuming that the healthy child will manage, invest, and safeguard the property on the disabled child's behalf – there are many potential problems. For instance, neither the disabled person nor the donor parents has any control over how the joint-owner sibling uses the property, because the healthy sibling is a co-owner rather than a fiduciary and therefore has no fiduciary responsibilities.

If a court appoints a legal guardian for the property of a disabled person, the healthy sibling would – in essence – be a joint owner with the guardian – but may not agree with the guardian's decisions. If title to property is held jointly with right of survivorship between the disabled person and the healthy sibling, neither party can dispose of the property, nor use the property as collateral – without the other's consent. On the other hand, either party (assuming both are legally competent) can sever (or partition) the joint tenancy and thereby extinguish the relationship. For these and other reasons (such as the potential gift/income/and estate tax implications on the creation and termination of the tenancy), the authors generally suggest against the use of joint tenancies with disabled persons.



## TRUSTS

There is no better vehicle for assuring management, protection, and dispositive assistance for a disabled person than a well designed trust.

Through a judicious choice of trustees, trusts can provide the needed flexibility – or the rock solid rigidity – desired by the client. If drafted properly, the trust provisions can continue to be responsive to the changing needs of the disabled beneficiary. In addition, a trust can continue for the lifetime of one or more beneficiaries – and beyond that point for generations. There are several states that allow trusts to last perpetually.

However, there are disadvantages if a trust is drafted exclusively for a disabled person. If the income or assets of a disabled person exceed statutory limits (see Part I of this two-part commentary), that person may be disqualified from receiving certain state and federal benefits, or there may be a reduction in such benefits, or all or a portion of the assets in the trust may have to be paid over to the government agency for payment to health care providers, or to reimburse governmental agencies.

Let's examine the various advantages and disadvantages of trusts that are typically used for persons with disabilities.

**The Discretionary Support Trust:** The first type of trust for disabled individuals is the so called "discretionary support" trust. The discretionary support trust permits the trustee, in his/her/its sole and absolute discretion, to use income and principal for the support and maintenance of a disabled beneficiary. Proponents claim that, because of the discretionary nature of the trust and the fact that the beneficiary technically has no real right to demand either income or principal, any obligation for the trust to provide support or maintenance of the beneficiary is negated. According to their rationale, since the disabled beneficiary cannot demand distribution from the trust, the government should have no right to trust assets or to deny governmental benefits on the basis that the beneficiary has assets of his own.

However, note that not all states agree with this line of reasoning. For instance, in Pennsylvania, courts have held that if a trust's wording could be interpreted as requiring the trustee to administer the trust solely in the interest of the beneficiary, who had the legal right to require the trustee to do so, that right would make the beneficiary ineligible for medical assistance. In one such case, the trustee refused to reimburse the Pennsylvania Department of Public Welfare for expenses incurred for medical assistance provided to a trust beneficiary living in a county home. The terms of the trust gave the trustee sole and absolute discretion to pay as much of the trust's income and principal as he deemed necessary for the beneficiary's "maintenance and support."



But the court held that such language made trust assets an "available resource." In other words, the court interpreted the trust language as giving the beneficiary power to compel a distribution. In turn, that power made trust assets available to the beneficiary and, therefore, to the Commonwealth of Pennsylvania. The beneficiary was denied further state-provided medical assistance when the trustee refused to reimburse the state for its costs. On the other hand, a more recent case in the same state held that if the evidence showed that the recipient of discretionary income could not force a distribution of the trust's income or principal – for his basic food, clothing, and shelter (i.e., for support) – the recipient should continue to receive medical assistance. Obviously, legal counsel must check the latest cases and rulings in the state in which the disabled person lives to determine what the likely effect of using a discretionary support trust will have with respect to governmental benefits.

As we discussed in the first of these two issues, Congress has given a major boost to the use of special needs trusts. If federal law recognizes the use of such trusts to shelter assets already vested in a person with a disability, then assets which have never vested (such as those belonging to parents or other family members) placed in trust by a parent or other interested family member should be secure (assuming, of course, that there are sufficient limitations imposed on the use of trust assets).

**The Discretionary Non-Support Sprinkle or Spray Trust:** Consider a trust that gives the trustee absolute and sole discretion to pay out income or principal for the disabled person – but only to meet expenses not met through available governmental programs. In other words, this trust would make funds available only to "enhance the quality of the beneficiary's life" and to "supplement rather than supplant public assistance." For instance, this type of trust would provide for holiday and birthday gifts, entertainment, vacations, and rehabilitative services. So the discretionary non-support sprinkle or spray trust may be the proper course of action when state law is uncertain or adverse to other types of trusts.

When a beneficiary is disabled, the professional must give extra thought to making the trust as flexible as possible, to consider not only the disabled individual but all the client's children and other beneficiaries and their individual and/or changing needs. Typically, the trust should be revocable and established during the client's lifetime, so that he or she will have the peace of mind of knowing that the trust is "up and running," and that an election against or attack on the will cannot jeopardize the effectiveness of the financial planning he or she desires.

(Note that, in some cases, it will be more appropriate to make the trust contingent upon the occurrence of certain events. But in most situations involving disabled individuals the trust should be in place and operating as quickly as possible.)

In many cases, the trust will be "funded" with cash or other income-producing assets placed into it from inception and with provision for additional assets to be "poured over" from the property owned by the beneficiary's parents and other relatives at their deaths. Essentially, the trust becomes a "pot" into which assets from the client's will, proceeds from personal and group life insurance, pension and IRA, and even the proceeds of a lawsuit can flow.

A popular way to leverage a client's assets and enhance the funds in the disabled person's trust is the use of life insurance on the lives of both parents. If designed properly, the benefits and advantages of an irrevocable life insurance trust can be incorporated into the discretionary trust to keep the life insurance proceeds out of the taxable estates of both parents.

Certain provisions may help to accomplish the objectives discussed above. First and foremost would be the very specific language that makes it clear that trust funds could only be used to provide "non-necessaries." Second, the trust should allow the trustee to apply income and principal – in his/her/its sole discretion – in varying amounts among "all my children" i.e., to sprinkle income or spray principal to the child or children who, in the trustee's absolute discretion (from year to year) is deemed to need it the most for non-necessaries (needs other than food, clothing, and shelter).

This may help to document that no specific person is a sole (or even primary) beneficiary, and that the assets are held in a family "bank" or "pool" from which the trustee is free to dip into and make distributions. The trust should allow the trustees to accumulate income and to pass any remainder to someone other than the disabled person or his/her estate. The trustee should be authorized to pay social workers, psychologists, or other agents to evaluate the beneficiary's abilities and needs, and to monitor services and programs available or currently being provided to him/her/them. (The authors suggest that the trustee and/or guardian be provided by the client with a checklist of qualifications and procedures in selecting and compensating tutors, nurses, and other health specialists.)

Other provisions that should be considered in a discretionary non-support sprinkle or spray trust include the right to allow the trustee to accept and invest gifts from relatives and other third parties, and to accept and invest the proceeds from a personal injury settlement to be held in the trust as a separate fund. Some attorneys use an "escape clause" that terminates the trust and pays principal to someone other than the disabled person if the trust is successfully challenged in court. (The authors question if this type of clause, in a given state or jurisdiction, might be considered void because it tends to thwart public policy, or at least raises a "red flag.") Certainly, counsel should consider broad investment powers to cope with long-term shifts in economic climate and market trends in order to cope with swings from inflation to recession.

Typically, any trust for a disabled person should contain a provision that authorizes the trustee to make direct payments on behalf of the disabled person, or to make payments to or on behalf of a disabled person's spouse or other dependant. Non-corporate trustees should be protected – even more than in a typical trust – by exculpatory language that exonerates the person who must shoulder

this long-term, potentially awesome burden, and encourages creative techniques in using trust assets on behalf of the disabled person. A spendthrift clause which stipulates that trust assets cannot be reached by the beneficiary's creditors, even though it may not be effective against tax authorities or governmental agencies, may provide an important measure of protection against creditors' claims.

Consideration should be given to a provision which allows the trustee to make charitable contributions to organizations (for example, to the United Cerebral Palsy Association) which are important to the welfare of a disabled child, provided that trust assets are sufficient to meet other purposes of the trust. The trust document may also provide that holding or renovating real estate owned by other family members was permissible if the person with a disability will reside in that property. A provision might also be included in a trust empowering the trustee to purchase community trust services (described below) if such services have not already been purchased by the date of the disabled person's parents' deaths.

**The Two-Trust Approach:** The problem with the first type of trust, which gives the trustee the sole discretion to make distributions for the disabled person's needs, is that it may not survive a governmental attack. The problem with the second type of trust is that, if the disabled person is discharged from the institution or if governmental assistance is reduced or eliminated, the terms of the trust may make it impossible for the trustee to use funds to provide necessary support – since it was designed for non-necessaries and not for food, clothing, and shelter.

What is the solution? Like heads, two trusts are often better than one. The first trust would be a non-necessaries trust that would be designed to meet only those financial needs to enhance the disabled person's quality of life that cannot, or will not, be provided through governmental or private programs. The second trust would be used only if, or when, or to the extent a financial gap existed between the total of what the government and private programs together with the first trust provide, and the needs of the disabled person.

**Who should be named as trustee?:** The authors suggest that at least two co-trustees be considered, one a family member, relative, or friend and the other a bank. The combination would offer personal concern and guidance, as well as professional management, investment, and security of the financial aspects of the trust. It is imperative that at least two and preferably three or four back-ups be selected for each trustee, because it is highly probable that at least one named trustee (or successor trustee) over a long period of time will die, become disabled, move away, or for some other reason be unable or unwilling to serve or continue to serve. We strongly recommend that clients discuss at length their objectives, their fears, hopes, and personal inclinations with each person nominated as trustee.

Selection of trustees when there are disabled beneficiaries requires even greater care. Given the special needs of the disabled beneficiary and the complexity of the trust, the trustee will undoubtedly encounter numerous issues that are, at times, protracted and unpredictable, and the burden of trusteeship can be daunting and overwhelming. Your client must find one (and preferably several) trustee who will be available when needed and who is or will be willing to serve as long as the need lasts – no matter how long that may be.

From a "human" point of view, the person selected must be impartial, of unquestionable integrity, and able to avoid conflicts of interest. He or she must be able to take continuing fiduciary risks inherent in serving in such a difficult situation. Most importantly, the trustee must be willing to learn the needs of the disabled beneficiary as well as of the others, have a strong commitment to provide a significant amount of attention to the disabled person's problems over a long period of time, and be able to make difficult personal decisions. From a financial point of view, the trustee would ideally have some investment, accounting, and tax expertise, be able to keep adequate records, and charge affordable and reasonable fees.

Obviously, few individuals can meet all these criteria. This is why most trusts for disabled individuals have co-trustees, one for the people-oriented problems and the other (often a corporate trustee) to handle asset-based issues.

## THE COMMUNITY TRUST

Many communities have recognized the urgent need parents of disabled persons have for trust provisions, and the costs they face of setting up and maintaining one. The community trust, essentially a nonprofit corporation with parents of disabled children serving as members on the board of directors, involves a pooling of resources to make it easier and less expensive to accomplish family objectives by providing for a group or community of severely disabled persons. Anyone can contribute to a community trust. The cost of qualifying someone as a beneficiary is based on the level of lifetime services the disabled person needs. If services are not needed until a parent's death, life insurance on the life of one or both parents can finance the needed capital. Planners should also consider disability insurance since the disability of a working parent could exhaust the funds that would otherwise be available to provide for the disabled beneficiary.

## LIFE INSURANCE SOLUTION

If there is sufficient cash or other assets, many problems can be solved. Absent sufficient cash or other assets, many problems will be insolvable. Without question, life insurance is the single most effective way to assure the significant financial security necessary for dependants who require perpetual care. It is also the most certain means of providing peace of mind to a disabled person's parents as to how their child's expenses will be paid after their deaths. At pennies on the dollar, the "instant estate" created by life insurance proceeds may be the only means by which the family of a disabled person can afford to provide adequate security, if governmental care is either not desired, or the disabled person is, or becomes, ineligible for such support.

Because it is essential that the coverage be available whenever it is needed, some form of permanent life insurance is indicated. The cost of term insurance rises sharply at the very ages where the insurance is most needed: as the risk of the parent's death (and the consequent cut-off of income to the disabled person from that source) increases. Since the need to provide continuing financial support for a disabled child can easily outlive the child's parents, term insurance is typically inappropriate.

Although survivorship life insurance contracts are sometimes more cost effective than single-life coverage, they may not be appropriate under certain circumstances. For example, if both parents of a disabled child are employed, the loss of one parent will inevitably trigger financial hardship/adjustment to the family. If the parents were insured under a joint/survivorship life insurance policy, no proceeds would be payable upon the first death! Therefore, single-life insurance on each working parent should be considered – to provide the "buffer" against the upheaval in the event of a parent's premature death.

Do not overlook the need for insurance on a parent who does not work outside of the home, but is the primary caregiver of the disabled child. The income-tax free proceeds (even if it's only a modest amount) will alleviate some of the stress brought on by the loss of the caregiver parent, and provide the means to hire someone to look after the child.

Life insurance on the parents (or grandparents) may be used to "compensate" the healthy siblings of the disabled child. The insurance proceeds (from either second-to-die or single life policies) may be used to "replace" the money or resources expended for the care of the disabled child that otherwise would have been inherited by his or her healthy siblings.

If structured properly, life insurance can be used to supplement and even perpetuate the income stream from personal injury suits. For example, insurance on the life of one parent may be purchased through a family non-equity split dollar arrangement – with a trust previously established to hold the disabled beneficiary's personal injury settlement as the policy owner, and the insured's spouse as the premium sponsor (who is entitled to all the policy cash values for his or her premium contribution). Under this scenario, the family can retain control of the cash values and use them – if necessary – for an emergency or opportunity. At the insured parent's death, the proceeds (in excess of the amount equal to the cash value) payable to the trust will be available to provide financial security for the disabled child. (NOTE: Discussions of estate tax implications of life insurance and taxation of split dollar arrangements are beyond the scope of this commentary.)

Certainly, before switching jobs or starting a new business, parents of a disabled person must give extra consideration to life and health insurance coverage. Check the "pre-existing condition" provisions of the health insurance plan, and look into MERPs (Medical Expense Reimbursement Plans). (See also **Tools and Techniques of Estate Planning**.)

## SOME ADDITIONAL THOUGHTS

- When dealing with parents of disabled or special needs children, it is essential that you consider how to arrange assets and income in a way that does not jeopardize the dependant's eligibility for supplemental social security or other such government programs.
- Grandparents and other relatives who are considering bequests to the disabled person should be included in the planning process at an early stage.
- Every aspect in the lives of the family of a disabled child is more complicated and expensive. Aside from the direct and obvious costs of home nursing care, laundry, cooking, and housekeeping, there are many indirect costs such as the time and expense of transporting a child to and from medical appointments or a hospital (which typically requires an adult to accompany the child). The cost of lodging and meals adds up quickly and significantly to ancillary outlays. Even a recreational day trip can be both physically and financially draining. Hidden costs also include the income loss that occurs when a parent must curtail or quit work to take care of a disabled child.
- Group health insurance coverage of a child does not last indefinitely. It is essential that plans be made before a child's coverage expires (at age 19 or in some cases 22 for full-time students). There may be a state-wide insurance pool through which insurance can be purchased for a disabled child.

## CONCLUSION

Nowhere is the need for estate and financial planning more urgent or important than when the problems include providing financial security for a special needs or disabled person. Yet parents of such children are often so preoccupied with day-to-day crises that they sometimes have difficulty allocating the time, energy, and economic resources to plan for the future. The need for continual updating of information, plans, and tactics is essential. An annual "Financial Fire-Drill" – a meeting with professional advisors to review goals, resources, and plans of action and the staging of a dry run – can make an incredible and invaluable difference to the overall emotional and financial well-being of the family.

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Prudential Financial Planners can prepare financial plans incorporating many of the planning techniques discussed above. Financial Services Associates and producers can work as knowledgeable members of clients' professional teams to provide suitable products.

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