

FAMILIES WITH SPECIAL NEEDS CHILDREN: A FINANCIAL GUIDE FOR THE PERPLEXED

PART 1

When planning for clients with special needs children, saving federal or state death taxes (usually a primary focus of our planning efforts), becomes secondary to other considerations. This is Part I of a two-part commentary co-authored by my friend, Herbert D. Hinkle, an attorney who practices in Lawrenceville, Florham Park and Marlton, New Jersey and in Yardley, Pennsylvania, and who has represented people with disabilities and their families since 1974.

This commentary focuses on the economic problems faced by those who support physically, mentally, and emotionally disabled persons. We will examine the latest tools and techniques used to solve those problems. Emphasis will be placed on practical solutions that supplement available government assistance and enhance existing financial security.

A SOCIAL PERSPECTIVE

Many positive changes have taken place in the last decade with respect to special needs individuals. Among the most important of these changes is that services for people with disabilities or special needs are now emphasizing independence and "normalized" living arrangements for them. Large, insulated institutions that traditionally segregated special needs persons from society are becoming extinct and are being replaced by widely scattered supervised homes, apartments, and other residential arrangements.

The use of computers and improved communications technology has created exciting new educational and vocational opportunities for the disabled. The attitude of the federal and state governments, particularly in regard to assets which are vested in the person with a disability, has also improved. This makes it more likely for a special needs person to both qualify for governmental benefits and be able to shelter personal assets for their lifetime protection.

But during that same decade, services have become more expensive. Small and scattered facilities are more costly to operate, and the technology that offers such incredible possibilities vastly increased the costs incurred by parents, local, state, and the federal governments.

STAGE ONE: ASCERTAIN THE PROBLEMS

Planners working with parents of special needs individuals must consider and confront both people – and asset-oriented issues. Unfortunately, these issues are like mathematical interdependent variables – each issue or problem must be considered in relation to the others. The variables are often complex, uncertain and, at times, highly emotionally charged – particularly when the special needs person is a child and even more so when there are other children in the family. The true extent of impairment may not presently be evident, medical procedures may be in a state of flux, or treatment may have to be delayed until the child is older or better able to undergo the treatment. A child's ability to cope and adjust may not yet be fully evident.

Clearly, special needs persons (particularly children who are adopted) have much greater than normal medical and continuing care costs. William H. Fuser of the Lilliput Children's Services has detailed expenses faced by families that have adopted children with special needs. Those expenses include special equipment for children with medical conditions, modifications to homes to accommodate their particular or special medical conditions or large sibling groups, medical bills, and/or therapy bills for the emotionally troubled. Even otherwise simple tasks such as obtaining a baby sitter take on difficult and expensive overtones, and specially trained caregivers or respite homes are sometimes needed to make it possible for the parents of such children to go to a movie or take a short trip.

In the case of adopting children with special needs (many of whom may also have backgrounds of neglect, abuse, and/or drug exposure) it may mean that special equipment will be required, or modifications to a home be made. A van that is wheelchair accessible may need to be purchased, or adopting families may have to add on rooms to their homes or have to move to a larger house to accommodate a sibling group.

Families taking children with emotional difficulties incur significant therapy costs both for the children, as well as to help the families adapt to meeting the needs of the adopted children. Some parents may have to work fewer hours or even resign from their jobs to be able to meet the needs of special needs children. If a special needs child does not qualify or loses his/her benefits from governmental programs (explained below) even a relatively large estate can be quickly depleted or lost.

KEY QUESTIONS

Planners should ascertain the clients' or parents' answers to the following questions and carefully record them in writing as part of the documentation that should be available for successor advisors and caretakers:

- (1) To what degree can (or will) _____ fend for himself (herself)? (What are the nature, extent, and prognosis of the disability (or disabilities)?)
- (2) When you die, retire, or if you become disabled or suffer a financial setback, who can (and will) continue to assure adequate care, services and other needs for _____? (Most banks and trust companies are not capable or willing to make these highly necessary but personal decisions.)
- (3) What plans have you made for multiple "back-ups" – so someone you have selected can step in and make decisions and/or assure services if the primary person you named dies, becomes disabled, moves, has a financial reversal, or, for any other reason, cannot or will not serve?
- (4) What back-up plans do you have if there is no family member or friend willing and able to assume these responsibilities?
- (5) Who will help enhance _____'s life and help observe religious traditions, celebrate birthdays, holidays, and other special times?

PUTTING PROBLEMS INTO FINANCIAL PERSPECTIVE

To the extent possible, you must help your client/parent translate needs into dollar amounts. For instance, depending on the location and the degree of care required or desired, home care now can cost between \$30,000 and \$50,000 a year and residential care can cost between \$40,000 and \$150,000 (or more) a year!

Here are some questions you should ask:

- (1) Does ____ now (or will ____ eventually) need residential care and, if so, what do you expect the annual cost will be?
- (2) What are you now paying for ____'s lifetime support?
- (3) What are you now paying for ____'s habilitation – or rehabilitation?
- (4) What are you now paying for ____'s medical care?
- (5) What are you now paying for ____'s room and board?

- (6) Where will ____ live if you are no longer here? Can ____ live alone? With a friend or relative? In a group home? What costs would you estimate in each case? (Note that if a disabled person lives in the home of an aging family member or even with young family members with children of their own, the result is often that the special needs person is isolated from his or her peers. An often forgotten issue is the additional expenditures necessary in the home of the relative or friend – and the financial, physical, and emotional drain on them and their family. On the other hand, residential programs operated by private organizations under contract to governmental agencies – if available – usually offer ongoing opportunities for work and recreation.)
- (7) Is ____ able to work? To what extent? Is that likely to continue? What are ____'s earnings?
- (8) Can ____ handle routine affairs? Small amounts of income each week? Large sums of money? (Discuss ____'s financial maturity and capability at length.)
- (9) Who else are you supporting and what are the monthly or annual dollar needs for those persons?
- (10) What are your feelings about taking financial resources from other children if money is needed for ____? (This question may indicate a need to provide for the special needs person through a life insurance/trust combination and providing for other children through a will and/or separate life insurance/trust combination.)
- (11) What will be the impact of guardianship on the finances of the person you have named in your will? (It may be necessary to make specific provision in a will and/or trust – or purchase life insurance – to financially assist the personal guardian who may be forced to employ someone to take care of the child or to work fewer hours in order to help ____.)
- (12) What, if any, personal financial resources does ____ have? What have you done to protect those assets? Do you anticipate an inheritance for ____? Do you expect a settlement from litigation?

Planners should make a rough "guestimate" of family financial circumstances and needs and then compute the present value of the projected needs. Against those potential needs you must total the client's personal assets that would be available upon death, disability, or retirement, and estimate the dollar value of available governmental programs. The net shortfall (and there inevitably is a significant shortfall) should be covered by life insurance whenever possible.

STAGE TWO: ASCERTAIN THE RESOURCES?

In estimating available personal, non-governmental resources, don't overlook those that may be available from grandparents, aunts, and uncles. Quite often, family members fail to financially assist parents of children with disabilities more often because they do not know what to do or how to do it,

rather than because they do not want to help. For example, grandparents may have been advised that they should not maintain a bank or mutual fund account in the name of a child, because it would disqualify the child for governmental benefits at age 18.

Although the advice may be technically correct, such statements often lead the grandparents (or others) to do nothing. Why not counsel them to purchase additional life insurance on their own lives (e.g. on a single life and/or second-to-die basis) or help the parents (or grandparents) of the special needs child (either through a private non-equity split dollar arrangement or through direct gifts or loans of cash) purchase insurance on their lives for the child's benefit?

AVAILABLE GOVERNMENT PROGRAMS

Both the federal government and every state offer some financial assistance to special needs individuals. One type of benefit bases qualification on the disabled person's financial needs. The other type of benefit is based on factors other than need. Generally, state programs follow these two patterns, but it is necessary to examine the rules and regulations of your client's home state. It is important to note that although the programs are essentially the same, there are variations from state to state.

Programs based on need include Social Security Income (SSI) and Medicaid described below.

SOCIAL SECURITY INCOME (SSI): The SSI program provides aid to elderly, blind, and disabled persons who are financially needy. This program is administered by the Social Security Administration and – based on need – makes both outright financial and medical assistance available.

Requirements: To qualify for SSI, an individual must be unable to engage in any substantial, gainful employment because of a medically established mental or physical impairment that can be expected to result in death, or has lasted or can be expected to last continuously for not less than 12 months.

Benefits: Benefits currently range from \$350 a month upwards. The actual maximum depends on the disabled person's marital status, living arrangements, and income. SSI provides a guaranteed annual income but this amount is reduced as the disabled person's income from any source increases.

Benefits are forfeited entirely when a person owns personal resources in excess of \$2,000 and receives more than a very modest amount of income. The exact income threshold levels vary from state to state. Note also that there are SSI equivalents to "attribution" (constructive ownership) rules called "deeming" rules. These deeming rules attribute to the SSI applicant income and resources which in actuality belong to someone else, typically a spouse or a parent with whom a minor lives.

However, a person can own a home of any value without loss of benefits – assuming that he or she lives in that house. Certain household possessions, personal effects, and a car are also exempted from the asset limitation – assuming certain conditions are met

MEDICAID: Medicaid is a medical assistance program which is a joint project of the federal and state governments, and is administered by each state with federal funds. It pays for hospital care, doctor bills, home health care, and other long-term care in public or private intermediate term care facilities. Medicaid is therefore a very important source of funding for residential services for people with disabilities.

Requirements: Medicaid provides only for low-income and needy persons but allows benefits regardless of age. Eligibility for Medicaid is subject to federal guidelines but is determined at the state level using your client's home state criteria. Persons who meet the tests for SSI will also meet Medicaid requirements. In other words, eligibility is typically based on both an applicant's assets and income.

As is the case with SSI, the applicant's home is an exempt resource. It can therefore be transferred to a spouse, child, and if certain rules are met, other relatives. But there is a 36-month "look-back" rule that imposes a period of ineligibility based on the amount of assets transferred and the date of transfer. Assets transferred prior to that look-back period are not counted. A constructive ownership rule treats wealth owned by the applicant's spouse in excess of a specified amount as if it were the applicant's asset. Cynics may view this "deemed ownership" provision as encouraging divorce or transfers of property to children.

It is generally not possible to avoid these harsh eligibility rules through trusts. Ironically, trusts set up to avoid the Medicaid rules and qualify the applicant for benefits are called "Medicaid Qualifying Trusts." The term is ironic, because it does not qualify the applicant for the benefits. To the contrary, assets in such trusts are considered as available to the applicant – to the extent that any part of the principal (or income) in the trust is or can be paid to the applicant. The trust's assets are considered "available" if the trustee merely has the discretion to pay trust funds to the Medicaid applicant.

These rules don't allow an exception – no matter why the trust was created. Nor does it matter whether the trust is revocable or irrevocable. In fact, benefits will be denied even if the trustee never makes a distribution to, or on behalf of, the applicant. Essentially, the only realistic exception is that one spouse can set up a trust under his or her will for the other spouse. A special exemption places a shield around assets placed into such a trust at the testator's death for purposes of the Medicaid resource availability tests.

There are, however, two types of trusts that may work and should be considered. The first is a "non-necessaries" trust created by someone other than the Medicaid applicant or his or her spouse. The trust should provide that no trust principal or income can be used for any expense that would or could be paid by, or through Medicaid or any other needs-based federal or state program. It should be designed to merely supplement government benefits and provide for "non-necessities" (such as therapy, recreation, transportation, and other items not related to necessities).

The second type of trust that may work and that should be considered is the so-called "special needs" trust. Since 1993, Medicaid (as well as the Social Security Administration) has permitted the assets of a person with a disability to be placed – without endangering benefits into such a trust – if the trust is

created by a parent, grandparent, or court. The catch is that the trust must provide for repayment to Medicaid when the beneficiary dies. Some states, such as Pennsylvania, have tried to impose additional requirements on these trusts. These legislative provisions seek to limit trust outlays and require the trust to conserve principal. To date, the legality of such restrictions has not been tested.

These special needs trusts present an enormous planning opportunity. They make it possible to protect the disabled person's inheritance or the settlement proceeds of a personal injury claim, and still preserve the applicant's eligibility for Medicaid since such assets will not be considered a resource of the applicant. Of course, Medicaid income requirements must still be satisfied. But countable income is limited to payments which can be used for "necessities," i.e., food, clothing, and shelter. This leaves special needs trust assets available for cars, computers, adaptive equipment, supplemental therapy, education, home care, recreation, financial and estate planning, legal advocacy, and insurance. Many states have issued guidelines or regulations outlining additional requirements for special needs trusts.

Now we turn our attention to programs that provide benefits which are not based on need. They include Social Security for Disabled Adults, Social Security for Unmarried Children, Medicare, Vocational Rehabilitation, and Veterans' Benefits. These programs are discussed below.

SOCIAL SECURITY FOR DISABLED ADULTS (SSD): The Social Security Administration provides cash benefits for disabled adult individuals who have worked a specified number of years and who have an earnings record that meets certain tests.

Eligibility: To qualify for SSD benefits, a person must have been disabled for at least six months and, during that time, is unable to have any gainful employment. So, the ability to perform any work for compensation disqualifies the applicant. The disabled person must be examined by a doctor selected by Social Security Administration officials before any benefits will be paid.

We strongly suggest that the applicant contact the local Social Security office prior to the six-month threshold, obtain the name of each person contacted at that office, and record the date and content of the conversation. This will facilitate the application process, make it easier to establish a relationship with the people involved, obtain answers to questions, and track down and resolve problems. If the applicant experiences problems, the authors suggest a call (or, better yet, a visit) to the office of a state representative or congressperson where a legislative aide is usually assigned to assist the applicant. We suggest the applicant speak to and correspond with only that person.

Certainly, prior to any medical examination (and as soon as possible after the disability occurs), an attorney with expertise in dealing with governmental benefits should be consulted. He or she may want to accompany the applicant. Copies of any documentation of the disabling injury or sickness should be given to the Social Security doctor at the time of the examination.

SOCIAL SECURITY FOR UNMARRIED CHILDREN: If a disabled child becomes sick or is injured prior to age 22 and his or her parent is entitled to social security benefits, the child will also be entitled to payments starting at the death, disability, or retirement of the parent.

Eligibility: A child who meets the tests above will be entitled to benefits regardless of the value of his or her assets. But the amount of other benefits receivable by that child may be affected by any income payable to the child. Planners should be aware that Congress is acutely aware of the need to maintain benefit levels when baby boomers begin to retire. One (hoped-for) solution may be for Congress at some point to add a financial means test to social security programs providing benefits for disabled individuals.

MEDICARE: Medicare is a federal health insurance program. It is based on age or status rather than on need. Payments of medical bills are made for individuals and their dependents who are receiving Social Security retirement or disability payments.

There are two parts to Medicare. The first part consists of hospital insurance. This is called "Part A." The second part, "Part B," provides medical insurance. The Part A hospital insurance under Medicare can be used not only for hospital expenses but also to help pay medically necessary inpatient care in a skilled nursing home or even for care in a patient's home by a home health agency. Before accepting services from any home health services agency, we suggest your client ask for references. At a minimum, the client should ask if the care given is adequate and appropriate, the facilities are clean, and the staff efficient and courteous.

Part B Medicare medical insurance can help pay for medically necessary physician's services and certain supplies that Part A does not cover. There are certain types of health-related expenses that Medicare will not reimburse. In other cases Medicare pays half the costs. Hospital and health care facility social workers and staff will often be able to assist clients with their questions on what medical treatment or prescriptions will or will not be covered by Medicare. "MediGap" coverage should be purchased by clients for themselves and for children with disabilities who are covered by Medicare.

Eligibility: Once a person has been receiving SSD benefits for at least two years, he or she becomes eligible for Medicare.

VOCATIONAL REHABILITATION: Every state provides some form of services to help disabled people return to the workforce. The easiest way to find out about such benefits is to contact a local state vocational rehabilitation agency. If the "Yellow Pages" fails, try the social services department of a local hospital for information. Use the internet and use the various search engines to locate state-offered services.

Eligibility: Typically, the criterion for assistance is a physical or mental disability that proves a substantial handicap to gainful employment. State vocational rehabilitation agencies make the determination as to whether or not an individual's problem amounts to a handicap to obtaining or retaining a job or becoming an independent homemaker. We have found that it is helpful for an applicant to request that his or her doctor send in a statement noting why he or she feels the patient is likely to "succeed" at rehabilitation and the types of employment the patient might be able to maintain once rehabilitated.

BENEFITS FOR VETERANS: Monthly cash payments, education assistance, medical care, home health care, vocational rehabilitation assistance, and other benefits are available to disabled individuals who are veterans or whose parents or spouses are currently or were veterans.

Eligibility: State or local Veterans' Administration offices should be contacted for information.

STAGE THREE: FORMULATE THE OBJECTIVES

Stage one of the planning process requires that you ascertain and quantify the client's economic and other problems. Stage two necessitates an assessment of the private and governmental resources that could be used to meet the problems you have uncovered. In both of those stages of the process, we have suggested that you encourage the client to look beyond the specific problems of the special needs person in the family and examine the issues from the entire (and often enlarged) family's needs and circumstances. Here, we urge you to continue that holistic approach. Do not allow your client to overlook or shortchange their own personal needs and those of healthy non-disabled family members. Encourage the client to consider what we call a "baseline question:"

"What financial plans would you make for your family if none of you had "special needs?"

Turn around the constant and, typically, sole focus that is brought to bear on the problems of – and created by – the special needs person; instead, examine what must be done to protect the interests and enhance the opportunities of other family members. We like to repeat the admonition of airline attendants, who caution passengers in the event that oxygen masks drop down from the ceiling, to "Put on your own mask first before assisting the person next to you." If a breadwinner dies or becomes disabled, and there is neither adequate disability nor life insurance, the whole family unit must do with less - or do without. For example, the same principle encourages providing for the college education of healthy children. They, in turn, will be better able to help their parents provide for the support of a special needs sibling once they graduate.

ETHICAL AND MORAL VIEWPOINTS

It may come as a shock to many planners that clients often have ethical and moral positions varying widely from their own with respect to the use of federal and state benefits. Not everyone feels that there is a right or entitlement to federal or state services. But some people do not feel a family should first exhaust or bankrupt their own resources before the government benefits kick in. Differences, if any, in ethical and moral viewpoints must be recognized and, in some cases, reconciled by planners – with a constant eye to the line between the spirit and the letter of the law – as well as paying close attention to the severe costs and penalties of counseling a client to cross it.

NEXT ISSUE

In next month's issue we will focus on estate planning tools and techniques that can be used to help solve the problems of those who must deal with physically, mentally, and emotionally disabled or otherwise challenged individuals. These include disinheritance, guardianships, outright gifts to a third party, outright gifts to the disabled individual, and property management alternatives such as a power of attorney, the use of joint accounts, trusts, wills, safe deposit boxes, anatomical gifts, and life insurance.

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