

A STEP AHEAD

SOMEONE TO WATCH OVER MY CHILD:

WHAT TO CONSIDER WHEN PLANNING FOR CHILDREN WITH SPECIAL NEEDS

In our last newsletter we addressed various factors which should be considered by families when planning for the care and support of children with special needs. This article is intended to provide an overview of some of the strategies utilized by parents of minor and/or adult disabled children to ensure their ongoing financial security and enhance the quality of their lives.

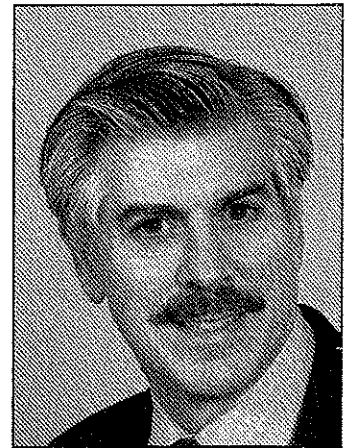
Establishing a Supplemental Needs Trust

A Supplemental Needs Trust (SNT) is designed to hold assets for the benefit of an individual who is receiving or may subsequently receive local, state or federal governmental benefits such as Medicaid. It is intended to ensure that the assets will be utilized for the care, maintenance, support and education of the beneficiary, to supplement and not replace those benefits. There are two types of SNTs, "first party" and "third party" trusts. The difference between these trusts is the source of the assets which fund the trust.

A third party SNT is funded with the property of someone other than the disabled beneficiary. Anyone may create such a trust except one who has a legal responsibility of support for the beneficiary. Under New York State law, a spouse and the parent of a minor disabled child (under 18 years of age) are specifically precluded from funding a third party SNT for the benefit of such

spouse or child. The creator of this type of trust may specify who is to receive the balance of the assets upon the death of the disabled beneficiary.

A first party SNT (often called a "Special Needs Trust") is funded with the assets which actually belong to the disabled individual, most often the proceeds from medical malpractice or personal injury awards, or inheritances. It is a strategy that is only useful for individuals who are under 65 years of age. While the transfer of the beneficiary's assets to the trust will not jeopardize his or her entitlement for governmental benefits, and the principal and accumulated income will be considered "exempt" resources, the disabled individual cannot establish and implement the trust. It must be created by the beneficiary's parent, grandparent, guardian or upon court order. Also, there must be a post-death payback provision, pursuant to which, at the death of the disabled beneficiary, Medicaid is reimbursed, from the trust assets,



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for all funds it expended on the disabled beneficiary's behalf.

Ensuring Equitable Transfer of Your Estate

Some parents of children with disabilities do not make provision, in their own estate plans, for their disabled child, believing that their other children will use a share of the inherited assets to provide care for a disabled brother or sister. In essence, they are disinheriting their disabled child. Often they do this in the mistaken belief that, if their disabled child inherits assets, he or she will lose public assistance and other governmental benefits.

With proper planning, parents of a disabled child may significantly increase the future financial security of this child. The parents' estate planning documents can expressly incorporate an SNT to benefit this child. The child does not receive a share of the estate outright but, instead, it is paid to the Trustee of the SNT. This is a form of third party SNT and can specify particular terms and conditions for the utilization by the Trustee of

the assets for this child.

Guardianship and Advance Directives

Once a child reaches the age of 18, the parents' rights, as the natural guardians, to make decisions on behalf of their child regarding health care and property management, terminate. It is at this point that the parent of a disabled child must make a decision concerning guardianship. Whether a guardianship proceeding is necessary or appropriate will depend on the mental, physical and



emotional capabilities of the disabled child. In some circumstances, properly executed Advance Directives may obviate the need for a guardian.

Advance Directives are: Power of Attorney, Health Care Proxy and Living Will. Persons over

the age of 18 years may execute these documents, provided they have the capacity to do so. A Health Care Proxy is a document in which one designates a medical decision-maker when one is unable to communicate his or her wishes. This decision-maker can be empowered to refuse or consent to medical treatment even with respect to maintaining or withdrawing life support. A Living Will expresses personal wishes with regard to health care matters. It can state a restriction on the use of life-sustaining medical procedures when there is no reasonable expectation of recovery or, alternatively, direct that aggressive measures be provided to prolong life. A Power of Attorney is a document which provides for ongoing financial and property management by an agent. To the extent that a disabled individual is capable of understanding and expressing his or her wishes with respect to these matters, and can select agents to act, a guardianship proceeding may be avoided.

Preparing a Letter of Instructions

There will come a time when the

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parent will become disabled or die. Crucial questions should be considered and addressed in anticipation of this event: Who will care for my disabled child? To whom should the other family members look for advice and assistance if my disabled child is unable to communicate his or her wishes? Have my child's special needs, preferences, likes and dislikes been

recorded? Who has access to this information and where shall it be memorialized? How should my funds be utilized for the benefit of my disabled child? It is advisable for parents to prepare a Letter of Instructions. This very useful tool provides personal, financial and other pertinent information concerning the disabled child. Having this data in one place and

readily accessible may be especially crucial for successor caregivers who step in when the parent is ill, injured or dies unexpectedly. Implementing these and other strategies may provide the greatest relief to parents of disabled children so that they can be assured that, in the future, there will be someone qualified and empowered to watch over their child. ♦

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with terminal cancer patients. Most families wait too long to have their doctor prescribe hospice and some do not even consider this a care alternative for Alzheimer's, degenerative old age, or other debilitating illnesses. They should.

Hospice involves a team approach, involving family caregivers, the personal physician, the hospice physician, nurses, home health aides, social workers, clergy or other counselors, trained volunteers, and speech, physical, and occupational therapists where appropriate. The goal is to manage the patient's pain and symptoms, assist the patient with the emotional, psychosocial and

spiritual aspects of dying, provide needed medications, medical supplies, and equipment, coach the family on how to care for the patient,



deliver special services like speech and physical therapy when needed, make short-term inpatient care available when pain or symptoms become too difficult to manage at home,

provide the family caregivers with much needed respite, and provide bereavement care and counseling to surviving family and friends.

A patient can receive hospice through Medicare if he or she is: (1) eligible for Medicare Part A, and (2) the doctor and the hospice medical director certify that the patient is terminally ill and probably has less than six months to live, and (3) the patient or health care agent signs a statement choosing hospice care instead of routine Medicare-covered benefits for the terminal illness, and (4) care is received from a Medicare-approved hospice program. ♦

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HOSPICE CARE

Unfortunately, some people who die in a hospital emergency room, or who received extraordinary treatment to prolong life in a hospital or nursing home, may have had the alternative of dying at home in familiar surroundings, with family or other loved ones at their sides.

Often, when a loved one is near death, even when there really is no hope for recovery, the family calls for emergency services and begins a process which can result in the patient being transported to a hospital emergency room, a

strange, public and typically uncomfortable environment, connected to tubes and monitoring devices. He or she may be frightened and confused. This may not be the ideal way in which to spend one's last hours on earth.

Attending to a dying loved one in the peace and quiet of the home, with caring children and grandchildren surrounding the bed, can be a spiritual experience for all involved. Hospice can allow this to happen. Memories of a loved one passing in peace can provide great comfort for

the family in years to come. When there is no longer hope for prolonging life, especially when this decision is made months in advance, hospice may be a better alternative to other medical intervention.

Hospice is a form of medically supportive care for patients who are terminally ill, those who have a progressive, incurable illness that is anticipated to end in death within six months despite good medical care and treatment. It allows for compassion and dignity in the process of dying. Hospice care is generally underused except

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