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Planning for the Disabled Child with a Supplemental Needs Trust

It is public policy in Virginia to allow parents (or other relatives) of a disabled child to set up a trust for their inheritance which will not disqualify them from government benefits, such as Social Security and Medicaid. The reasoning behind these supplemental needs trusts is simple: prior to the protection now afforded by these trusts, some parents would simply disinherit their disabled children rather than see them lose their benefits. Since the state wasn't getting the inheritance monies anyway, why not allow it to go to the disabled child for his or her extra needs, above and beyond what the state supplies, such as sundries, clothing, meals, vacations, over-the-counter medicines, upgraded medical procedures, reading material, recreation, improved housing, etc.

These trusts, however, offer traps for the unwary. Since payments to the child will generally reduce their SSI payments dollar for dollar, trustees of such trusts should be advised to make payments *directly* to the providers of goods and services (not to the child). Preserving SSI benefits is crucial since eligibility for SSI determines eligibility for Medicaid. In other words, if SSI is lost, the recipient in many cases loses her Medicaid benefits. In addition, any benefits previously paid by Medicaid may be recovered. For this reason, one also should be wary of outright bequests from well-meaning grandparents or other relatives.

Distributions from the trust to the beneficiary should generally be "in kind" rather than in cash. For example, the trust may own items such as furniture and allow the beneficiary child the use of them. In addition, the supplemental needs trust must be carefully drafted so that it only allows payments for any benefits over and above what the government provides, not only now but also in the future. The disabled child may not control or have direct access to any portion of the trust.

A major concern for many parents today is the increased life expectancy of their disabled child. With major advances in medical care, a disabled child who might have previously died before her parents, now may survive them. In order to address this problem, parents often make the planning error of leaving a disproportionate share of the estate to the disabled child. This can engender hard feelings in siblings who, although agreeable to such an arrangement initially, may find themselves in need of funds later on and resentful of the uneven distribution in favor of the disabled child. The surviving siblings are often the only support network available for the special needs child, so that it is all the more important to keep peace and harmony in the family.

Often, an analysis with the estate planning attorney will reveal that the income from an equal division of the estate will, in fact, be sufficient to provide for the disabled child's needs. If

such is not the case, "second-to-die" insurance may be purchased to provide for any additional funds needed. These policies are written over two lives, those of both parents. Since the insurance company only has to pay when the second parent dies (i.e., when the funds are needed) the premiums are significantly lower than on a single life policy.

Some parents, feeling the family is close enough, think that they can simply leave the inheritance to a brother or sister, who will then take care of the disabled sibling. This offers no protection to the disabled child in the event the sibling runs into financial difficulties, has a divorce or predeceases them. The supplemental needs trust allows the sibling, as trustee, to manage the assets for the benefit of the disabled child while providing complete protection for the funds and the naming of back-up trustees to continue the trust in the event of the death or disability of the initial trustee. Remember, these trusts may have to last for many years.

With the complexity of modern trust administration, many parents are choosing both a personal and a professional trustee, so that the family member can provide the personal input while having the professional trustee handle the administrative items, such as monitoring investments and preparing tax returns. For more on the choice of trustee, please request information on "Choosing a Professional Trustee".

As part of the planning process, it is critical to review beneficiary designations on IRAs and 401(k)s as well as on annuities and insurance policies so that the disabled child's supplemental needs trust is named as the beneficiary, rather than the child herself. Watch out for simple designations such as "my spouse first, and my children second".

Another key issue is continuity of care for the child upon the surviving parent's death. Revocable living trusts are often used as the estate plan of choice since the trustee may use and distribute assets for the benefit of the disabled child immediately after the parent's death, unlike the case of a will, which must first be probated, a court proceeding to determine its validity. These proceedings may tie up the estate assets for many months or even years.

Another tool in planning for the disabled child is the "Letter of Intent" or personal needs notebook, where the parents may provide the following information to the trustees (1) the nature of the child's disability (2) emotional and financial care provided by the family (3) persons involved with the child (4) the child's capabilities and limitations (5) their likes and dislikes (6) their behavioral quirks and nuances (7) their daily routine, and (8) how they act with other people and in other places when the parents are not around.

One final word of caution. Where a disabled child is involved, it is of greater importance that funds be available when needed. As such, long-term care insurance for the parents should be arranged so that the money the family is depending on to support the child is not lost for the parents' potential nursing home expenses.

RESOURCES

National Institute on Life Planning for Persons with Disabilities

447 E. College Avenue
Jacksonville, IL 62650-2590

www.thunder.sonic.net/nlfp

Clearinghouse for information on housing, employment, guardianship, wills, trusts and long-range planning.

The Arc of the United States

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
(301) 565-3842

www.thearc.org

National voluntary organization dedicated to the needs of children and adults with mental retardation and their families. Website includes useful links and a list of planning resources.

www.commonwealthcommunitytrust.org

Statewide voluntary organization provide Virginia residents a convenient and economical way to have trust funds administered for people with disabilities. (804) 740-6930 or toll-free (888) 241-6039

"A Family Handbook on Future Planning", by Rick Berkobien (The Arc, 301-565-3842)
Step-by-step planning for families of children with mental retardation.

"Disability and the Family: A Guide to Decisions for Adulthood"; by H.R. Turnbull and others (Paul H. Brookes Company, 800-638-3775).

Information and advice on determining mental competence, guardianship, financial planning and government benefits.

"Planning for the Future: Providing a Meaningful Life for a Child with Disability After Your Death", by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph and Rich W. Fee (Book Masters, 800-247-6553)

How to work with lawyers, financial planners and other professionals in creating life and estate plans.

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