



Living...Not Just Surviving

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Life Planning for
Special Needs Children
A Division of KFDE

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ADMINISTERING THE SPECIAL NEEDS TRUST

With this trust you are creating an estate plan with the express intent of maintaining the disabled person's eligibility for public benefits, while at the same time preserving adequate funds to provide special items needed by that person that are not otherwise provided. This plan is extremely important because it avoids disruption of benefits and promotes stability for the beneficiary.

As trustees, you will be authorized to provide certain items and assistance to the beneficiary. The key is to provide ONLY what is permissible and only on the terms permitted by the source of the public benefits.

There are basic rules. While this memo will not comprehensively discuss these rules, it provides an overview.

The most common available public benefits are Social Security Disability, SSI, Medicare, and Medicaid.

Social Security Disability is an entitlement, available to an individual who meets the test for disability under Social Security regulations and either has worked and contributed to Social Security or was disabled from childhood and qualifies for Social Security Disability based on the Social Security contributions of a retired or deceased parent. The disabled individual can have assets worth thousands of dollars and still qualify for this *entitlement*.

Two years after first receiving Social Security Disability, the individual is entitled to Medicare coverage even if under age 65.

Supplemental Security Income (SSI) is a need-based program. The individual must meet the same requirements for disability under the Social Security regulations and, in addition, have very limited assets and income. Your son can own certain assets, considered exempt assets for SSI purposes, and still qualify for SSI. The most important of the exempt assets is the home.

The purpose of SSI is to cover food, clothing, and shelter. **The general rule for the trustee of the Special Needs Trust is never pay out of the trust for the beneficiary's food, clothing, and shelter and never give the beneficiary**

cash or anything easily convertible to cash. Any deviation from this general rule must be carefully considered with counsel before action is taken.

An SSI recipient is categorically entitled to Medicaid. Medicaid pays for most medical expenses not covered for the individual by Medicare and Supplemental Health Insurance. For many disabled individuals Medicaid provides the only safety net.

As trustees of the Special Needs Trust, you make payments for the beneficiary (not to the beneficiary) at your discretion. The beneficiary cannot expect payment on demand out of the trust. If the disabled person were to have this power, the trust would disqualify him or her for SSI benefits.

Payments out of the Special Needs Trust *supplement* rather than replace public benefits. The trustee, at the trustee's discretion, can pay for such things as medications, medical equipment and therapy not provided by Medicare and Medicaid, educational instruction, musical instruments, travel, entertainment, and other supplementary items provided that assets given to the beneficiary are not easily convertible to cash.

It is critical that you as trustee accurately, honestly, and promptly report income and assets according to program rules. You will be able to obtain copies of the specific program reporting rules at the site of each program or by calling the appropriate agency, and requesting copies of the reporting obligations. You must keep clear and accurate records of what you have spent on behalf of the beneficiary and any other fund spent by the trust.

It is critical that the sum total of all assets in accounts in the beneficiary's own name be an amount less than the asset limit for the benefits program. Pay particular attention to accounts held by a facility trust fund or to jointly owned or other possibly obscure accounts. If the beneficiary as SSI recipient receives (even innocently) benefits to which are not entitled, they may be considered to have received an overpayment which may have to be repaid to SSI.

If your beneficiary *ever* receives a notice terminating the beneficiary's benefits, SEEK HELP IMMEDIATELY; you may have only ten days from the date of the notice to appeal. DO NOT DELAY. Also, be sure that you have organized the beneficiary's affairs so that you do see all invoices from the funding agency. If you use direct deposit, be sure you are the addressee for correspondence.

Normally, recipients of public benefits will be required to fill out forms or visit the agency at least once each year. DO NOT IGNORE requests for information.

The rules of Medicaid, SSI, and any other public benefits, such as Veterans Compensation, Veterans Pension, Aid to Families with Dependent Children, Food Stamps,

Social Security or Medicare are all different; do not assume that eligibility for one accords eligibility for another benefit.

To see a discussion and list containing examples of items for which a special needs trust could pay for, see “**What the Special Needs Trust Can Purchase**”, which is for illustrative purposes only.

If properly drafted and managed, the Special Needs Trust can be a valuable tool for enriching the life of a beneficiary who receives minimal income for food, clothing, and shelter. Normally, individuals eligible for Social Security Disability and SSI cannot obtain private health insurance. Medical costs for a disabled individual can quickly wipe out a sizeable inheritance. Therefore, your efforts in preserving public benefits for the beneficiary are highly worthwhile.

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