ADMINISTERING A SPECIAL NEEDS TRUST

PREPARED BY:

WALSH & WILSON, PLLC

Attorneys at Law

159 St. Matthews Avenue Suite 8 Louisville, Kentucky 40206

Phone: (502) 410-5080 Facsimile: (502) 899-9095

Website: www.elderlawoflouisville.com

INTRODUCTION

This guide is to help you as you administer the Special Needs Trust. You should set aside a quiet hour to read this letter, as it is lengthy and complicated. It may not answer all of your questions, but it will answer many. Please put it with your Trust records, as it will be helpful to have it available to read again and again.

This guide is designed to explain the SSI rules so you can understand how and when to make distributions from the Trust without jeopardizing benefits. It also makes some practical suggestions on how to obtain help in recognizing and dealing with some of the special needs of your beneficiary in Section 1. I have divided this guide into four sections, to help you find an answer to a specific question quickly.

- I. The first section reviews the SSI benefits program, the focus of your duties as Trustee and suggests how to prepare your agenda for deciding on distributions;
- II. The second section describes the rules about how and when to make payments from the Trust. It also contains a list of permissible distributions from a Special Needs Trust;
- III. The third section outlines the reporting rules for SSI and Medicaid benefits, suggests ways to prevent a reduction in benefits and the importance of staying current with new developments, and includes a section on record-keeping; and
- IV. The fourth section reviews the accounting requirements for a Trustee.

SECTION I

A. OVERVIEW OF PUBLIC BENEFITS

The federal Social Security Administration (Social Security or SSA) operates the SSI program. The Kentucky Department Cabinet for Health and Family Services (CHFS) has agreed to administer the Medicaid program under contract with the federal government. The Department for Community Based Services (DCBS) in each county administers the Medicaid program locally.

An SSI beneficiary receives a monthly cash payment for support because the beneficiary is aged, blind or disables <u>and</u> his or her assets <u>and</u> income are low enough to meet a "means test." SSI is intended to pay for the beneficiary's <u>food</u> and <u>shelter</u>. An SSI recipient is automatically entitled to receive Medicaid benefits because he or she is "categorically needy." If the beneficiary receives too much income or has assets that are too great, he or she is likely to lose his or her SSI eligibility-and the automatic Medicaid coverage along with it. The loss of Medicaid coverage can be a more serious problem than the loss of SSI benefits, especially if alternative medical insurance is not readily available.

B. YOUR DUTIES AS THE TRUSTEE

The terms of your Special Needs Trust give you substantial discretion over the funds, but they require you to administer the Trust for the beneficiary's benefit to <u>supplement</u> any benefits the beneficiary receives from the SSI and Medicaid programs or elsewhere. That is why the Trust is called a "Special Needs Trust." It is also commonly referred to as a "Supplemental Needs Trust." The funds are not considered available to the beneficiary and do not count as the beneficiary's property in determining eligibility for SSI.

Being appointed and serving as a Trustee is a very serious undertaking. Every Trustee is held to a high standard of performance, considerably higher than the performance acceptable for your own affairs. A person who holds property for another is a fiduciary. Every Trustee is a fiduciary and has certain duties which must be strictly carried out. These duties include:

- 1. **Duty** to carry out the terms of the Trust agreement.
- 2. **Duty** of loyalty to the beneficiary.

- 3. **Duty** to act and invest prudently.
- 4. **Duty** not to delegate Trustee responsibilities.
- 5. **Duty** to maintain the books and records and keep the beneficiaries reasonably informed of the Trust administration.

Of these duties, perhaps the most significant duty is that of undivided loyalty to the beneficiary. The Trustee must administer the Trust **solely** in the best interests of the beneficiary and exclude from consideration his or her own advantage. The Trustee must also exclude the welfare of any other person, including minor children, because the trust is for the **sole benefit** of the beneficiary.

Because the Trustee is in a position of such intimacy with the beneficiary and has such control over the beneficiary's property, a Trustee is held to a higher standard than would govern in an ordinary business transaction. Chief Justice Cardozo eloquently described this duty in the case of *Meinhard v. Salomon* (249 N.Y. 458, 464, 164 N.E. 545, 546 (1928)) by saying:

"Many forms of conduct permissible in a workaday world for those acting at arm's length, are forbidden to those bound by fiduciary ties. A Trustee is held to something stricter than the morals of the marketplace. Not honesty alone, but the <u>punctilio</u> of honor the most sensitive, is the standard of behavior."

Achieving the goal of supplementing the public benefits can be tricky because this means not violating complicated eligibility rules. But if you don't satisfy these rules, you may cause the beneficiary to lose some or all of his or her public benefits, and you **also** fail to carry out the requirements of the Trust, which is the first duty set out above. This guide is intended to explain the basic rules to you so that you can better carry out the purpose of the Trust and your duties as Trustee. Then you can avoid the loss of needed public benefits and any reason to remove you as Trustee.

Please note that if you are also the beneficiary's Conservator, Guardian, or Representative Payee, you have different legal obligations in those roles. You **must** keep those roles and the funds **separate**. For example, if you are the Representative Payee for the beneficiary, and receive his or her SSI check, you **must not** mix or commingle the SSI money with the assets that are part of the Trust. Instead, each fund must be kept totally separate from any other (you should have one checking account for the Trust and another for the SSI benefits) and all funds **must** be kept separate from your own assets. Of course, you should have a separate bank account or accounts for the Trust, in the name of the Trust.

This guide does not discuss your duties as Trustee for distribution of the Trust when the beneficiary dies. Please let us know if you would like that information.

C. SETTING THE AGENDA FOR DISTRIBUTIONS

To help you make decisions about purchasing goods or services for the beneficiary, you should ask the beneficiary and those who know him or her well to tell you what he or she wants that he or she cannot get now. Then, working with the beneficiary and keeping in mind the rules described below, you should decide which items, if any, you want to pay for out of the income and principal in the Trust. You may also want to obtain information from the beneficiary's school records, such as an Independent Education Plan, as they may help you determine a "wish list."

We also suggest that you obtain an initial evaluation of the beneficiary and then update it at least once a year. This evaluation should include the following items:

- 1. An evaluation of the beneficiary's physical condition, and any rehabilitation, educational and training programs in which s/he participates.
- 2. Recreational leisure time and social needs and appropriateness of existing program services.
- 3. Educational needs and programs.
- 4. Laws and administrative practices relating to various governmental financial assistance and private contractual benefit programs, as it is essential to secure these benefits unless the beneficiary has a reasonable chance of earning sufficient income to support him/herself.
- 5. Legal rights, treatment in accord with his/her needs, payment of a fair wage for work performed, the right to vote and the right to marry.

The evaluation should be based on individual contacts with the beneficiary, his/ her social worker (if any), his/her family and other individuals who are in regular contact, including service providers.

Since the Trust encouraged you to employ professionals to help in the administration of the Trust, consider hiring a case manager or another

qualified persons to prepare an annual assessment of the beneficiary's needs for your review. This report should include both (1) assessment of the beneficiary's current needs and (2) recommendations for maximizing his or her quality of life. We can furnish a list of persons for you to contact regarding these reports. In return, we simply ask you only to let us know if you were satisfied with their services.

SECTION II

A. HOW AND WHEN TO MAKE DISTRIBUTIONS FROM THE TRUST

This section describes the rules about **distributions**: how and when to make payments from the Trust. To do this properly, you need to have some familiarity with the SSI rules on assets and income. Then, using these rules, it suggests how and when to make payments from the Trust to maintain eligibility. These rules will help you determine the kinds of distributions that you will want to make.

SSI Rules

Social Security will categorize any distribution you make to or for the beneficiary as some form of income, subject to its "income rules." Then, if the income buys some kind of asset (or becomes an asset itself such as money in a bank account), the asset will be subject to separate "resource rules."

We will discuss the asset rules first, and then the income rules. Classifying the distributions from the Trust as "income" or as a "resource" will usually make a big difference to the beneficiary's eligibility and benefit levels, so it is important to have some understanding of them.

In order to be sure that your distributions fall into the desired category, you must maintain very accurate records of how the Trust funds are invested and spent. These records will be needed if Social Security of the Department of Social Services wants verification of the expenditures you have made. It is not unusual for the agencies to make a demand for verification, and you should expect it. See Section 3 for more information on record-keeping.

SSI Rules- Assets

Countable Resources

Generally, a "countable resource" is any asset considered by SSI rules to determine eligibility (therefore a resource is sometimes called a "countable asset"). It could be tangible, like a second car, or it could be intangible, like a savings account. A SSI recipient and beneficiary is allowed to have only \$2,000, or less in "resources." If resources exceed \$2,000 during any whole calendar month (even by a few cents), the beneficiary's public benefits may be terminated.

Income that is received during the month is considered "income" throughout the calendar month of receipt, even if it is deposited in a bank account. If, at the end of the month, it is still in the account, it becomes a "resource" in the next month and is then subject to "resource" rules.

Excluded Resources

The beneficiary is allowed to have certain <u>exempt</u> assts, which are <u>excluded</u> from the \$2,000 limit. These exempt assets are not counted in determining eligibility, and the beneficiary's ownership of them will not jeopardize his or her SSI benefits. Therefore, you may freely purchase exempt assets for the beneficiary and give them to him or her (except for food and shelter, as explained below). You should <u>not</u> give the beneficiary the money to purchase exempt assets himself or herself - payments of money are <u>always</u> considered countable income as explained below. You must also be careful as to what assets you transfer to a beneficiary if your Trust has a "payback" provision. The following assets are exempt:

- A home, including adjacent land, if the beneficiary lives in it or intends to return to it, up to a specific value;
- Household goods (furniture, furnishings, household equipment, household supplies), and personal effects (toiletries, items of personal care and education, clothing and jewelry-however, giving the beneficiary food is "in-kind support," as explained below)- now unlimited;
- One automobile (or other vehicle) of unlimited value;
- Life insurance with a cash surrender value, if its face value is less than \$1,500, and all term life insurance;
- A burial plot, or other burial space, worth any amount; and
- An irrevocable burial fund, worth up to \$1,500.

All the assets above are specifically exempted by law. You might note that a number of common and useful items are not specifically mentioned as exempt in the SSI regulations, but are not counted because they are included among "personal effects" or are services. These include:

- Recreational equipment, games and crafts;
- Books and magazines;
- Telephone, answering machines;

- Television, radio and cable service;
- Musical instruments and stereo;
- Travel and education;
- Recreational and entertainment; and
- Some home maintenance, such as gardening

<u>Income</u>

Even though the Trust principal is not considered a resource of the SSI beneficiary, disbursements from the Trust may be considered "income" to the beneficiary, depending on the nature of the disbursement. SSI rules will treat distribution you decide to make from the Trust in one of four ways:

- a. Direct income to the beneficiary;
- b. Not income;
- c. In-kind income; or
- d. In-kind support and maintenance.

We will discuss these in order. Remember, if your distribution becomes an asset, SSI rules will treat it as either a "countable resource" or an "excluded resource," which we discussed above.

Direct Income

Any money you give to the beneficiary directly will be considered income to the beneficiary, and, after a set-aside of the first \$20.00 each month, will reduce his or her SSI benefits on a \$1-for-\$1 basis. As a result, you should avoid making direct payments \underline{to} the beneficiary, since there will be no net advantage from doing so. If your actions reduce the beneficiary's SSI benefits to zero, then both the beneficiary's SSI **and** Medicaid benefits will be jeopardized, because the Medicaid benefits depend on SSI eligibility.

Not Income

Other kinds of distributions from the Trust are "not income" because they are not cash, nor are they food or shelter. Examples of benefits that are "not income" include payments you make to someone **other** than the beneficiary, such as for certain kinds of medical care and social services. Also, bills you pay for the beneficiary to receive services are not income from you. However, if the beneficiary receives any asset as a result of your paying the bill, the value he or she receives is counted under the "in-kind income" rules discussed below.

In-Kind Income

Generally speaking, "in-kind income" exists when you give the beneficiary something other than money. In most cases, it is safe to provide such "income" to the beneficiary. This is because the value of any non-cash item (other than food or shelter) is **not** counted as income if the item will become an exempt asset when it is retained into the following month. You can also give the beneficiary something that will be used in the month it is received, such as a vacation or a tank of gas.

As a result, you may give the beneficiary most of the exempt assets mentioned above (such as books, furniture or recreational equipment). For example, if you give the beneficiary a television, it will not be counted as income. This is because it would be an exempt household item if retained into the following month.

Distributions of Allowable In-Kind Income

- The safest (but least convenient) way is to distribute these services or goods directly to the beneficiary personally. In other words, you can buy a television and deliver it to the beneficiary personally. You do <u>NOT</u> give the beneficiary the money to buy the television;
- You can make a direct payment to a "provider," such as an appliance store, which then provides the goods or services to the beneficiary, such as delivering the television; or
- You can give the beneficiary the right to obtain the goods or services, for example a gift certificate to a book store. This is risky because, if the beneficiary can obtain cash for the gift certificate, it will be considered a cash equivalent.

Thus, when you give the beneficiary the right the receive goods or services, it should <u>always</u> be non-transferable and non-refundable (such as an airline ticket to take a trip). Please consult with use before you provide any airline tickets to the beneficiary, as the rules are different for domestic and foreign tickets. Also, and SSI beneficiary loses his/her benefits if he/she is out of the country for too long. Check with us before you send a beneficiary on a trip outside the U.S.

One safe way to use the gift certificate or voucher approach is to buy the certificate or voucher with a credit care in your name as Trustee. Then, any refund would be credited to the Trust instead of to the beneficiary. Then the beneficiary can show that he/she cannot obtain a cash refund.

In-Kind Support and Maintenance ("ISM")

If the beneficiary receives food or shelter as a result of payments by the Trustee to other persons, then the beneficiary will have income in the form of "in-kind support and maintenance" (ISM). ISM causes a reduction in the beneficiary's SSI payments. This is why the Trustee is directed to exercise his or her discretion in the Trust agreement to make distributions which will supplement and not provide for the beneficiary's basic needs.

However, in many cases, the Trustee has authority to make decisions which are in the best interest of the beneficiary. That may require examining carefully how the rules regarding "in-kind support and maintenance" will be applied. Problems can arise when "in-kind income" consists of food or shelter. The beneficiary's SSI benefits will be reduces or eliminated if s/he receives ISM.

The theory behind the reduction or elimination is that SSI benefits are specifically intended to pay for a person's food and shelter, so if that person receives those things from another source, then less SSI benefits are needed. As a result, if you pay the beneficiary's grocery bill, rent, or meals (for example, in a restaurant), you are providing ISM to the beneficiary. In theory, you are then also reducing his or her need for SSI benefits.

There are sometime very fine distinctions between allowable in-kind income and countable ISM. For example, you can pay for some entertainment expenses, but not others (for example, a movie ticket but not a restaurant meal, as that is food).

Note also that you can pay for certain medications and alternative health treatments if they are not covered by Medicaid or other benefit programs. If the beneficiary purchases a home, ISM can arise in each month when the Trust pays the beneficiary's mortgage payment, property taxes, insurance or utilities (gas, water, electricity, sewer, garbage collection). ISM can also arise if the Trust purchases a home in which the beneficiary resides. If you are thinking about buying a home where the beneficiary will reside, please call us. We must discuss the decision in detail to determine if the SSI benefit will be reduced and if so, by how much.

If you do give ISM to the beneficiary, his or her SSI benefits will be reduces, but not on a dollar-for-dollar basis, like with cash. There are two different formulas that the Social Security uses to reduce the SSI benefits for a person who receives ISM. Which formula is used depends on the household and living arrangements of the SSI recipient. Determining which rule and how it applies can be complicated and quite detailed, like income or

estate-tax planning. If you have questions or concerns about the impact on your beneficiary of ISM distributions from the Trust, please ask us for assistance before you make any such distributions. We are here to help you on issues like that.

Conservatorships: You should note that the SSA rules regarding conservatorships take a completely different approach. The rules consider that funds in a conservatorship estate are available for the conservatee's support and maintenance. Thus, assets in a conservatorship estate that exceed \$2,000 will cause the beneficiary to lose his or her SSSI and Medicaid benefits. Therefore, it is important to administer the Trust properly and consider the consequences of placing assets in a conservatorship for the beneficiary.

I find that it is helpful to summarize for you expenditures that you should not make and expenditures that you should make. I suggest that you do NOT give a copy of the list to the Trust beneficiary, as you will probably then be overwhelmed with distribution demands. Rather, review the list periodically to see if it suggests a special need that the Trust could meet. I have included a list of permissible expenditures. That list is below. If your Trust is court supervised, not all courts agree that these are proper trust distributions, and may question some of them. While we have successfully defended such expenditures, we may not always succeed.

- 1. The Trust should never distribute cash to the beneficiary. As indicated above, if you distribute any cash to the beneficiary, his/her SSI benefits will be reduced by and equivalent amount and he/she will be no better off than if he/she had not received any funds. This is true regardless of whether he/she uses the cash for food and shelter, or for supplemental, non-support needs. The rules allow you to give the beneficiary \$20.00 cash. I do not recommend doing that, because if you forget for one month, the beneficiary will want \$40.00 the next month and that will reduce his/her benefits by \$20.00.
- 2. **Generally, do not use funds from the Trust to pay for food or shelter for the Trust beneficiary**. These items will constitute "in-kind" income and would most likely result in a 1/3 reduction of the beneficiary's grant level. Normally, you won't want to do this. Let the beneficiary use his/her SSI benefits for such items, and use distributions from the Trust for "nonnecessities." In an emergency, you may use trust distributions for food and shelter. Please call us first, however, for further information. Also, if your Trust authorizes distributions that

reduce benefits and you want to do that, we need to discuss that decision in detail before you implement it.

- 3. Any distributions from the Trust should be made directly to the supplier of the good and services to be received by the Trust beneficiary. This is necessary because, as indicated under rule #1 above, you cannot give the beneficiary cash for goods and services, regardless of whether it will ultimately be used for non-support items.
- 4. Distributions related to medical needs which are not already provided by Medicaid or other public benefit programs will always be exempt from consideration as income under the SSI program and most other public programs. As a result, the purchase of any good or medical service for the Trust beneficiary not already available through Medicaid or another public benefit program that can be justified by a medical authority's order will not cause a reduction in SSI benefit levels. The term "medical authority" is broadly interpreted and includes in addition to medical doctors, many other health care providers, such as podiatrists, chiropractors, physical therapists, and psychologists.

The following expenditures are permissible from the Special Needs Trust:

- 1. Automobile/Van
- 2. Accounting services
- 3. Acupuncture/Acupressure
- 4. Appliances (TV, VCR, DVD player, stereo, microwave, stove, refrigerator, washer/dryer)
- 5. Bottled water or water service
- 6. Bus pass/public transportation costs
- 7. Camera, film, recorder and tapes, development of film
- 8. Clothing
- 9. Clubs and club dues (record clubs, book clubs, health clubs, service clubs, zoo, advocacy groups, museums)
- 10. Computer hardware, software programs, and Internet service
- 11. Conferences
- 12. Course or classes (academic or recreational) including books and supplies
- 13. Curtains, blinds, drapes, and the like
- 14. Dental work not covered by Medicaid, including anesthesia
- 15. Down payments on home or security deposit on apartment

- 16. Dry cleaning and/or laundry services
- 17. Elective surgery
- 18. Fitness equipment
- 19. Funeral expenses
- 20. Furniture, home furnishings
- 21. Gasoline and/or maintenance for automobile
- 22. Haircuts/salon services
- 23. Hobby supplies
- 24. Holiday decorations, parties, dinner dances, holiday cards
- 25. Home alarm and/or monitoring/response system
- 26. Home improvements, repairs and maintenance (not covered by Medicaid), including tools to perform home improvements, repairs and maintenance by homeowner
- 27. Home purchase (to the extent not covered by benefits)
- 28. House cleaning/ maid services
- 29. Insurance (automobile, home and/or possessions)
- 30. Legal fees/advocacy
- 31. Linens, towels, kitchen supplies such as potholders, aprons, sponges, etc.
- 32. Magazine and newspaper subscriptions
- 33. Massage
- 34. Musical instruments (including lessons and music)
- 35. Non-food grocery items (laundry soap, bleach, fabric softener, deodorant, dish soap, hand and body soap, personal hygiene products, paper towels, napkins, Kleenex, toilet paper, and household cleaning products)
- 36. Over-the-counter medications (including vitamins and herbs, etc.)
- 37. Personal assistance services not covered by Medicaid
- 38. Pet and pet's supplies, veterinary services
- 39. Physician specialists if not covered by Medicaid
- 40. Private counseling if not covered by Medicaid
- 41. Repair services (appliance, automobile, bicycle, household, fitness equipment)
- 42. Snow removal/landscaping/gardening (lawn) services
- 43. Sporting goods/equipment/uniforms/team pictures
- 44. Stationary, stamps, cards, etc
- 45. Storage units
- 46. Taxicab
- 47. Telephone service and equipment, including cell phone, pager, etc.
- 48. Therapy (physical, occupational, speech) not covered by Medicaid

- 49. Tickets to concerts or sporting events (for beneficiary and an accompanying companion)
- 50. Transportation (automobile, motorcycle, bicycle, moped, gas, bus passes, insurance, vehicle license fees, gas, car repairs)
- 51. Utility bills (Direct TV, cable, TV, telephone-not gas, water or electric)
- 52. Vacation (including paying for a personal assistant to accompany the beneficiary)

Examples of Trust Distributions that Will Reduce SSI Benefit:

- 1. Basic shelter-related expenses
- 2. Food
- 3. Cash for any purpose

Examples of Impermissible Trust Distributions:

- 1. Paying for a service already paid for by another source
- 2. Distribution not in the best interest of the beneficiary (made primarily for the benefit of another person)

*If this is a litigation Special Needs Trust, or otherwise has a payback provision in it, then you should consult us first before paying for any single item over \$1,500. Remember that several government agencies are entitled to any funds remaining in the Trust as the beneficiary's death and may request that you pay back to the Trust any expenditures that those government agencies consider improper.

SECTION III

A. REPORTING GUIDELINES-SSA RULES

The SSI program requires periodic reports for all SSI recipients. These reports MUST be completed for eligibility to continue. The representative payee must report the existence of the Special Needs Trust to SSA, and provide a copy of it if requested. In addition, the beneficiary must report all of the following:

A change in: (1) the beneficiary's address, (2) employment status, (3) his or her living arrangements (such as adding or losing a roommate), (4) his or her income (including the receipt of any direct income of ISM from you as Trustee), (5) any countable resources, (6) health insurance coverage, (7) the beneficiary's marital status, as well as (8) changes or improvements in the beneficiary's physical or medical condition (for example, the beneficiary improves so much that he or she is no longer disabled), (9) admission to or discharge from any health facility or public facility (such as a hospital or nursing home), (10) any trip outside the U.S. and (11) new eligibility for other public benefits.

The report may be brief, but it should be in writing to the Social Security Administration and it should include the beneficiary's name and Social Security number, description of the event that triggered the report and the date of the event. The report is due within 10 days after the end of the month in which the event took place. You, as Trustee, are not required to send these reports to SSA, but if you do, be sure to **keep a copy**.

If a required report is not made on time, the SSI program is entitled to reimbursement for all SSI benefits incorrectly paid to the beneficiary, and SSI can assess a penalty of up to \$100, depending on how late the report is. Thus, you will want to remind the Trust beneficiary of this requirement. You may also need to inform the representative payee of this requirement. Remember that the SSA will have access to any K-1's you file itemizing the income from the Trust used for the Trust beneficiary. This may raise questions about the distributions and you may receive an inquiry from SSA about them. If you receive any correspondence from SSA, please inform us of it immediately. We are here to help you response to these inquiries. Failure to respond, or an incomplete explanation, may result in a loss of benefits.

Encourage the beneficiary to report all distributions. It is safer to report and explain a distribution to the beneficiary than to be discovered

later by SSA's Income and Eligibility Verification System (IEVS). At that point, the explanation will then have to be made to a very skeptical investigations unit.

NOTE: If your Trust is required to file tax returns, and most Special Needs Trusts are, the IRS and the Kentucky Revenue Cabinet will know about all income distributed from the Trust, and they regularly exchange reporting information with SSI and the Medicaid program. This is why all reports should be filed on time as required by the governmental agencies and in the proper fashion. You need a **separate taxpayer identification number** for the Trust. **DO NOT** use the beneficiary's social security number on the Trust bank account as this will cause the income to be reported as his/her income and cause disqualification.

B. PREVENTING A REDUCTION IN BENEFITS-APPEALS FROM ADVERSE ACTIONS

In administering the Trust, you must pay attention to any notice regarding a change in benefits and keep reasonably well informed of new developments. If SSI or Medicaid notifies you or the beneficiary that it intends to reduce or eliminate the beneficiary's benefits, you should appeal in writing, **within 10 days**. If you act quickly, the SSI and Medicaid benefits will continue and not be suspended during the appeal. Although you are allowed up to 60 days to appeal an SSI decision, and 90 days to appeal a Medicaid notice of action or decision, asking for an appeal **after** 10 days have passed will result in the **loss** of the SSI and Medicaid benefits while you await the results of the appeal.

You must also stay informed about changes in the beneficiary's benefits in order to make intelligent decisions as Trustee of the Trust. Failure to learn about a change in benefits can have catastrophic results. Although SSI is a federal program run by the Social Security Administration, the federal contribution is only a portion. Make sure that the SSI and Medicaid programs have your address, in addition to the beneficiary's address, and request that you receive copies of all communications affecting the beneficiary's benefits. Instruct the beneficiary to be sure to let you know promptly of receipt of any such notice, and remind the beneficiary of that often. You might find it helpful to be named the Authorized Representative for Medicaid for the beneficiary. If you are the Authorized Representative you have the responsibility to report changes in income or assets, so you will need to report all Trust distributions. Be sure to keep copies of all correspondence from each benefit agency. This will help in determining the applicable rules on eligibility, reporting and appeals.

C. RECORD KEEPING

As we have seen, it is very important to determine whether distributions from the Trust are income, not income, in-kind income, or in-kind support and maintenance for the beneficiary. To be certain that your distributions fall into the desired category, **you must maintain very accurate records**. You should keep a record or each disbursement as it is made, keep the receipt for the disbursement and review the records monthly, when you balance the Trust checking account. You should review the records again each year, in preparation for the accounting and filing the income tax returns. These records will be needed if Social Security, CHFS, or DCBS wants verification of the expenditures that you have made.

The director of the federal Centers for Medicare and Medicaid Services (CMMS), who is responsible for implementing the Medicaid program, has advised the Kentucky Medicaid director on how to treat "disability/payback" Trusts. If your Special needs Trust requires repayment at the death of the beneficiary to the Cabinet for Health and Family Services (for the Medicaid program) of all benefits received by the beneficiary, then it is a "payback" Trust. That memo indicated that the states have the right to "monitor distributions from the Trusts to be sure that the funds are used for the benefit of the disabled person." Thus, such a demand for verification of Trust disbursements is likely, and you should expect it.

If you need help on this, we can help you to get set up to keep good records.

SECTION IV

A. ACCOUNTINGS

You, as Trustee, are required to account at least annually to all Trust beneficiaries to whom income and principal must or may be distributed. Generally, that will be only the disabled beneficiary. We can verify that for you. If your Trust is a "payback trust," or court supervised, the accounting requirements are broader.

The accounting must include a list of receipts and disbursements for the last year, set out the Trustee's compensation, name the agents hired by the Trustee, their relationship to the Trustee, if any, and their compensation, and statements that the beneficiary can petition the court regarding the accounting and the time limit for objections. Generally, the time period to object is three years. This can be shortened if certain technical requirements are satisfied. We can assist you in meeting the accounting requirements. If you wish our help on accountings, please call us to discuss how to set up your records to make accounting as easy as possible.

CONCLUSION

We have reviewed many complicated rules in this letter. Being Trustee of a Special Needs Trust may be viewed very differently from anything you have done. The rules to administer it properly are varied and many. As you work with the Trust administration and the beneficiary, please let us know how we can help you.