

## Paying Living Expenses for Disabled Adult Child

[Note: This article based on a Special Needs Alliance reader response newsletter item, edited here for Mississippi application.]

Who determines whether an irrevocable special needs trust (SNT) can be used to supplement residential home cost (room and board) for my 51 year old son (who has been disabled from birth)? He receives both Supplemental Security Income (SSI) and Social Security Disability, but the home costs more than the total of both monthly payments. We -- his parents -- have saved from our working years and established an irrevocable SNT fund from our own savings for the time when we are too old to continue providing care for him. Do different states have different rules regarding the above question? Are some homes (perhaps not-for-profit facilities, for example) allowed to receive monies from a special needs trust to supplement the cost of living in the home by counting the SNT money as "a gift" to the home?

**Answer:** The specific terms of your special needs trust determine whether the trustee has the authority to make distributions to help pay room and board (support) costs of the disabled beneficiary. Properly written special needs trusts are drafted to make clear they are intended to supplement, but not replace, the benefits that the disabled beneficiary may be eligible to receive, and that the trustee has discretion in making distributions that will best serve the needs of the beneficiary.

Some very conservatively drafted SNTs do prohibit the trustee from making any distributions for food or shelter, or from making distributions of cash that could pay for food or shelter, but most SNTs that we prepare give the trustee the discretion to decide whether it is in the beneficiary's best interest to help with these costs.

You say you have established and funded the SNT. This is what is generally called a "third-party" special needs trust. These trusts typically give the trustee much more flexibility in making distributions than do "self-settled" special needs trusts -- the kind that might be funded by a personal injury settlement for your son, for example. These third-party trusts are often written to give the trustee the absolute discretion to make distributions for any purpose (including providing supplemental support) that the trustee believes are in the beneficiary's best interest, or to make no distributions at all.

If your son is receiving SSI benefits and the trustee pays some kinds of support expenses (called "ISM," or "in-kind support and maintenance" in Social Security jargon), the payment would constitute income to him, reducing his monthly SSI benefit. The reduction of SSI benefits won't be more than \$232.33 (in 2008) even if the trustee pays more than that amount for food or housing expenses. If the SSI portion of his benefits is more than that amount, then he will still receive at least a small SSI check -- and, more importantly, the Medicaid and other program benefits that flow from that automatically.

Though the rules of each state's Medicaid program may differ, a low income developmentally disabled person in Mississippi who has been receiving benefits under

the mental retardation/developmentally disabled programs (MR/DD) could still receive Medicaid and state assistance even if he were not eligible for SSI. It is likely that even if your son lost his SSI benefit entirely he would still be eligible for Medicaid or MR/DD benefits in Mississippi. You should check with your son's caseworker or an attorney experienced in these benefits programs and special needs trusts to verify these points, however.

Some MR/DD state programs pay for limited services, requiring that the disabled person or his family pay for some or all shelter and food costs. A private home or other facility that does not accept Medicaid or other state benefits for the developmentally disabled could easily cost more than the SSI or other Social Security benefits, but generally the payment of supplemental benefits by a third party, including a special needs trust, can help the disabled person live more comfortably without causing the loss of his other benefits.

If your son is living in a state supported facility (e.g., a group home or other intermediate care facility for developmentally disabled) the actual charges to the resident are usually expenses that are not for room and board. For example, there may be separate charges for field trips, caregivers, private health insurance premiums or co-pays, clothing, and other non-food, non-shelter items. Even a strictly written SNT that doesn't allow payments for food and shelter would permit the trustee to pay for these expenses, and the trustee's payment of these expenses would not cause a reduction in SSI.

It is very likely the residential home charges for food and shelter are completely covered by the existing state and Medicaid benefits, and the actual amounts being billed are for expenses that do not constitute food or housing. It may be that the trustee could simply specify on the check that he is not paying any expenses that are food or shelter.

You ask whether in some non-profit facilities it might be possible for the SNT to make a (charitable) gift that could be used to pay for a resident's services. No, this won't be possible, particularly if the facility operates as a tax-exempt organization. In general, tax-exempt organizations can't accept such "gifts" in return for providing services, since the payments are not really gifts at all.

**The bottom line:** You have taken the most important first step in preparation for the time when you might not be able to provide the same kind of care and support you now provide for your son. Your special needs trust is an important part of the plan for your son's future. It will help provide the same kinds of benefits and support you now provide, and it will do so after you are no longer able to direct or manage the payments.

*For information and help establishing or administering a special needs trust for a disabled child, contact us at 601-987-3000 or [rcourtney@frascourtlaw.com](mailto:rcourtney@frascourtlaw.com).*