

Providing for Your Disabled Child in Your Estate Plan

By: Barbara A. Isenhour and Sean R. Bleck

One of the biggest worries for parents of a disabled child is how to protect and provide for the child after both parents have died. In addition to worrying about who will care for your child and what your child's quality of life will be without you to provide for him or her, you need to plan for how to pay for care your child will require when you are no longer there. In addition to your own assets that you plan to set aside to care for your child there may be important government benefits that will be part of your overall plan to protect your child. If your child is currently receiving SSI or Medicaid benefits (or may be eligible for those benefits at age 18) it is very important that your estate plan take into account the SSI and Medicaid eligibility rules.

Qualifying for SSI and Medicaid

The SSI program is a cash benefit program available to disabled individuals. Even if your child is able to work in a sheltered workshop environment, he or she may still qualify for SSI benefits to supplement earnings. The SSI program is intended to be a safety net for disabled individuals to provide a minimum monthly income. The SSI benefit amount for 2005 is \$579 per month.

Medicaid is a very important health benefit for many disabled individuals. Medicaid can pay for hospital care, physician services, durable medical equipment (wheelchair, hospital bed, etc.), medications, group home care, in-home caregivers, nursing home care and respite care for parents. For some individuals the cost of the care paid by Medicaid can come to several thousand dollars per year. People who receive SSI will automatically receive Medicaid benefits.

To qualify for SSI or Medicaid the assets that your child owns directly cannot exceed **\$2,000**. There are a few assets that are not included in this \$2,000 amount including a car, a residence, household furnishings and certain burial arrangements. If your estate plan leaves your disabled child an outright bequest at your death the result is that your child will not longer be eligible for SSI or Medicaid benefits.

Special Needs Trust

There is a way to provide for your disabled child in your estate plan while still preserving your child's SSI and Medicaid benefits. If you leave the bequest for your disabled child to a special needs trust instead of directly to your child, SSI and Medicaid eligibility will not be threatened. If the special needs trust is properly drafted the assets in the trust will not be considered to be owned by your child and therefore not included in the \$2,000 asset limit for SSI and Medicaid eligibility.

A special needs trust directs the trustee to supplement government benefits received by the disabled person, not replace those benefits. The trustee cannot be required to support the trust beneficiary and instead must be given absolute discretion to make distributions

from the trust. The disabled beneficiary of the trust cannot be the trustee and cannot have any control over the trust funds.

You can provide in the special needs trust where you want any remaining trust funds to go after the death of your disabled child. You do *not* need to provide that any remaining funds in the trust be repaid to the state Medicaid agency for Medicaid benefits received by your child.

How Will the Special Needs Trust Benefit My Child?

Parents often want to know how a special needs trust can be used to benefit their child. It is easier to start with what the special needs trust should *not* be used for. If your child is receiving SSI or Medicaid benefits the trustee should not make cash distributions from the trust. Cash is treated as “unearned income” and will reduce your child’s SSI or Medicaid benefits. So for example if Tim is receiving SSI and the trustee of his special needs trust gives him \$50 per month for spending money, his SSI will be reduced by \$30 per month (\$20 of unearned income is disregarded under the SSI/Medicaid income rules.)

If your child is receiving SSI and the trust pays for food or shelter expenses (rent, utilities, mortgage, etc.) your child’s SSI benefit amount will be reduced by up to one third of the SSI benefit amount plus \$20 (\$213 in 2005). Payments from the trust for food or shelter expenses are called “in-kind support and maintenance” under the SSI income rules. The trustee may decide that it is a good use of the trust funds to pay for shelter expenses or food. In that case the trustee will need to take into account the affect the in-kind support and maintenance will have on the SSI benefit amount. In-kind support and maintenance must be reported to the Social Security Administration.

How the trustee uses the trust funds to benefit you child will depend upon many factors including:

- how much money is in the trust;
- your child’s medical needs;
- your child’s living arrangements;
- your child’s interests.

The following are a few illustrations of how a special needs trust can be used to provide for a disabled beneficiary:

- Tim has cerebral palsy and has lived in his own apartment since his mid twenties. Tim receives Medicaid benefits to help with attendant care and medical expenses so his parents included a special needs trust for him in their estate plan. The trustee purchased a handicapped accessible condo for Tim which is owned by the trust. The trust has purchased a handicapped modified van to transport Tim and pays for additional attendants to supplement the hours of care paid by Medicaid. Without this supplemental support paid from the trust Tim would probably have

to move to a group home

- Rachel is autistic and moved to a group home after her parents died when she was 40. Her group home care is paid by Medicaid. Her parents left a bequest for Rachael in a special needs trust. The trustee determined that Rachel has an aptitude for computers and loves to swim. The trustee has purchased a computer for Rachel and has hired a tutor to enhance her computer skills. The trustee pays for an annual trip to send Rachel to visit with her brother in California. Because Rachel is unable to travel alone, the trustee pays for a companion to accompany Rachel on the trips. The trustee has also hired a companion to take Rachel to swim at a local pool twice a week. Medicaid pays the group home for a shared room so the trust pays an additional monthly payment to the group home so that Rachel can have her own private bedroom.
- Mike has MS and receives SSI and Medicaid benefits. When his mother died she left a bequest to Mike in a special needs trust. Mike had been living in a substandard apartment in Seattle, paying \$400 of his SSI income for rent. After consulting with Mike about how to help him, the trustee decided that the best way to improve Mike's living condition was to have the trust pay \$600 per month to rent an apartment for him and pay his utility bills. The new apartment was handicapped accessible and in good condition. Mike will lose \$213 of his SSI benefit because he is receiving in-kind support and maintenance but more of his monthly income will now be available for his other expenses since the trust is paying for all of his shelter expenses.

Picking a Trustee

You will name the person or institution you want to serve as the trustee of your child's special needs trust. The trustee will play a critical role in your child's future so selection of a suitable trustee should be done with careful deliberation. You can name more than one person to serve as co-trustees if that is appropriate.

The following are important qualities any trustee should have:

- Honesty, integrity and good judgment;
- Good money management skills;
- Empathy with your child's needs;
- Knowledge about the issues unique to your child's disabilities.

There may be a family member who would be a suitable trustee. You may also want to consider a professional trustee, including a bank, trust company or guardianship agency to serve as trustee. Your attorney preparing your estate plan or parent support groups should be able to give you recommendations regarding potential professional trustees. You can interview the professional trustee and reach your own conclusions about who you want to select as the trustee.

As a general rule your special needs trust established in your estate plan will not be supervised by the court. If, however, the trustee you named is unable to serve or is not properly handling the administration of the trust anyone can ask the court to step in. The court can appoint a suitable successor trustee and can demand that a trustee provide an accounting if there is a question of mishandling finances.