

ESTABLISHING A SPECIAL  
NEEDS TRUST FOR YOUR CHILD  
WITH A DISABILITY

A Publication of the  
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## **Introduction**

So your son or daughter with special needs has their therapies in place, they have an IEP for school or are in a transition program or they are in a group home and go to a job daily; have you planned as well as you can for their future?

Circumstances in your child's life have been difficult up until now. How can you plan for the financial future of your child to balance private resources of a family with public assistance?

A Special Needs Trust or Supplemental Needs Trust is the only reliable way of making sure that an inheritance of any size has a chance of being available to your child with a disability when he or she needs it. The special needs trust allows the disabled beneficiary to use the trust monies for areas of need such as education, recreation, counseling, and travel while maintaining eligibility for Federal or State public benefits programs such as SSI or Medi-Cal.

A special needs trust also allows the child with a disability to receive gifts, lawsuit settlements or an inheritance from other family members and not lose eligibility for SSI or Medi-Cal. Often these public benefits also serve as an entry point for receiving other vital community support services.

## **Supplemental Needs Trusts and Planning for children with disabilities**

Americans are living longer than they did in years past, including those with disabilities. According to one count, 480,000 adults with mental retardation are living with parents who are 60 or older. This figure does not include adult children with other forms of disability nor those who live separately, but still depend on their parents for vital support.

When these parents can no longer care for their children due to their own disability or death, the responsibility often falls on siblings, other family members, and the community. In many cases, expenses increase dramatically when care and guidance provided by parents must instead be provided by a professional for a fee.

Planning by parents can make all the difference in the life of the child with a disability, as well as that of his or her siblings who may be left with the responsibility for caretaking (on top of their own careers and caring for their own families and, possibly, ailing parents). Any plan should include the following elements:

## **A Plan of Care**

Where is your son going to live when he can no longer live with you? Will he move in with a sibling? Will she move into a group home? Who will make the decision? Who will monitor the care he or she receives? It's never too soon to begin answering these questions and making sure that the living and support arrangements are in place.

In some cases, it can ease the transition for all concerned if the child moves to the new living arrangement while his parents can still help with the process. In many parts of the country, non-profit organizations and private consultants can help set up the plan, research available options, and assist in the move.

It will help everyone involved if the parents create a detailed written statement of their wishes for their child's care. A Letter of Intent. They know their child better than anyone else. They can explain what helps, what hurts, what scares their child (who, of course, may be an adult), and what reassures him. When the parents are gone, their knowledge will go with them unless they pass it on.

In almost all cases where a parent will leave funds at death to a child with a disability, this should be done in the form of a trust. Trusts set up for the care of a child with a disability

generally are called "supplemental" or "special" needs trusts, which are described in more detail below.

Money should not go outright to the child, both because she may not be able to manage it properly and because receiving the funds directly may cause the child to lose public benefits, such as Supplemental Security Income (SSI) and Medi-Cal. Often, these programs also serve as the entry point for receiving vital community support services.

Some parents choose to avoid the complication of a trust by leaving their estates to one or more of their typical children, relying on them to use the funds for the benefit of their sibling with a disability. Except in the case of a very small estate, this is generally not a good idea. It puts the typical child in the difficult position of having to decide how much of her money to spend on her sibling. Such funds also will be subject to claim by creditors and at risk in the event of divorce or bankruptcy. Finally, the child who receives the funds may die before the child with a disability without setting these funds aside in her estate plan.

### **Life Insurance**

Finally, a parent with a child with a disability should consider buying life insurance to fund the supplemental needs trust set up for the

child's support. What may look like a substantial sum to leave in trust today may run out after several years of paying for care that the parent had previously provided. The more resources available, the better the support that can be provided the child. And if both parents are alive, the cost of "second-to-die" insurance--payable only when the second of the two parents passes away--can be surprisingly low.

The good news is that advance planning for a child with a disability can make a significant difference in his life. You just have to take the first step.

### **Supplemental Needs Trusts**

Supplemental needs trusts (also known as "special needs" trusts) allow a disabled beneficiary to receive gifts, lawsuit settlements, or other funds and not lose his eligibility for certain government programs. Such trusts are drafted so that the funds will not be considered to belong to the beneficiary in determining his eligibility for public benefits. As their name implies, supplemental needs trusts are designed not to provide basic support, but instead to pay for comforts and luxuries that are not available from public assistance. These trusts typically pay for things like education, recreation, counseling, and medical attention beyond the simple necessities of life. (However, the trustee can use trust funds for

food, clothing and shelter if the trustee decides doing so is in the beneficiary's best interest despite a possible loss or reduction in public assistance.)

Very often, supplemental needs trusts are created by a parent or other family member for a child with a disability (even though the child may be an adult by the time the trust is created or funded). Such trusts also may be set up in a will as a way for an individual to leave assets to a disabled relative. In addition, the individual with a disability can often create the trust himself, depending on the program for which he or she seeks benefits. These "self-settled" trusts are frequently established by individuals who become disabled as the result of an accident or medical malpractice and later receive the proceeds of a personal injury award or settlement.

Each public benefits program has restrictions that the supplemental needs trust must comply with in order not to jeopardize the beneficiary's continued eligibility for public benefits. Both Medi-Cal and SSI are quite restrictive, making it difficult for a beneficiary to create a trust for his or her own benefit and still retain eligibility for Medi-Cal benefits. But both programs allow two "safe harbors" permitting the creation of supplemental needs trusts with a beneficiary's own money if the trust meets certain requirements.

The first of these is called a "payback" or "(d)(4)(A)" trust, referring to the authorizing statute. "Payback" trusts are created with the assets of an individual with a disability under age 65 and are established by his or her parent, grandparent or legal guardian or by a court. They also must provide that at the beneficiary's death any remaining trust funds will first be used to reimburse the state for Medi-Cal paid on the beneficiary's behalf.

Medi-Cal and SSI law also permits "(d)(4)(C)" or "pooled trusts." Such trusts pool the resources of many disabled beneficiaries, and those resources are managed by a non-profit association. Unlike individual disability trusts, which may be created only for those under age 65, pooled trusts may be for beneficiaries of any age and may be created by the beneficiary herself. In addition, at the beneficiary's death the state does not have to be repaid for its Medi-Cal expenses on her behalf as long as the funds are retained in the trust for the benefit of other disabled beneficiaries.

Income paid from a supplemental needs trust to a beneficiary is another issue, particularly with regard to SSI benefits. In the case of SSI, the trust beneficiary would lose a dollar of SSI benefits for every dollar paid to him directly. Some attorneys draft the trusts to limit the trustee's discretion to make such payments.

Others do not limit the trustee's discretion, but instead counsel the trustee on how the trust funds may be spent, permitting more flexibility for unforeseen events or changes in circumstances in the future. The difference has to do with philosophy, the situation of the client, and the amount of money in the trust.

Choosing a trustee is also an important issue in supplemental needs trusts. Most people do not have the expertise to manage a trust. An alternative is retaining the services of a professional trustee. For those who may be uncomfortable with the idea of an outsider managing a loved one's affairs, it is possible to simultaneously appoint a trust "protector," who has the powers to review accounts and to hire and fire trustees, and a trust "advisor," who instructs the trustee on the beneficiary's needs. However, if the trust fund is small, a professional trustee may not be interested. This can be an argument for pooled trusts.

#### **About the Author:**

Steven M. Ratner is the founder of the Law Offices of Steven M. Ratner. Steven M. Ratner has been certified as a Specialist by the State Bar of California in Estate Planning, Trust & Probate Law.

California attorneys certified as specialists must pass a written examination in their

specialty field, demonstrate a high level of experience in the specialty field, fulfill ongoing education requirements and be favorably evaluated by other attorneys and judges familiar with their work.

Steven M. Ratner graduated from the University of Oregon School of Law where he was first in his class, a member of the Order of the Coif, and an Associate Editor of the Oregon Law Review. Mr. Ratner received an LL.M. in Taxation from New York University where he was a Student Editor of the Tax Law Review and the recipient of the Harry J. Rudnick Memorial Award.

Mr. Ratner's work experience includes a one-year clerkship with the Honorable Herbert Y.C. Choy of the United States Court of Appeals for the Ninth Circuit in Honolulu, Hawaii.

Steven M. Ratner served as an Adjunct Professor of the San Diego State University Seminar in Estate Planning. The seminar is part of the CFP Board Registered Executive Financial Planner Program.

Mr. Ratner is admitted to practice in California and New York. Mr. Ratner is a member of the San Diego County Bar Association, the National Academy of Elder Law Attorneys, and is the co-Chair of the Elder Law Section of the San Diego County Bar Association.

