



FINANCIAL & ESTATE PLANNING FOR PEOPLE WITH SPECIAL NEEDS

PROVIDING FOR A CHILD WITH SPECIAL NEEDS LONG TERM

A Three-Part Plan

Each part of the plan plays a distinct and important role in the care of a child with a physical, mental or emotional disability.

By Andrew M. Cohen, Esq.

For many families with a special needs child, no matter what his or her age, the questions concerning who will take care of the child in the future and the source of the money to support that child, are daunting thoughts. Some choose to postpone planning rather than address the difficult reality that faces them. However, early,

careful planning can secure a disabled child's future, long after his or her parents are no longer around.

There are three important parts of a comprehensive plan that parents should consider setting up or preparing:

- *A Supplemental or Special Needs Trust;*
- *Guardianship (including those over age 18);*
- *A Family Love Letter or Letter of Intent.*

Each plays a distinct role in the care of a child with a physical, mental or emotional disability. The following is a brief overview of each:

THE SUPPLEMENTAL OR SPECIAL NEEDS TRUST

Parents and grandparents who continually put money and other assets in the name of a child with a disability, even as part of a jointly held account, actually may be doing a disservice to that child. By having such funds in their name, a child with a disability is actually precluded from receiving means based government entitlements, such as Medicaid and Supplemental Security Income (SSI). By contrast, completely disinheriting the child, and relying solely on



the government, is not necessary and hardly qualifies as sound planning.

Smart and proper planning is best accomplished by creating a plan that includes full eligibility for the government assistance, while also providing whatever private resources the family can leave for their family member. This “best of both worlds” approach is accomplished through the creation and use of a Supplemental or Special Needs Trust.

The Supplemental or Special Needs Trust is often referred to as the cornerstone and most important tool in formulating a plan to care for a special needs child. It is typically created as part of a comprehensive estate plan and funded with an inheritance and/or life insurance products, such as a second to die policy. If drafted correctly, the assets that fund the Trust, provide for the

“extras” for the beneficiary (the child with a disability) without affecting or disqualifying the child from those important government programs. The child retains the right to receive these means based benefits, as this type of Trust is not considered a countable resource by the government.

“My Mom had put off preparing a Will and setting up a Trust because of the considerable expense and the emotions this type of planning brings,” shared Denise Vargas, a young woman with a disability who graduated from the Henry Viscardi School at The Viscardi Center, an accredited model school serving Pre-K through High School students with severe physical disabilities, and is now the president of the Viscardi Alumni group.

Vargas explained why they decided to move forward with establishing the Trust,

“We needed to ensure that I would still be able to maintain the 24/7 care that I currently receive in the future and that I would also not lose the government assistance I am entitled to. Our attorney explained all of our options in language we could understand and, having a child with a disability himself, could relate to the concerns and needs we had. Thanks to his solid guidance, the process went quicker than we had planned and my Mom is much more at ease.”

Once the Trust is created, it is managed by a person known as a Trustee, usually someone similar in age to the individual with a disability. There are also organizations and institutions which provide Trustee services. It should also be noted that special rules apply (which require payback to the State at the conclusion of the disabled individual’s life) if the Trust is

WHAT SHOULD I CONSIDER WHEN DEVELOPING A PLAN FOR A FAMILY MEMBER WITH SPECIAL NEEDS?

Planning for the future for those with special needs is a common goal for many of today’s families with a physically, mentally and/or emotionally disabled family member. The creation of a solid plan will help meet the financial needs of the child or family member with special needs, allow him or her to maintain a high quality of life in your absence and ensure that the needs of the rest of your family are met. When developing this plan, there is a variety of care, financial and family issues to consider. It is important that you, and the advisor you select to assist you with developing a proper plan, consider the following:

Guardianship of the Child

- ✓ Who is best suited for the physical and emotional care of my child and can assume my role as the primary caregiver after my death or disability?
- ✓ Is one of my other children or another family member appropriate for this role?
- ✓ Should the designated guardian of my child also control the assets and property left to, or for the benefit of, that child?

Financial Considerations

- ✓ Are government programs currently being used to assist in the care of my child?
- ✓ Will government programs be used to assist in the care of my child after my death?
- ✓ If government programs are used, will my child continue to meet the “means” tests (i.e., eligibility based upon income and net worth) used to qualify for these programs?
- ✓ Is the level of care provided under government programs sufficient for the financial and physical well-being of my child?

Other Family Issues

- ✓ Are there other children in the family that are minors and what level of support will they need?

- ✓ Are there any special concerns to address with the other children in my family?
- ✓ How do I avoid the possible perception of preferential treatment towards a child?

Estate Tax Issues

- ✓ What is the expected size of my gross estate?
- ✓ What impact, if any, will potential estate taxes have on my estate and what I leave to my children?
- ✓ Is there sufficient liquidity to meet this estate tax liability and still meet the needs of my family?

Planning Considerations

- ✓ How important will it be to qualify for public assistance for the benefit of my child?
- ✓ Will what is known as a “special needs trust” be appropriate for the current situation?
- ✓ Have the needs of the rest of the family been accounted for in the planning process?
- ✓ Am I treating everyone fairly?

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funded with money or assets of the beneficiary, such as a recovery from a lawsuit or a gift/inheritance directly to the disabled individual from another family member.

When properly created, this type of Trust provides a comfortable and secure future for the child, enhancing the quality of his or her life, by providing funding for the “luxuries” in life, not covered by the government, while not affecting that person’s rights to receive the government benefits.

GUARDIANSHIP

Most people are aware that as a parent, they are also the legal guardian of their child, responsible for food, shelter, clothing, medical health and education, until the age of 18. As such, most parents name a family member or close friend as a guardian for their minor children as part of their Last Will and Testament. At the age of 18, the law recognizes your child as an adult, with full legal authority to make his or her own decisions, whether they are capable of doing so or not.

For most people, having a set of directives and their wishes known is the first and best course of action. In the case of

someone losing mental capacity (or never having that capacity in the first place), the law provides a number of options to insure that the disabled individual’s rights are protected and preserved.

For instance, in New York, the law provides two types of Guardianship Proceedings for circumstances where a Guardian, usually a parent, is appointed to manage and take care of the personal affairs and/or financial decisions of an incapable individual.

The first type of Guardianship is known as a “17A” and is done through your

County’s Surrogate Court. It is intended for mentally retarded and/or developmentally disabled individuals who have reached the age of majority and who are incapable of making their own “life” decisions. A 17A Guardianship includes the authority to make medical decisions. Once this type of Guardianship is completed, there will always be someone with the legal right to act on behalf of the special needs individual and have the authority to make such important decisions such as (1) where the disabled person should live, (2) overseeing that proper medical attention is being provided and (3) making sure that the disabled individual’s time is being spent safely and productively.

The second type of Guardianship is known as an “Article 81”, and is done in the Supreme Court. This proceeding is typically initiated by family or friends for a person who once had full mental compe-

tence, but is no longer capable of handling some or all of his/her own affairs and who have failed to take the appropriate safeguards of executing a set of advance directives (Power of Attorney, Health Care Proxy and/or Living Will). It is not uncommon to seek an Article

81 Guardianship for a young adult who suffers from mental illness or other similar infirmity. In this case, a Court Order is tailored to meet the specific needs of the incapacitated individual, while preserving as much autonomy for that individual as possible. The Guardian is only granted such powers as is necessary for the needs of the individual.

Guardianship options vary by state so families should find out what is available to them and work with an expert to determine what is best for their individual needs.



Early, careful planning can secure a disabled child’s future, long after her parents are no longer around.

A FAMILY LOVE LETTER OR LETTER OF INTENT

While it is not a legally binding document, a useful part of an estate plan is a “Family Love Letter” or “Letter of Intent.” The purpose of the letter is to reduce confusion and/or stress on family members during an otherwise traumatic time. In sum, the letter provides basic information to family and loved ones about assets and liabilities, as well as important information and personal desires upon one’s death or incapacitation. For a family with a special needs child, it is an exceptionally useful tool for conveying information about the unique needs and desires for and/or about their child.

A typical letter includes a list of important contacts, such as family doctors, attorneys, accountants, insurance/financial advisors and clergy. Many choose to include a list of their assets, liabilities and insurance and retirement plan information. It is suggested that a person’s important personal information and documentation be included, such as the location of their Will, Living Will, Trusts, Powers of Attorney, bank accounts, Citizenship and Social Security documents, as well as funeral and burial instructions.

For the family with a special needs child, inclusion of biographical, medical and educational information provides a helpful history of the child and a desired roadmap of the parent’s desires for the child’s future. Moreover, inclusion of a detailed description of personality characteristics, abilities and limitations, hobbies and interests, as well as any food, hygiene, behavioral preferences, provide a virtual user’s manual for taking care of the child. Finally, it is recommended that those persons who will/should play a significant role in the future care and development of the child, be identified in the letter. •

About the Author:

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