

Issues in Special Needs Planning

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Estate Planning - Special Needs Planning- Elder Law-Guardianship-Medicaid Planning

A Plan for Special Needs

As a parent of a child living with a disability – whether it is a physical disability, intellectual disability, developmental disability, autism or mental illness – you are well aware of your loved one’s extraordinary requirements. In his or her life to date, almost everything has needed more time, more attention and more care than you might reasonably have anticipated. It is no wonder, then, that you might not have completed planning for the next stages in your child’s life – when you are not able to oversee your child’s care.

We urge you to take time now to plan for your child’s future. This will give you peace of mind and assure that your child enjoys a life that meets his or her needs and matches his or her preferences even if you are not there as an advocate. The planning process – and it is a process – is going to take some research. It is also going to require some careful consideration of your child’s situation.

Since no two situations are the same, there is no pre-crafted solution that works for everyone. Still, three major underlying elements are common:

1) **Lifestyle** - Routine is one of the most important things in all of our lives. For individuals with special needs it is often essential, providing the stability they need to function at the highest level they can achieve. When a special needs child is under 21, he or she is typically in an

educational program, which establishes the routine. But what is going to happen when the child reaches majority? Pay particular attention to:

- **Social interaction:** If your child does well with, or even requires, social interaction, you might consider a day program or special employment. You should also consider whether simply being with others is enough or whether your child needs a sense of accomplishment.
- **Living arrangement:** Even if living alone is an option, your child might do better living in a residential facility. Consider this carefully and get to know the options in your area. It is a good idea to transition your special needs child while you are still able to visit and get a sense of how well the placement is meeting his or her needs.
- **Advocacy and emotional support:** While it is tempting to keep the planning process to yourself – after all, you have been your child’s primary advocate for all these years – there might be other members of the family or community who should be involved. This can be important from both your child’s perspective and your own. For one thing, you will not have to bear the entire burden alone. For another, this will go a long way toward ensuring that the plan is followed when you are no longer there to oversee it.

2) **Medical** – Assuring continuous access to appropriate treatment and competent, caring medical attention is a tremendous worry for most parents of special needs children. The growing costliness and complexity of our medical system have made this an even greater concern than ever before. There are steps you can take to ensure quality care on behalf of your child. We have found these five to be essential to future care planning:

- **Determine the degree to which your child has the capacity to manage his or her own person.** If your child does have this capacity, ensure that the legal documents are in place to make certain that his or her wishes are respected. These include a Power of Attorney, Health Care Proxy, HIPAA Release, and Living Will.
- **Explore whether Guardianship makes sense.** If your child does not have the capacity to manage his or her person, a guardianship might be an appropriate path (*see* pages 4-5).
- **Consider appointing an advocate.** Even if your child can manage his or her person, an advocate can be a welcome reinforcement. Any advocate should have a thorough knowledge of your child's medical needs, as well as complete caregiver information. This is done through a Power of Attorney or Guardianship.
- **Review insurance coverage.** Finance is a critical factor in the American medical system. Many insurance policies cover children with special needs even after they reach adulthood.
- **Research government benefits.** Your child might also be eligible for government benefits under Medicare, Medicaid, Social Security Disability (SSDI), Childhood Disability Benefits (CDB) and Supplemental Security Income (SSI). Medicaid and SSI will pay for placement in a group home or other facility. Many of these residences will only accept Medicaid

recipients. Keep in mind, though, that navigating the application process can be quite tricky and require some technical knowledge. Many of our clients come to us for help in matters related to this.

3) **Legal/Financial** – Budgeting and financial planning are crucial. Without them, you and your child will have fewer options in the other areas. Although your child may be employed in a special work program or receiving SSDI or SSI benefits, these monies are seldom enough to guarantee an acceptable standard of living. You should establish a trust to provide additional monetary support, while preserving your child's eligibility for means-tested benefits. Establishing a trust requires special planning, and there are many things to consider, including how it will be funded, what assets your child will receive, and who will be the beneficiary after your child's death. A trust is a critical tool for managing assets and providing flexibility. See page 3 for more information.

As you go through this process, be sure to make an honest assessment so that lifestyle, medical, financial and legal needs are met, just as you intended. Also be sure to document your decisions in a **Letter of Intent**. This document, while not legally binding, can provide a roadmap for future caregivers, detailing your child's history, preferences and needs. It can also serve as a single-source reminder for you.

Our firm would be pleased to provide you with an assessment questionnaire to help you begin to organize your tasks and goals as you begin this special planning. We would also be glad to consult with you, talking you through the issues, or speak with your family or group. Contact Frances Pantaleo at (914) 287-6113

Special Needs Trusts

A **Supplemental Needs Trust** (“SNT”), sometimes also referred to as a **Special Needs Trust**, is an important and flexible tool when you are doing long-term planning for an individual with special needs. Most commonly, SNTs are used for three things:

- To guard against the beneficiary’s inability to handle finances due to spendthrift propensity; lack of capacity to invest funds and pay expenses; or limited judgment.
- To create or protect a disabled individual’s current eligibility for government benefits.
- To lay the groundwork for a future application for government benefits.

The properly drafted SNT is not counted as income or as a resource for government benefit eligibility purposes. The trustee retains the ability to make discretionary lifetime distributions for the benefit of the disabled person. Sometimes the trust is “turned on” when the beneficiary is functioning well and “turned off” when the beneficiary is incapacitated because of an episode. In most cases, an SNT will preserve eligibility for benefits even if that is not its primary purpose.

There are three types of SNTs:

First Party SNT

This type of SNT is funded with the beneficiary’s own assets. It is created when: (1) a person receiving government benefits comes into a financial windfall through inheritance or a lawsuit settlement or (2) a person has suffered an accident or has a disability and needs to apply for government benefits. A First Party SNT can be created by the individual with disabilities (if competent to do so) or by a parent, grandparent, legal guardian or a court but the trust must be both created and funded the beneficiary reaches age 65. Upon the disabled beneficiary’s

death, the State will have the right to be paid back from any remaining funds for the cost of services provided to the trust beneficiary by the Medicaid program.

Third Party SNT

This type of SNT is used by parents or other family members to establish a nest egg for a person with a disability. It does not become an asset of the beneficiary, and allows him or her to receive the financial help without threatening eligibility for means-tested government benefits. Once the beneficiary dies, any funds remaining in this trust are not subject to the Medicaid payback provision, but may pass to other heirs designated by the trust’s creator.

Pooled Income Trust

A Pooled Income Trust allows individuals with disabilities who do not have a family member or trusted person to manage their affairs to protect their assets by pooling them with those of others in a similar situation. The assets are placed in a trust established and managed by a nonprofit organization. Funds are pooled for purposes of investment and management, but are treated as the disabled person’s separate property and held in a discrete account for his or her benefit. The funds remain available for his or her use at the discretion of the nonprofit trustee. Some Pooled Income Trusts provide special focal points, such as case management and advocacy for a fee or services for those who need special assistance. When considering this type of trust, it is essential to research the nonprofit that administers the trust to determine whether its priorities for the trust are aligned with your family member’s needs. Pooled Income Trusts are available for both first party and third party SNTs.

Regardless of the type of SNT created, it will provide flexible options for safeguarding the assets of people with disabilities, both for purposes of protecting government benefits and for providing personalized financial assistance.

Guardianship FAQ

Q. *What is the difference between the two types of guardianship that New York State law provides?*

A. The first type, **Article 17-A of the Surrogate's Court Procedure Act**, is available only to persons who are intellectually or developmentally disabled, provided the disability began before the age of 22 (except for traumatic head injuries). A 17-A guardianship is relatively simple. An application is submitted to your county Surrogate's Court and a brief hearing may be held. This type of guardianship is not always the best choice for qualifying individuals with significant assets, as investment and distribution are controlled by the court. The second path to guardianship in New York is set forth by **Article 81 of the Mental Hygiene Law**. This proceeding takes place in the county Supreme Court and follows a highly structured process including a formal petition (prepared by an attorney) and a hearing at which the individual with the disability must be present. It can take longer and cost more money to institute an Article 81 guardianship, but the guardian typically has greater freedom in investments and distributions subject to an annual court review. Of course, this is also the only option for individuals who are not intellectually or developmentally disabled.

Q. *What is the difference between guardianship of the person and guardianship of the property?*

A. A **guardian of someone's person** makes essential basic life decisions, such as where that person will live, which doctors he or she will see, what medical treatments will be administered, and what day programs or supervised work experiences he or she may participate in. However, the guardian cannot force the individual to undergo psychiatric treatment or drug or alcohol rehabilitation. A **guardian of someone's property** oversees

investment of all his or her assets as set out by the court that awarded the guardianship. Sometimes both of these types of guardians are the same person. When the person with a disability has substantial assets, the court may appoint a professional or corporation as guardian of the property.

Q. *My son is 17 and is developmentally disabled. Should I seek appointment of a guardian to ensure that he is taken care of?*

A. Appointing a guardian is a serious step. Fortunately, the guardianship can be custom tailored to provide your son with direction in the areas where he is unable to provide it himself. These typically include financial and serious medical decisions. You can limit the guardian's power to just these areas and allow your son to make his own decisions in other aspects of his life.

Q. *My 20 year old daughter is only physically disabled. Should I consider a guardianship?*

A. Probably not, because physical disability does not prevent her from making her own decisions about who should be her surrogate. Guardianship involves taking away rights from the affected individual, which the courts are reluctant to do. She should execute a Health Care Proxy, Power of Attorney, HIPAA Release, and Living Will so she can select trusted surrogates who can make substantial decisions about her treatment and her assets, if necessary. She might also consider placing her assets into her own Special Needs Trust (see "First Party SNT" on page 3).

Q. *My 35 year old sister is developmentally disabled and is employed at a special work program. Is guardianship necessary?*

A. It is a deeply personal decision in which both your sister's needs and your family's ability to advocate for her must be carefully considered. For example, changes in staffing or policy at the work program could suddenly make the situation very uncomfortable for your sister. She probably will not be able to advocate effectively for

herself and without a guardianship or some other sort of legal standing, family members may not be able to readily help her.

Q. *My daughter is 21 and has a severe eating disorder. Can I be appointed as her guardian so that I can have her hospitalized?*

A. No, except if she is a danger to herself or others. The guardianship law does not allow guardians to compel treatment. We recommend that you contact an advocacy organization for help with these issues.

Q. *Mom is getting older and is starting to show signs of dementia. She is unable to make her own medical decisions, let alone financial ones. Should I seek to be appointed as her guardian?*

A. It is possible that this approach will work for you, but many families choose a team approach which keeps the aging parent involved. This involves a Health Care Proxy, HIPAA Release and other appropriate advance directives and trusts. The directives would come into effect as soon as two doctors believe your mother is in danger. If your mother still has the capacity to issue advance directives such as these, this is probably the best route. If not, the guardianship is the secondary route.

Disability Benefits

Families typically work hard to provide for members with disabilities, but a regular income stream is vital. The government benefits profiled below are the primary sources of dependable income for persons with disabilities. All are administered by the Social Security Administration (“SSA”) and all pay monthly cash benefits.

The Definition of Disability

Before we explain the programs, it is important to note that SSA defines disability in its own particular way. Unlike the Worker’s Compensation program, SSA does not allow for partial disability. For adults, the definition is based strictly on the ability to

work (or, in legal terms, to engage in “substantial gainful activity” for 12 continuous months), while for those disabled before the age of 22, the definition centers on the inability to engage in age-appropriate activities of daily living.

Social Security Disability Insurance (SSDI) and Childhood Disability Benefits (CDB)

Who:

- Disabled workers and their dependents or heirs
- Disabled adult children or parents either deceased or currently receiving Social Security, retirement, or disability benefits. The beneficiary’s disability must have begun before age 22 (this is usually referred to as CDB benefit).

How Much:

- The monthly benefit depends on the individual’s (or parent’s) Primary Insurance Amount, following the same formula as Social Security retirement benefits. It is based on the length of time worked, the maximum Social Security wage base during the work history and the worker’s overall income.

Means Testing:

- There is no means test for SSDI or CDB.

Supplemental Security Income (SSI)

Who:

- Individuals who are disabled or blind and have limited income and few financial resources. People who receive SSI benefits also automatically receive Medicaid.

How Much:

- The monthly payment varies and increases with annual cost of living adjustments. Each state can also add supplemental income, which varies year to year. In New York, the maximum monthly benefit is calibrated to federal and state poverty

levels. In New York, the monthly stipend for 2016 is \$784 for an individual living alone. This amount may be reduced when an individual receives SSDI or CDB, or if the beneficiary receives other income or assistance with shelter.

Means Testing:

- To receive SSI, an individual must meet a rigorous means test which examines three types of income:
 - Earned (work/self-employment)
 - Unearned (annuities, interest, Social Security, alimony, rent)
 - In-Kind (food, shelter, or something used to get one those items)

This limit is redefined each year.

Resource Levels:

- The maximum allowable asset level for individuals to qualify is \$2,000.

The Application Process

Much has been written, and many urban legends circulated, about the process of applying for SSI, SSDI and CDB. Here are some valuable tips to help you navigate the application process:

- **Start off by applying.** You can obtain the application forms (and more information) online at www.ssa.gov/disability. However, the forms must be filed in original hard copy.
- **Prepare to demonstrate the disability.** SSA is very strict about this, and there are few automatic findings of disability.
- **Be ready to appeal.** According to many experts, first-time applications for disability benefits are often denied. Once you receive the first denial letter, file a Request for Reconsideration immediately. This **MUST** be done within 60 days of the original denial using a form available from SSA. If your reconsideration is denied, you have 60 days to file a Request for

Hearing. At this informal private hearing an administrative law judge will hear your case. You will want to bring new evidence or present your argument in a new way. You may even want to be represented by an attorney with experience in this area.

Conclusion

Government benefits can be important to helping your child retain a reliable income stream to meet ongoing needs and expenses. Typically, a complete financial strategy for a person with a disability should include both government benefits and a Special Needs Trust.

For assistance with exploring your family's eligibility for benefits – and with the application process – contact Frances M. Pantaleo at Bleakley Platt & Schmidt, LLP today.

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Frances M. Pantaleo is a partner at Bleakley Platt & Schmidt LLP, concentrating in the areas of Elder Law, Trust and Estates , Medicaid Planning, Special Needs Planning and legal issues affecting individuals with disabilities and their families. She is a member of the National Academy of Elder Law Attorneys and a Past Chair of the Elder Law and Special Needs Section of the New York State Bar Association and a member of its Special Needs Planning Committee. She has previously served as Chair of the Elder Law Committee of the Westchester County Bar Association and Chair of the Health and Elder Law Section of the Westchester Chapter of the Women’s Bar Association.

Ms. Pantaleo has been repeatedly recognized as a “Super Lawyer” and a “Best Lawyer” in the area of Elder Law and has been named one of the top twenty-five attorneys in Westchester County by the Super Lawyer publication. She has received an AV rating (the highest available) from Martindale-Hubbell.