

LOOKING TO THE FUTURE The Most Fundamental Issues Confronting Families With Special Needs

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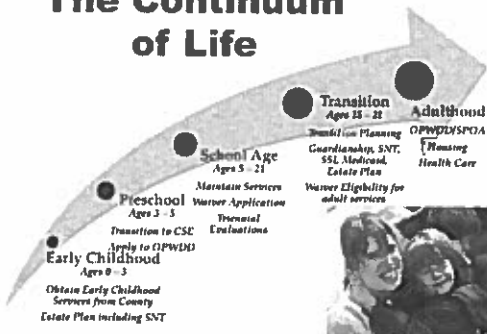
Looking towards the future . . .

Who will take care of our loved one
after we are no longer able to do so?

Will my loved one be able to maintain a decent
quality of life?

QUALITY OF LIFE CAN BE ASSURED BY PLANNING

The Continuum of Life



A. Does my loved one need a Guardian?

- (a) Can he/she make life decisions?
- (b) Can he/she make financial decisions?
- (c) Can he/she take care of his/her own money?
- (d) Can he/she make medical or dental decisions?
- (e) Can he/she live alone?

If the answer to any of these questions is No, consider having a guardian appointed.

3. In New York State, a person is considered an adult
- upon reaching the age of 18
 - whether or not they suffer from a disability.
 - decisions about health care, finances, etc. are discussed only with the individual.
 - healthcare professionals are not required to include a parent or sibling in these conversations.



B. What does a guardian do?

1. makes the kind of decisions a parent would make to insure the welfare of the disabled person.
2. makes decisions about where the individual lives, insures that he has good medical and dental care, takes care of the individual's finances and handles other medical, financial and life decisions.
3. Healthcare professionals, financial institutions and others are required to discuss the individual's affairs with a guardian.
4. Guardians should permit the individual to make as many decisions as the person can make with guidance from the guardian.

C. How does someone become a guardian?

1. By filing a special simplified proceeding for those who have intellectual and developmental disabilities called a 17A Guardianship in Surrogate's Court.
2. Certification of two doctors is required.
3. The procedure is not difficult -filing fees are minimal; It is paper intensive and technical.
4. A standby guardian and alternate standby may also be appointed

5. Fingerprint checks are required for the guardians and adults who live in the guardians household.

6. A decree and Letters of Guardianship are issued to the guardian. This document should be kept in a safe place and the guardian should take a copy of it with them when dealing with medical practitioners, etc.



Article 81 Guardianships

1. Petition is filed with the Supreme Court.
2. Full trial is held with the alleged incapacitated person in attendance.
3. No medical evidence is permitted.
4. Can be used for anyone.
5. Very expensive.

D. Guardianship for the Unexpected: What Happens if...?

1. What if a distant relative dies and leaves money directly to the handicapped person? A disabled person cannot have more than \$2000 in assets.

A guardian can set up a *special needs trust* for the funds preserving the individual's eligibility for government benefits.

2. What if the child are in a car accident or suffers some other injury?

Only a guardian can commence a lawsuit on behalf of the disabled person.

Transition to Adulthood - Age 18 & 21

- Government Benefits - Supplemental Security Income, Medicaid, Medicaid Waiver.
- IDEA and Transition Issues - What happens when the child turns 18
- Life Planning - Letter of Intent, Estate Planning and Supplemental Needs Trusts

Government Entitlements: SSI And Medicaid

•Apply for SSI at age 18 — adult services funded by Medicaid and want to maximize funding.

•\$1 of SSI qualifies you for Medicaid in Nassau/Suffolk.

•Apply the month in which the individual turns 18. Funding will begin, retroactively from award date, on the month following the month you turn 18.

Planning Starts With The Family – The Estate Plan

The Will
Advance Directives
Trusts



PITFALLS IN PLANNING

Failure to plan—analyze the family's circumstances and put a plan into effect NOW.

Leave all assets to non disabled children with verbal instructions to take of your disabled child ("The Tooth Fairy Plan").

Allowing assets to pass directly to the disabled child resulting in loss of entitlements (SSI and Medicaid).

Estate Planning For Special Needs

- Decide who gets what assets
- Create a special needs trust for assets for the disabled child
- Determine who gets SNT assets after disabled child's death

With minor exceptions, it is **CRITICAL** to have a **VALID WILL, HEALTH CARE PROXY, LIVING WILL AND EXPANDED POWER OF ATTORNEY IN PLACE** prior death.

IF YOU DIE WITHOUT A WILL....

**...AND ARE SURVIVED BY
Your Spouse only**

Everything you own will
go to your spouse

IF YOU DIE WITHOUT A WILL....

**...AND ARE SURVIVED BY
Your Spouse and
One or More Children**

Your spouse will receive \$50,000 and 1 / 2 of the rest
of your estate. Your remaining estate will be given
to your children *by representation*. No consideration is given to
special circumstances.

IF YOU DIE WITHOUT A WILL....

**...AND ARE SURVIVED BY
No Spouse but
Several Children**

Your property will be given to your
children *by representation*.
Again, no consideration is given
to special circumstances.

WHAT IS A SUPPLEMENTAL NEEDS TRUST?

OBRA 1993 and EPTL Sec 7-1.12 allows families of disabled children to create a trust to provide for supplemental needs above basic food, clothing and shelter

If properly drafted, an SNT does not affect eligibility for government benefits (SSI, Medicaid).

A trust is a contract where the grantor or creator of the trust delivers assets to a trustee to hold and use for the benefit of the beneficiary.

Third Party SNT

- Assets placed in the trust come from a third party (parent, grandparent)
- Can be testamentary, created in your will
- Can be inter vivos, created and funded during your lifetime
- Other family members can be named to receive any assets remaining after death of disabled person.
- No Medicaid pay back.
- Funding can be from any asset: life insurance, 401k, retirement plans, etc.

Medicaid Payback (Self Settled) SNT

Created by a parent, grandparent, guardian or Court with funds of the disabled person (law suit proceeds or an inheritance)

Requires Court approval where beneficiary is not competent.

Medicaid lien must be "paid back" at the death of the disabled person.

Who serves as Trustee

An age appropriate, trusted person

Has some understanding of money and investment

Competent and honest

Potential Conflicts

Pooled Trusts provide professional management, cost effective, provides long term peace of mind that your loved one will be cared for.

Pooled Trusts

- A pooled trust is a trust operated by a not-for-profit that works with individuals with disabilities
- AHRC Nassau, Life's WORC, NYSARC
- Benefits: never die
 - professional management
 - experienced in government benefits

Child Support, Alimony and Government Benefits

- Child support: deemed income to the child unless a Court allocates the amount of support between children and orders payments be made to an SNT.
- Alimony: will be deemed income unless a Court orders payment to an SNT.

Income Tax Issues

The trust is a taxable entity
It is a disability trust under IRS rules
Files a tax return
First \$3,000 of income is exempt from taxes

ABLE ACT

- o 529A Plan
- o Onset of severe disability prior to age 26
- o Maximum annual contribution is \$14,000 from all sources
- o Use to supplement private insurance, employee benefits, government benefits

ABLE ACT (cont)

- o Maximum in NYS \$100,000
- o Use for items not paid for by private insurance, government benefits, etc.
- o Never lose Medicaid, SSI suspends at \$100,000
- o Medicaid payback at death of beneficiary

REMEMBER

Planning makes all the difference –

Guardianship

Supplemental Needs Trust.

Government Benefits

Able Accounts

**See financial and legal advisors to see
which options work best for you.**

Saundra M. Gumerove, Esq., the mother of a daughter with special needs, focuses her law practice to serving those with special needs. Special education, guardianship, life planning (including special needs trusts) or government entitlements, Sandy is there to assist. Prior to opening her private practice Sandy was counsel for a money center bank and served as General Counsel for a national commercial finance company. Having practiced in the area of special needs for over twenty years, Sandy further serves the disability community as a Vice President of the Board of Nassau AHRC, a member of the NYSARC Executive Committee, Treasurer of the Brookville School for Children, and by authoring articles of interest to the disability community. Sandy often speaks on subjects of interest to the disability community.
