FUTURE PLANNING

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Introducing NYLPI

Our Mission

NEW YORK LAWYERS FOR THE PUBLIC INTEREST works to advance equality and civil rights, with a focus on disability, health, and environmental justice, through the power of community lawyering and partnerships with the private bar.

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More About NYLPI

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- **The Disability Justice Program** works to advance civil rights and ensure equality of opportunity, self-determination, and independence for people with disabilities. Our advocacy spans many areas, including housing, transportation, education, community integration, and equal access to programs and services in New York City.

- **The Environmental Justice Program** provides organizing and legal assistance to low-income neighborhoods and communities of color that bear an unfair burden of environmental threats.

- **The Health Justice Program** works to achieve equal access to health care in low-income communities of color and immigrant communities in New York City.

- **The Pro Bono Clearinghouse** maintains a network of over 80 law firms and corporate legal departments willing to volunteer their time to address the legal needs of New York's under-represented communities.

Disability Justice

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Protect and promote the civil rights of people with disabilities

Educational Rights: Ensure that children with special needs receive the educational services to which they are entitled.

Community Integration: Ensure that people with Intellectual and developmental disabilities and mental illness are integrated into the community.

Housing: Remove barriers to accessibility and other discrimination in housing for individuals with disabilities.

Access to Public and Private Buildings and Services: Eliminate barriers and other discrimination against individuals with disabilities in public and private buildings and services.

Why Plan for the Future?

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Preserve government benefits including Medicaid, Social Security Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI)

Educate individuals with IDD and their families regarding supported decision-making

Improve quality of life

Expand NOT limit choice

IDDO OMBUDSPROGRAM

The Intellectual and Developmental Disabilities Ombudsprogram (IDDO)

IDDO is a statewide, independent, ombudsman program for individuals with intellectual and developmental disabilities and their families.

IDDO helps individuals access needed services through the Office for People with Developmental Disabilities (OPWDD) and advocate for their rights.

IDDO
Intellectual and Developmental Disabilities Ombudsprogram

How to get Help:

Call the IDDO helpline:

1-800-762-9290

Monday-Friday, 9am-5pm

Visit the IDDO Website

www.iddony.org

How to Start

Understand the individual with IDD capacity & available decision-making options

- **Think about the person's needs:**
  - Medical, behavioral, social, emotional, vocational, etc.
  - Is this person capable of supporting himself/herself?
    - If the person with disabilities has a Life Plan, s/he has already gone through this process
- **Possible Actions**
  - Do nothing and hope for the best? **NO**
  - Rely on government benefits only? **NO**
- **Think about the person's assets**
  - Life insurance, pensions (401K/403B), house

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Agenda

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- Letter of Intent
- Financial Planning
  - Supplemental Needs Trust
  - 529A (Able Act)
- Assessing Decision Making Capacity
- Health Care Proxy
- Power of Attorney
- Supported Decision Making
- Surrogate Decision-Making Committee (SDMC)
- Family Health Care Decision Act (FHCDA)
- Guardianship

Letter of Intent

A Non-Legally Binding Document

- **Provides a guide to future caregivers for the person with disabilities**. You can use this letter to describe needs/wants and what is reasonably available for the person with disabilities in a number of areas: housing, education, employment, leisure activities, etc.

- The goal of a letter of intent is to memorialize your knowledge of the needs/wants of the person with disabilities so that you may guide future caregivers, guardians and trustees in providing the best possible care.

- TIPS:
  - Always review the Life Plan

Definitions Relating to Capacity

Capacity: Under New York State law, everyone who is 18 years old is presumed to have decision-making capacity.

Incapacitated Person: A person who is impaired by reason of mental illness or "mental deficiency" to the extent that s/he lacks sufficient capacity to manage her/his affairs.

Ward: A person for whom a guardian is appointed.

Guardian: A person who has been appointed by a court to make decisions on behalf of a minor or incapacitated person.

Surrogate Decision Maker: Any individual who is authorized by law, or who is in fact, making decisions for another.

The Family Health Care Decision Act (FHCDA): An act providing a process for a surrogate decision maker to make an end-of-life decision on behalf of an incapacitated person.

Evaluating Decision-Making Capacity

Explore decisions individual has made or is facing.

Balance respect for the individual's self-determination and protection of his or her well-being.

Decision-making capacity may not be determined immediately prior to an event for which a decision is required (e.g. undergoing surgery, entering into a contract, etc.) Capacity must be assessed well in advance

A person may be competent in one area and not competent in another or may not be competent to make more complex decisions in the same area.

Components of Decision-Making Capacity

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Ability to communicate a choice

Ability to understand relevant information

Ability to appreciate the nature of the situation and its likely consequences

Ability to manipulate information rationally

Steps in Decision-Making

Gathering	Gathering information
Understanding	Understanding that information
Identifying	Identifying possibilities and alternatives
Considering	Considering consequences
Weighing	Weighing the choices
Communicating	Communicating the decision to others
Implementing	Implementing the decision

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Decision Making Domains

- Living Arrangements
- Social Activities
- Work
- Training Programs
- Legal Action
- Health Care
- Personal Routine

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What Is a Trust?

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- A fund comprised of a variety of assets intended to provide benefits to an individual or organizational beneficiary. The trust is set up by a grantor. The trust can be set up while the grantor is alive (Inter-Vivos/living trust) or after the grantor passes away via a will.
- Can contain cash, stocks, bonds, property, or other types of financial assets.
- Managed by a single trustee or a group of trustees in a manner appropriate to the trust specifications.
- Usually includes some allowance for living expenses and perhaps educational expenses, such as private school or college.

  - **Grantor/Settler:** the creator of a trust whose assets are put into the trust.
  - **Trustee:** Any person or organization that holds the legal title of an asset or group of assets for another person -- the beneficiary.
  - **Beneficiary:** The individual or group of individuals for whom a trust is created.

Supplemental Needs Trust (SNT)

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An SNT is a special type of trust. The purpose of an SNT is to preserve the beneficiary's public benefits.

An SNT must have two characteristics:

- **Irrevocable:** it must be unchangeable in order for the assets to preserve eligibility for public benefits and not be considered available income

AND

- **Discretionary:** it must provide the trustee the authority to make or refuse to make distributions.

Types of SNTs:

- **First Party** (self-settled)
  - Pooled Trust
- **Third Party**

First Party SNT (Self-Settled)

Funded With the Assets of the Person With Disabilities

Self-Settled SNT

- May be desirable when an individual with special needs has assets - or expects to receive assets - that would disqualify him or her from eligibility for public benefits (*for example: an inheritance, a settlement from a lawsuit).*
- Self-settled SNT for a minor must be established by a parent, grandparent, guardian, or the court
- Every SNT must be irrevocable, that is, unchangeable in order for the assets to preserve eligibility for public benefits and not to be considered available income.
- The beneficiary must be under age 65 at the time the trust is established.
- Must contain a payback provision such that, at the beneficiary's death, the state Medicaid agency will be reimbursed.

Self-Settled SNT

Pooled SNT

- Established and managed by non-profit organizations.
- The assets in the trust are “pooled” together for investment purposes, but the non-profit agency manages a sub-account for each beneficiary.
- Established with individual’s own money or with the money of a third party on the individual’s behalf.
- Some portion of the remainder is paid back to Medicaid when the beneficiary dies, and the rest is retained by the non-profit organization.

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Third-Party SNT

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- Funded by assets that never belonged to the trust's beneficiary and are set up by a donor.
- Can be funded through a will.
- Upon the beneficiary's death, the remaining assets do NOT need to be paid to the State to reimburse for Medicaid benefits received by the beneficiary during his or her lifetime.
- **Must be:**

  Irrevocable

  AND

  Discretionary

What is a 529A Account?

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- With the Achieving a Better Life Experience (ABLE) Act, families are able to save money for future expenses in a tax-deferred 529A account, without having to give up eligibility for public benefits, as long as the funds are spent toward qualified disability-related expenses.
- Qualified expenses include education, housing, employment training and support, health care and financial management.

Contribution limits

- NY ABLE contributions must be made directly to the designated qualified program and not through an ATM or a bank branch.
- The maximum allowable contribution to a NY ABLE account is generally **$19,000 in 2025.** Once this balance is reached, no further contributions can be made until the start of the next calendar year.
- If the account balance goes over $100,000, the person with disabilities will remain eligible for ***Medicaid but not for SSI.***
  - ***To learn more about the ABLE account, please click*** 529ABLE

Decision Making Options for People with Disabilities

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Less Restrictive Options:

- *Person makes his/her own decisions*
- *Health Care Proxy*
- *Power of Attorney*
- *Supported Decision Making*

More Restrictive Options:

- *Guardianship*
- **Surrogate Decision Making**
- **Power pursuant to the Family Health Care Decision Act (FHCDA)**

Less Restrictive

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Power of Attorney

Individual must have capacity

- The Power of Attorney gives legal authority to an *Agent* or *Attorney-in-Fact* to make property, financial, and other legal decisions.
- A **springing** POA names an agent in advance but does not grant them legal authority for decision making until the principal becomes incapacitated.
- A **durable** POA, like a traditional POA, becomes effective immediately once the principal signs it. The agent obtains the legal authority to make decisions about matters detailed in the document, and maintains it, whether or not the principal ever becomes incapacitated.
  - For more information, please see TheNationalLawReview-POA

Health Care Proxy

Individual must have capacity

- The Health Care Proxy allows an individual to name a Health Care Agent who will make decisions if that individual cannot make them on his/her own.
- The Health Care Proxy only takes effect after two doctors decide a person no longer has capacity to make decisions on his/her own.
  - Hospitals, nursing homes, doctors and other health care professionals must follow the Agents' decisions as if they were the patients.
  - The individual can give a health care agent as little or as much authority as s/he wants.

Less Restrictive: Supported Decision-Making (SDM)

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- Designed to assist an individual with a disability to make, and to communicate to others, decisions about the individual's life
- Based on the understanding that all people make decisions and choices with the help of others, while recognizing that people with disabilities may need more or different kinds of help
- "Support" may include gathering information, helping people with disabilities evaluate that information or understand the consequences of a decision, communicating decisions to third parties, and supporting persons with disabilities to take responsibility for their decisions

Supported Decision-Making (SDM)

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Remainder: MHL 82.03 Presumption of Capacity

- For supported decision-making, every adult is presumed to have the capacity to enter into a supported decision-making agreement, unless that adult has a legal guardian, appointed by a court of competent jurisdiction, whose granted authority is in conflict with the proposed supported decision-making agreement. This presumption may be rebutted only by clear and convincing evidence
- Capacity includes capacity with decision-making support and/or accommodations
- A diagnosis of a developmental or other disability or condition does not constitute evidence of incapacity
- The manner in which an adult communicates with others **does not** constitute evidence of incapacity
- A decision-maker may make and execute a supported decision-making agreement, if the decision-maker understands that they are making and executing an agreement with their chosen supporters and that they are doing so voluntarily.

Supported Decision-Making (SDM)

SECTION 82.05
Mental Hygiene Law (MHY) CHAPTER 27, TITLE E, ARTICLE 82

Duties, Responsibilities, and Authority of Supporters

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A supporter must:

1. Respect the decision-maker's right to make a decision, even when the supporter disagrees with the decision or believes it is not in the decision-maker's best interests;

2. Act honestly, diligently, and in good faith;

3. Act within the scope set forth in the executed supported decision-making agreement;

4. Avoid conflicts of interest;

5. Notify the decision-maker in writing, and in a manner the decision-maker can understand, if the supporter intends to resign as a supporter; and

6. Participate in facilitation and/or education programs developed under regulations promulgated by the New York State Office for People with Developmental Disabilities in order to enter a formal supported decision-making agreement.

Supported Decision-Making (SDM)

SECTION 82.05
Mental Hygiene Law (MHY) CHAPTER 27, TITLE E, ARTICLE 82

Duties, Responsibilities, and Authority of Supporters

A supporter is prohibited from:

1. Making decisions for the decision-maker, except to the extent otherwise granted in an advance directive;

2. Exerting undue influence upon the decision-maker;

3. Physically coercing the decision-maker;

4. Without the consent of the decision-maker, obtaining information for a purpose other than assisting the decision-maker in making a decision authorized by the supported decision-making agreement;

5. Obtaining, without the consent of the decision-maker, or as expressly granted by the supported or clinical records or information; and

6. Communicating a decision-maker's decision to a third-party without the participation and presence of the decision-maker.

You can learn more about SDM at https://www.aimservicesinc.org/supported-decision-making/

Main Phone: (518) 587-3208
Email: aimservices@aimservicesinc.org
Fax: (518) 587-7236

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Brochure (second page explains SDM vs Guardianship)

- **https://www.aimservicesinc.org/wp-content/uploads/2026/03/AIM-Supported-Decision-Making-Brochure-updated-Feb-2026-FINAL.pdf**

Supported Decision-Making (SDM)

Decision-Maker & Supporter Relationship

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The relationship between a decision-maker and a supporter is one of trust and confidence and serves to preserve the decision-making authority of the decision-maker.

A supporter is prohibited from considering a surrogate or substitute decision maker for the decision-maker and does not have the authority to sign legal documents on behalf of the decision-maker or bind the decision-maker to a legal agreement. However, if the supporter is specifically authorized in the supported decision-making agreement, the supporter can co-sign legal documents with the decision-maker.

If the supported decision-making agreement specifically authorizes it, and the decision-maker signed a specific release, the supporter may assist the decision-maker in obtaining educational records under the Family Educational Rights and Privacy Act, protected health information under the Health Insurance Portability and Accountability Act , clinical records and information under the Mental Hygiene Law,, or patient information under the Public Health Law.

A supporter must keep all information obtained as part of the decision-making process confidential.

More Restrictive: Surrogate Decision-Making Committee (SDMC)

- An SDMC is an alternative to the court system for individuals who lack capacity to provide informed consent, do not have a legally-authorized decision maker to act on their behalf, and are in need of non-emergency major medical procedures non-emergency major medical treatment and end-of-life care decisions for people who qualify.
- The program consists of volunteer panels that make the decision, providing for quicker, more accessible, cost-free, and personalized decision on behalf of individuals receiving services.
- An SDMC uses specially trained volunteers to review declarations regarding a person's capacity and need for treatment and then renders a decision at a quasi-judicial hearing. Whenever possible, the person in need of treatment attends the hearing. Decisions are made within 14 days.

*If you would like to learn more about the medical decisions that are covered under SDMC, eligibility criteria, and which forms to complete when requesting a decision, please review the **SDMC Services Video** AND*

To learn more about SDMC, please check **Surrogate Decision-Making Committee Services | Justice Center for the Protection of People With Special Needs (ny.gov)**

More Restrictive: The Family Health Care Decision Act (FHCDA)

- The FHCDA establishes the authority of a patient's family member or close friend (a "surrogate") to make medical treatment decisions for the patient in the event the patient lacks capacity to make such decisions personally and did not previously make such decisions or appoint a health care agent.
- The FHCDA applies to a person over the age of 18 who is in a hospital or nursing home and who is determined by the attending physician and a second physician to unable by reason of illness to participate in making health care decisions. If the patient is deemed unable to participated in making health care decisions and does not have a Health Care Proxy, the FHCDA mandates that a surrogate be chosen in the following order: legal guardian, spouse, adult child, parent, brother/sister, close friend.
- The FHCDA Information Center is a project of the New York State Bar Association Health Law Section. It is designed as a resource for all persons - including health care professionals, health care attorneys, advocacy groups, policymakers and members of the public - who are seeking information about the FHCDA.

More Restrictive: Guardianship

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- A guardian is someone appointed by a court to make decisions on behalf of a person with a disability when that person is not capable of making decisions for himself or herself.
- A guardian can be appointed to make financial decision (known as guardian of the property) OR personal decisions (known as guardian of the person) OR both.

Types of Guardianship – Article 17-A

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This guardianship is only available for people diagnosed with intellectual disabilities or developmental disabilities. This guardianship is not individualized and gives very broad decision-making powers to the guardian.

- A Surrogates Court proceeding in the county of residence is required
- No attorney is needed
- The guardianship petition must be filed in person in the Surrogate's Court (no appointment needed)
- Forms are available from the Surrogate's Court or on-line

Types of Guardianship – Article 81

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This guardianship is Intended to be more protective of the rights of the person with a disability. It is harder to obtain, requires an attorney and extensive court proceedings, requires annual reports, and it is more expensive to pursue.

- The judicial determination is based on “clear and convincing evidence” that the individual lacks capacity.
- The court typically appoints an evaluator to conduct an investigation and provide the court with a report.
- Orders are specifically tailored so that the powers that are granted to the guardian are those that are specifically necessary to meet the needs of the person who lacks capacity.
- Any person for whom a guardianship is sought has the right to be represented by an attorney of his/her choice. Mental Hygiene Legal Services (MHLS) can be appointed to represent the person.

Is a Guardianship Appropriate?

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Reasons to Pursue

- Without a guardian, the individual may not receive appropriate services, or his/her rights may be violated.
- Health care providers may require proof of authority to consent and/or obtain information.
- There may not be any suitable alternative.

Reasons to Avoid

- It is an intrusion on the person's autonomy.
- The court also intrudes into the life of the guardian.
- There may be suitable alternatives.

Surrogate's Court Locations

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Bronx

851 Grand Concourse
Bronx, NY 10451

(718) 618-2380

http://ww2.nycourts.gov/COURTS/12jd/BRONX/Surrogates/index.shtml

Queens

8-11 Sutphin Blvd.
Queens, NY 11435

(718) 298-0500

https://ww2.nycourts.gov/courts/11jd/surrogates/index.shtml

Manhattan

31 Chambers St.

New York, NY 10007

(646) 386-5000

http://ww2.nycourts.gov/courts/1jd/surrogates/index.shtml

Brooklyn

2 Johnson St.

Brooklyn, NY 11201

(347) 404-9700

https://ww2.nycourts.gov/courts/2jd/surrogates/index.shtml

Staten Island

18 Richmond Terrace,

Staten Island, NY 10301

(718) 675-8500

https://ww2.nycourts.gov/courts/13jd/surrogates/index.shtml

Resources

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- Supplemental Needs Trust (SNT)/**TRUSTEE GUIDELINES**-Human Resources Administration-Dept. of Social Services.**TrusteeGuidelines**
- National Legal Resources Database. **Lawhelp**
- For more information about Supported Decision Making New York (SDMNY), please contact **SupportedDecision-MakingNY** - **(212-396-7747/7754)**
- Surrogate Decision-Making Committee (SDMC) **JusticeCenter/SurrogateDecisionMaking** – **(800-624-4143)**
- Family Healthcare Decisions Act Resource Center is a resource for all persons who are seeking information about the FHCDA – including health care professionals, health care attorneys, advocacy groups, policymakers and members of the public. For more information, please check **FHCDA** – **(518- 463-3200)**
- Guardianship Forms/do it yourself. **DIYGUARDIANSHIP17A**
- Office for People with Disabilities (OPWDD) is responsible for coordinating services for people with IDD. **OPWDD** – (**866-946-9733**)
- For more information about Supplemental Needs Trust (SNT) please visit **SNTResourcesOPWDD**

More Resources

NYC Councils on Developmental Disabilities were established to assist in the planning, promotion, and development of supports and services for individuals with developmental disabilities and their families throughout their lifespan. There is one in each borough. To join the councils, please check

- QueensDDCouncil (Queens)/MANHATTANDDCOUCIL (Manhattan)
- BRONXDDCOUNCIL (Bronx)/BROOKLYNDDCOUNCIL (Brooklyn)
- STATENISLANDDDCOUNCIL (Staten Island)

- New York Foundation for Senior Citizens. Serves as court-appointed guardian. NYfoundationofSeniorCitizens – **(212-962-7730)**
- The Vera Institute for Justice Guardianship Project. VeraCentersGuardianship-project – **(212-334-1300)**
- AHRC New York. Assists families in obtaining guardianships for family members. AHRCNYC – **(212-780-4491)**
- CUNY School of Law Disability & Aging Justice Clinic. Generally, receives referrals through the court. Offers a Guide to Becoming A Guardian (Article 81)Without a Lawyer. CUNY – **(718-340-4300)**
- Brooklyn Law School Disability and Civil Rights Clinic. Offers representation for alternatives to guardianship and removal of Guardianships. BROOKLYNLAW – **(718-780-7994)**
- NYS ABLE Savings Program**.** This is a saving account for individuals with disabilities administered by the State. NYSABLEACCOUNT – **(855-569-2253)**

Thank You
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धन्यवाद (dhanyavaad)
Grazie
고맙습니다 (gomabseubnida)
شكرا(Shukraan)