
17-A Guardianship and Alternatives; Considering the Rights of Individuals Under Guardianship

Kimberly Weisbeck, Esq.

Supervising Attorney, Disability Rights New York
(She/Her/Hers/Ms.)

Naomi Brickel

Project Director, SDMNY

DISABILITY RIGHTS NEW YORK

Disability Rights New York is the Statewide Protection and Advocacy System and Client Assistance Program

DRNY advocates for New Yorkers with disabilities to enable them to:

- Exercise their own life choices
- Fully participate in their communities
- Enforce their civil and legal rights

DRNY Authority

P&A's have broad access to monitor and investigate abuse and neglect, including to:

- Visit service provider sites;
- Interview service recipients;
- Interview service provider staff;
- Review individual records;
- Review records of investigations by other agencies.

The Role of DRNY

- Provide Information and Referrals to Individual Clients;
- Pursue legal, administrative, and other appropriate remedies and approaches for Individuals and Classes;
- Educate Policy Makers
- Establish Goals and Priorities;
- Coordinate and Collaborate With Other Advocacy Agencies.

My Child Is almost 18 – Now What??

- Traditional Misconceptions:
 - Guardianship Will Keep My Adult Child Safe
 - A Person Living in a Group Home Needs a Guardianship
 - Convenience of Agency
 - Desire to “Protect”
 - My Child Is Not Capable of Making Adult Decisions Alone
 - What if they get in trouble?
 - What if they need help with things like the cable or phone company?

17-A Guardianship And What It Does

- Granted By Surrogate's Court
- Plenary In Nature – Strips the Person of All Independent Decision- Making Ability and legal personhood
- Loss of Dignity and Dignity of Risk
- Often Lowers Self Esteem and Motivation To Be Independent
- Restricts Activities In Community, Makes Person Dependent On Others To Permit Community Involvement
- Restricts Choices of Services, Residential Alternatives
- Can Strain Family Relationships

What's the problem with 17-A Guardianship?

- Guardians are substitute decision makers and often undermine the independence and autonomy of persons with developmental, cognitive or intellectual disabilities
- Persons without guardians can participate more fully in both their own life and their community by regaining autonomy and being their own decision makers
- Guardianship is often far more restrictive than an individual needs
- *Assisting with defending against or removing guardianship is both personally and professionally rewarding*
 - *Client contact and relationship building*
 - *Enforcement of Constitutional rights*
 - *Interesting legal issues*

What 17-A Guardianship Cannot Do

- Control Relationships
- Control Opinions
- Control Negative Behaviors
- Keep a Person “Safe”

Do Our Clients Lose Any Rights With a Guardian?

YES. Our clients lose “decision making rights” – these rights which are lost vary by type of guardianship and by state law, but may include:

- The right to decide where they live
- The right to decide who they associate with (like your friends or family members)
- The right to marry without court intervention
- The right to have children
- The right to vote independently
- The right to decide how their money is spent
- The right to decide on their education



Image description – stick figure with bubbles that say “health care, education, insurance, housing, managing money” over its head.

Some Shortcomings of the 17-A Process

- Failure to include the individual in the process – lack of notice and full explanation of 17A guardianship (often described as someone wants to help you make decisions and protect your benefits)
- Reliance on hearsay and lack of actual hearings where the individual facing guardianship can meaningfully participate

Right to Counsel

- There is no Right to Counsel for people facing guardianship, or seeking to terminate guardianship
- Despite the personal freedoms and liberty, usually protected by the US Constitution, that are taken away when guardianship is imposed
- “Consent” to guardianship accepted despite failure to disclose meaning of guardianship
- Failure to engage person facing guardianship in the process
- Forms and do it yourself toolkits for petitioners, but not respondents

Problems in Granting Guardianship

- Reliance on certifications containing outdated information
- Some medical professionals rely on evaluations conducted by others
- Reliance on certifications that may contain private health information in violation of HIPAA
- Presence of person facing guardianship
- Explanation of guardianship
- Lack of sworn testimony

What happens after 17-A Guardianship is Granted

- Lack of reporting mechanism (clients have lost contact with guardian, CCO can't get signatures/consent, aging guardians leaving ward in unsafe conditions, or without a functioning guardian yet still living under 17A guardianship)

Alternatives to 17-A Guardianship

Supported Decision-Making

Personhood: WHAT'S AT STAKE?



“[A]t its simplest, our personhood is the consequence of all the decisions we have made over our lives. We become something or someone—a student a spouse, a professional, a parent, a beekeeper, a marathon runner, etc.—by virtue of a series of choices we make ...”

*– Kristen Booth Glenn,
University Professor and Dean Emerita,
CUNY School of Law.*

Why Supported Decision-Making?

“The principles of the present Convention shall be:

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”

– *United Nations Convention on the Rights of Persons with Disabilities
Article 3 - General Principles (principle #1)*

Article 82: Supported Decision-Making Act

§ 82.01 LEGISLATIVE FINDINGS AND PURPOSE.

THE LEGISLATURE FINDS THAT A PERSON'S RIGHT TO MAKE THEIR OWN DECISIONS IS CRITICAL TO THEIR AUTONOMY AND SELF-DETERMINATION. PEOPLE WITH INTELLECTUAL, DEVELOPMENTAL, COGNITIVE AND PSYCHOSOCIAL DISABILITIES ARE OFTEN DENIED THAT RIGHT BECAUSE OF STIGMA AND OUTDATED BELIEFS ABOUT THEIR CAPABILITY. THIS RIGHT IS DENIED, DESPITE THE REALITY THAT VERY FEW PEOPLE MAKE DECISIONS ENTIRELY ON THEIR OWN. EVERYONE USES SUPPORTS, AS DO PEOPLE WITH DISABILITIES; WHO MAY JUST NEED MORE OR DIFFERENT KINDS OF SUPPORTS.

July 2023: Article 82 of the Mental Hygiene Law

- Recognizes SDM, both informal and with an SDMA, as a less restrictive alternative that courts should consider before imposing guardianship
- Prevents discrimination by requiring third parties to accept decisions made by persons with SDMA
- Incentivizes courts/ parents to consider, and hopefully choose SDM as an alternative to guardianship

Guardianship:

The legal process by which the right and power to make decisions and enter into legal relationships is taken away from one person because of his/her alleged incapacity, and given instead to another, the Guardian

Supported Decision-Making:

“a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”

–Robert Dinerstein (2012)

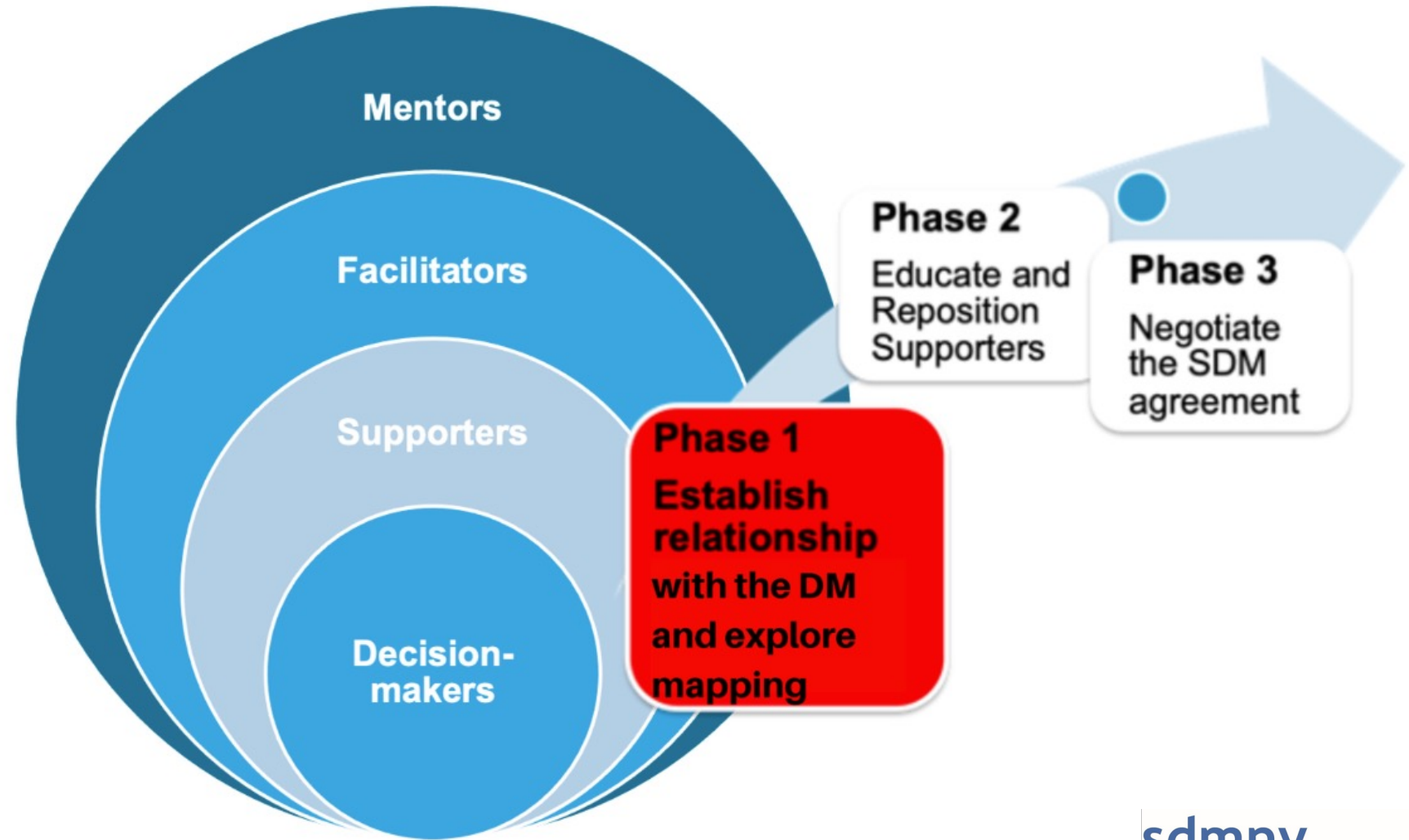
Supported Decision-Making

- Individuals with I/DD are the decision makers (DMs)
- DMs retain autonomy and civil rights. They chose:
 - What decisions they want help with
 - Who will help them make decisions (Supporters)
- The DM and Supporters work with a facilitator to develop a supported decision-making agreement (SDMA)
 - SDMA - who provides help with what types of decisions and how decisions will be made
- Participation is voluntary. Decision-maker may change or terminate the SDMA but the Supporters may not
- www.sdmny.org

Supported Decision-Making and Transition

- SDMA can be an effective part of transition from school to adulthood
- SDMA is considered a less restrictive alternative to guardianship
- SDMA creates freedom to make choices and empowerment, rather than a restriction

SDMNY Facilitation Process



For more information
Connect with SDMNY

Use the QR code to fill out "Contact Us" form— sign up for our newsletter, request more information, learn about upcoming events, or get materials to share.



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Other Supports and Alternatives to Guardianship

Article 81 Guardianship

- Granted By Supreme Court
- Provides Due Process Rights to people facing guardianship
- Thorough review of a person's functional abilities and deficits
- Tailored to meet the decision-making needs of the individual
- Expensive and seen as cost prohibitive, especially when there is a free option in 17A

What are the differences between 17a and 81?

Article 17A	Article 81
Article 17A petitions are heard in the Surrogate's Court.	Article 81 petitions are heard in the Supreme Court.
A diagnosis of intellectual or developmental disability is enough to start the guardianship process.	The petition must allege facts that the person is unable to manage their own personal or property needs.
The person with the disability has no right to participate in the guardianship hearing. In fact, there is no requirement to have a hearing at all.	The person with the disability must participate in the hearing.
Guardian gets very broad power to make all decisions, even though the person with the disability may be able to make some of their own decisions.	The court will create a tailored guardianship where the guardian only has the power to make the decisions that the person with the disability cannot make.
If the person with the disability wants the guardianship to be removed, they usually have to go to court and prove that they do not need a guardian anymore.	If the person with the disability wants the guardianship to be removed, they still have to go to court. However, the person opposing the removal of the guardianship has to prove to the court that the guardianship is still necessary.

Need Help With Money Choices?

- You and Your Supports May Benefit From:
 - Joint Bank Accounts
 - Power of Attorney
 - Able Account
 - Supplemental Needs Trust
 - Pooled Trust
 - Representative Payee

Joint Bank Account

- You and someone you choose open a bank account together.
- Both of you can put money in and take it out.
- The other person can help you keep track of your money and help with repeating payments like rent or insurance.

Power of Attorney

- This a legal document that gives someone you choose the ability to make certain decisions for you. They only have that ability for the specific types of decisions that you pick and write into the document. You can also remove this power at any time.
- Can be revoked at any time. The powers of the agent (the individual who has POA) can be very broad or very narrow. Powers can be effective now (Durable POA), or upon the happening of some future event (Springing Durable POA)

Able Account

- Earnings are tax deferred and tax free if used for qualified disability expenses (related to disability and are for the benefit of maintaining or improving their health, independence or quality of life)
- Money can be spent by debit card or check
- Account Owner can authorize someone else to make withdrawals (through POA).
- Automatic withdrawals can be set up to pay recurring bills
- Four different investment options from aggressive to conservative
- Balances under \$100,000 are excluded from the SSI resource limit
 - Medicaid eligibility continues regardless of balance
 - If the account balance exceeds SSI resource limit temporarily, SSI benefits are suspended until the balance goes down

Supplemental Needs Trust (SNT)

- The general purpose of an SNT is to enable persons with disabilities to preserve their eligibility for government benefits (primarily Medicaid and Supplemental Security Income) while also providing access to trust assets that enhance their overall quality of life and are not covered by Medicaid.
- Requirements for an SNT?
 - Beneficiary must have a disability (e.g. MI, ID/DD, other physical impairment);
 - Trust must be discretionary (trustee decides when and how much \$ to give);
 - Distribution of trust assets typically cannot impair beneficiary's eligibility for public benefits such as buying food, clothing, shelter, or health care; and
 - Trust must name a remainder beneficiary (Medicaid for First-Party SNT; Non-Profit for Pooled Trust; Anyone for Third-Party SNT).

Pooled Trust

- This is like the supplemental needs trust but an agency manages it.
- You still have your personal account, but your money is pooled together with many other people's money, so the company can manage it and make investments.

Representative Payee



- A representative payee can be a person or an organization, appointed by the Social Security Administration (SSA), whose job is to help a person with managing their social security benefits.
- The payee's main responsibility is to help pay for the individual's current and future needs (like food, shelter, clothing, dental or medical care). The payee can also help save any leftover money.
- Anyone can apply to be a rep payee, including a family member.
- The rep payee must act in the best interests of the person whose benefits they are managing. They must keep a record of expenses. A rep payee typically cannot charge for their services, unless approved by SSA.

Need Help With Medical Decisions?

- You and Your Supporters May Consider:
- HIPAA Release
- Health Care Proxy
- Family Healthcare Decisions Act
- Surrogate Decision-Making Committee
- Medical Orders For Life Sustaining Treatment (MOLST)
- Rights of Active Family Members

HIPAA RELEASE

- Written consent to access records and information – health providers (HIPAA release)
- You can fill out this form for any of doctors or medical providers. Anyone you choose to list on this form can access your medical records and talk to your doctor. You can choose a person to help you manage your medical appointments and needs without taking any of your rights to make medical choices.

Health Care Proxy

- A health care proxy is a legal document where the individual can appoint an agent to make health care decisions for themselves if they become unable to make their own decisions.
- The individual can allow their agent to make all or some of their health care decisions. The individual can also give their agent instructions that he or she has to follow.
- The agent will be able to make these decisions for the individual when a doctor determines that they are not able to make health care decisions for themselves.
- Health care proxy can be revoked at any time .
- Form can be found at:
http://www.health.state.ny.us/professionals/patients/health_care_proxy/index.htm

ACT NOW

- 2008 law which created a Simplified Health Care Proxy project.
- There was some initial activity on the project by OPWDD in consultation with MHLS and others, but it stalled.
- The idea was to have a simple form, accessible and approved by stakeholders, DOH, and OPWDD.
- The form would have an “act now” box that the individual could check, allowing an agent to make health care decisions at any time prior to the formal determination of loss of capacity by a physician.
- The “ACT NOW” only after consultation with the individual and the attending physician; if there is disagreement between the individual and their agent, the person’s decision prevails; and there must be a summary of the consultation between the doctor, the agent and the individual, in the medical record.
- There is some indication that OPWDD may be revisiting this project, which is promising.

Family Healthcare Decisions Act

- Establishes the authority of a patient's family member or close friend to make medical treatment decisions for the patient if:
 - 1. Patient lacks capacity; and
 - 2. Patient did not previously specify preference for that decision; and
 - 3. Patient did not appoint a health care agent/proxy
- If no involved family member, then the Surrogate Decision Making Committee kicks in

Surrogate Decision-Making Committee

- A committee, instead of a court, will make important, non-emergency medical choices and end of life choices for you when you are no longer able to make them yourself. This is for if you do not have an authorized surrogate or a health care proxy.
- Volunteer panels that make decisions free and quicker than court system after an informal hearing
- Unable to consent = unable to assess risks, benefits and alternatives to treatment
- Panels of app. 4 people appointed by Justice Center (doctor, lawyer, former patient or family members of people with DD and advocate)

Medical Orders for Life Sustaining Treatment (MOLST)

- Intended for end of life/critical medical situations
- The MOLST (medical orders for life sustaining treatment) are medical orders, signed by a doctors, following requirements in the Surrogates Court Procedure Act.
- This requires a finding of incapacity to make health care decisions by the attending physician, and a concurring opinion by a doctor or psychologist
- This can be completed for people with no guardian, and no health care proxy. It goes into effect immediately – not conditioned upon incapacity.

Rights of Actively Involved Family Members of People Who Live in OPWDD Operated or Certified Residences

- OPWDD Related – MHL 33 – ensuring quality of care and the rights of individuals receiving medical treatment per NYS Reg 633.11 – Medical Treatment
- Any time professional medical treatment is proposed where informed consent is required, OPWDD or the provider agency must ensure the person is given an appropriate explanation, and obtain consent from the individual or their surrogate, except for cases of emergency treatment
- If lacking capacity, informed consent must be obtained from: Guardian, OR spouse, parent, actively involved adult child, adult sibling, adult family member, informed consent committee (For COVID vaccines) or surrogate decision-making committee



Thank You! Questions?

Disability Rights New York (DRNY) is the Protection & Advocacy System and Client Assistance Program (P&A/CAP) for persons with disabilities in New York. As the P&A/CAP for New York, DRNY advocates for the civil and legal rights for New Yorkers with disabilities.

DRNY Has Offices In Albany,
Rochester and Brooklyn

Our Mailing Address:

279 Troy Road

Ste 9 PMB 236

Rensselaer, NY 12144

(518) 432-7861

(800) 993-8982 (Toll Free)

(518) 427-6561 (Fax)

Website: www.DRNY.org

Email: mail@DRNY.org

Kimberly.Weisbeck@drny.org