

sdmny

Supported Decision-Making New York

*Building Statewide Capacity for
Supported Decision-Making*

Historical Context: 17a Guardianship

- 1965 - RFK tours Willowbrook (Staten Island) refers to overpopulated institution as a “snakepit”
- 1969 - Surrogate’s Court Procedure Act, Article 17-A, allows a "surrogate" the power to appoint a "guardian" over the person and/or property of someone with an intellectual disability. The purpose was to create an easier procedure for when the individual turned 18, as they were considered "perpetual children"
- 1972 - Geraldo Willowbrook exposé

The special education inclusion movement did not gain momentum until the 80’s and 90s

- November 2024 - The New York State Bar Association report advocating for reform argues that Article 17-A is outdated, violates the constitutional rights of individuals with disabilities, and contradicts the principles of the Americans with Disabilities Act (ADA).

Guardianship Under NY State Law (courtesy DRNY)

Article 17-A	Article 81
Petitions are heard in Surrogate's Court	Petitions are heard in Supreme Court
A diagnosis of intellectual or developmental disability is enough to start guardianship process	Petition must allege facts that the person is unable to manage personal or property needs
Person with a 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 a disability must participate in the hearing.
Plenary: Guardians have very broad power to make <u>all decisions</u> .	The court must create a <u>tailored guardianship</u> where the guardian has the power to make decisions the individual cannot make.
If the person with a disability wants the guardianship removed, they have to go to court and prove they do not need a guardian.	If the person with a disability wants the guardianship removed, the party opposing removal must prove continuing need for guardian.
No regular accounting required	Guardian must submit accounting to court

Unintended Implications of Guardianship

Individuals under guardianship are **less likely** to:

- Live in their own homes
- Be involved in making choices about their lives
- Be included in their community
- Have their rights respected
- Work or plan for a job
- Have friends
- Be able to go on dates
- Be married

National Core Indicators Data Brief: Guardianship (2019)

What Is Supported Decision-Making?

“a process by which a third party (e.g., a support person (or a peer support group) assists or helps a person with the intellectual disability to make legally enforceable decisions by themselves, without substituting their decision for the person supported.”

Nandini Devi (2013)

“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)

What Is Supported Decision-Making?

- Support for autonomy vs. substitute decision-making
- Formal or informal arrangements that enable that enable an individual to make their own decisions

Where Does SDM Come From?

- Our common experience of how everyone makes decisions
- Social vs. Medical model of disability
- Human/Constitutional rights of every person to make their own decisions regardless of race, sex, disability, etc.

SDM as an alternative to Guardianship

- Support for Decisions vs. Substitute Decision-Making
- Competence = Ability + Support
- SDM allows a person to take some risks and learn from “bad” choices
- SDM helps to form a network of supporters that can protect against exploitation

SDM and Self-determination

- People with disabilities who have more self-determination are more likely to work, live independently, be involved in their community, and be safer.

Wehmeyer, M.L., & Schwartz, M. (1997)

- Young adults with disabilities who used SDM were more independent, self-confident, better at making decisions, and made better decisions

Martinis, J. & Beadnell, L. (2021)

Supported Decision-Making Can Take Many Forms

- Completely informal (so it is often invisible)
- Informal but with an oral or written Supported Decision-Making Agreement (SDMA)
- Formalized through a facilitated process that results in a written and signed SDMA (SDMNY model)
- Legalized by statute, with third parties (health care providers, financial institutions, landlords, etc.) required to accept decision made by persons with SDMAs

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.

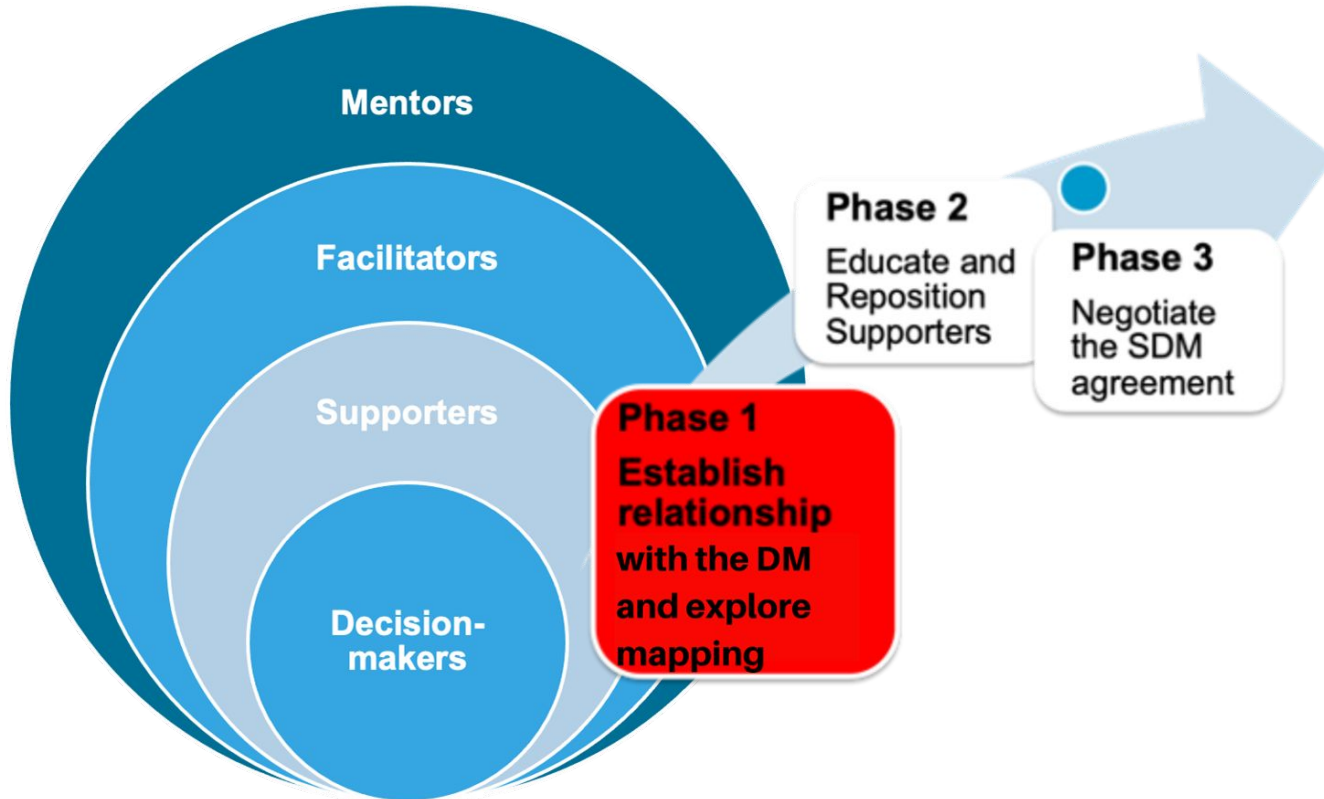
NYS Article 82 of the Mental Hygiene Law

- Recognizes SDM, both informal and with an SDMA, as a less restrictive alternative that courts should consider before imposing guardianship
- Describes formalities of an SDMA, Supporters and requirements, how to change or terminate an SDMA, etc.
- Prevents discrimination by requiring third parties to accept decisions made by persons with SDMAs
- Authorizes a specific SDM Facilitation process = SDMNY

Responsibilities of Care Management

- CCOs must ensure CMs are appropriately trained on SDM, both formal and informal
- CMs must be able to advise members about availability of SDM, provide materials/information to member and rest of team
- Make appropriate referrals to facilitation providers for interested member
- Maintain appropriate records of all members who have formal or informal SDMA
 - include copies in care management record (and EHR, where possible) and keep current

SDMNY Facilitation Process



OPWDD Implementation Pilot

- 3 year pilot funding to develop statewide capacity for SDM
- A network for Facilitation services to create legally binding SDMAs
- develop necessary infrastructure to support sustainability
- Educate stakeholders
- Ensure access from all touchpoints in OPWDD system
- Evaluate! Build a system that works.

Statewide Facilitation Network

- Providers offering SDM Facilitation under contract with SDMNY
- Staff trained through SDMNY Facilitator training
- Reimbursed hourly basis through the pilot funding
- ~30 contracts: Provider Agencies, CCO's, private bar, FI's and Broker agencies, Independent SD brokers
- 95% of Facilitation happens on Zoom

SDMNY's Statewide Facilitation Network

- Adapt Community Network (NYC)
- Westchester Institute for Human Development (WIHD)
- The Arc Westchester
- New Hope Community Services (Hudson Valley)
- ACMENY (LI)
- Independent Support Services (LI)
- AHRC Suffolk (LI)
- East End Disability Associates (LI)
- AIM Services (Capital Region)
- Parent Network of Western NY
- Advanced Care Alliance CCO
- Lifeplan CCO
- Person Centered Services CCO
- Southern Tier Connect CCO

Opportunities for Partnership:

- Facilitation Network
 - Family and SA engagement
 - Sustainability: waiver, self-direction, etc.
 - Incorporate SDM into other programming and agency operations
 - Curriculum for Transition-aged youth
 - Pilot to expand role of Care Managers in SDMA
- Follow-up

Challenges in the SDM Movement

- Awareness Issues: Many people don't know about SDM or how it works.
- System Resistance: Traditional guardianship systems often resist change.
- Legal Inconsistency: SDM laws vary by state, causing confusion and questions about interstate reciprocity.
- Resource Shortages: There aren't always enough trained supporters or resources.
- Safety Concerns: Balancing independence with safety can be challenging.

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.



sdmny.org



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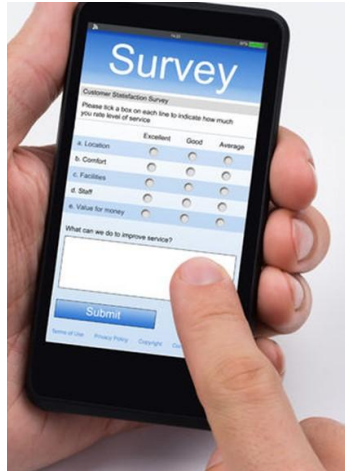


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