

New York State



*transition
partners*

September 13, 2018

1 pm – 2 pm


Learning Community

**Supported Decision-Making
as an Alternative to Guardianship**

sdmny

Supported Decision-Making New York

Hunter/CUNY | NY Alliance | DRNY | The Arc Westchester



Kristin Booth Glen, University Professor,
Dean Emerita, CUNY School of Law
Project Director, SDMNY

Partners in Transition

September 13, 2018



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



Guardianship for People with I/DD in New York; Surrogate's Court Procedure Act Article 17-A

- Removes *all* legal rights from the person with I/DD (voting, marriage, ability to contract, where to live, with whom to associate, healthcare decisions, employment, etc.)
- Plenary, not “tailored” or limited like MHL Article 81
- Continues indefinitely



Why Do Parents Seek Guardianship?

- They are told by school officials or others that it is “necessary” to get services, continue to participate in IEPs, etc.
- They see their children with I/DD as vulnerable, and believe guardianship will “protect” them



Common concerns that guardianship is thought to solve

- Ability to stay involved in educational decisions
- The “emergency room” hypothetical
- Interactions with law enforcement (both asking for help and excusing behavior)
- Issues of intimacy/sexuality (pregnancy)



Does Guardianship Really Protect?

- Lack of data/evidence from “on the ground”
- Many press stories and government reports about abuses (mostly financial)
- Not a “silver bullet”
- Little or no court oversight (none under SCPA 17-A)
- Creates conditions for isolation and possible abuse and neglect
- Inhibits self-determination and learning how to make good and healthy decisions that survive when parents are no longer around



“Protection” of Persons with Intellectual Disabilities

- 1880 to 1970, institutionalization in “schools” for the retarded
 - 1964, Willowbrook
- 1966 to present, guardianship
 - 1969, Article 17-A enacted
- 2017 and forward, supported decision-making?



Supported Decision-Making (SDM) as an alternative to Guardianship

- Persons with I/DD **never lose important rights**: e.g., to contract, to vote, to work, to marry
- 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
- Persons with I/DD have a **human right to make their own decisions**



What Is Supported Decision-Making?

- Supported decision-making (SDM) is “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 can take many forms

- Completely informal (so it is often invisible)
- Circles of support
- Formalized through a facilitated process that may involve a written agreement/contract (SDMNY model)
- Legalized by statute



Where does SDM come from?

- Our common experience of how everyone makes decisions
- The human right of every person to make her/his own decisions regardless of disability



Kinds of Support

- Gathering necessary information
- Educating the person with I/DD, the Decision Maker (DM), about that information
- Identifying possibilities and alternatives
- Aiding the DM in weighing choices and understanding consequences
- Communicating the DM's decision to others
- Helping to implement the DM's decision



And What About Human Rights?

- They give us a different, more affirmative way of looking at rights and about the place of people with disabilities in the world
- They are based in equality and non discrimination (like the *ADA*) *and*
- Dignity



Dignity: A fundamental principle of human rights

- UN Convention on the Rights of Persons with Disabilities (CRPD), Art. 3
- General Principles:
- (3) Respect for inherent dignity, individual autonomy including the *freedom to make one's own choices...*



U.N. Convention on the Rights of Persons with Disabilities (CRPD)

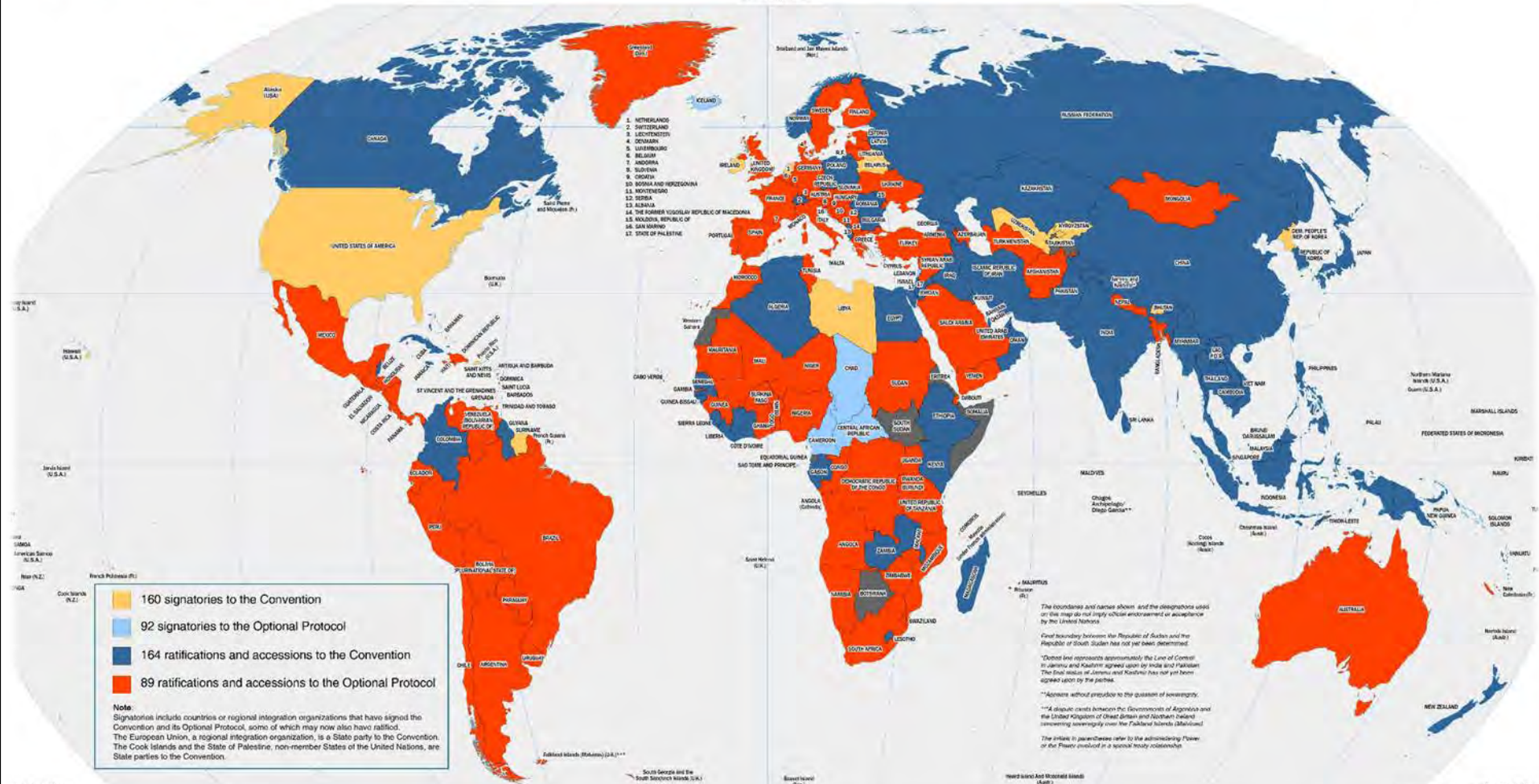
Article 12

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to **the support they may require** in exercising their legal capacity.

CRPD and Optional Protocol Signatures and Ratifications

Not Signed
 Signed Convention
 Signed Convention & Protocol
 Ratified Convention
 Ratified Convention & Protocol

As of 11 May 2016





How is SDM being implemented around the world?

- Legislation to limit or abolish guardianship and/or recognize SDM
- Pilot projects to demonstrate that SDM can empower and protect persons with I/DD

SDM Pilots Around the World



Who Supports SDM?

2018	<ul style="list-style-type: none">• Wisconsin & Washington, DC pass legislation recognizing SDMA's, Alaska awaiting Governor's signature
2017	<ul style="list-style-type: none">• American Bar Association adopts Resolution 113• Uniform Law Commission revises UGPPA• U.S. Dept. Educ. OSERS issues guidance on transition
2016	<ul style="list-style-type: none">• AAIDD & The Arc issue Joint Position Statement• Social Security Administration releases Issue Brief• National Guardianship Association issues Position Statement• Delaware passes legislation recognizing SDMA's
2015	<ul style="list-style-type: none">• Texas passes legislation recognizing SDMA's
2014	<ul style="list-style-type: none">• Administration for Community Living creates Supported Decision-Making Program

Increasingly, Judges Are Asking 17-A Petitioners to Consider SDM

Reporter

2013 NYLJ LEXIS 3334 *

Proceeding for the Appointment of a Guardian of the Person, Kings County
Akiva Pursuant to SCPA, respondent would resist
petitioners, would identify as necessary or desirable
for the Appellate Division, Second Department
Pursuant to SCPA, respondent would resist

Notice: ©

rights res
permission

(Proceeding
Akiva Pu
for the
Pursuant
11, 2013

Core T

respond
of guar
yeshiva.

disorder, travel, guardian
petitions, funds, guardian
therapeutic, rabbinical, religious
interest, second wife, cross-examination, a
diagnosed, requires, visits, guardianship

Judges: [*1] Surrogate Margarita Lopez Torres

Opinion

respondent would resist
petitioners, would identify as necessary or desirable
simply strains credulity. The respondents' father has
undertaken minimal efforts, if any, to create a
supported environment for each respondent that
adequately addresses each individual's needs and
maximizes his opportunity for growth and self-
determination. Nonetheless, the respondents have
in place a system, however "narrow" or limited, of
what might be characterized as "supported
decision-making," by which they have managed
themselves and their affairs for the entirety of their
adult lives.

It has not been demonstrated to the court's
satisfaction that either respondent is a person with a
developmental disability originating prior to the age

After a careful review of the
support of the request for the appointment of a guardian
the factors to be considered in such cases (Matter of Morris, 57
Dep't 2008), the Court has fixed at the fair and reasonable value of the legal
the guardian ad litem, which fees are directed to be
paid by the respondents' father.

This constitutes the decision and order of the court.

Date: May, 2013

Brooklyn, New York

New York Law

at Verified objections to both petitions have been
filed by the respondents' sister, Simcha (the
respondents' sister, or the sister), pursuant to which
she asserts, inter alia, that neither respondent is in
need of a guardian pursuant to Article 17-A, and, in
the alternative, that should the court determine that
the appointment of a guardian is in the best interest of



Who We Are

- SDMNY is a collaboration among Hunter/CUNY, the New York Alliance for Innovation and Inclusion, the Arc of Westchester, and Disability Rights NY (DRNY)
- SDMNY is the recipient of a 5 year grant from the NYS Developmental Disability Planning Council (DDPC) to create an educational campaign about Supported decision-Making (SDM) and to develop pilot projects to demonstrate SDM as an alternative to guardianship

Objectives of SDMNY

1. Education
2. Facilitation
 - a) *Diversion*
 - b) *Restoration*
3. Transformation





The SDMNY Diversion and Restoration Pilots

- Facilitating persons with I/DD (who we call “the Decision Maker”) to choose a person or persons with whom they have trusting relationships to support them in making decisions in specified domains (i.e. health, finances, education, residence, etc.) and to enter into a written document, the SDMA, that incorporates the terms of their agreement



Diversions and Restoration Pilots. Cont'd

- Diversion: Utilizing the facilitation process and SDMA to make guardianship unnecessary (less restrictive alternative)
- Restoration: Utilizing the facilitation process and SDMA to persuade a court that guardianship is no longer needed or in the person's "best interest"



SDMNY Facilitation Process: The Cast of Characters

- The person with I/DD who we call “the Decision-Maker” or DM
- The Facilitator
- The Mentor
- The Supporters Chosen by the DM



AT THE HEART OF SDMNY FACILITATION—THE “BIG FOUR”

- WHICH areas the DM wants to receive support (*health, finances, education, relationships, etc.*)
- WHO s/he wants to provide support in any given area (*trusted persons in her/his life*)
- WHAT kinds of support s/he wants to receive (*e.g. gathering information; explaining information, weighing pros and cons; communicating decision to third parties; implementing decision*)
- HOW s/he wants to receive the support (*logistics*)



The three phases of SDMNY facilitation

- **Phase 1:** Facilitator works with DM on how s/he makes decisions, creating a “Big Four” chart, identifying potential supporters
- **Phase 2:** Facilitator works with supporters to educate them about SDM, and to “re-position” them from making decisions for, to supporting the DM in making her/his own decisions
- **Phase 3:** Facilitator works with DM and supporters to negotiate the Supported Decision-Making Agreement (SDMA) that incorporates the “Big Four”



A required provision in every SDMA

- That the DM has the right to revoke the agreement or remove and/or add supporters for the duration of the agreement



Purpose of the SDMA

- Serves as a goal/end product for the facilitation process and signals its success
- Formalizes parties' agreement and provides a reference if misunderstandings occur
- Allows for flexibility as
 - the DM's decision-making skills and confidence increase
 - Supporters "age out" or otherwise become unavailable
 - the DM needs to make decisions in new areas
- Demonstrates that there is a clear system in place that is a "less restrictive alternative" that avoids guardianship
- Provides an evidentiary basis for passage of an SDM law in New York



Legal Effect of SDMAs

- Third parties (health care professionals, bankers, etc.) *may* accept, but SDMAs are currently not legally binding on private third parties; mandatory acceptance (as with Powers of Attorney) would need legislation; such legislation currently in place in Texas, Delaware, Washington. D.C. and Wisconsin, but not in New York
- SDMNY is working on getting acceptance by OPWDD and DOE/schools (for the latter, there is precedent in D.C. and Nevada)



But What about Protection?

- SDM creates a circle of supporters with “many eyes” to protect against abuse, exploitation or undue influence
- SDM fosters self-determination which results in being “more independent, more integrated into [the] community, better problem solvers, better employed, healthier, and better able to identify and resist abuse” National Council on Disability, Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination (2018)



The National Council on Disability Report continues

- “People with intellectual and developmental disabilities learn through the process of making decisions...It’s not about protecting someone. It’s about teaching them how to best protect themselves”

SDMNY, Today

- In New York City, we are currently facilitating over 30 Decision-Makers towards making SDMAs with their Supporters
- Last year, we began facilitating Decision-Makers in Westchester County
- Later this year, we will begin facilitating Decision-Makers in the Rochester and Capital areas, and on Long Island




**An SDMNY decision-maker
at the United Nations in
June 2017**

For Persons with Intellectual Disabilities For Parents For Attorneys For Professionals For Advocates For Staff [Select Language](#)

sdmny
Supported Decision-Making New York
Hunter/CUNY | NYSACRA | DRNY | Arc of Westchester

[Home](#) [About SDM](#) [About SDMNY](#) [Resource Library](#) [News & Events](#) [Contact Us](#)



Everyone has the right to make her or his own decisions, regardless of disability.

education facilitation transformation easy read

Supported Decision-Making New York | SDMNY is funded by the NYS Developmental Disabilities Planning Council

**For more information about SDMNY,
please visit www.sdmny.org**

And thanks for joining me today!