September 13, 2018
1 pm – 2 pm
Learning Community

Supported Decision-Making as an Alternative to Guardianship
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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.
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

- Massachusetts
- New York
- Texas
- Colombia
- Sweden
- Latvia
- Bulgaria
- Czech Republic
- Israel
- Kenya
- Australia
## Who Supports SDM?

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<tr>
<th>Year</th>
<th>Organizations and Actions</th>
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<td>2018</td>
<td>- Wisconsin &amp; Washington, DC pass legislation recognizing SDMAs, <strong>Alaska</strong> awaiting Governor’s signature</td>
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| 2017 | - **American Bar Association** adopts Resolution 113  
- Uniform Law Commission revises UGPPA  
- U.S. Dept. Educ. OSERS issues guidance on transition |
| 2016 | - AAIDD & The Arc issue Joint Position Statement  
- Social Security Administration releases Issue Brief  
- National Guardianship Association issues Position Statement  
- **Delaware** passes legislation recognizing SDMAs |
| 2015 | - **Texas** passes legislation recognizing SDMAs |
| 2014 | - **Administration for Community Living** creates Supported Decision-Making Program |
Increasingly, Judges Are Asking 17-A Petitioners to Consider SDM
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
Diversion 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.”

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
For more information about SDMNY, please visit www.sdmny.org
And thanks for joining me today!