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)
What is SDMNY?

SDMNY is a joint project by:

1. Hunter College/CUNY
2. New York Alliance for Inclusion & Innovation
3. The Arc Westchester
4. Disability Rights New York (legal arm)

SDMNY is funded by the New York State Developmental Disability Planning Council (DDPC).

Check out our website: www.sdmny.org
Guardianship in New York State

Surrogate’s Court Procedure Act, art. 17-A (1969)

- Minimal oversight
- Very limited scope for restoration

- No due process guarantees
- Best interest determination
- Diagnosis-driven
- Plenary (person / property)
SDMNY Objectives

- Education
- Facilitation
- Transformation
Education

VIDEOS, PUBLICATIONS, AND WEBINARS—OH MY!
Videos with Outside Voices
Theater Company

SDM COMICS PRESENTS:
SUPPORTERMAN VS.
THE SUBSTITUTER

Have you ever needed a little help to make a decision?

ONE SIZE DOES NOT FIT ALL
Legal & Other Publications
Awareness-Raising

94+ events reaching 4,274+ people:
- Information sessions
- Trainings
- Webinars
- Podcasts
- Conferences
- Symposia

6,341+ unique web visitors
Facilitation

TRAINING, DIVERSION & RESTORATION
Designing the SDMNY Facilitation Model

- Built on lessons from Massachusetts, South Australia, Bulgaria, Israel, and beyond
- Focuses on process (facilitation), not just end result (SDMA)
- Participants = “Decision-Makers”
- Decision-Makers choose SDMNY; we don’t choose them
- Includes Decision-Makers with and without guardians
- Designed not to provide decision-making support
- Emphasizes decision-making areas, not goals – the “Big 4”!
- Facilitators don’t necessarily know their Decision-Makers
Defining Facilitation

We have a 100-page manual!

What it is not...
- Managing
- Problem-solving
- Counseling
- Giving direct support
- Mediating

What it is...
- Providing structure where needed
- Avoiding goalspeak
- Creating space for reflection and discussion
Designing the SDMA

Surveyed 14+ other templates → Built on the “Big 4” → Tailored to the New York State context

Addenda:
 Process overview plus Attestation, Revocation & Modification forms

Presented to self-advocate focus group → Consulted with Advisory Council members
SUPPORTED DECISION-MAKING AGREEMENT

OF

[INSERT YOUR NAME HERE!]

This Agreement was made under the supervision of Supported Decision-Making New York (SDMNY), a project funded by the New York State Developmental Disabilities Planning Council (DDPC). (See “Attachment A.”) The undersigned “Decision-Maker” and “Supporter(s)” have completed a professionally evaluated facilitation process that began on [INSERT DATE] and concluded with the signing of this Agreement. A facilitator trained and supervised by SDMNY assisted the parties in negotiating and fully understanding the terms of this Agreement.

This Agreement must be read out loud or otherwise communicated to all parties to the Agreement. The form of communication shall be appropriate to the needs and preferences of the Decision-Maker.
Notice to the Decision-Maker

“Your Supported Decision Making Agreement is an important document. It lets you choose people you trust to help you make decisions in the areas where you want support.

“This document describes how you get support to make decisions. It also lets others know that these are the ways you want your Supporters to help you. It lets others know you want them to respect your decisions, too. And it lets others know the ways in which you make decisions.”

“By signing this document, you agree to the following (make your mark below):

- I have freely completed the SDMNY facilitation process.
- I want Supporters to help me make decisions.
- My Supporters cannot make decisions for me.
- I can end this Agreement at any time.
- I can change this Agreement at any time.
- I can change my Supporters at any time.
- My Supporters can quit or resign at any time.
- I will let my Supporters know about major changes I make to this Agreement and get their agreement on the changes, if needed.
- If needed, I will tell others about my Agreement and any major changes I make to it.
- Only I am responsible for my decisions, even if I receive support in making those decisions.”
The Decision-Maker’s Path to a Supported Decision-Making Agreement

A. ONBOARDING

Outreach
Follow-up
Sign-up
Assignment

B. FACILITATION

Phase 1
- Establish rapport
- Complete the "Big Four" Chart
- Preview SDMA template

Phase 2
- Invite Supporters
- Educate & re-position Supporters

Phase 3
- Present the "Big Four" Chart to Supporters
- Revise the "Big Four" Chart with Supporters

C. AGREEMENT

SDMA Drafting & Review
- SDMA Revision
- SDMA Approval by Parties
- SDMA Signing Ceremony

sdmny
Supported Decision-Making New York
Hunter/CUNY | NY Alliance | DRNY | The Arc Westchester

NEW YORK STATE
Developmental Disabilities Planning Council
Getting Started

Outreach  Follow-up  Sign up  Assignment
Who are the Facilitators?

- Transition coordinators & special educators
- Guardianship coordinators & Service provider staff
- Mediators & Community volunteers
- Occupational therapists
- Parents, Siblings & Peers
- Social workers
- Parents, Siblings & Peers
- Social workers
Phase 1

Facilitators help DMs explore the “Big 4”! They are:

1. **the areas** in which you want to make your own decisions
2. **who** you want help or support from to make those decisions
3. **what kinds** of support you want from your Supporters
4. **how** you want to use Supporter(s) for to make your own decisions
Phase 2

Facilitators help DMs to invite Supporters to be on their support teams and also “re-position” them.
Phase 3

Facilitators help DMs and their Supporters “negotiate” the SDMA based on DMs’ Big 4.
# Role of the Mentor

## Administrative
- Ensure meetings happen
- Confirm stage of process

## Programmatic
- Review and help draft SDMAs
- Provide ongoing support for facilitator

## Professional development
- Build facilitator’s capacity and skill set
- Impart knowledge and share experience

## Model fidelity
- Ensure Facilitators follow the SDMNY model
## Crafting the SDMA

<table>
<thead>
<tr>
<th>Customizing areas</th>
<th>“support for bi-romantic, non-sexual relationships”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying sub-areas</td>
<td>“everyday banking transactions” vs. “large financial transactions and all financial contracts”</td>
</tr>
<tr>
<td>Anticipating areas</td>
<td>“future housing decisions”</td>
</tr>
<tr>
<td>Limiting Supporters’ roles</td>
<td>limiting a “health” Supporter to “helping me to understand information”</td>
</tr>
</tbody>
</table>
SDMA Signing Ceremony

Supporters make this promise:

“I agree to provide support in accordance with the Agreement and not act as a substitute decision-maker. In this role, I agree to avoid conflicts of interest and not to exert undue influence.”
What the SDM Process Has Meant for Me
What the SDM Process Has Meant for Me

sdmny
Supported Decision-Making New York
Hunter/CUNY | NY Alliance | DRNY | The Arc Westchester

SDMA Signing Ceremony
Ketrina Hazell, Harvey Pacht, & Tony Philips
December 17th 2018
SDMA Users Focus Group
By End of Year 3

**Recruitment Numbers**

<table>
<thead>
<tr>
<th>Expansion Sites</th>
<th>New York City</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>5</td>
</tr>
<tr>
<td>Year 2</td>
<td>10</td>
</tr>
<tr>
<td>Year 3</td>
<td>30</td>
</tr>
</tbody>
</table>

**Facilitation Progress**

- **New York City**
  - Phase 1: 30
  - Phase 2: 5
  - Phase 3: 0
  - SDMAs: 0

- **Expansion Sites**
  - Phase 1: 10
  - Phase 2: 0
  - Phase 3: 0
  - SDMAs: 0
5 Pilot Program Sites

- Rochester: 8
- Albany: 3
- Westchester: 5
- New York City: 33
- Long Island: 4
“I believe that SDMNY has helped my self-esteem and strengthened my relationships with those around me.”

- Decision-Maker
“I feel very fortunate to have been introduced to SDMNY just as my family was facing decisions on guardianship for our 18-year-old son. SDMNY has been incredibly path-changing opportunity to us.”

- Parent
What People Are Saying...

“I find it more empowering than self-direction. ... I’m enjoying the Dickens out of it, probably more than my Decision-Maker. ... Self-direction starts with person-centered planning—it’s a forward-looking plan that focuses on the logistics of providing services, staff, etc. ... SDM takes a really detailed accounting of the decisions in your life and gets into the specific types of assistance a Decision-Maker wants.”

- Facilitator
Lessons Learned

- It’s hard to swim upstream!
- It’s hard to avoid goalspeak and focus on decision-making
- Facilitation takes time
- Beyond traditional disability service provision
- Process *plus* SDMA
- It takes a village
- Providing supports post SDMA
Big Questions

What to do when a Decision-Maker has no supporters?

How to reach folks living in restrictive settings?

How to ensure SDM is not “just another program”?

How to build SDM into existing services?