sdmny

Supported Decision-Making New York

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

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)**

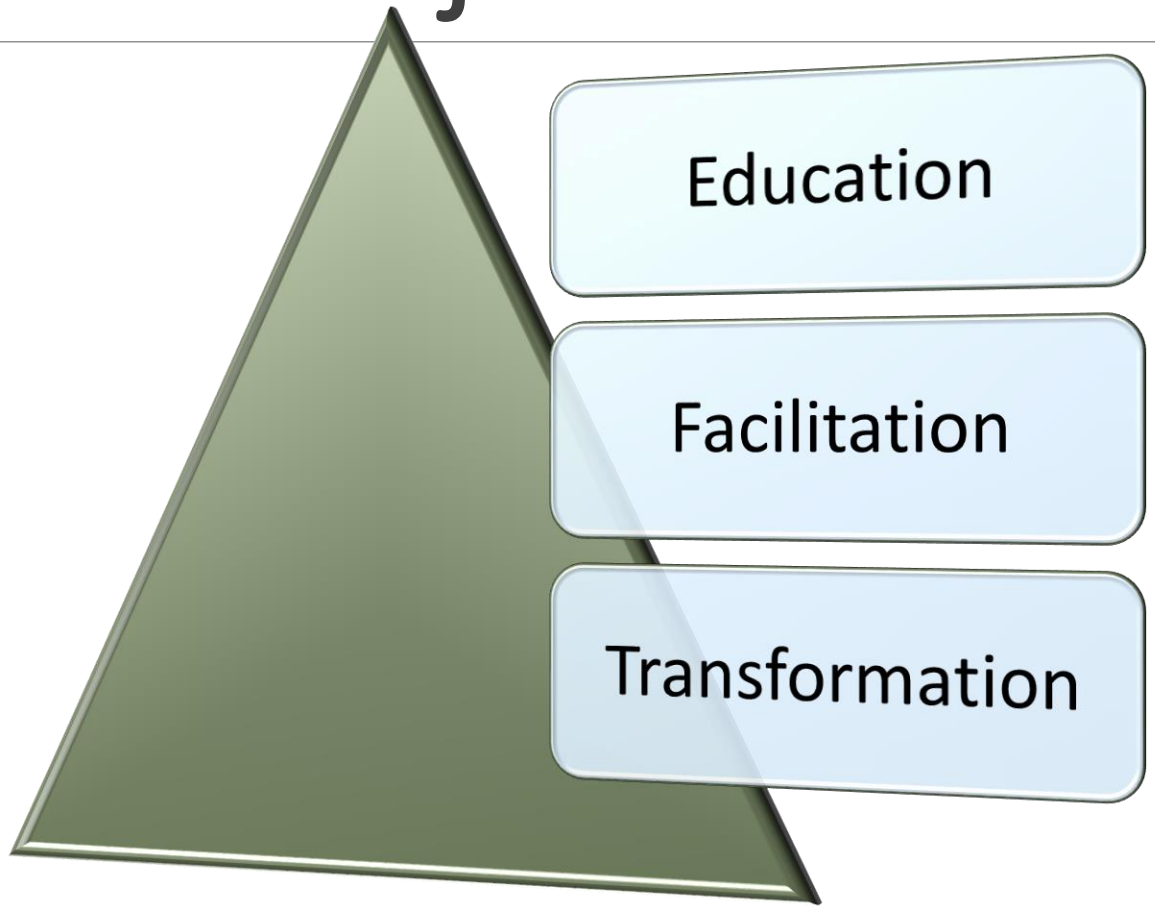
SDMNY is funded by the New York State Developmental Disability Planning Council (DDPC).

Check out our website: www.sdmny.org

Guardianship in New York State

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

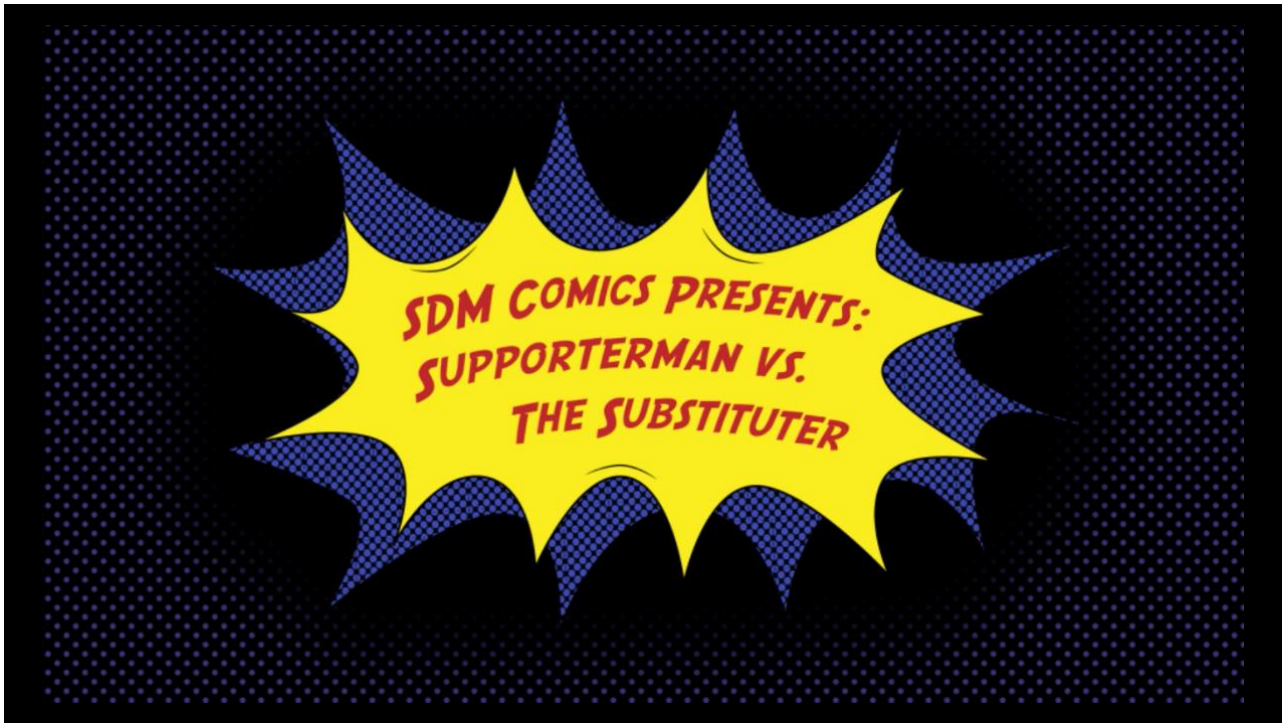
SDMNY Objectives



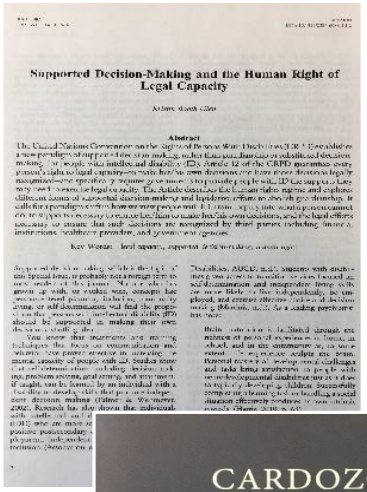
Education

VIDEOS, PUBLICATIONS, AND WEBINARS—OH MY!

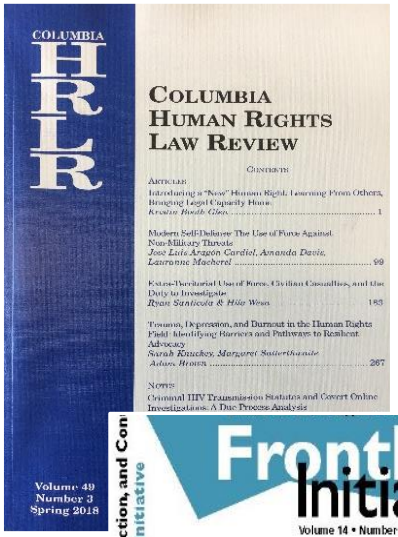
Videos with Outside Voices Theater Company

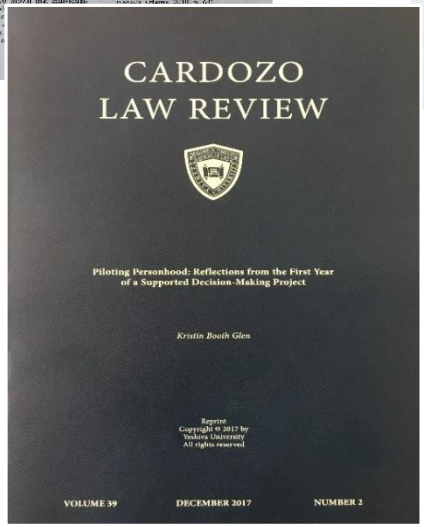


Legal & Other Publications


Supported Decision-Making and the Human Right of Legal Capacity

Abstract





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

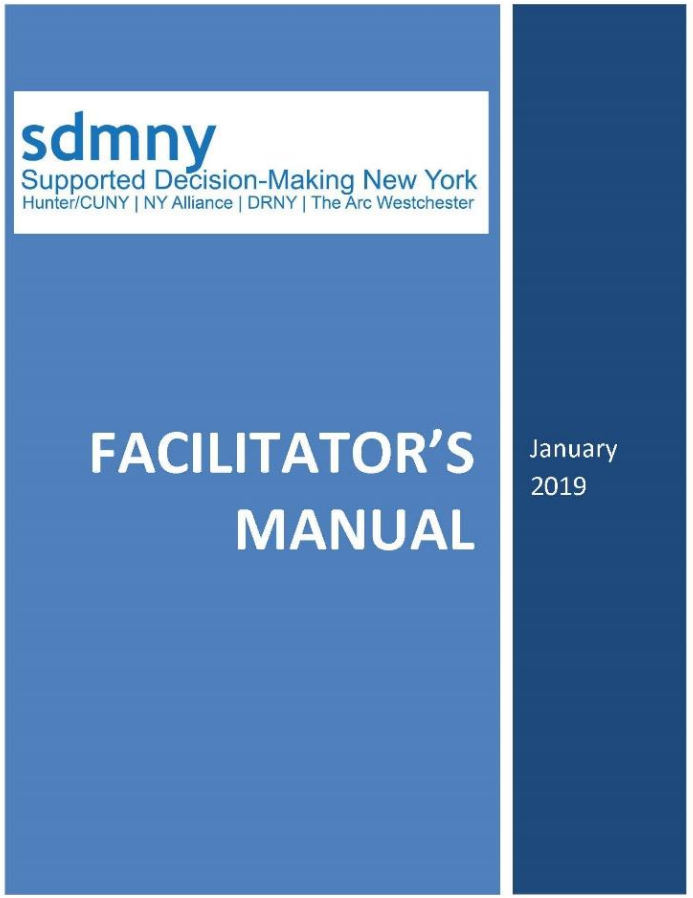
We have a 100-page manual!

What it is not…

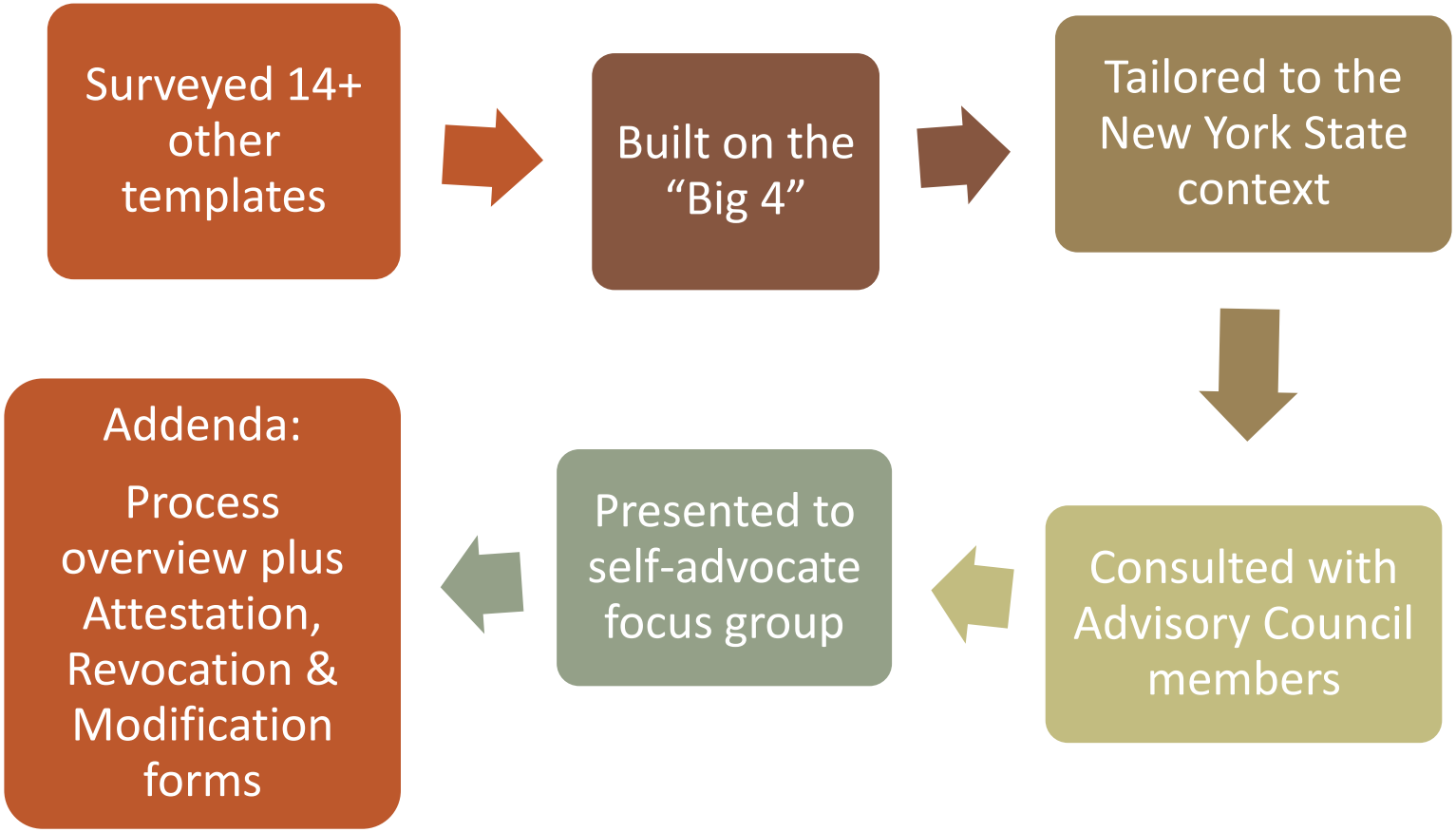
- Managing
- Problem-solving
- Counseling
- Giving direct support
- Mediating

What it is…

- Providing structure where needed
- Avoiding goalspeak
- Creating space for reflection and discussion



Designing the SDMA



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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.

(1) 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."

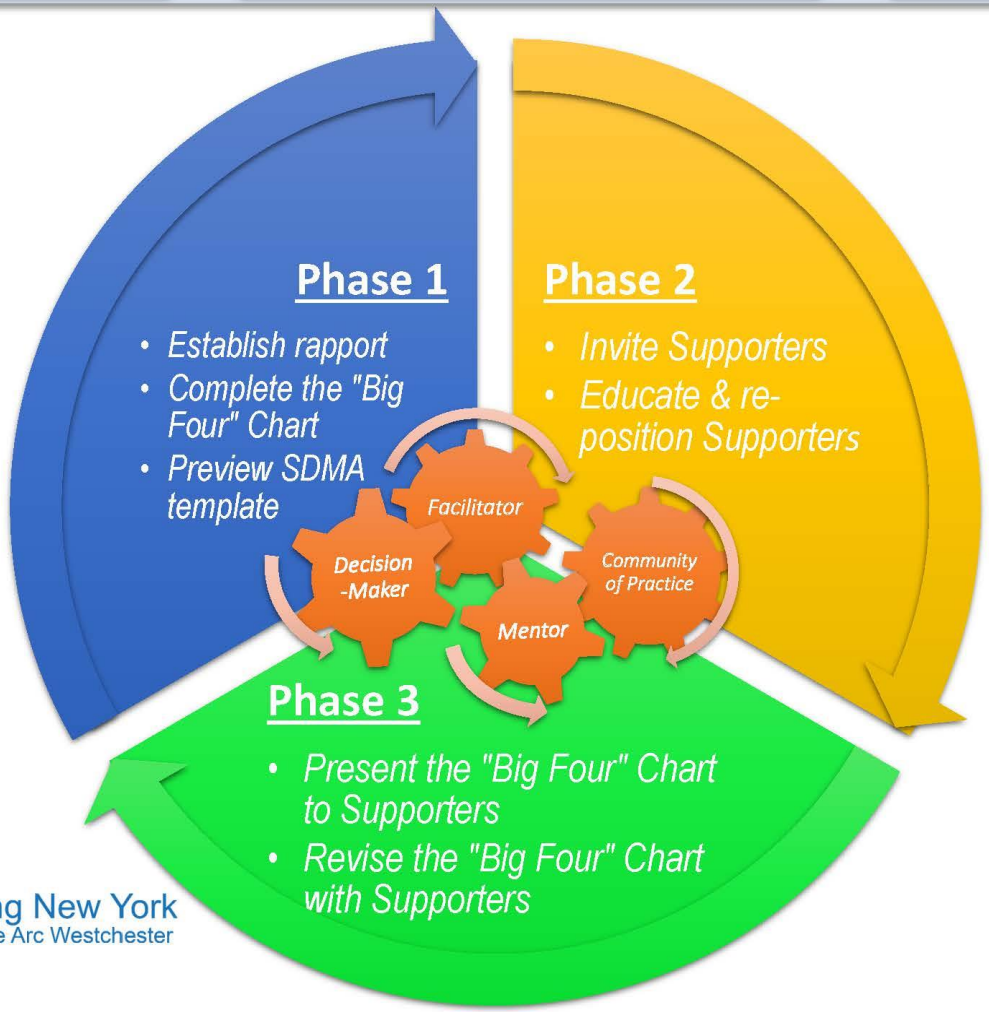
The Decision-Maker's Path to a Supported Decision-Making Agreement

A. ONBOARDING | **B. FACILITATION** | **C. AGREEMENT**

A. ONBOARDING

- Outreach
- Follow-up
- Sign-up
- Assignment

B. FACILITATION



C. AGREEMENT

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

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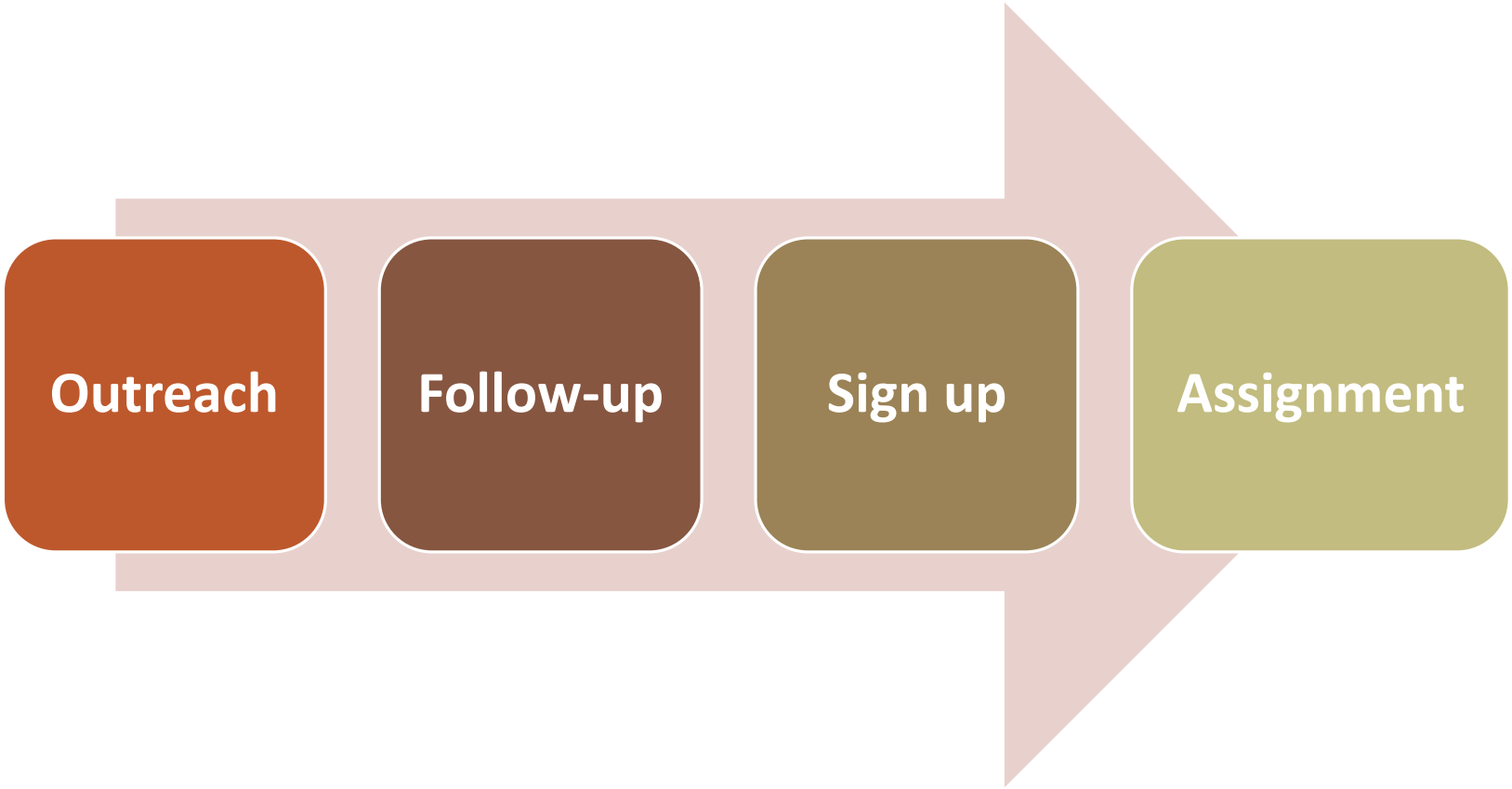
NEW YORK STATE Developmental Disabilities Planning Council

Getting Started



Who are the Facilitators?

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

Name: _____ **Big Four Chart** Date: _____

Which **decision-making areas do you want to work on?**	***Who*** **will support you?**	***What*** **types of support do you want?**
Health		☐ Gather information ☐ Help understand information ☐ Identify possibilities and alternatives ☐ Help weigh options ☐ Help understand consequences ☐ Communicate decisions to others ☐ Help implement decisions
Work		☐ Gather information ☐ Help understand information ☐ Identify possibilities and alternatives ☐ Help weigh options ☐ Help understand consequences ☐ Communicate decisions to others ☐ Help implement decisions
Money		☐ Gather information ☐ Help understand information ☐ Identify possibilities and alternatives ☐ Help weigh options ☐ Help understand consequences ☐ Communicate decisions to others ☐ Help implement decisions
Education		☐ Gather information ☐ Help understand information ☐ Identify possibilities and alternatives ☐ Help weigh options ☐ Help understand consequences ☐ Communicate decisions to others ☐ Help implement 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	Programmatic	Professional development	Model fidelity
• Ensure meetings happen • Confirm stage of process	• Review and help draft SDMAs • Provide on-going support for facilitator	• Build facilitator's capacity and skill set • Impart knowledge and share experience	• Ensure Facilitators follow the SDMNY model

Crafting the SDMA

Customizing areas	• “support for bi-romantic, non-sexual relationships”
Identifying sub-areas	• “everyday banking transactions” vs. “large financial transactions and all financial contracts”
Anticipating areas	• “future housing decisions”
Limiting Supporters’ roles	• limiting a “health” Supporter to “helping me to understand information”

SDMA Signing Ceremony

Supporters make this promise:

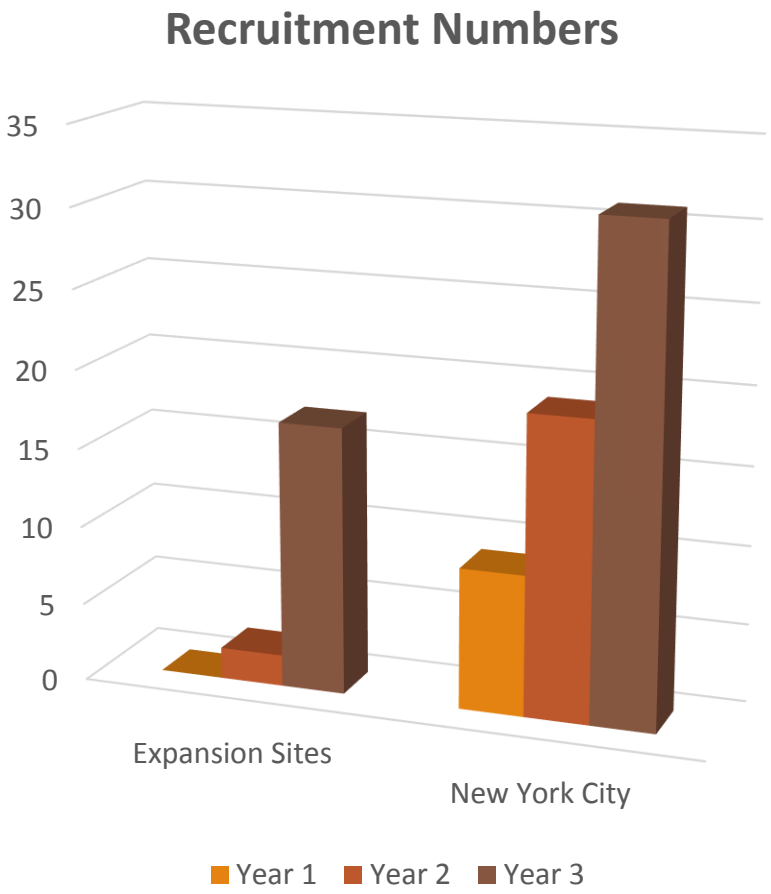
"I agree to provide support in accordance with the Agreement and not act as a substitute decision-maker. In this role, I agree to avoid conflicts of interest and not to exert undue influence."

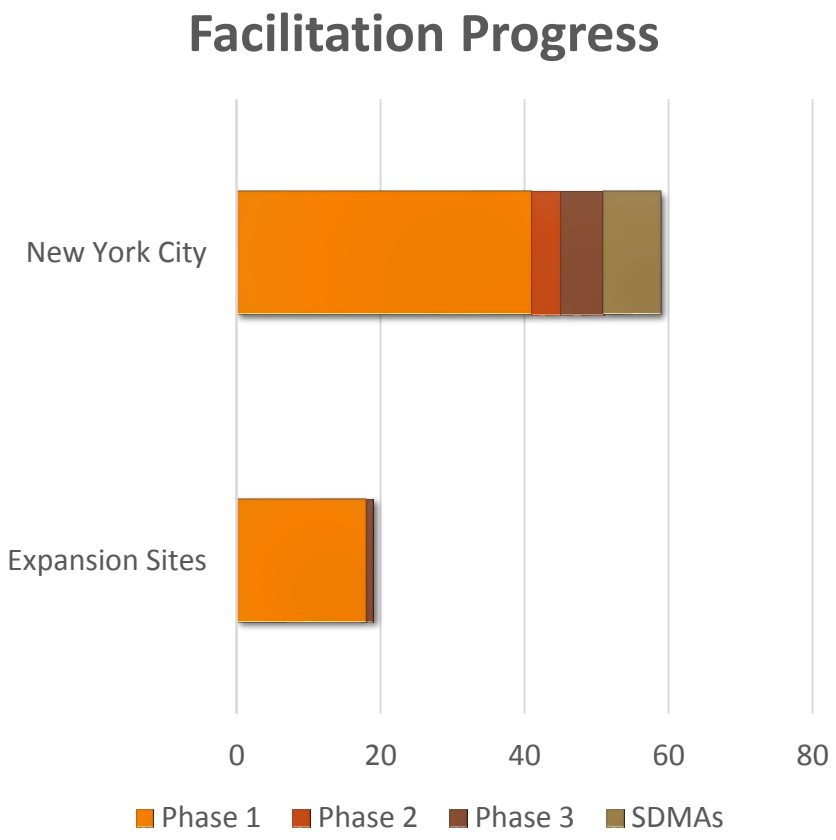
What the SDM Process Has Meant for Me

What the SDM Process Has Meant for Me

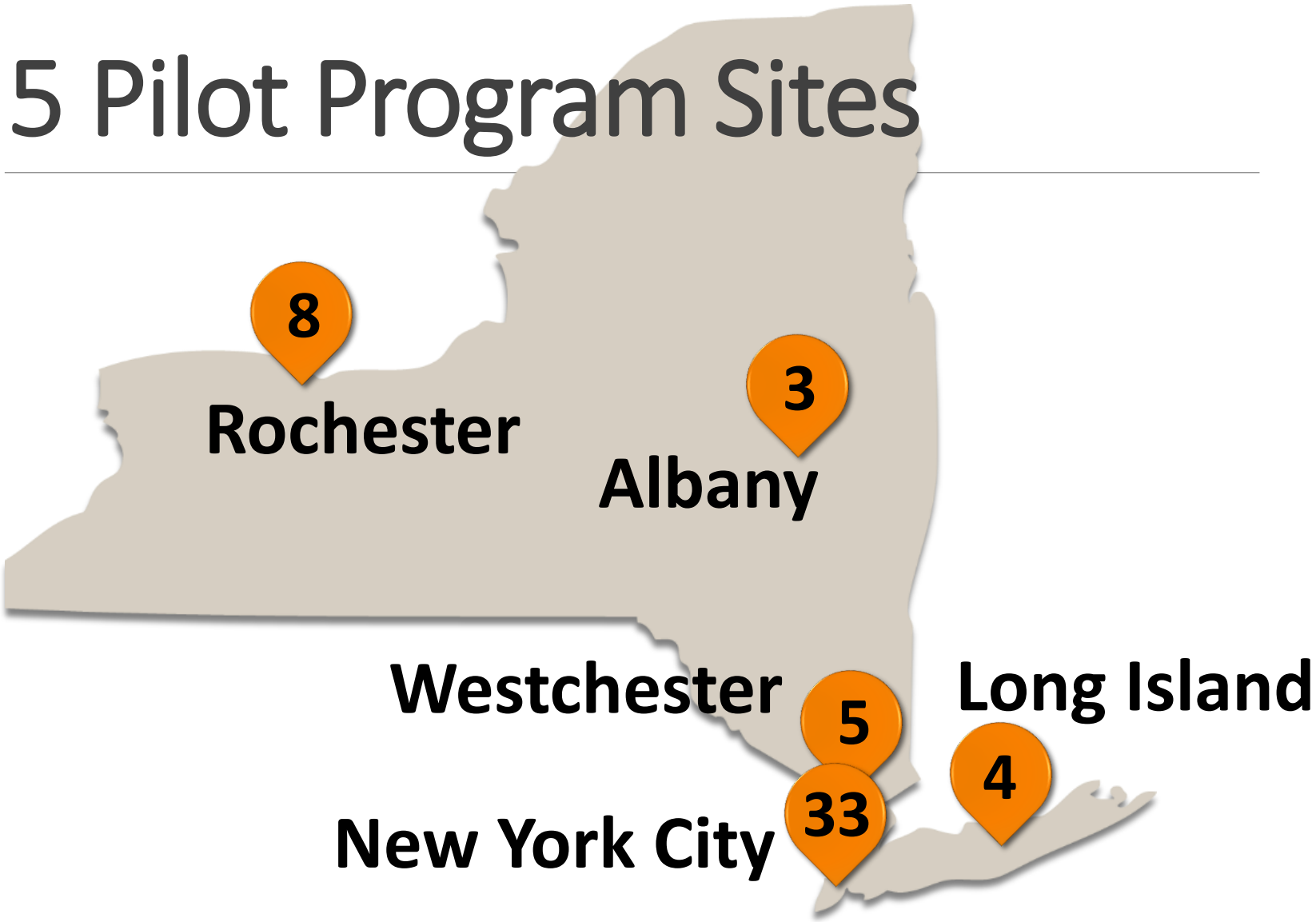
SDMA Users Focus Group

By End of Year 3





5 Pilot Program Sites



What People Are Saying…

"I believe that SDMNY has helped my self-esteem and strengthened my relationships with those around me."

- Decision-Maker

What People Are Saying…

"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."

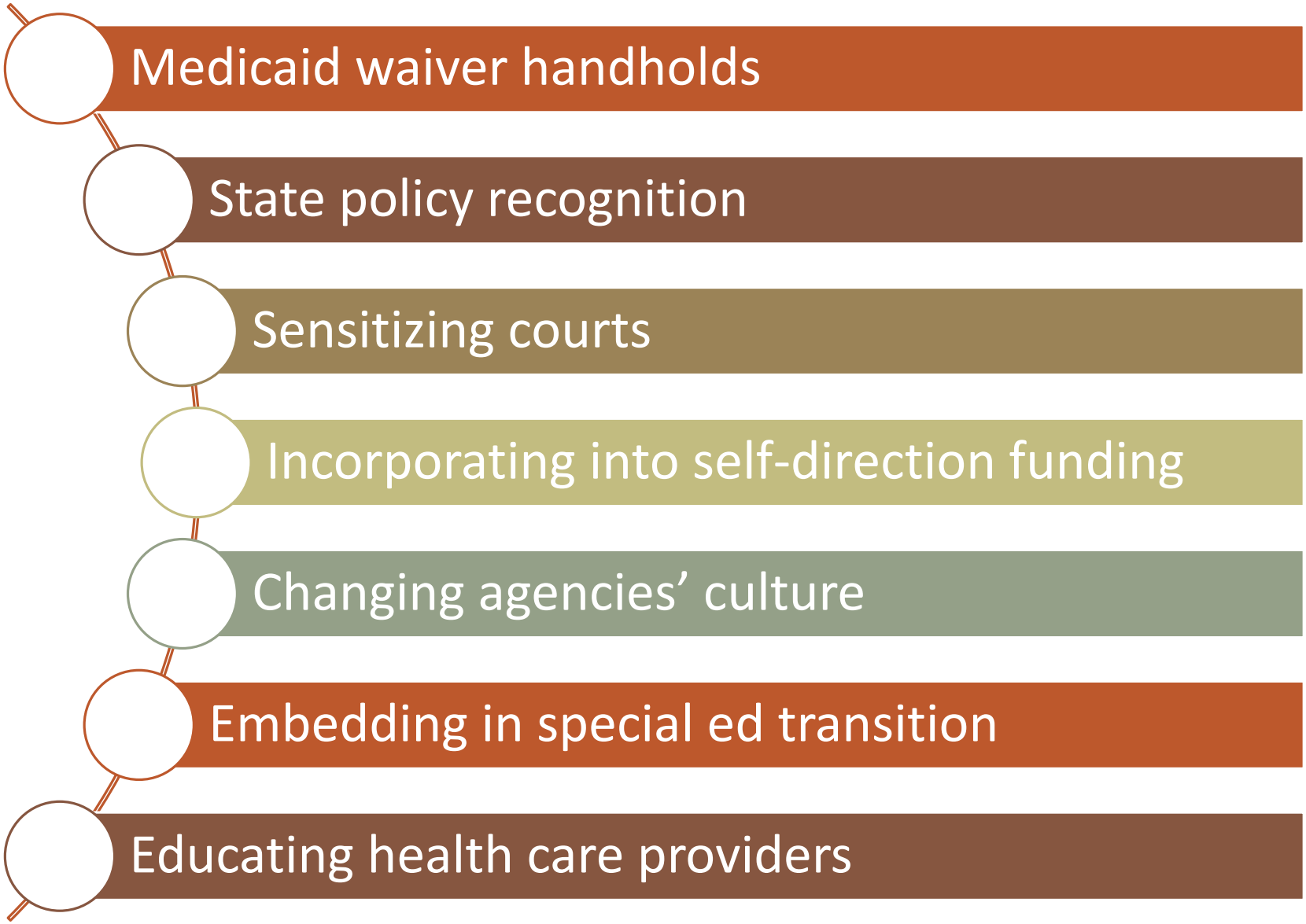
- Parent

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

Transformation

LAWS, POLICIES & PRACTICES


Medicaid waiver handholds
State policy recognition
Sensitizing courts
Incorporating into self-direction funding
Changing agencies' culture
Embedding in special ed transition
Educating health care providers

Lessons Learned

It's hard to swim upstream!

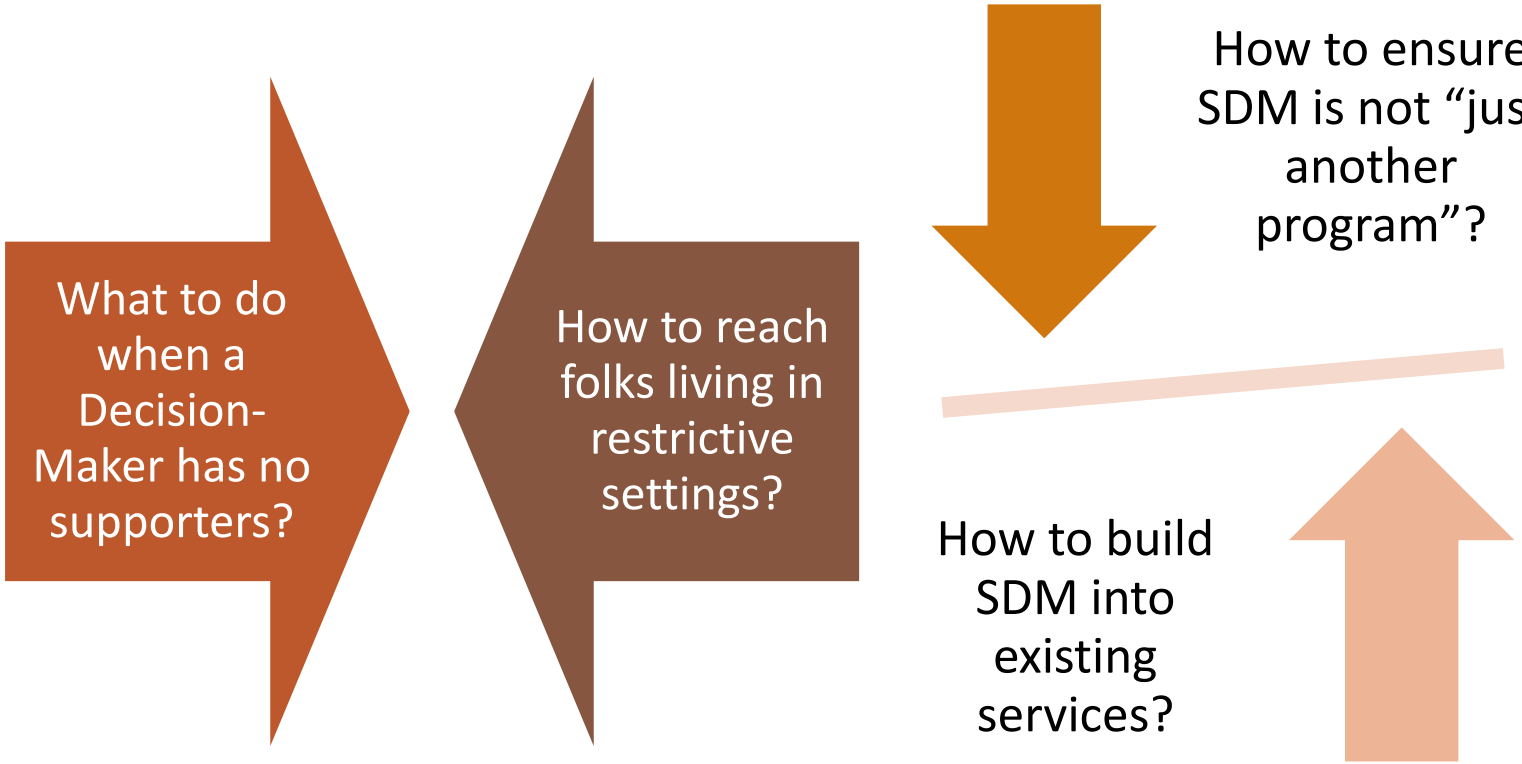
It's hard to avoid goalspeak and focus on decision-making

Facilitation takes time

Beyond traditional disability service provision

Process ***plus*** SDMA

It takes a village

Providing supports post SDMA

Big Questions