

Supported Decision-Making: An Alternative to Guardianship

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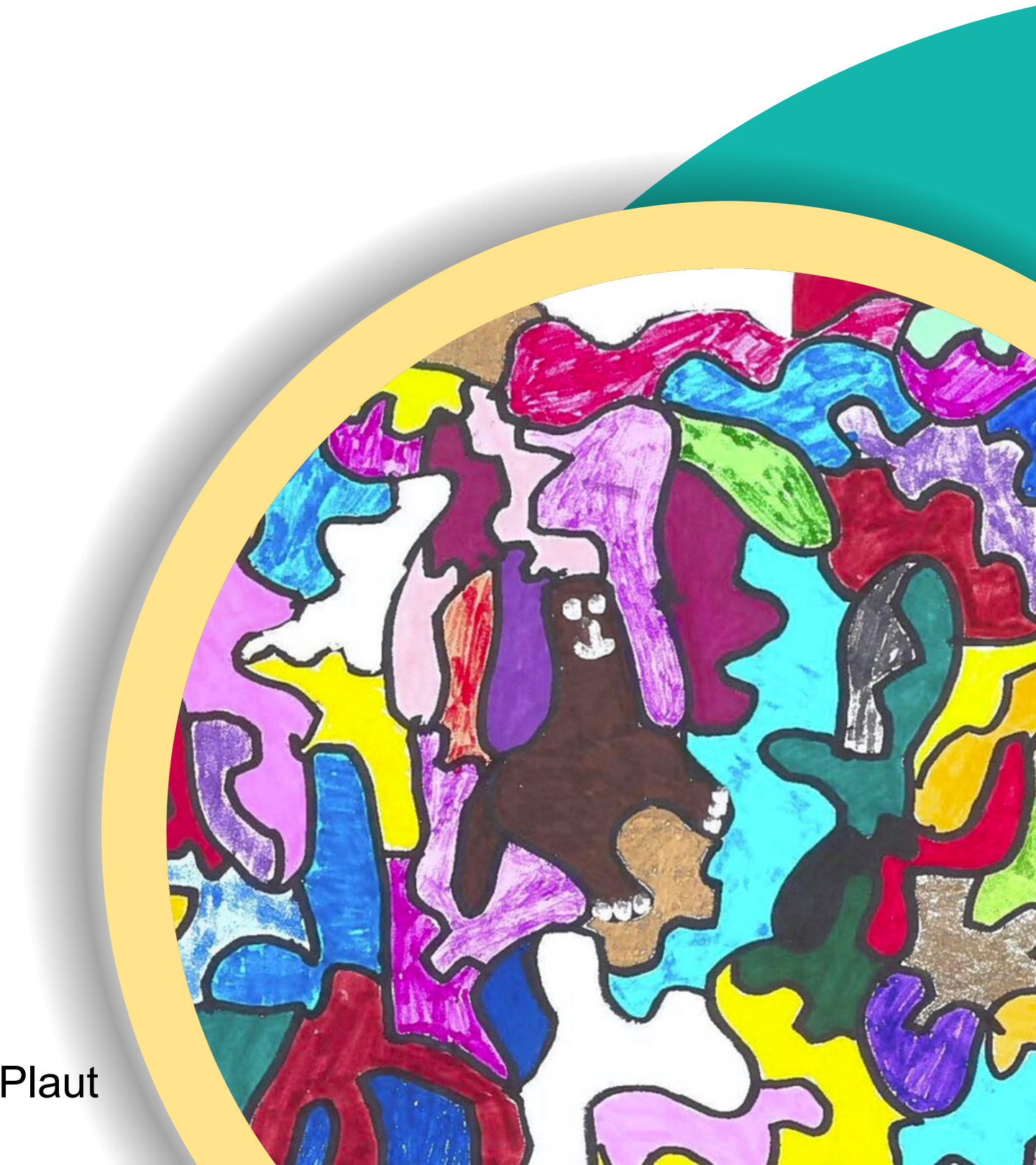
Jennifer Ivery, Senior Mentor, SDMNY

sdmny
Supported Decision-Making New York



Overview

- SDMNY Timeline from 2016-2025
- SDM vs. Guardianship: a human rights lens
- What is Supported Decision-Making?
- SDMNY's Process
- The Future of SDM in NYS



SDMNY from 2016-2025

- **2016-2021:** 5-year pilot funded by the NYS Developmental Disabilities Council (DDPC)
- **2021-2022:** pandemic “bridge” year funded by the Ford Foundation, the FAR Fund, and the Taft Foundation
- **2022-2025:** OPWDD grant: design and implement a sustainable SDMNY facilitation and service delivery system throughout NYS



Goals Met in First 5 Years

- Educated stakeholders on the emerging global practice of supported decision-making (SDM)
- Developed and piloted an SDM facilitation process as an alternative to guardianship for individuals with I/DD
- Developed an evidentiary base for Supported Decision-Making Agreement (SDMA) legislation



SDMNY Results and Successes

- SDM widely recognized by the courts, AAIDD, ARC US (and NY), National Council on Disability, American Bar Association, Administration for Community Living, Social Security Administration, National Guardianship Association as a “less restrictive alternative to guardianship”
- SDMA Statute signed by Gov. Hochul July 26, 2022



What is 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.



Surrogate's Court Procedure Act

Article 17-A – Instituted in 1969

Indefinitely removes all legal rights from the person with I/DD, based on determination of lack of capacity to make decisions (voting, marriage, ability to contract, where to live, with whom to associate, healthcare decisions, employment, etc.)

Why do parents seek Guardianship?

- Misinformation that it is necessary for continued services, to participate in the IEP process, etc.
- A belief that guardianship will protect their children and concern that their loved one is not ready or able to be in charge of making big life decisions (healthcare, finances, etc).
- Third parties (e.g. health care providers, landlords, and financial institutions) may refuse to provide services unless they are dealing with a guardian



Since 17-A Changes in the Landscape

- The Americans with Disabilities Act, IDEA, and Rehabilitation Act of 1973
- Concept of “least restrictive environment”
- Availability of services and opportunities to promote inclusion and self-determination
- Disability rights movement --> individuals with I/DD advocating for their rights



What is

Supported Decision-Making?

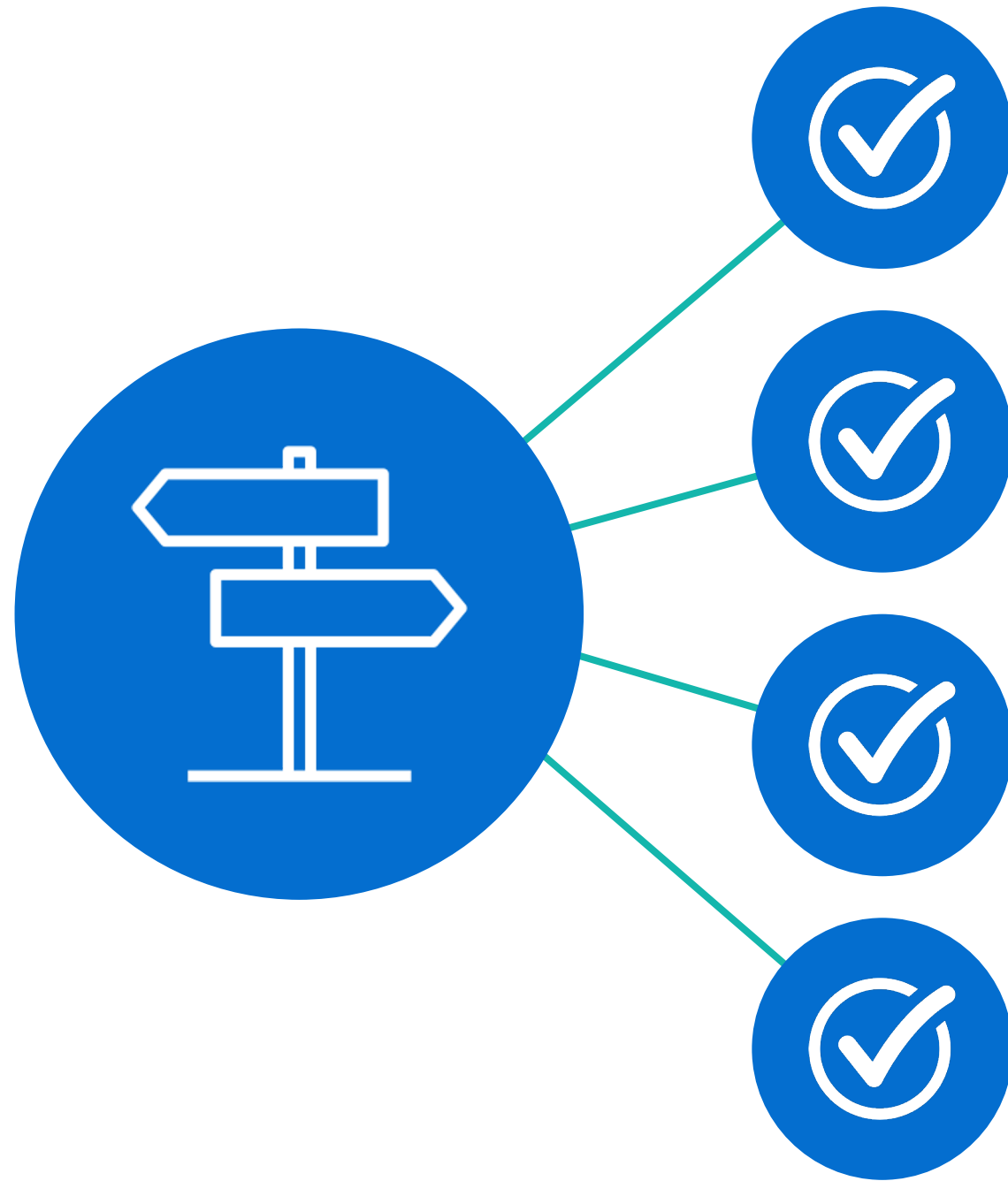
Supported decision-making (SDM) is “a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”

-- Robert Dinerstein, 2012

Director of the Disability Rights Law Clinic at
American University Washington College of Law



Supported Decision-Making An Alternative to Guardianship



Retain Rights

Persons with I/DD never lose important rights: e.g., to contract, to vote, to work, to marry

The Dignity of Risk

SDM allows a person to take risks and learn from their choices

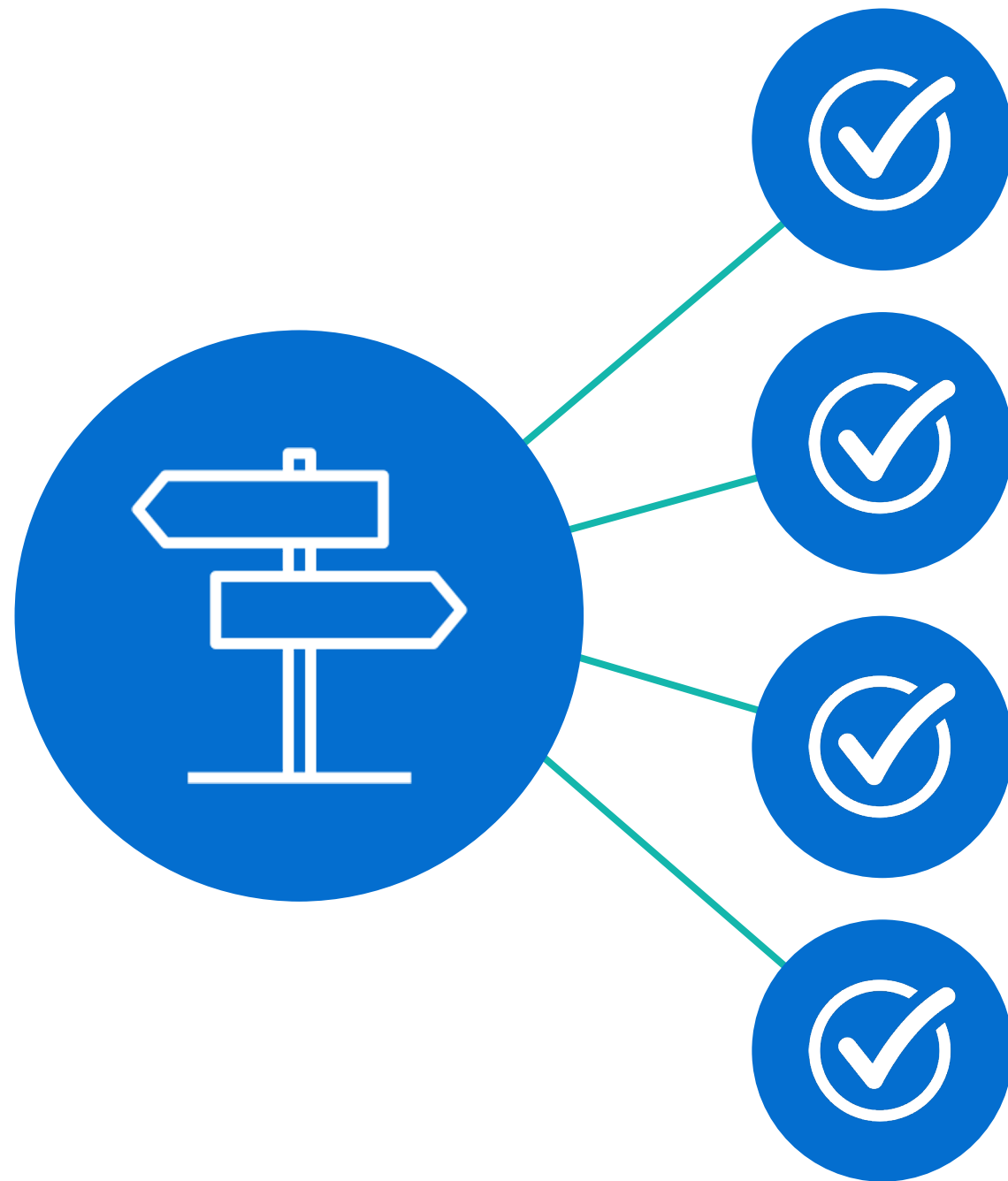
Enhanced Support

SDM helps to form a network of supporters that can protect against exploitation

Exercising Human Rights

Persons with I/DD have a human right to make their own decisions

Types of Supported Decision-Making



Informal

Can be invisible-- natural supports

Informal with SDMA

Informal, but with an oral or written Supported Decision-Making Agreement (SDMA)

Formal Facilitated SDMA

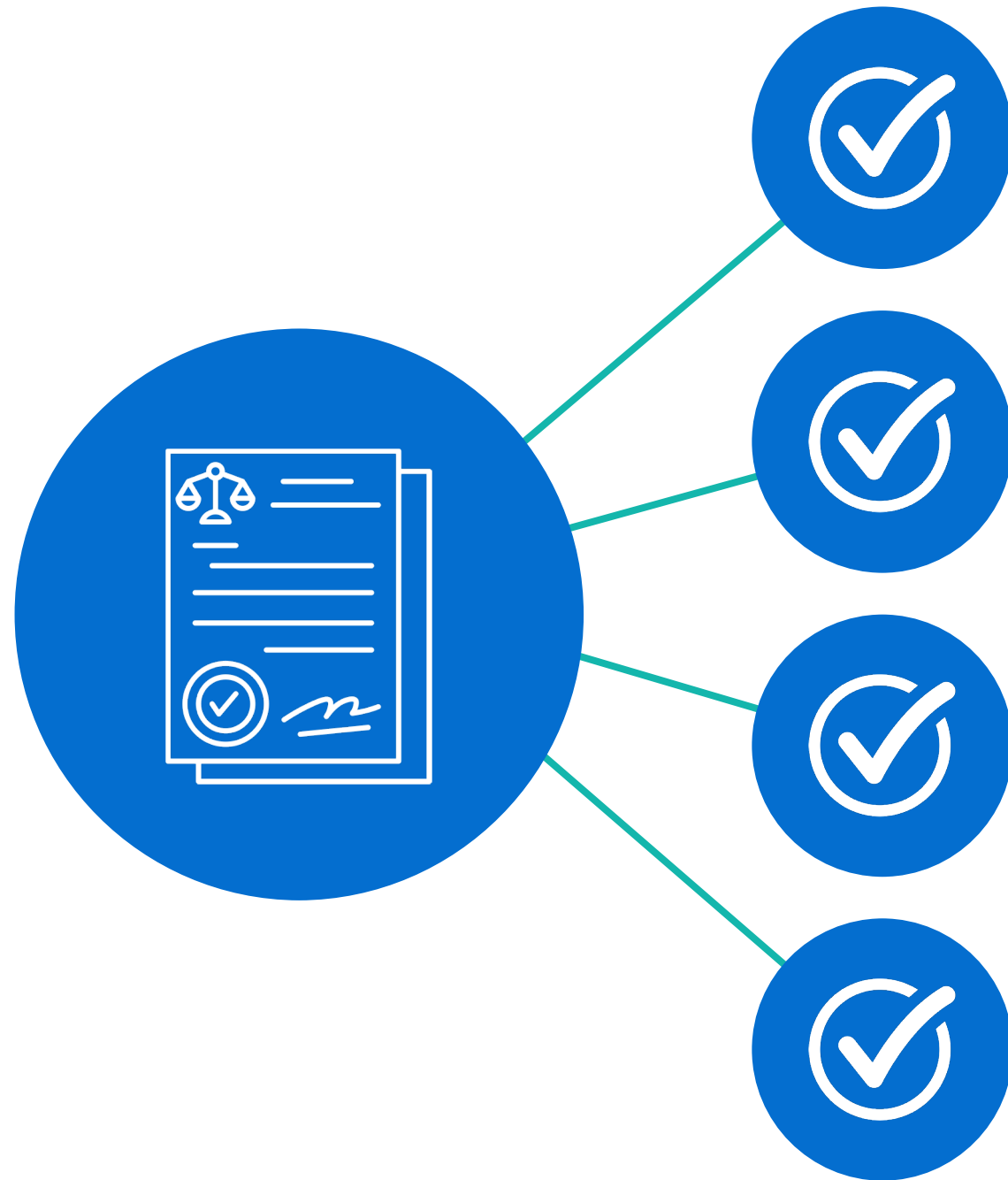
Formalized through a facilitation process that results in a written and signed SDMA (SDMNY model)

Legalized by Statute

Third parties required to accept decisions made by persons with SDMAs (Future NYS model - regulations in process)

SDM Statute in NYS

Article 82 of the Mental Hygiene Law



Passed in July 2022

Signed into law by Governor Hochul

Establishes SDM as a Valid Alternative

Acknowledges SDM as a “less restrictive alternative to guardianship”

Decisions must be Recognized

Third parties required to accept decisions made with SDMAs, and must presume competence

Protection Against Liability

Third parties are protected against legal action when they recognize decisions made using SDMAs

SDMNY

Facilitation Process

Phase 1: Exploration of decision-making; strengths and interests; ways of receiving support

Phase 2: Supporters invited to learn about SDMNY and to understand roles and responsibilities to the decision-maker

Phase 3: Decision-maker and Supporters create a Supported Decision-Making Agreement (SDMA)

SDMA Signing Ceremony





Gather Information



Weigh options
(decide!)



Understand
Information



Communicate
decision to others



Identify & consider
possibilities & alternatives



Carry out what I
decided!



Think about consequences

Steps in
Decision-Making

SDMNY Resources


Decision-Making Mapping Tool

i
gather info


**understand
info** 

**identify & consider
possibilities and
alternatives**


**Think about
consequences**






**Weigh
options
(decide)** 


**Communicate my
decision to
others**

**do what I
decided!**






SDMNY Resources

Big Four Chart: Page One

<u>Which</u> decision-making areas do you want to work on?	<u>What</u> types of support do you want?	<u>Who</u> will support you?	<u>How</u> do you want to receive support?
Health 	<ul style="list-style-type: none"> <input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions 		
Work 	<ul style="list-style-type: none"> <input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions 		
Money 	<ul style="list-style-type: none"> <input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions 		
Education 	<ul style="list-style-type: none"> <input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions 		

SDMNY Resources

Big Four Chart: Page Two

<u>Which</u> decision-making areas do you want to work on?	<u>What</u> types of support do you want?	<u>Who</u> will support you?	<u>How</u> do you want to receive support?
Housing 	<input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions		
Services 	<input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions		
Community Access 	<input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions		
Relationships 	<input type="checkbox"/> Help gather information <input type="checkbox"/> Help understand information <input type="checkbox"/> Identify & consider possibilities & alternatives <input type="checkbox"/> Help understand consequences <input type="checkbox"/> Help weigh options (decide) <input type="checkbox"/> Communicate decisions to others <input type="checkbox"/> Help carry out decisions		

SDMNY Voices

Beth: SDMNY Parent & Supporter



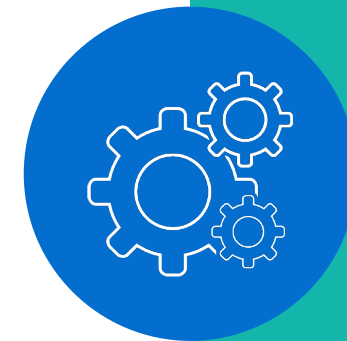
Results of SDMNY Facilitation

Supported Decision-Making Agreement (SDMA)– a signed contract that outlines the areas, types, and sources of support determined by the Decision Maker in a collaborative process

A flexible (modifiable) document that describes the process the Decision-Maker will use in making decisions and utilizing support throughout their life

Enhanced self-determination, confidence and autonomy for the Decision-Maker

Changed relationships between the Decision-Maker and supporters, with recognition of the Decision-Maker as an adult with the ability to make their own decisions with support



New York State

The Future of SDM & SDMNY



Legislation

Article 82 of the Mental Hygiene Law is the SDMA law of NYS, signed July 2022

Statewide Service Delivery

Pilot funded by OPWDD to develop service delivery model for SDMNY facilitation process across NYS

Outreach & Education

Connections with third parties, curriculum pilot, and school systems

Advocacy

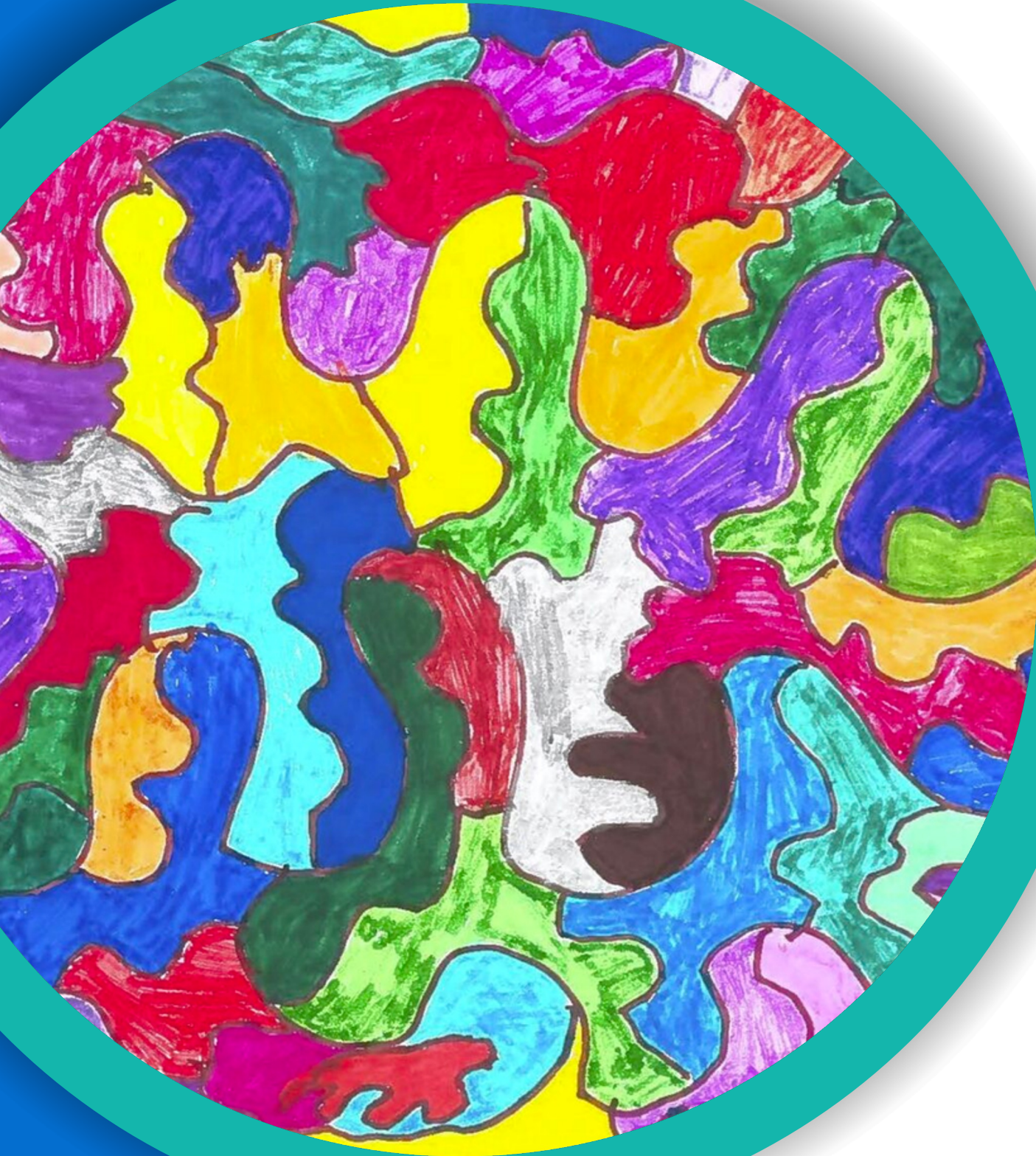
Amplifying the voices of Decision-Makers to protect the rights of people with I/DD

Questions?



SDMNY Voices

Jessica: SDMNY Decision-Maker



<https://sdmny.org/resources/jessica-statement/>

Artwork by Decision Maker Kim Plaut

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.



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