

SUPPORTED DECISION-MAKING: THE WHAT, WHY AND HOW

You may have learned that supported decision-making can be a good alternative to guardianship for a loved one with intellectual or developmental disabilities and are interested in knowing more. Here are some common questions and answers.

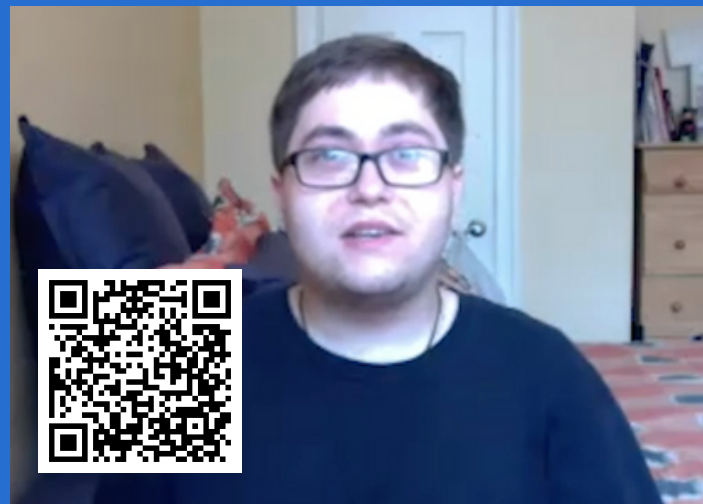
What is Supported Decision-Making?

Supported decision-making is a now well-recognized practice by which people with intellectual and developmental disabilities (I/DD) are able to make their own decisions with the support of trusted persons in their lives, retaining all their legal and civil rights. It comes from our common understanding that no one makes decisions in a vacuum, and we all use supports from family, friends and/or experts; people with I/DD may just need more or more intensive support. Supported decision-making has been found by New York courts and by the New York legislature to be a less restrictive alternative to guardianship, which takes away all of a person's rights.

Hear two Decision-Makers speak about Supported Decision-Making:



Jessica



Andrew

What is Supported Decision-Making facilitation?

In order to make their own decisions, people with I/DD need to learn what decisions are, and what steps go into making them. They can then explore which steps they are good at, where they want and need support and who they want that support from. Supported decision-making facilitation is a well-tested three-phase process in which a trained facilitator works first with the person with I/DD (the “Decision-Maker”) and then with the Decision Maker and their chosen supporters to craft a written agreement, the Supported Decision-Making Agreement (SDMA). The SDMA describes the areas in which the person wants support, what kinds of support they want for decisions in each area, and from whom they want that support. The SDMA is not just a piece of paper; it is a process that the Decision-Maker and their supporters will use over time, with the flexibility to add or subtract supporters, areas for support and kinds of support as circumstances change. On average, the facilitation process takes about 14 one-hour meetings over 6 to 12 months.



What is the legal status of SDMAs?

Because of stigma, prejudice or fear of liability, third parties, like health care providers or financial institutions often refuse to accept decisions made by people with I/DD, insisting instead that a guardian must be appointed in order for them to provide the requested/needed service. A new statute passed in 2022, Article 82 of the Mental Hygiene Law, provides that third parties must accept and honor decisions of persons with SDMAs that are made in accordance with regulations promulgated by the NYS Office for People with Developmental Disabilities (OPWDD); those regulations are expected to require a facilitation process similar to that piloted and utilized by SDMNY, and to “grandparent” SDMAs already made pursuant to SDMNY facilitation.



Governor Kathy Hochul signs the new SDMA law, July 26, 2022

What are the benefits of Supported Decision-Making facilitation?

In addition to protection from discrimination provided by the new SDMA law, Article 82, supported decision-making facilitation has been shown to increase self-determination, confidence, inclusion and overall wellbeing for Decision-Makers. It provides parents with confidence that there will be a robust



and caring support system in place when they are no longer around. It changes relationships between the Decision-Maker and their supporters from paternalism to appreciation and recognition of the Decision-Maker as an adult, capable of making their own decisions. Supported decision-making facilitation has been described by virtually everyone who has gone through it, Decision-Makers, supporters, and even facilitators, as “transformative.” And, while parents often seek guardianship because they are told it will “protect” their adult children with I/DD, in a major report, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination*, the National Council on Disability wrote that supported decision-making

“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” and that “[P]eople 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”

Hear a parent speak about Supported Decision-Making



Beth

Who/What is Supported Decision-Making New York (SDMNY)?

SDMNY is an organization based at Hunter College, CUNY that, beginning in 2016, designed and piloted supported decision-making facilitation under a 5-year grant from the NYS Developmental Disabilities Planning Council (DDPC), with a sixth year funded by the Ford Foundation, The FAR Fund and The Taft Foundation. With passage of the SDMA law, SDMNY was awarded a 3 year, \$4million grant by OPWDD to design and pilot a model for a statewide facilitation delivery system that will make supported decision-making facilitation available to anyone in New York who wants it.

SDMNY is currently accepting referrals of potential Decision-Makers from the courts, private attorneys, service providers, care managers, families and, of course, people with I/DD-Self-Advocates themselves. The service is entirely free.

How do we begin the process?

For more information, or to begin the process of signing up for SDMNY facilitation, please visit our website at sdmny.org.

