

FROM CHOOSING SDM TO USING YOUR SDMA: A RECENT SDMA SIGNING REFLECTS THE “ARC” OF SDMNY’S WORK

We didn’t plan this, but the story of Rebecca’s SDMA signing last month also turns out to illustrate the entire continuum of SDMNY’s work from the very beginning—our DDPC grant for a 5-year pilot project in 2016—to what will soon be the unimaginably successful conclusion, as OPWDD prepares to award a contract to the entity that will provide facilitation services to people with I/DD statewide.



Facilitator Samantha and Decision-Maker Rebecca signing her SDMA

But first—and for us, Decision-Makers always come first—Rebecca, 19, who lives in Irvington in Westchester County with her family and who signed up with SDMNY in April of 2024. Rebecca loves animals, enjoys arts and crafts and music; like so many teenagers, she’s a Taylor Swift fan with “You Belong with Me” her favorite song. Rebecca attended Irvington public schools from K–12. Now in a BOCES (Board of Cooperative Educational Services) program,

she recently completed a teacher’s aide internship in a kindergarten class at the very same elementary school where she had been a student. Rebecca especially loved reading to the children; they reciprocated her caring and enthusiasm with cards of appreciation they made for her at the end of the year.

During her year-long work with facilitator Samantha, Rebecca shared some of her goals that included becoming a teacher’s aide or, as an animal lover, a vet assistant. She and Samantha used these two goals to map out the decision-making steps Rebecca might utilize to explore these areas of interest more deeply as she moves forward into adulthood.



Mom Linda, dad Marlon, facilitator Samantha and Decision-Maker Rebecca



Brother Daniel, in the physics lab at Boston University where he works while pursuing a Master's degree in material science and engineering

How Rebecca came to SDMNY, the participants in her facilitation process, and how she is already using her newly minted SDMA are, however, not only her story, but ours as well. When SDMA officially began in 2016, and Rebecca was, we're guessing, still in elementary school, one of our partners was ARC Westchester. One member of their team was none other than Samantha, who attended our first training, and who has participated in several successive trainings as we revised and refined our facilitation process. One of the trainers at that first session, and the heart and soul of what we know about facilitation and mentoring, was Joan Cornachio, who was Samantha's mentor for Rebecca's facilitation!

There's more. As we got started in 2016, we were not only developing the facilitation process but beginning to educate stakeholders about SDM as an alternative to guardianship. We did presentations to a few school districts that were open to this potential paradigm shift; one of them, if memory serves, was Irvington, which subsequently has included discussion of SDM in the post-transition choices it offers families. That's where Rebecca's mom, Linda, and dad, Marlon, learned about SDM and SDMNY. As Linda reports:

"This is how we found out the differences between guardianship and supportive decision-making documents. We wanted Rebecca to do her own decisions with us as supporters. We wanted her to be her own person. I think other parents will like this option but are afraid to try or they think their child isn't capable."

At the signing, Linda attested to how successful their and Rebecca's choice had been, saying, "This process has given her confidence to make choices... [and] to have her own dignity in life."

And there is still more. For us, SDM is not just a "thing" or process, but an embodiment of the human right of legal capacity. That means not only the right to make one's own decisions—which obviously requires avoiding guardianship and promoting self-determination—but having those decisions legally recognized by third parties, regardless of disability. That's what New York's groundbreaking SDMA statute does, and that's what Rebecca's post-signing experience so perfectly illustrates. Mom Linda reports:

"We have used [the SDMA] at [Rebecca's] recent surgery at Westchester Medical Center, which they recognized immediately. It has been shared with all her doctors, the school district, her care manager, and anybody else who needs to know. It's so nice to see the doctors and nurses speaking to her directly and having me present in case she didn't understand them. They're patiently waiting for her reaction..."

Finally, and completing the SDM/SDMNY arc in this story (pun intended), the human right of legal capacity requires government to "provide the support necessary to enable the [person with disability] to exercise that right." Through our nine-year journey, with the support of New York State and others, we have designed, piloted, and operationalized that support through SDMNY facilitation. The upcoming award by OPWDD of a contract to "provide the support necessary" marks the completion of our work, even as Rebecca's SDMA signing marks the beginning of a life with full legal rights, autonomy, and dignity.

**CONGRATULATIONS TO REBECCA AND HER
SUPPORTERS, AND THANKS TO FACILITATOR
SAMANTHA AND THE IRVINGTON SCHOOL DISTRICT!**