

# AN SDMA SIGNING AND THE TRANSFORMATIVE POWER OF SDMNY FACILITATION

At the information sessions and trainings we do, we often say that SDMNY facilitation is “transformative,” and an SDMA signing last week provides a great example.

Ben, now 40, was placed under guardianship in 2004 when his parents Barbara and James petitioned Surrogate's Court, as they were advised to do, because “there was no alternative for an adult child with a disability.” The guardianship statute for people with I/DD, Article 17-A of the Surrogate's Court Procedure Act, had been enacted in 1969 when the common understanding of I/DD (then, unfortunately called “retardation”) was that it was a permanent, static diagnosis. Those who “suffered” from I/DD were perceived as “forever children,” needing continued protection and governance at the cost of all their civil and legal rights. In the more than 50 years since 17-A was passed, the statute remains unchanged, although the way we understand disability, the shift from a medical to a social model, the interventions and services available, and, above all, the understanding that people with I/DD can learn and grow and live inclusive, self-determined lives, have created a massive paradigm shift.



*Ben with his parents in Barcelona, Spain*

Ben, who at 19 was said to be “unable to manage his affairs” and to “have difficulty in making decisions and planning [and thus was] dependent on his parents to act on his behalf,” has grown into a responsible adult, who lives with a neurotypical roommate in supportive housing in Riverdale, cooks for himself, utilizes all means of public transportation, is successful in a job he has held for 20 years, has his own bank account, and volunteers with the Visiting Nurse Service (VNS). He has good friends, has traveled widely with his parents, enjoys movies, video games, basketball and WWE, makes and follows his own complex schedule, and is much beloved and appreciated by the many people in his life. But, at 39, Ben was still under the guardianship of his parents, relying on and deferring to decisions made primarily by his mom, Barbara, who he referred to as “the Big Boss.”

As Barbara and dad James aged, they became concerned about what would happen when they were no longer around; when they learned about passage of New York's SDMA law, they finally saw the "alternative" to guardianship that had been missing 20 years before. They started the legal proceeding necessary to terminate Ben's guardianship and, with his consent, signed him up with SDMNY. On April 8, the New York County Surrogate dissolved the guardianship, noting, among other facts, his participation in "decision making sessions at [SDMNY]," and finding that "the imposition of an Article 17-A guardian is no longer appropriate to meet Benjamin's needs, and thus the current guardianship is not in his best interest." Restoration of Ben's rights is, of course, a wonderful result that also reaffirms our belief in the importance of our groundbreaking legislation. But there is more, equally important, in his story.



*Ben at Arches National Park in Utah*

According to both Barbara and facilitator Pam, when Ben began SDMNY facilitation, it wasn't clear that he really wanted to make his own decisions—not only because he was comfortable with Barbara doing so for him, but because he simply did not see himself as, or able to be, a decision-maker. Over the course of a year working with Pam (and the behind-the-scenes efforts of Mentor Karen), that perception changed as Ben engaged in extensive "unpacking" of decisions he had already made, and "mapping" decisions he was about to, or might, make in the future. As he learned the steps that go into making every decision, began to identify those he could do on his own and those for which he wanted support, he gained confidence in his ability and (intrinsic motivation!) satisfaction in being "his own boss." Through facilitation, he was, in fact, transformed into a Decision-Maker, as Pam, Karen, his parents, and other supporters attest. Watching that transformation over the course of the facilitation enabled Barbara to "reposition" her relationship from that of a parent who knows best, to a supporter who recognizes and acknowledges Ben's right and ability to make his own decisions with the support of trusted people in his life. Here's what Barbara says:

“Guardianship limited Ben’s ability to make decisions and also reinforced his belief that he was someone who could not make decisions. As a result of the efforts of the caring and helpful people at SDMNY, Ben realized that he could make decisions on his own and incorporated that new-found understanding in an SDMA that provided him with a structure by which he could rely upon supporters in case he needed assistance. Ben has demoted me from ‘Big Boss’ to ‘Little Boss,’ but I very much appreciate SDMNY’s efforts in helping Ben grow and reach his potential.”

Two small incidents at the signing ceremony provide concrete examples of Ben’s transformation into the self-determined, autonomous Decision-Maker that we believe SDMNY facilitation achieves. Karen describes them as moments when a Decision-Maker can say “it’s time to be the leader, the captain of the ship, steering your own life.” First, Ben took charge of the order of comments that participants would make, putting Barbara last because she was “the most important,” and unexpectedly (to her, at least) calling on Karen to acknowledge her contributions to the process. Then, asked about whether his story could be used for Good News, he agreed but with the proviso that the screenshot—usually the only visual record we have—would not be used. And why? Not because it wasn’t flattering or because he didn’t want to be seen (the pictures above show what a handsome man he is), but because one of his supporters wasn’t able to be on-camera for the Zoom recording, and it wouldn’t be right to exclude her! What a thoughtful and generous decision, and how reflective of Pam and Karen’s characterization of Ben as “one of the loveliest human beings you’ll ever meet.”

We are both proud and humbled to have played a part in Ben’s transformation, and the transformation of his parents into authentic supporters. We are grateful to them for sharing this story, which reaffirms the transformative power of SDM and SDMNY facilitation, and the human right of legal capacity.

**CONGRATULATIONS TO BEN AND HIS SUPPORTERS,  
AND THANKS TO FACILITATOR PAM!**