

AN SDMA SIGNING=SERENDIPITY X 2

There are many reasons why people with I/DD and their families pursue SDMNY facilitation and SDMA. We've always believed, and have a great deal of support for, the transformative nature of the process – the growth in confidence, self-determination, and autonomy that comes from learning how to make one's own decisions with support, developing new relationships based on respect rather than protection, and experiencing yourself as an authentic Decision-Maker.

Some Decision-Makers need more – the legal protection for their decisions that might otherwise be denied by third parties who doubt their competence because of ignorance, bias, or prejudice. This is especially true for non-verbal Decision-Makers, which is why their successful completions of SDMA are so important and so worthy of note.

Recently we celebrated Emma, a “non-speaking autistic” (her characterization) who utilized a more informal kind of SDM facilitation to make an SDMA in Virginia, and who is using that SDMA to end her guardianship. (Good News 9/19/25) By sheer serendipity, this week we celebrate an SDMA signing by one of our SDMNY Decision-Makers who is also non-speaking.



Emma

Will is 20 and lives with his family in Altamont, NY. He enjoys playing both the piano and video games, art, cooking and baking, bowling, and working out. He and his whole family love the outdoors, and he is an avid camper as well as an accomplished horseback rider. He'll graduate from high school this year, and he and his family decided that pursuing SDM and an SDMA would be important to him as they look forward to what comes next.



Will

When Decision-Makers sign up for SDMNY facilitation, our team works hard to match them with an appropriate facilitator. In Will's case, responding to the survey question:

"SDMNY meetings usually take place virtually (i.e., Zoom, Teams, FaceTime, Google Meets, etc.). Tell us about any accommodation needs or special considerations,"

Will and his mom answered, "We would need a facilitator who would be able to communicate with a non-verbal self-advocate." While this might have been seen as a challenge, SDMNY quickly rose to the occasion, assigning a recent graduate of our 17th Facilitator Training.



Facilitator Carrie

Carrie recently obtained her master's degree in Human Development (at 51!) and works in the Division of Developmental & Behavioral Pediatrics at the University of Rochester Medical School, where she educates health care professionals about communication with people with disabilities, so she seemed like a perfect choice. This would also, however, be her first facilitation, and here's where the second serendipity came into play. Carrie is also the mom of a wonderful young adult non-speaking daughter with I/DD who has been informally using SDM. Assigning her to Will promised to be, as they say, a match made in heaven. And, in fact, it definitely was!

Carrie describes Will as easy-going, with a gentle manner, as well as a "total communicator," who is very expressive and uses body movements, facial expressions, and eye contact to have meaningful conversations even when not using his communication device. His supporters – mom Bridget, dad Chris, and three siblings, Nicole, Jennifer, and Troy – are a big, happy family who have always been Will's champions, treating him as an equal and "wanting him to find what gives him joy." Carrie says "they made everything so easy," with a supporter always available, but non-intrusive, if necessary.



Dad Chris, Sister Jennifer, Brother Troy, Sister Nicole, and Will

It is a basic principle of SDMNY facilitation that the Decision-Maker drives the process. Here, because Will often tired after half an hour of work, sessions were limited to 30 minutes, so there were more and more frequent meetings than are usual. But also, observing the family's constant teasing of each other and all the fun they had together, Carrie and Will collaborated in including a 5-minute "fun" segment in every facilitation session that kept him engaged and committed to becoming an authentic Decision-Maker.

This individualized facilitation process was a true collaboration, with everyone working to ensure that, despite Will's communication challenges, his voice was always heard. The SDMA signing ceremony was both joyful and emotional for all, as Will affirmed both his autonomy and grateful acceptance of support from his loving family, and they, in turn, attested to their commitment to honor his decisions going forward. We are also grateful, as SDMNY approaches its conclusion, for this moving and serendipitous affirmation of how, with appropriate support, people can – and have the right to – make their own decisions regardless of their diverse and/or multiple disabilities.

**CONGRATULATIONS TO WILL AND HIS SUPPORTERS,
AND THANKS TO FACILITATOR CARRIE!**