

SDMNY'S ACCOMPLISHMENTS INSPIRE A SPECIAL VIRGINIA DECISION-MAKER AND HER MOM

We often hear from advocates around the country—and even around the world—about how impactful what we have done in New York has been. A CUNY colleague recently participated in a conference, Motormorphosis—the largest conference for nonspeakers in the world—where she met a mom from Virginia who specifically noted and expressed appreciation for the work of our Founding Director Kris Glen in promoting SDM and the human rights of people with I/DD over so many years. We were both delighted and curious, and when we reached out, we learned how her amazing daughter Emma is “pushing the envelope” for the use of SDM and SDMA as an alternative to guardianship in her home state.



Motormorphosis Conference 2025

In many ways, Virginia is quite progressive; it passed an SDMA law in 2021 that recognized SDM and SDMA, providing that they could be a less restrictive alternative to guardianship. ([Click here](#) for the Va. Statute) Although, unlike many other SDMA statutes (including ours), the law doesn't provide for legal recognition of decisions made pursuant to an SDMA, it was and is unique in requiring its Department of Behavioral Health and Developmental Services—the state agency similar to OPWDD—to:

“develop and implement a program to educate individuals with intellectual and developmental disabilities, their families, and others about supported decision-making agreements, provide training opportunities, develop model agreements, and establish protocols for preventing abuse and exploitation.”

The state, as well as various advocacy groups, have created SDMA templates and educational materials for creating SDMA, and Emma has taken advantage of these services, especially from the ARC of Northern Virginia, to build an impressive circle of support and sign an SDMA with a large and varied group of supporters.

What is special, however, is not only that Emma is currently under guardianship (something her parents obtained, as so many do, because they were told to, and given no alternatives), and that she is petitioning the court for termination on her own, without an attorney (also made possible by Virginia law) ([click here](#) to read her petition), but that she is, by her own description, a “nonspeaking autistic”—the first such person to use an SDMA to seek restoration of rights in the state. Emma tells her story better than we possibly could in this moving video which, we’re sure, will provide inspiration to the many other nonspeakers for whom she is a tireless advocate. ([Click here](#) to see the video) As her petition movingly concludes:



Emma outside the court where she filed her petition on August 15

“I think it is important that people with disabilities, even those of us with significant communication challenges and support needs, have a right to live our fullest lives where we contribute to society.”

And did we mention that she is also featured in the Sundance-award-winning documentary “Why I Jump”? (It’s no longer available on Netflix, but we’re told that if enough people ask, they will bring it back!)

We are moved and inspired by Emma’s courage, determination, and generosity of spirit and look forward to hearing the successful resolution of her petition and the restoration of all her rights—so well deserved and well earned. We are also grateful to her mom, Donna, herself an important figure in the inclusive housing community (she’s Director of Partnerships and Advocacy at Our Stomping Grounds, which creates opportunities for independent living in the community), and for her kind and affirming words about SDMNY:

“Emma and our family are beyond grateful for your work and that of other advocates who have consistently advocated for PWD to live self-determined lives in their communities. Most of the families we know in Virginia are still very suspicious of our decision, and it is clear that a great deal more education and leadership is needed to demonstrate that the SDM is actually safer for our adult children in Virginia. We absolutely could not have figured this out on our own. We only knew what we were told by case workers, educators, and other parents, and are very grateful to your decades of work and advocacy that has made this possible for Emma and her friends. Thanks for lighting the fire in New York. We will carry the torch down here in the Commonwealth and report on our progress.”



Emma and her mom celebrating inclusive living in Arlington, VA

We are honored and humbled by this acknowledgement, but also proud of how New York is, indeed, leading the way. We're especially proud to share how we have also committed to advancing the rights of nonspeakers; one such Decision-Maker signed her SDMA several years ago, and three more are currently in facilitation, with one of them scheduled to sign his SDMA next week (stay tuned!)

**THANK YOU EMMA AND DONNA FOR SHARING EMMA'S
STORY, AND FOR YOUR CONTINUING COMMITMENT TO
"CARRY THE TORCH!"**