

TWO RECENT PUBLICATIONS ADVANCE SDM AND SDMNY

(with apologies for length, but lots of important information)

“To publish” is to make information known to the general public. “Publication” is the act of publishing, but also has multiple legal meanings: under New York Law, agency regulations (the “Regs”) do not become final and operative until the “publication” of their Notice of Adoption (the Notice) in the New York State Register (the Register). This latter form of publication is something we’ve been anxiously awaiting since, as we have previously reported, New York’s ground-breaking SDMA law directed OPWDD to write implementing regulations and further provided that the law would not go into legal effect until 90 days after their adoption through publication in the Register. ([Good News, 08/15/25](#))

Now, finally, on August 20, more than 3 years after the law was signed by Governor Hochul, THE REGS HAVE BEEN PUBLISHED! And in 90 days, on November 19, Decision-Makers with SDMNY-facilitated SDMA will be able to use those SDMA to require third parties to accept their decisions regardless of their disability, or how the third party may assess that disability, and to enforce their right “in law or equity on the same basis as all others.”

As we have previously explained, after OPWDD drafts regulations, they are put out for public comment, and then, where appropriate, changes may be made. The Notice generally describes the nature of comments that were filed, many of them dealing with technical details. (For a summary of all the comments and OPWDD’s responses, see [here](#).) The final Regs, published in the NY Code of Rules and Regulations (NYCRR, Part 346), reflect those changes. (For the Notice, click [here](#); for the final Regs, click [here](#).) We highlighted the major sections that might be of interest to our community in [our initial story](#) about the draft Regs and so won’t repeat them here.

Notably, the Notice reported:

“Most commenters were supportive of the regulations as written, and of the concept and proliferation of supported decision-making in New York State, both as a less restrictive alternative to adult guardianship and as a means to promote greater self-determination for people with intellectual or developmental disabilities. Among others, OPWDD received comments from self-advocates expressing their personal wish to use supported decision-making as a way to maintain their autonomy and receive decision-making assistance consistent with their will and preferences.”

There was, however, one set of comments that caught our attention, and, apparently, OPWDD’s. As the Notice reported:

“Some commenters expressed concern about the presumption of capacity to make use of supported decision-making, as described in MHL Article 82 and the corresponding regulations. Some of these commenters requested that OPWDD require clinical evaluations of capacity for those who wish to use supported decision-making. This would be outside the scope of OPWDD’s regulatory authority, as the law is clear that adults who wish to explore supported decision-making are presumed capable of doing so, absent one of the statutory exceptions. The regulations further explain these exceptions. Moreover, the facilitation process and service associated with the formalization of an SDMA (as described in the regulations) also serves as a protection against the inappropriate use of supported decision-making by those who may require greater or more restrictive decision-making assistance than supported decision-making can provide.”

In Article 82, the Legislature unambiguously reiterated already existing law that everyone over 18 who is not under guardianship is presumed to have capacity; the Regs repeat and further reiterate that basic principle. Importantly, the Regs recognize that a facilitated SDMA now *legally requires* third parties to accept and act on that capacity, while there is no such legal obligation for those with informal SDMA or who practice SDM with no written agreement. The statute and the Regs recognize and encourage all forms of SDM including informal SDMA, but the unique provision of our statute is that legal recognition is not conferred unless there has been meaningful facilitation in accordance with the Regs—and, as we previously reported, all SDMA previously completed with SDMNY facilitation are covered by the statute and Regs.

There is a second publication that makes information about SDM and SDMNY available to the larger national (and probably also some international) I/DD community. Last year we reported on the annual meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the creation of working groups convened to propose national goals to enhance the lives of people with I/DD in several areas. ([Good News, 06/14/24](#)) SDMNY Director Naomi Brickel was one of ten experts chosen for a committee to create Recommendations for the next ten years (decanal) on, *inter alia*, universal policies for supported decision-making; building and supporting state SDM and SDMA laws; clarifying a definition of SDM and informal and formal supports and systems.



SDMNY Project Director Naomi Brickel

The Recommendations have now been published in AAIDD's influential journal *Inclusion*, with Naomi's participation clearly reflected, and SDMNY's "on the ground" achievements prominently featured. (For the complete article, [click here](#)) Mirroring our insistence that SDM be grounded in human rights, the Recommendations describe the "first value" as: "emphasiz[ing] that all people, inclusive of people with IDD, have a human and civil right to autonomy and self-determination." They continue: "[t]o promote autonomy for people with IDD as it relates to consent and decision-making, prioritizing the supports needed by the IDD community to build decision-making capacity, creating a culture of consent is imperative."

The Recommendations go on to note, as we have often said, how SDM is "understood and applied in various ways in practice, ranging from informal support from friends and family to formal agreements" with "[d]ifferent approaches to SDM... often built around distinct concepts" and "distinctly different approaches regarding SDM legislation." They note that "The ongoing reforms and debates around SDM and guardianship informed [its] recommendation for identifying a clear definition, as well as engaging in consistent implementation and robust education initiatives for SDM." Although the committee "[did] not endorse any single existing SDM implementation model," "[it] instead encourage[d] a deliberative process led by people with IDD to merge what has been learned." Only one example is noted as "worth closer examination... for its state-led effort and dedicated funding"—SDMNY! Also reflecting SDMNY's influence, the Recommendations contain multiple citations to publications by SDMNY Founding Director Kris Glen, one of which comprehensively describes SDMA legislation in the US ([Good News, 03/24/25](#)) and an early [article](#), foreshadowing SDMNY's creation, notably published in *Inclusion* in 2015.

Adoption of OPWDD's Regulations to Article 82 has "made information known" about how this groundbreaking law will be implemented to advance the human right of legal capacity and everyone's right to make their own decisions, regardless of disability. Publication of the AIDD committee's "decanal" Recommendations ensures continuing and focused attention to actualizing that right, even as it highlights SDMNY's extraordinary achievements. We celebrate and take pride in both!