

# COMMENT PERIOD ON OPWDD REGULATIONS IS CLOSING: SDMNY IS “IN THE HOUSE”!

As you may know, after a long wait, OPWDD’s Draft Regulations implementing our new SDMA law (Mental Hygiene Law Article 82) were put out for comment at the end of July (Good News 8/9/2024) giving the public 60 days to send in their comments. That period ends this Sunday, so if you have something to say, better get to it! Comments can be submitted to:

**Regulatory Affairs Unit, Office for People With Developmental Disabilities 44 Holland Avenue, Albany, NY 12229;  
(518) 474-7700;  
[rau.unit@opwdd.ny.gov](mailto:rau.unit@opwdd.ny.gov)**

We thought you’d like to know (and be reassured) that SDMNY and our friends are well represented in what has already been filed. Naomi Brickel, our Project Director, wrote comments on behalf of SDMNY ([click here](#) for those comments), particularly acknowledging and thanking OPWDD for “the substantial effort spent on additions and edits to existing regulations, especially in areas around consent, capacity, notification, clinical protocols, and others where the statute was impacting for people with formal and informal SDMA’s.”

A number of Decision-Makers, families and supporters also added their voices, raising a variety of issues.

One mom, for example, noted that there was confusion about the role a guardian might or could play when a person with I/DD participated in facilitation, even when the guardian was in support of the person’s desire to terminate the guardianship. Another focused on the need to educate many stakeholders and participants within the system on the practical and legal implications of SDMA’s. We have enthusiastically greeted the growing interest in SDM and our process by Care Coordination Organizations (CCOs), but drawing on her own experience, this mom pointed out that

“NYS Care Managers do not seem to be aware of SDM as a ‘real’ entity. Standard forms ask for guardianship information but not designated supporters who should be included on the check box options (of course this would be in cases where Decision-Makers have designated Supporters to be included in their Care Management, etc.). Having recently changed CMs after a move, we should not have to go through any special process to ‘be included’ as supporters (and yet this is the case, I’m dealing with now).”

Describing the lack of knowledge that she and her daughter have also experienced from doctors and the healthcare system, she noted

“Having a great system in place—and I must say I was SO glad, as a mom, that SDMNY exists as an option for those of us who want our children to be as independent as possible—is not at all useful or helpful if NOBODY (literally NOBODY) knows about it [because they have not been officially notified]” but continued with helpful suggestions on “[h]ow to rectify this lack of communication situation[.]”

We were also thrilled to see the significant and valuable efforts of SANYS, the statewide self-advocacy organization, which prepared an excellent, easy-read summary of the regs for its members ([click here to see the easy-read version](#)), and then filed extensive and thoughtful comments with OPWDD.

We know how important it is that OPWDD hears from those most affected by the new law, people with I/DD, their families and supporters, and are grateful to the members of our community who shared their thoughts and experiences. We enthusiastically endorse the words of a parent of a Decision-Maker who wrote:

“I’m hopeful that all the hard work that’s been done by both the Decision-Makers and all those involved in making SDM come into being—will ultimately allow SDMA’s to reap the benefits and have SDM recognized officially by professionals, as it should be.”

**THANKS TO EVERYONE WHO SUBMITTED COMMENTS AND,  
THOUGH TIME IS SHORT, IT’S STILL NOT TOO LATE!**