

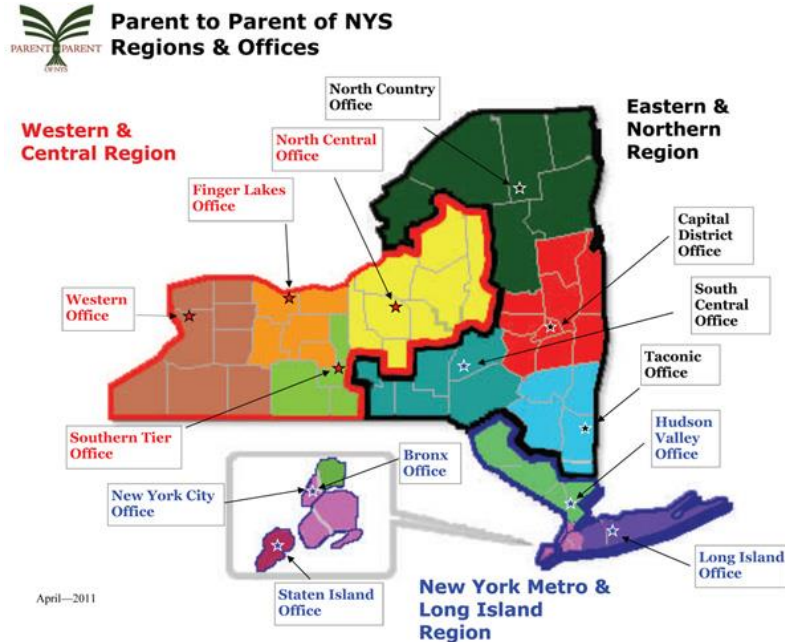
REPORT OF PARENT TO PARENT OF NEW YORK STATE-CONVENED
FOCUS GROUPS ON SDMA LEGISLATION

In six (6) groups across New York State, parents discussed Supported Decision-Making (SDM) and the need for legislation to recognize decisions made with Supported Decision-Making Agreements (SDMAs)

May 2021

PARENT TO PARENT OF NEW YORK STATE

Parent to Parent of New York State, which began in 1994, is a statewide not-for-profit organization established to connect families of individuals with developmental disabilities. Parent to Parent's mission is to build a supportive network of families to reduce isolation and empower those who care for people with developmental disabilities or special healthcare needs to navigate and influence service systems and make informed decisions.



Parent to Parent subcontracted with Supported Decision-Making New York through a Memorandum of Understanding in the fall of 2020 to ascertain its parent-members' views and opinions on SDMNY's Legislative Principles for proposed Supported Decision-Making Agreement (SDMA) legislation, as well as on a proposed SDMA law.

SUPPORTED DECISION-MAKING NEW YORK

Supported Decision-Making New York (SDMNY) was created in 2016 in response to an RFP from the NYS Developmental Disabilities Planning Council (DDPC) to educate stakeholders and the public about supported decision-making (SDM), and to pilot the use of SDM for persons with I/DD to divert them from guardianship or restore their rights if already subject to guardianship.

The terms of SDMNY's state grant explicitly provided that SDMNY's education and demonstration activities establish an evidence base for systemic changes that will establish SDM use as a viable alternative to guardianship, and one that extends beyond the project's conclusion. Specifically, DDPC charged SDMNY with delivering recommendations for legislative change based on the evidence produced through DDPC-funded SDMNY pilot programs. That evidence, now based on five years of experience and more than 140 participants, militates for the inclusion of a well thought out, careful facilitation process. The SDM facilitation process ensures that decisions made through SDM will be truly the decisions of the person with I/DD, as well as ensures that the supporters are just that—"supporting" individuals with I/DD and not substituting their own decisions in the "best interests" or in place of those of the person with I/DD. The SDM facilitation process is designed to also prevent and reduce decision-making that is the product of undue influence or conflicts of interest. The SDMNY model has demonstrated the integrity and legitimacy of

incorporating and requiring mandatory acceptance of SDMA (i.e., Supported Decision Making Agreements) by third parties.

SDMNY has begun a statewide education campaign comprised of organizations representing the main stakeholder groups, primarily persons with I/DD and their parents, to build support for legislation that would recognize SDM and SDMA reached through a SDM facilitation process similar to or built upon that developed by SDMNY, including the incentivizing of the State to fund a system providing access to facilitation for everyone desiring it, regardless of ability to pay.

LEGISLATIVE PRINCIPLES AND PARENT TO PARENT OF NEW YORK STATE FOCUS GROUPS

Over more than a year, from 2019 to 2020, SDMNY convened a Legislative Working Group (LWG) from among members of its diverse Advisory Council (AC) of stakeholders to draft “Principles” for potential SDMA legislation in New York. The draft was further vetted through three (3) presentations, including to a Spanish-speaking group, and four (4) focus groups of parents in the late fall of 2020, convened by Parent to Parent of New York State.

Introductory Principle regarding SDMA legislation for New York

A statute that provides legal recognition for SDMA should initially apply to persons with developmental disabilities, while affirming the right of all persons to use SDM and to make their own SDMA

General principles for initial legislation recognizing SDM and SDMA

1. SDM and SDMA should be defined in easily understandable and nonexclusive terms.
2. Everyone should be able to make an SDMA and there should be no negative consequences for doing so. No one should be prevented from making an SDMA based on traditional definitions of “capacity” that discriminate against persons with disabilities.
3. Persons making SDMA, the “Decision-Makers,” have the sole right and power to choose the areas in which they want support, the kinds of support they want, and the person(s) from whom they want to receive that support.
4. A decision made pursuant to an SDMA can only be made by the Decision-Maker, and not by Supporters, and only the Decision-Maker is responsible for the decision.
5. Supporters should respect the right of all Decision-Makers to make their own decisions, and should not engage in substitute decision-making, undue influence, or conflict of interest.
6. The Decision-Maker can change or revoke the SDMA at any time.
7. There should be only modest formalities for execution of an SDMA.
8. Because guardianship is a significant or total deprivation of a person’s liberty and/or property rights, and less-restrictive alternatives must be considered before guardianship can be imposed, relevant state actors should make information about SDM and SDMA easily available, including in plain language.

Principles for legislative recognition and third-party obligation to honor SDMA in order to receive legal recognition

1. SDMA should be in a form, or using a template, authorized by the legislature, but Decision-Makers and their Supporters should be able to vary or modify the form/template so long as the SDMA substantially complies with its terms and provisions.
2. SDMA should be signed in the presence of two adult witnesses who are not themselves parties to the agreement, and who understand, with support if necessary, the Decision-Maker’s chosen means of communication.
3. SDMA should be the result of a process of facilitation or education designed to ensure that the Decision-Maker understands what goes into making a decision and obtaining support, and that Supporters

understand their roles and how those roles may differ from their pre-existing relationships with the Decision-Maker.

When an adult with DD makes a decision pursuant to an SDMA that meets all the requirements of the above Principles, then

1. A person (third party) should be obligated to accept the legal capacity of the person with DD (the Decision-Maker) and give full legal effect to their decision made pursuant to that SDMA unless the person (third party) has reasonable cause to believe that the decision is the product of exploitation or abuse.
2. A person (third party), who in good faith relies on a decision made pursuant to that SDMA, should not be subject to civil or criminal liability, or discipline for unprofessional conduct.
3. A person (third party) who receives a copy of an SDMA and reasonably believes that the adult with DD (the Decision-Maker) is being abused or exploited should be protected if they report the alleged abuse or exploitation to the appropriate protective agency.

METHODOLOGY

Parent to Parent subcontracted with SDMNY to ascertain its parent-members' views and opinions on the Principles and a proposed SDMA law. Parent to Parent's Executive Director, who is also on SDMNY's Advisory Council, and Regional Manager/Education Specialist met during the summer of 2020 with SDMNY's Project Director, NYC Site Coordinator, and Senior Project Coordinator to plan the format of the focus groups and determine the regions from which to invite parents to participate and ensure representation from a cross-section of New York State. The initial plan was to offer two, 2-hour sessions for six (6) regional focus groups; the first an overview of supported decision-making as well as SDMNY's 3-phase facilitation process, and the second an in-depth discussion of the Principles and proposed legislation. A key decision was to first pilot this format with Parent to Parent's staff and ask for their impressions and feedback on structure and content based on their experience working with parent-members.

One staff member said, Some history is important and the impact of Civil Rights; relate it to everyday progress, such as curb cuts.

Another said, I liked that you discussed human dignity and also made it more real; it will resonate with people rather than a cut-and-dry history lesson. Equate what's being discussed with how it can benefit someone, then parents might be more open to having this conversation with a loved one and consider it.

Finally, one other said, I like the human rights point of view. If I know that human rights come from a legal standpoint then I am more willing to listen.

The pilot presentation equated to a focus group as well, because all staff are parents of someone with I/DD and attendees offered keen insights about supported decision-making and proposed legislation:

In conversations with other parents there is a misconception that we should just file for guardianship and then decide.

Too often we're told as parents, 'you want to do what's best for your children,' but we're never given an alternative; it's this or nothing.

Parents are not around forever. Parents may have guardianship and treat it like SDM, but whoever takes over guardianship after the parents can't [do it] may treat guardianship to the letter of the law.

Maybe it is a way to bring this to the parents and students early on...at 14 or so. We all need practice in making decisions and starting a lot earlier than 18 would be helpful.

There are also so many who have no idea this option even exists. IEP meetings are a good starting point in educating families of these options. I write that knowing it's a long shot of happening unless a law is made to require it.

I also think that stating that everyone has the right to make decisions is important as well. That is the fundamental of SDM.

It needs to be pushed as soon as a child starts their transitional IEP.

Yes, folks need to know there are options and understand those options.

I like the human right approach. It gives me a legal foundation to think about how SDM should work so they [our children] can make the best decision for them.

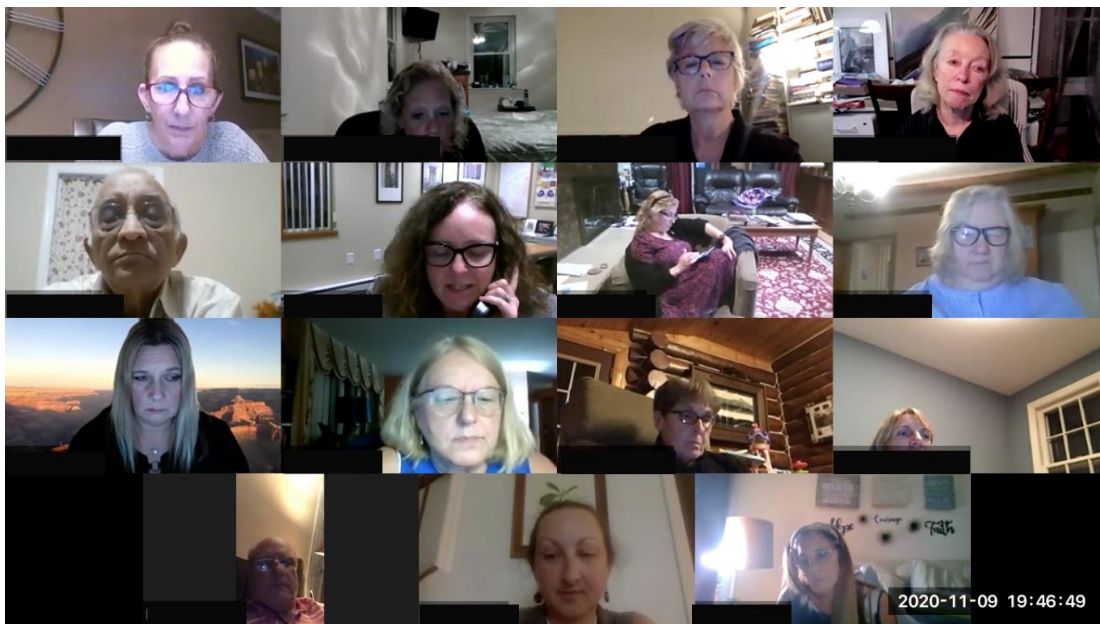
Staff thought that the two, 2-hour sessions as originally conceived contained too much information to cover in the allotted time and would not be conducive for parents to discuss their views and opinions, so the format was revised. A 1-hour webinar was held in early November for all Parent to Parent regions, during which Parent to Parent's Executive Director interviewed SDMNY's Project Director about supported decision-making and SDMNY's 3-phase facilitation process. The format provided ample time for conversation and questions. Four (4) small, interactive regional focus groups on the Principles followed throughout November and December. Also in December, a presentation on SDM and SDMNY's 3-phase facilitation process was held for Parent to Parents' Spanish-speaking members. Regarding content, staff felt it was imperative to begin both the webinar and focus groups by stating the important point that SDM is an alternative to, not a replacement for guardianship, and that it may be the appropriate choice for some, but not all families. Staff also stressed the importance of choosing appropriate language, *You'll want to make it as effective and meaningful as possible; words matter and everyone uses different language to describe things in different regions.*

Parent to Parent disseminated regional flyers to recruit interested parents (**see Appendix**). There was such a considerable response that the presentations and focus groups reached capacity quickly. There were far more parents who wanted to participate than could be accommodated, so Parent to Parent created a waiting list. The enthusiastic response is consistent with Parent to Parent's experience that parents across New York State increasingly seek information about supported decision-making. Parents who attended both the webinar and focus group received \$40 gift cards as a token of thanks. Presentations and focus groups were held remotely due to the COVID-19 pandemic and intentionally kept small (6–8 participants) to create an intimate environment in which parents could feel comfortable asking questions and discussing their personal circumstances. Participants' knowledge of supported decision-making ranged from those who were completely unfamiliar to those who had fundamental knowledge, and some who had in-depth knowledge and seek an alternative to guardianship.

Parents asked many detailed questions about SDM and SDMNY's 3-phase facilitation process during the webinar, and requested a review of these during the focus groups. SDMNY modified the focus group format to include a brief slide presentation/review (**see Appendix**). All four (4) focus groups followed the same format: first, remaining questions from the webinar were answered; the slide presentation/review was shown; the process of drafting the 14 Principles was explained; a slide presentation of the Principles was shown; and finally, parents discussed their responses to the Principles. Though focus groups were scheduled to last two (2) hours, they all went over time, to allow for full discussion.

Below is a chart of the dates each regional event was held and the number of participants.

Date	Event	Regions	Number of Participants
August 31, 2020	Presentation on SDM/SDMNY	Parent to Parent Staff	15
November 9, 2020	Presentation on SDM/SDMNY	All	29
November 17, 2020	Focus Group/Legislative Principles	Adirondack & Central NY	4
November 19, 2020	Focus Group/Legislative Principles	Western NY & Southern Tier	6
December 2, 2020	Focus Group/Legislative Principles	Long Island	5
December 7, 2020	Focus Group/Legislative Principles	Capital District & Hudson Valley	10
December 14, 2020	Presentation on SDM/SDMNY- Spanish	All	19



Key Outcomes from Presentations and Focus Groups

1. Parents in all four (4) focus groups unanimously agreed that all of the 14 Legislative Principles enumerated earlier should be included in an SDMA Law. One parent enthusiastically remarked, *I agree with all of the Principles, definitely. I hope that the OPWDD proposal is successful!* Principle #6—*The Decision-Maker can change or revoke the SDMA at any time*—resonated most, with reflective discussion concerning questions such as, *What does changing it really mean? How do we create a model to make sure that any changes done are still in same spirit of first agreement?*
2. Parents in all four (4) focus groups repeatedly expressed their enthusiasm for supported decision-making and several articulated that more people need to fully understand the impact of guardianship and know about SDM as an alternative. Many have transition-age children who have already conveyed to them that they do not want guardianship obtained. Others noted that they would be more willing to pursue SDM if legislation existed. Discussion responses included:

It (SDM) should be incorporated as part of a transition plan... parents should know what other alternatives have been considered before jumping into guardianship... it should also be discussed as part the transition from pediatric to adult health care.

I think it would help young adults become more invested in the process and learn about decision making early on during transition.

I think it's great. Not sure yet if it's for my son but we should have the option.

I know this is a transition year. The Care Manager mentioned that New York state is trying to look at this type of program and guardianship might not be appropriate. It's me investigating all the options like I always do. I think he will be able to make guided decisions as he gets older, but I don't know that it's right right now for us.

Legislation is path forward to have SDMA's legally recognized and sustain supported decision-making as option.

Yes, yes to legislation!

Regarding decision making...everyone grows in experience in making decisions. None of us would want our adult life reputation to be based on the decisions we made at 17–18.

I have been feeling like a bit of a hypocrite honestly. I have been encouraging him to advocate for himself for over a decade...and now to have the only option be guardianship...It hasn't felt right.

I have a son who is 17 years old. I reached out to his Care Manager because I've been kind of anxious about taking the next step for him. His doctors, his psychiatrists, everyone's just basically pushing me, 'guiding me' [air quotes] to go for guardianship. I've been expressing my concern with

that. I don't want to take his rights away. I want him to have guidance and I just want him to be safe...It came at a good time; I have to say.

3. Parents substantially agreed, whether or not they and their children intend to pursue supported decision-making, that any SDMA law should require a recognized, fairly lengthy and quality facilitation process that leads to an SDMA with integrity. They discussed that the facilitation process offers a form of protection, meaning it guards against parties who could take advantage of people with I/DD, forcing them to hastily sign agreements. One parent noted, *I would think it would be important to think about facilitation beyond signing of SDMA.* Another said, *I like the fact you are [doing it] with such thought and support though the process.* Conversations included SDMNY's current discussions with the Office of People with Developmental Disabilities to permit participants in the Self-Direction Program to spend their funds to pay for SDM facilitation. One parent remarked, *That is exciting!! Because potentially, if a parent starts Self-Direction very early, this could be built in along the way.*
4. Parents uniformly expressed their understanding that a proposed SDMA law would not abolish guardianship; *We're talking about providing a very valuable alternative...it allows adult children to retain all of their legal rights.*
5. Parents were reassured by the fact that Supporters who sign SDMAs do not assume liability for Decision-Makers' decisions, as is the case with guardians who make decisions on behalf of their wards, and that the *Notice to Decision-Maker* section of SDMNY's SDMA contains language that emphasizes that actuality, "Only I am responsible for my decisions."
6. Parents were reassured to hear and understand that SDMA legislation would continue to provide people with I/DD the same legal protections (such as the ability to void contracts for fraud, duress, or overreaching) that exist for everyone else. Also, several expressed being reassured that there will be a system in place to resolve any issues that may arise out of the signed SDMA over time—namely, mediation through New York State's Community Dispute Resolution Centers. One parent remarked, *this gives a family the feeling that there are some protections if they choose supported decision-making.*

CONCLUSION

Overall, parents were excited about SDM, supportive of SDMA legislation, and supportive of the provisions in the SDMNY Principles. They felt particularly strongly about Principle #8, that is, the need for there to be information about SDM in the education and court systems, so that parents know that there is a real alternative. They also appreciated tying recognition of decisions made under SDMAs to a facilitation process because it meant that unscrupulous people could not simply get people with I/DD to sign SDMAs without a real understanding of what was involved.

APPENDIX

- I. Parent to Parent's Focus Group Regional Flyers

- II. SDMNY's PowerPoint Presentation: Supported Decision-Making (SDM): A Quick Review