LESSONS FROM 4 YEARS OF THE SUPPORTED DECISION-MAKING NEW YORK (SDMNY) WORK
The Project
In 2016, Hunter College/CUNY, New York Alliance for Inclusion and Innovation, Disability Rights New York, and The Arc Westchester began a project funded by the New York State Developmental Disabilities Planning Council to promote supported decision-making in New York State.

By 2021, we hope that many persons with I/DD will be able to make their own decisions just like everyone else.

Education
SDMNY is getting people talking about supported decision-making by creating spaces for information sharing and dialogue with key stakeholders at conferences, information sessions, and trainings.

Check out our upcoming events at: www.sdmny.org/calendar

Facilitation
SDMNY is helping people with I/DD work towards supported decision-making agreements. SDMNY's trained facilitators help people with I/DD think about the types of support they may need to make important decisions about their lives.

These agreements are an important alternative to guardianship that allow people with I/DD to keep their right to make decisions.

Transformation
SDMNY is developing model diversion and restoration programs so that key stakeholders will have the tools they need to make supported decision-making a viable option for people with I/DD.

SDMNY is working with policy-makers and professionals to develop sustainable systems, policies, and practices to increase access to supported decision-making in New York State for years to come.

Contact us at: www.sdmny.org/contact-us
We believe that every person has the right to make his or her own decisions, regardless of disability, and to have those decisions legally recognized, consistent with the United Nations Convention on the Rights of Persons with Disabilities.

“Supported decision-making will help me be more independent. It will help me with doing more things for myself.”
OUR APPROACH

SDMNY uses a three-phase facilitation model to help adults with intellectual disabilities create supported decision-making agreements as an alternative to guardianship. SDMNY’s trained facilitators, supervised by SDMNY’s experienced mentors, work one-on-one with Decision-Makers and their chosen Supporters.

"Why is my agreement important to me? Because I can make all my own decisions and my supporters cannot make those decisions for me. ... I also like knowing that if anything happens to my folks, I have a group of supporters who can help me."

"I liked working with my facilitator to come up with the right words to let everyone know how I make decisions ... and seeing how my family has gained understanding about how my rights were so limited by guardianship."

ABOUT US

SDMNY is a 5-year joint project by Hunter College at the City University of New York, in partnership with the New York Alliance for Inclusion and Innovation and the Arc Westchester, with Disability Rights New York as the project’s legal arm, and with funding from the New York State Developmental Disabilities Planning Council.

We aim to establish a model for how supported decision-making can be used as a viable alternative to guardianship for adults with intellectual disabilities throughout New York State.

“Executing my agreement has given me more confidence in my ability to make decisions and to share the process of making those decisions with my Supporters’ guidance and trust.”

Get in touch and find out how SDMNY can help you create a supported decision-making agreement.
Factsheet

Interested in our pilot program? This factsheet tells you what you need to know if you want to sign up. If you have questions, you can reach us at www.sdmny.org/contact-us.

What is SDMNY?
SDMNY is a joint project of Hunter College/CUNY, New York Alliance for Inclusion and Innovation, Disability Rights New York, and the Arc Westchester with funding from the NYS Developmental Disability Planning Council. SDMNY aims to promote supported decision-making as an alternative to guardianship for persons with intellectual or developmental disabilities (I/DD) in New York State. In our project, we refer to persons with I/DD as “decision-makers” or “DMs.”

How does the SDMNY pilot program work?

1) First, you work with a trained facilitator on a worksheet to map out how you make decisions now and how you want to make decisions in the future, including:
   - in what areas—like money or education—you might want support,
   - in what areas you want to make decisions without any support,
   - what kinds of support you want, and
   - how you want to receive those supports.

2) Then, you work with your facilitator to choose one or more trusted decision-making supporters. You begin to think about how you want your supporters to support you to make decisions in the future.

3) Next, you and your facilitator meet several times with your chosen supporters, using your worksheet to map out a supported decision-making agreement (SDMA). The SDMA spells out:
   - how you would like to receive support from your supporters,
   - whom you would like to receive support from,
   - what decisions you would like to receive support for, and
   - how you will make decisions with your supporters.

4) Last, you and your supporters will all sign the SDMA and you can begin using it for making decisions in your daily life. You can also take steps to restore your rights, if you choose to do so, and if you have a guardian.

What is your role in the SDMNY pilot?
You will work with your assigned facilitator through each step of the process. Although you will have a facilitator to help you, you drive the process. You choose your supporters, you make an agreement with them, and you tell your supporters how you want to receive support to make decisions.
What do you get out of participating in the SDMNY pilot?
Working with one of our trained facilitators, you will end up with an SDMA that may help you and your supporters deal with your school, with benefits and services, or with others who might want to be sure that you can make your own decisions. You will also become part of a very big, very exciting movement involving people from all over the world, who are working together to help people with I/DD use alternatives to guardianship.

How will SDMNY use information about you?
SDMNY will make sure all information about DMs is kept secure and confidential. We will keep any written information about you in a secure storage available only to the people working on the pilot program. We will keep electronic material in a folder secured with a password that only the people working on the pilot will know.

How long will the facilitation process last?
The facilitator will meet with you approximately once a month for an hour per meeting for about 12 months to develop the SDMA with your chosen supporters. Depending on many factors, the process may go more quickly or more slowly.

What happens after the pilot program is over?
After making your SDMA, you will meet with your facilitator to talk about how you and your supporters want to work together in the future. We will follow up with you from time to time to see how things are going or if you need any more help from us. You can keep any materials and tools we give you during the pilot program. Also, based on your feedback, we will try to improve the supported decision-making materials for future DMs.

What if I want to stop doing SDMNY?
Our pilot program may not be right for everyone. You can stop at any time without problems. Also, you can ask us to make changes to the process, such as accommodations that will make the process easier for you. If you decide to leave the project, we will want to talk with you about your decision and try to resolve any issues you had, while respecting and honoring your decision.

What if I want to make a complaint?
If you are not happy with the way we do things in our pilot program, you may make a complaint to the SDMNY Project Coordinator Matthew Smith, Esq. at (212) 396-7754 or matthew.smith@hunter.cuny.edu.
FREQUENTLY ASKED QUESTIONS (FAQs)

Supported Decision-Making (SDM)
Everyone has the right to make their own decisions.

WHAT IS SDMNY (SDMNY)?
Supported Decision-Making New York is a 5-year pilot project by Hunter College/CUNY, the Arc Westchester and the New York Alliance for Inclusion and Innovation in partnership with Disability Rights New York. SDMNY has three goals: to raise awareness about supported decision-making as an alternative to guardianship for persons with intellectual or developmental disabilities (I/DD), to help persons with I/DD either with or without guardians to try supported decision-making to see if it works for them, and to encourage policy-makers and organizations to help others to learn about and use SDM. SDMNY is funded by a grant from the New York State Developmental Disabilities Planning Council (DDPC).

WHAT IS SUPPORTED DECISION-MAKING?
Supported decision-making is an alternative to guardianship that empowers persons with I/DD to make their own decisions in the ways they prefer and with the support of people they trust. Persons with I/DD may choose to create Supported Decision-Making Agreements (SDMAs) to put their preferences into writing. (See other side for more.)

WHAT IS A DECISION-MAKER?
SDMNY uses the term “Decision-Maker” to describe the persons with I/DD participating in SDMNY’s pilot programs. It helps remind everyone involved that at the end of the day, supported decision-making is about enabling a person with I/DD to make her or his own decisions while getting the support she or he may also need to make that happen.

WHO ARE SUPPORTERS?
Supporter(s) can be anyone that a person with I/DD deems reliable, trustworthy, and knowledgeable, including both natural supporters (family members, friends, and neighbors) and paid professionals (direct support staff, clinicians, and therapists).
**WHO ARE FACILITATORS?**
Facilitators are persons who have experience and/or specialized training in working with persons with I/DD and are trained by SDMNY on good practices in supported decision-making. SDMNY recruits Facilitators from a variety of places, including Master in Social Work (MSW) programs, provider agencies that share our mission, Occupational Therapy (OT) and Occupational Therapy Assistant (OTA) academic programs, retired and currently active professional volunteers. They receive 2 days of intensive training from SDMNY staff and ongoing supervision from SDMNY Mentors.

**WHO ARE MENTORS?**
Mentors are recruited by SDMNY based on their facilitation experience. They supervise Facilitators, checking in with them before and after every meeting with regularly during the process. They help to ensure that Facilitators follow the facilitation process developed by SDMNY and to troubleshoot issues that may arise.

**WHAT IS A SUPPORTED DECISION-MAKING AGREEMENT?**
A Supported Decision-Making Agreement (SDMA) sets out four basic things: the areas in which a Decision-Maker wants support, what kinds of support the Decision-Maker wants in each area, whom the Decision-Maker wants support from, and how the Decision-Maker wants to work with Supporters. This way, the Decision-Maker and Supporters can discuss and write down the Decision-Maker’s process for making decisions and system of supports. The SDMA is like a contract in that it describes how the Decision-Maker and Supporters will work together to make certain decisions, but it’s not legally binding in New York State. An SDMA can be an important advocacy tool to educate others about how Decision-Makers want to make decisions and to remind Supporters about their roles.

**WHAT IF THE SDMA NEEDS TO BE CHANGED?**
As circumstances change, the Decision-Maker may wish to change the agreement by adding or subtracting Supporters (as, for example, when a Supporter moves away, or is no longer able to participate), or changing the areas in which she or he wants support, or the kinds of support she or he wants. The Decision-Maker has the right to change or terminate the SDMA at any time, and can ask SDMNY for help to do so.

**HOW LONG DOES IT TAKE TO MAKE AN SDMA?**
In SDMNY’s pilot programs, Decision-Makers generally meet once a month with their Facilitators and it can take between 6 and 12 months to complete an SDMA.

**WHAT HAPPENS IF A DECISION-MAKER WANTS TO STOP THE PROCESS?**
Decision-Makers are free to stop or delay their process towards an SDMA at any time. They can pick up right where they left off, too.
Guardianship and Alternatives: Frequently Asked Questions

What is guardianship?
Guardianship is the means by which the state (through a court proceeding) takes the right and power to make choices away from a person (often called the "ward") and gives the power to another, the guardian. In New York, the ward loses all legal capacity to make decisions about healthcare, finances, where to live, who to associate with, what kind of education or work s/he will have, and every other aspect of her/his life.

What is the purpose of guardianship?
Historically, guardianship has been seen as a way of protecting vulnerable persons, including persons with intellectual and developmental disabilities (I/DD). Changes in the way that we understand disability today challenge this view. For example, research indicates that promoting self-determination and inclusion in the community is often the best protection. Even if guardianship may have made sense in the past when no one expected persons with I/DD to strive for greater independence, today self-determined and inclusive lives are the goal.

The current law in New York allows parents to obtain guardianship, often without even a hearing, based entirely on affirmations by healthcare professionals attesting to their child's I/DD and the conclusion that it would be in the child's best interest to have a guardian appointed. This law has been widely criticized by scholars and practitioners and new versions of the law with more procedural protections are being considered by the legislature.

Why do people seek guardianship for their children?
Parents are often told that they need to obtain guardianship when their child with I/DD turns 18 in order to participate in their child’s educational planning or to seek benefits from the Office of Persons with Developmental Disabilities (OPWDD). This misinformation often leads parents to seek guardianship without realizing that guardianship entails the total deprivation of their child’s rights and without considering available alternatives.

What are alternatives to guardianship?
There are many alternatives, depending on why people think guardianship may be desirable in the first instance. For example, if the issue is financial, there are alternatives
including representative payeeships for SSI payments, authorized representation for Medicaid benefits, joint or limited bank accounts, credit or bank cards with predetermined limits, and powers of attorney. For healthcare, the persons with I/DD may execute a health care proxy. Also, New York’s Family Health Care Decisions Act permits involved family members to make decisions on behalf of persons with I/DD without guardianship.

**Is supported decision-making an alternative to guardianship?**

Yes. It is based on the understanding that all people make decisions and choices with the help of others, while recognizing that persons with I/DD may need more or different kinds of help. Supported decision-making allows persons with I/DD to choose trusted others, often family members, to support them in making *their own decisions*. Supports may include gathering information, helping persons with I/DD evaluate that information or understand the consequences of a decision, communicating decisions to third parties, and supporting persons with I/DD to take responsibility for their decisions.

Often the arrangement will be reduced to writing in a contract called a “supported decision-making agreement.” Some institutions, like schools or OPWDD may agree to accept such agreements instead of guardianship as, for example, is the case in Washington, DC. Some states, like Delaware, Texas, Wisconsin, and Washington, DC, now have laws requiring private third parties (like doctors, financial institutions, or landlords) to accept supported decision-making agreements. While New York does not yet have such a law, the Supported Decision-Making New York (SDMNY) project, funded by the NYS Developmental Disabilities Planning Council, hopes to develop evidence that will support such legislation in the future.

**What are the benefits of supported decision-making?**

A person with I/DD never loses her/his rights, including important rights to contract, to vote, to work, to marry—all of which are critical to her/his human dignity and personhood. Making one’s own decisions fosters self-determination and teaches a person to learn from bad choices and to make good choices in a way that will serve and protect her/him when her/his parents are no longer able to do so. Being connected to supporters protects against the kind of exploitation or abuse that can occur when a person is isolated and powerless. Supporting persons with I/DD to make their own decisions is the best way to carry out the purpose of laws like the Americans with Disabilities Act, which requires persons with I/DD to receive equal treatment, and the Individuals with Disabilities Education Act, which requires that persons with I/DD have opportunities to lead self-determined lives.
PROJECT UPDATES
Year 3 (Apr 2018 - Mar 2019)

In Numbers

Pilot Program Sites
- Rochester
- Albany
- Westchester
- Long Island
- New York City

Milestones
- Facilitators Trained: 57
- Stakeholders Educated: 1,141
- Website Views: 29,133

Decision-Makers
Total: 71

Testimonials

Facilitator, Westchester:
“It totally changes the power dynamic. I'm not providing a traditional service. I'm just facilitating her in making decisions about how she wants to receive support in her life. . . . It gives a lot more autonomy to the person.”

Supporter, Queens:
"Every person warrants the ability to develop a sense of control over his life, especially someone as deserving, responsible, and level-headed as my cousin."

Decision-Maker, Rochester:
“it reassured me that my process for decision-making is good for me. It works for me.”

Learn more at: www.sdmnyny.org

Supported Decision-Making New York
Hunter/CUNY | NY Alliance | DRNY | The Arc Westchester

Developmental Disabilities Planning Council
Project Statement

What is “supported decision-making”?
Supported decision-making is not a strange, new thing, but rather a process by which a person with an intellectual or developmental disability (I/DD) can be supported in making his or her own decisions. Supported decision-making draws on our common experience of consulting or seeking assistance from others when we make decisions or choices in our own lives. Whether it is renting an apartment, buying a car, or choosing to get married, we do not make decisions in a vacuum, but with "support" from friends, family or experts of some kind.

People with I/DD also have a right to make their own choices and decisions, but may need more, or different kinds of support to do so. Supports may include helping a person access information that is useful or necessary for a decision, helping her/him weigh the pros and cons, assisting in communicating the decision to third parties, and/or in carrying it out. But the decision is always the person’s (who we call the "decision-maker") and not the supporter’s.

Often the arrangement is reduced to writing in what is called a “supported decision-making agreement” which spells out the rights and obligations of the parties, including an understanding by supporters that they are to assist the decision-maker, but never to substitute their own decision in lieu of the person wanting the support.

What is the “Supported Decision-Making New York” project?
Supported Decision-Making New York (SDMNY), funded by a five-year grant from the NYS Developmental Disability Planning Council, comprises a consortium between Hunter College/CUNY, New York State Association of Community and Residential Agencies (NYSACRA), and the Arc of Westchester. The project’s goal is to increase awareness of supported decision-making as an alternative to guardianship for persons with I/DD.

SDMNY will conduct two pilot programs designed to divert persons with I/DD at risk of guardianship and to restore the rights of adults with I/DD already subject to guardianship, with legal assistance provided by Disability Rights New York (DRNY). Results of these pilots, which will begin in NYC and subsequently be rolled out statewide, will be used to create educational materials for a variety of stakeholders—including persons with I/DD, their parents and family members, professionals in special education, lawyers, judges and the court system, legislators—and to disseminate materials through information sessions, webinars, conference presentations, and an active social media awareness-raising campaign.

By project’s end, SDMNY hopes to have established a viable model for utilizing supported decision-making for persons with I/DD in New York that can result in legislative, administrative, and policy changes. Ultimately, by promoting SDM, the SDMNY will thereby promote the inclusion, ensure the self-determination, and protect the civil and human rights of persons with I/DD.

Learn more at www.sdmny.org.
A Supported Decision-Making Agreement can help!

- A supported decision-making agreement is like a contract that self-advocates can sign with their supporters.
- It describes the kinds of support that a self-advocate wants from only supporters the decision-maker chooses.

- A supported decision-making agreement can be an important self-advocacy tool.
- That’s why the SDMNY project is working at 5 sites in New York City, Westchester, Rochester, Long Island, and Albany.
- If you live in one of these areas, we can assign you a facilitator to help you make your own supported decision-making agreement for free!

Interested? Call us at 212-396-7806 or visit www.sdmny.org to learn more.

SDMNY
CALL FOR DECISION-MAKERS!

- Do you want to make more of your own decisions?
- Do you want support to make hard decisions?
- Do you want others to respect your decisions more?

A Supported Decision-Making Agreement can help!
Honest conversations about disability with parents, educators, and people with disabilities.

Episode 1: Defining Disability
Dr. Jessica Bacon from Montclair State University and Lori Podvesker from INCLUDEnyc explore how the opportunities, experiences, and education available to people with disabilities are shaped by the lens through which society views disability. They call on each of us to rethink our definition of disability.

Episode 2: Advocacy, Activism, and the Future
Susan Scheer, CEO at the Institute of Career Development and founder of ACCESS-A-RIDE, and Jean Mizutani of INCLUDEnyc discuss key legislation, such as the Americans with Disabilities Act, and other laws born of the vigorous activism of people with disabilities and their allies.

Episode 3: Unprepared: How People with Disabilities Paved the Way for Emergency Preparedness in NYC
Susan Dooha, Executive Director at The Center for Independence of the Disabled, NYC (CIDNY) and Ruth DiRoma of INCLUDEnyc discuss the movement to ensure that all New Yorkers are safe during emergencies and what the future holds after Hurricane Sandy.

Episode 4: Student Data, Privacy, and the Internet Age
Leonie Haimson, one of New York’s most influential education advocates and proponent of small class sizes, and Jean Mizutani of INCLUDEnyc address the challenge of controlling student data without adequate regulatory safeguards in education, today’s most data-minable industry.

Episode 5: Restorative Justice in Action in NYC Schools
Kailani Capote, Restorative Justice Coordinator at New York Peace Institute, shares her experiences implementing restorative justice at a Harlem high school with Colin Montgomery of INCLUDEnyc. Restorative justice practices aim to limit school suspensions and equip students and staff with social, emotional, and conflict resolution tools.

Episode 6: Obtaining High Quality Special Education Services in an Imperfect World
Oroma Mpi-Reynolds, education lawyer and parent, explores the impact of race, culture, and socioeconomic status on special education with Kpana Kpoto of INCLUDEnyc. Listen as they discuss the inequities in the special education system and how to ensure high quality supports and services despite them.

Listen to the entire series on

INCLUDEnyc info@includenyc.org | 116 E. 16th Street 5th Floor | New York, NY 10003
Join us for monthly series of live streamed, interactive online workshops on a wide variety of disability topics.

Below is an archive of all of our past episodes with resources you can use to follow along.

You can also register for an upcoming episode here.

- Bodies, Curiosity, and Touching For Parents of Young Children
  Video | Resources
- Charter Schools and Students with Disabilities
  Video | Resources
- Specialized Programs for Students with Disabilities
  Video
- Inclusion Programs for District 75 Students
  Video | Resources
- Turning 18 and Supplemental Security Income (SSI)
  Video | Resources
- Puberty, Sexuality, and Behavior: How to Guide Young People with Disabilities
  Video | Resources
- Disability vs. Language Barrier for English Language Learners
  Video | Resources
- Positive Supports for Young Children with Challenging Behaviors
  Video | Resources
- Applied Behavior Analysis (ABA) for Infants and Toddlers with Autism
  Video | Resources
- How to Talk to Your Child About Bullying
  Video | Resources
- From School to Work
  Video | Resources
Supported Decision Making - Alternative to Guardianship for People with Disabilities
Video | Resources

How to Get Assistive Technology on Your Child’s IEP
Video | Resources

Moving from Early Intervention to Preschool Services
Video | Resources

Autism & Wandering
Video | Resources

Accessibility for Young People with Disabilities in NYC Schools
Video | Resources

Life planning for families of loved ones with disabilities
Video | Resources

Kindergarten for Children with Autism Spectrum Disorder
Video | Resources

Student-led Individualized Education Program (IEP) Process
Video | Resources

Get the special education Services you want through mediation
Video | Resources

Discover how accessible reading materials work for students with disabilities
Video | Resources

Ask an Expert: Special Education
Video

Independence & Travel Training
Video | Resources
Is your child **struggling** in school?

Does your child have **special needs** or an **IEP**?

Do you have questions about your young person with a **disability**?

WE CAN HELP FOR **FREE**

INCLUDEnyc provides one-to-one help, information resources, and workshops on topics that are important to you, **at no cost**.

**CALL US**
(212) 677-4660

**TEXT US**
(646) 693-3175

**VISIT INCLUDEnyc.org**
**FOR INFORMATION AND UPCOMING WORKSHOPS**
¿Su hijo tiene problemas en la escuela?
¿Su hijo tiene un IEP (Programa de Educación Individualizada)?
¿No sabe cómo ayudar a su hijo con necesidades especiales?

**NOSOTROS LO PODEMOS AYUDAR GRATUITAMENTE**

INCLUYeNYC proporciona ayuda individualizada, recursos de información, y talleres gratuitos sobre temas que son importantes para usted.

**LLÁMENOS**
(212) 677-4668

**ENVÍE UN MENSAJE DE TEXTO**
(646) 693-3157

**VISITE INCLUYeNYC.org**
INFORMACIÓN, RECURSOS Y TALLERES