SUPPORTED DECISION MAKING
Supported Decision-Making New York

Ensuring the right of New Yorkers with I/DD to make their own decisions

The SDMNY Project

In 2016, Hunter College/CUNY, New York State Association of Community and Residential Agencies (NYSACRA), Disability Rights New York (DRNY), and Arc of Westchester began a project funded by the New York State Developmental Disabilities Planning Council (DDPC) 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.

1 Awareness

SDMNY will get people talking about supported decision-making by creating spaces for learning and dialogue at conferences, seminars, and trainings.

We will generate knowledge about promising practices by disseminating information with key stakeholders in the community.

2 Diversion

Sometimes people think that persons with I/DD need guardians to make decisions for them.

We will help them stop and think about if supported decision-making can be a good option instead.

We will link persons with I/DD with trained facilitators so that they can make supported decision-making agreements.
3 Restoration
Sometimes persons with I/DD receive guardians even if they do not want or need them.

We will help them get their rights back so they can make their own decisions.

We will link them to DRNY to regain their rights and take back control of their lives.

4 Sustainability
Persons with I/DD and their supporters need tools that will help them practice supported decision-making in their daily lives.

We will develop the tools they need and also train educators, social workers, providers, and lawyers on how they can promote supported decision-making.

SDMNY participants will form learning communities so that they can continue to learn how to make supported decision-making work for them.

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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 with I/DD’s (whom we call the “decision-maker”) and not the supporter’s.

Often the arrangement is reduced to writing in 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 instead 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), Disability Rights New York (DRNY), 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 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 facilitating 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.
Factsheet

This factsheet tells you what you need to know about and agree to if you want to participate in one of SDMNY’s pilot programs. You can ask for help to understand this information by contacting the SDMNY Project Assistant, Guadalupe Vidal, at (212) 396-7806.

What is SDMNY?
SDMNY is a joint project of Hunter College/CUNY, NYS Association of Community and Residential Agencies (NYSACRA), Disability Rights New York (DRNY), and the Arc of 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 do the SDMNY pilot programs work?
SDMNY has two pilot programs. The Diversion pilot is for DMs who are not under guardianship. The Restoration pilot is for DMs who are already under guardianship. Each pilot has 4 basic steps:

1) First, you will 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, and
   - what kinds of support you want.

2) Then, you will work with your facilitator to choose one or more supporters whom you trust to help you make decisions in the future and begin to think about how you want them to support you.

3) Next, you and your facilitator will meet several times with your chosen supporters, using your worksheet to write a supported decision-making agreement (SDMA), which 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 practice using the SDMA so that you can make decisions in your daily life, and then you will all sign the SDMA.

   If you are part of the Restoration pilot, you can get free legal assistance from DRNY to go back to court to undo your guardianship and restore your rights.

What is my 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 will drive the process. You will choose your supporters, you will make an agreement with them, and you will tell your supporters how you want them to help you.
If you want, you can also be part of the project evaluation done by Council of Quality and Leadership (CQL). CQL has helped organizations to improve the quality of services for persons with I/DD for over 40 years. If you agree to share your SDMNY experiences with CQL, you can help us to understand how to make our project better for future DMs. But speaking with CQL is optional. That means if you decide not to share any information with CQL, you can still participate in SDMNY without a problem.

What do I 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, or with benefits and services, or with others who might want to be sure that you can make your own decisions. You will also be part of a very big, very exciting movement, with people from all over the world, who are working to be sure that people with I/DD have the right to make their own decisions, and not to be put under guardianship.

How will SDMNY use information about me?
SDMNY will make sure all information about you is kept secure and confidential. We will keep any written information about you in a locked storage available only to the people working on the pilot. 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?
Your facilitator will meet with you at least once a month for about 6 months to develop the SDMA with you and your chosen supporters. But depending on many factors, the process may go more quickly or more slowly. We expect that you will meet with your facilitator at least once per month for an hour, but you may meet more often if needed.

What happens after the pilot program is over?
After making your SDMA, your facilitator will meet with you to talk about your involvement and how you and your supporters want to work together in the future. We will follow up 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. Using information from the pilot, we will revise the supported decision-making materials for future pilot participants like yourself.

What if I want to stop doing SDMNY?
Our pilot programs 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 for you, 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 difficulties you had with our pilot program.

What if I want to make a complaint?
If you are not happy with the way we do things in the pilot, you may make a complaint to the SDMNY Project Coordinator Matthew Smith, Esq. at (212) 396-7754 or matthew.smith@hunter.cuny.edu.
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 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 healthcare proxy. Also, New York’s Family Healthcare 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, but 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 their in making *their own decisions*. Supports may include gathering information, helping persons with I/DD evaluate the information and understand the consequences of a decision, communicating decisions to third parties and supporting persons with I/DD in taking 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 Texas and Delaware, 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 be treated equally as others, and the Individuals with Disabilities Education Act, which requires that persons with I/DD have opportunities to lead self-determined lives.
Is your child **struggling** in school?
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