



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

PARENTS / CAREGIVERS

Everyone has the right to make their own decisions.

Supported decision-making (SDM) is an alternative to guardianship that doesn't restrict a person with intellectual or developmental disabilities (I/DD)'s right to make decisions. Because guardianship takes away a person with I/DD's rights to make their own decisions, you should first consider SDM and other alternatives before going to court.



Supported Decision-Making Agreements are written agreements made by persons with I/DD who choose people they trust to be their Supporters in various decision-making areas like health, or money, the specific kinds of support they want to receive and how they want to receive those supports. These Agreements empower persons with I/DD to explain how they make decisions—including with the help of others—and so to challenge stereotypes others—like doctors, financial institutions, or landlords—may have about their capacity to do so on their own. Although they are not yet legally binding, third parties may choose to accept them instead of insisting on guardianship.

There are other legal means to avoid guardianship that can be used with or without SDM, including those listed below:¹

For financial decisions, powers of attorney allow persons with I/DD to transfer decision-making authority for financial and other types of decisions to another person or persons whom they trust.² They can do something similar that is specific to SSI payments by appointing representative payees. For Medicaid benefits, they can appoint an authorized representative. Even less restrictive alternatives that might be useful for managing money include joint or limited bank accounts and credit or bank cards with predetermined limits.

For health care decisions, health care proxies allow persons with I/DD to appoint trusted others as health care agents.³ An agent can make health care decisions for a person with I/DD in the event a doctor deems them unable to consent to treatment. Also, New York's Family Health Care Decisions Act permits involved family members to make decisions on behalf of persons with I/DD in a hospital or nursing homes without guardianship.

By avoiding guardianship, persons with I/DD retain important rights enabling them to make decisions about their lives and fostering self-determination. Talking with persons with I/DD about their decision-making options and supporting them to make their own decisions, even if you disagree with them, gives them the opportunity to develop the lifelong decision-making skills they need to be fully part of their communities.

¹ As of June 2018, Delaware, Texas, Wisconsin, and Washington, DC have laws making these Agreements legally binding on third parties; New York does not. SDMNY hopes to develop evidence that will support legislation, regulations, and policies that will make supported decision-making a more readily available alternative to guardianship in the future.

² Find the New York Power of Attorney Statutory Short Form here: <http://www.nysba.org/CustomTemplates/Content.aspx?id=6554>.

³ Find the New York Department of Health's health care proxy form here: <https://www.health.ny.gov/publications/1430.pdf>.

MYTHS:

Parents often receive confusing or misleading information about guardianship and/or the need to obtain guardianship for their child with I/DD.

Here are some of the common inaccuracies:

1. If you don't get guardianship when your child turns 18, you will no longer be able to participate in her/his IEP meetings or other educational planning.

False. Your adult child has the right to request that you attend IEP meetings. Also, your adult child can execute an educational power of attorney.

2. You need guardianship in order to obtain benefits for your child or otherwise to advocate for your child or negotiate with OPWDD.

False. There is no such requirement. If an OPWDD representative tells you otherwise, you may call Disability Rights New York.

3. Getting guardianship is the best way to protect your child with I/DD.

Not necessarily. Even if you have your child's best interests in mind, another guardian who succeeds you may not. Guardians have wide-ranging authority to change service plans and living arrangements and/or to handle your child's money. Empowering your child to learn how to make good and healthy decisions on their own, and whom they can trust for support, may be a more effective long-term strategy.

4. There is no downside to getting guardianship; everyone does it.

False. Even if you have your child's best interests in mind, getting guardianship may have far-reaching implications for your child's rights. For example, your child may not be allowed to sign up for a gym membership or to vote in elections or to choose whom to marry. Once your child is subject to a guardianship order, it will be difficult for your child to undo it later on, even if your child develops good decision-making skills when she or he is older.

5. "Good" parents get guardianship because their children with I/DD will always be "children" and they need to remain in a parental role.

Not true. When New York's guardianship law for persons with I/DD was made in 1969, no one expected them to go to school, get jobs, and live on their own. Now, more and more parents expect their children with I/DD to become self-determined adults who live rich and inclusive lives. And there are more services available than ever before to help them to reach that goal. That's why today more parents are preparing their children with I/DD for when they will no longer be around; encouraging your child to make her or his own decisions is an important part of that process.

About SDMNY

Supported Decision-Making New York (SDMNY) is a 5-year project of Hunter College/CUNY, the Arc Westchester and the New York Alliance for Inclusion and Innovation in partnership with Disability Rights New York. SDMNY is funded by a grant from the New York State Developmental Disabilities Planning Council (DDPC).

SDMNY has three goals: to raise awareness about SDM as an alternative to guardianship for persons with I/DD, to help persons with I/DD use SDM to avoid guardianship, or, if they already have a guardian, to have their rights restored., and to encourage policy-makers and organizations to help others to learn about and use SDM.

If you know someone who wants to try SDM, SDMNY can help her/him and her/his supporters make a Supported Decision-Making Agreement.

To get started:

You can contact us at www.sdmny.org/contact-us or visit www.sdmny.org/calendar to see the next information session in your area.