



Legislative Affairs
One Whitehall Street
New York, NY 10004
212-607-3300
www.nyclu.org

2021-2022 Legislative Memorandum

**Subject: Supported Decision-Making by People with Intellectual, Developmental, Cognitive and Psychosocial Disabilities
S.7107-B (Mannion) / A.8586-B (Simon)**

Position: SUPPORT

New Yorkers with intellectual and developmental disabilities (IDD) too often face discrimination. Whether because of stigma, prejudice, or fear of liability, third parties routinely refuse to accept their decisions on the basis that they “lack capacity.” A doctor may decline to perform a medical procedure that a person wants or needs; a bank official may deny a person a mortgage; a landlord may refuse to rent to the person just because they have a developmental disability. In order to feel comfortable providing a service or engaging in a transaction, a third party will often insist that a guardian be appointed – a process which deprives a person of all their legal rights.

Supported Decision-Making (SDM) is an important and tested means by which people with IDD can make their own decisions, with the support of trusted persons in their lives. An SDM agreement is a written record of the areas in which such individuals receive support, the kind of support they want in each area, and the persons who have committed to providing that support. Supporters agree to help the supported person understand, consider, and communicate their decisions, giving them the tools they need to make their own informed choices.

The NYCLU has long advocated for the rights of people with IDD to live independent, self-directed lives as active members of their communities.¹ Accordingly, the NYCLU supports the formal recognition of SDM as an alternative to restrictive guardianship.

S.7107-B / A.8586-B will permit people with IDD to choose trusted support people to help them direct their lives, without court intervention or loss of civil rights. The NYCLU strongly supports this legislation and urges its passage.

¹ Since 1972, the NYCLU has been lead plaintiffs’ counsel in the landmark Willowbrook class-action litigation on behalf of people with intellectual disabilities, a class action that was in the vanguard of the civil rights movement for people with disabilities that led, some two decades later, to the passage in 1990 of the American with Disabilities Act. The Willowbrook case currently bears the caption *New York State Assoc. for Retarded Children v. Hochul*, Nos. 72 Civ. 356/7, 393 F. Supp. 715 (E.D.N.Y. 1975).

SDM advances important constitutional and civil rights standards for affirming and non-discriminatory treatment of people with IDD.

People end up under orders of guardianship because a court identifies them as having disabilities. Guardianships are typically characterized as harmless, including by the courts and judges who routinely impose guardianship regimes on people with IDD. In fact, a guardianship is a serious and often permanent arrangement which drastically limit a person's civil liberties. Reflexive reliance on guardianships is a glaring example of institutional paternalism and infantilization of people with disabilities.

Rather than view guardianships as a means of first resort, constitutional principles demand that guardianship should be utilized *only* when less-restrictive supports are not available. Beginning with the U.S. Supreme Court decision in *O'Connor v. Donaldson*,² substantive due process has been understood to include a requirement that, when the state uses its police power to interfere with an individual's liberty, it must employ the least restrictive means available to achieve its objective of protecting the individual and the community. This means that alternatives to guardianship such as SDM should, whenever possible, be identified and considered *prior* to the commencement of guardianship proceedings.

In the years since that key Supreme Court decision, New York courts have embraced this principle of least restrictive alternatives.³ New York lawmakers have also incorporated least restrictive alternatives in liberty-curtailling statutes, including those dealing with “assisted outpatient treatment” or “Kendra’s Law,”⁴ and adult guardianship.⁵

² 422 U.S. 563 (1975).

³ See e.g. *Kesselbrenner v. Anonymous*, 33 N.Y.2d 161, 165 (1973) (“To subject a person to a greater deprivation of his personal liberty than necessary to achieve the purpose for which he is being confined is, it is clear, violative of due process”); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D.2d 189, 197–98 (1st Dept 2001).

⁴ N.Y. M.H.L. § 9.60. See, e.g., *Manhattan Psychiatric Center*, note 3 *supra* at 197 (noting the “underlying concern of the legislature in enacting Kendra's Law, i.e. to place as few restrictions as possible on persons who, though suffering from mental illness, are capable of living in the community with the help of family, friends and mental health professionals”); *Kendra's Law: The Process for Obtaining Assisted Outpatient Treatment*, OMH Q, Dec. 1999 at 416 (noting Kendra's Law requires that AOT be the least restrictive alternative); Illise L. Watnik, *Comment; A Constitutional Analysis of Kendra's Law: New York's Solution for Treatment of the Chronically Mentally Ill*, 147 U.Pa. L. Rev. 1181, 1199–1204 (discussing due process imperatives incorporated in the statute).

⁵ N.Y. M.H.L. § 81.01 (“The legislature finds that it is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable”). See also Rose Mary Bailly, *Practice Commentaries*, 34 A McKinney's Consol. Laws of N.Y. on N.Y. M.H.L. § 81.01 (“The legislature recognized that the legal remedy of guardianship should be the last resort for addressing a person's need because it deprives the person of so much power and control over his or her life”).

SDM is widely recognized as a constitutionally required “less restrictive alternative” to guardianship.⁶ The Uniform Law Commission has explicitly included SDM as such in its recently revised Uniform Guardianship, Conservatorship and Other Protective Proceedings Act,⁷ and several states have followed suit.⁸ The use of SDM, rather than a guardian's substituted decision making, is also consistent with international human rights, most particularly Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).⁹

In addition, SDM statutes also draw on the non-discrimination principles of the Americans with Disabilities Act. These principles validate SDM agreements as an “accommodation” that permits the person with IDD to engage in legal transactions free from discrimination.¹⁰

S.7107-B / A.8586-B will formally establish SDM in New York and provide meaningful autonomy and control to people with IDD.

This important bill will facilitate the equal treatment of people with disabilities who make decisions pursuant to a valid SDM agreement. It would require third parties to accept those decisions and confer immunity from liability in return for their good faith acceptance. Simply put, once SDM is formally recognized in New York, a person with IDD will be able to endorse an SDM agreement, a document that will help doctors, bankers, lawyers, landlords, and other third parties to feel confident in accepting the decision of the person with a disability – without fearing lawsuits or malpractice claims. By enacting this legislation, lawmakers are ensuring that people with IDD have the same right as anyone else to make their own decisions, and to have those decisions recognized by others.

Importantly, S.7107-B / A.8586-B also recognizes that SDM will look different for everyone. Where necessary, supporters will interpret a supported individual's words and behavior to determine their goals and preferences. This means finding tools and

⁶ SDM has been recognized as a “less restrictive alternative” to guardianship by, *e.g.*, the American Bar Association, the National Guardianship Association, ARC of the U.S., the National Council on Disability, and, most recently, the Fourth National guardianship Summit.

⁷ Nat'l Conf. of Cmmrs. on Unif. State Laws, UNIFORM GUARDIANSHIP, CONSERVATORSHIP, AND OTHER PROTECTIVE ARRANGEMENTS ACT (Unif. L. Comm'n 2017).

⁸ SDM legislation has passed in at least 8 states (TX, DE, AK, WI, NV, RI, IN, ND) and the District of Columbia; Kansas, Connecticut and Massachusetts are currently deliberating on SDM legislation.

⁹ The CRPD is available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.

¹⁰ *See* Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.* As one commentator has written, “Just as we recognize that the law—and common principles of human decency—generally require that we build a ramp so that an individual with a physical impairment can enter a building without being carried up the steps, we should also recognize a legal obligation to provide decision-making support to an individual with limitations in mental capabilities rather than assign a guardian to make decisions *for* that person.” Rachel Mattingly Phillips, *Note: Model Language for Supported Decision-Making Statutes*, 98 Wash. U. L. Rev 615, 624 (2020).

supports to help a person with a disability understand, make, and communicate their own choices. Examples of these tools might be:

- plain language materials or information in visual or audio form
- extra time to discuss choices
- creating lists of pros and cons
- role-playing activities to help the person understand choices
- bringing a supporter into important appointments to take notes and help the person remember and discuss her options
- opening a joint bank account to manage financial decisions together.

All people with disabilities have a right to lead self-directed lives and retain their civil rights as much as possible. What that looks like will be different for different people – some have significant support needs for some or all their lives. But as a society we must find ways to support people with disabilities and recognize that they are individuals with a full range of human experiences and preferences who have the right to exercise their civil liberties.

S.7107-B / A.8586-B is a necessary and long overdue step for people with IDD to live self-determined, autonomous, inclusive lives with dignity and respect. The NYCLU is proud to support this thoughtful legislation and urges its prompt enactment.