

# Supported Decision-Making: What You Need to Know and Why

By Kristin Booth Glen

Supported decision-making (SDM) has been described as “a newly emerging process” and that is true as a legal matter, especially where statutory recognition is concerned. But people with intellectual, developmental, psychosocial, and cognitive disabilities have been receiving support from family members, friends, professionals and providers for decades without ever denominating it SDM. A frequently quoted definition encompasses both ways in which support may be given, describing SDM as “[a] series of relationships, practices, arrangements, and agreements of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others, decisions about the individual’s life.”<sup>1</sup>

That is, SDM can range from entirely informal, to more formal processes involving a written agreement, and even to legislation requiring recognition of such agreements by third parties. This range also reflects two very different sources from which SDM is derived.

The first is our common understanding that no one makes decisions, especially important decisions, entirely in a vacuum. Faced with a decision to pursue graduate education, rent an apartment, buy a car, propose marriage, accept or reject a major medical intervention, etc., we all seek information and advice—supports—from a variety of people and sources. SDM reflects the fact that this can and should be equally true for people with disabilities, except that they may require more or different supports to make their decisions. These may include someone providing assistance in gathering relevant information, explaining that information in simple language, considering the consequences of making a particular decision or not making it, weighing the pros and cons, communicating the decision to third parties, and/or assisting the person in implementing the decision.<sup>2</sup>

The second source from which SDM derives is the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>3</sup> which locates SDM in Article 12’s enunciation of the human right of legal capacity. The CRPD states, as a general principle, “every person’s right to dignity, including the right to make his or her own choices.”<sup>4</sup> Legal capacity, as guaranteed to all persons, regardless of disability, has been defined as both the right to “equal recognition... before the law,” and the right to legal agency, that is, to have “the power to engage in transactions and create, modify, or end legal relationships.”<sup>5</sup>

Although SDM is not specifically mentioned as such in the CRPD, it derives directly from Article 12, Section 3, which requires Member States to provide “such supports as are necessary” to enable a person to exercise her or his legal capacity. The First General Comment on the CRPD describes SDM as an important means to accomplishing that end. Notably, SDM is explained as including advance directives, as well as ongoing support by trusted people in the life of a person with a disability.<sup>6</sup>

The CRPD has been signed but not ratified by the US. It has, however, prominently entered the discourse around the rights of persons with intellectual and developmental disabilities (I/DD) as well as, to a lesser extent, persons with psychosocial (mental health) disabilities, and older persons with progressive cognitive decline, dementia, Alzheimer’s, etc. And, in a different vein, as discussed below, this discourse also challenges us to think very differently about how decisions are, or can be, made, and thus how existing systems that impose substituted decision-making on purportedly “incapacitated” individuals might be re-conceptualized and reformed.

## Recognition of SDM

In a very short time, SDM has been recognized and embraced by a variety of stakeholders, including the U.S. Administration for Community Living (ACL)<sup>7</sup>, the American Bar Association, the Uniform Law Commission (ULC), the National Guardianship Association, and the Arc.<sup>8</sup> ACL has funded a number of related projects including the National Resource Center on SDM.<sup>9</sup> The ABA has passed a resolution promoting SDM, and similar official statements have been issued by the Arc<sup>10</sup> and NGA.<sup>11</sup> The ULC’s recent revision of the Uniform Guardianship and Protective Proceedings Act (UGPPA, now the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act, or UGCOPAA) specifically includes SDM as a “less restrictive alternative” that should be attempted before guardianship is sought or imposed.<sup>12</sup>

The National Council on Disability recently published a lengthy report, *Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination*,<sup>13</sup> that describes and promotes SDM as a promising modality providing a practical solution for allowing persons with disabilities to

---

**KRISTIN BOOTH GLEN**, University Professor and Dean Emerita at CUNY School of Law, is the Project Director of Supported Decision-Making New York (SDMNY) She was Surrogate, New York County, from 2005-2012.

maintain their autonomy. SDM has also been the subject of considerable scholarly attention, with law review articles and presentations at scholarly conferences,<sup>14</sup> as well as at bar association meetings here in New York.<sup>15</sup>

One particularly notable instance of recognition has been the passage of state statutes specifically recognizing SDM and Supported Decision-Making Agreements (SDMAs), beginning with Texas in 2015, Delaware in 2017, and most recently Wisconsin, and the District of Columbia.<sup>16</sup> Similar statutes are currently under consideration in a number of additional states.<sup>17</sup>

Although third parties are free to honor SDMAs, legislative recognition is critical to actualizing legal capacity. Without legislation, there is no obligation on private third parties to accept SDMAs. In our litigious society, fear of potential liability creates a powerful disincentive to do so. What use is the SDMA, no matter how much integrity went into the process of creating it, if the health care provider refuses to accept it as consent for treatment, or the banker for withdrawal from an account?

*“What use is the SDMA, no matter how much integrity went into the process of creating it, if the healthcare provider refuses to accept it as consent for treatment, or the banker for withdrawal from an account?”*

### SDM in New York and How It Works

In 2016 the New York State Developmental Disabilities Planning Council (DDPC) funded a five-year project to create an educational campaign about SDM for a wide variety of stakeholders throughout the state. As well, the grantee was to design and run two pilot programs testing the use of SDM to divert persons with I/DD at risk of guardianship, and to restore rights to persons with I/DD currently subject to guardianship. The project to which the grant was awarded, Supported Decision-Making New York (SDMNY), is a consortium of Hunter/CUNY, the New York Alliance for Inclusion and Innovation (formerly NYSACRA), The Arc Westchester, and Disability Rights New York (DRNY).

Now in its third year, SDMNY has developed, and is implementing, a three-phase model for facilitating the use of SDM by persons with I/DD (denominated “Decision-Makers”) and their chosen supporters.<sup>18</sup> Facilitators, who serve as volunteers (or, in the case of student facilitators, potentially for academic credit)<sup>19</sup> receive a two-day training and are supervised by experienced mentors with expertise in the SDMNY facilitation process.

In Phase 1, the facilitator works with the Decision-Maker to determine what kinds of decisions she or he is already making, or is able to make on her or his own, in which areas or domains she or he needs and desires support, and what kinds of support she or he wants in each area. Some relevant domains include health care, finances, education, employment, relationships, community services, etc. The facilitator also assists the decision-maker in identifying trusted persons in her or his life to serve as her or his supporters.

In Phase 2, the facilitator works with those chosen supporters, educating them about SDM and getting their buy-in to its process. This phase is also about “repositioning” them from their prior roles of making decisions for the decision-maker, to truly supporting her or him in making her or his own decisions. When the supporters understand, accept and commit to this new role, the process moves to Phase 3.

In Phase 3, the decision-maker and supporters come together with the facilitator to negotiate their SDMA.

The agreement they reach spells out the areas for support, from whom the support in each area will be given, and the kinds of support to be provided. Each SDMA is individually tailored, but follows a template developed by SDMNY based on review of all existing SDMAs in the U.S. and elsewhere, and consultation with a variety of stakeholders, including self-advocates.

The SDMA is intended both to memorialize the parties’ agreement, and to provide an ongoing process that the decision-maker will be able to use for years to come. To that end, it is a flexible document that can be amended as circumstances change—when supporters move, “age out,” or new people become important in the decision-maker’s life; where she or he gains sufficient capability in an area such that support is no longer needed, or when a new area opens up.

There is currently no statute in New York requiring acceptance of SDMAs by third parties, although SDMNY is working on efforts to have state agencies, including the Office of People with Developmental Disabilities (OP-WDD) and the Department of Education, honor them.<sup>20</sup> One goal of the project is to create an evidence base that will support such legislation in the future.

As of June, 2018 over 50 volunteer facilitators have been trained, and nearly 30 decision-makers are actively participating, with a number soon to execute SDMA's.<sup>21</sup> The Arc Westchester has already begun utilizing the facilitation model in that county and, in the third year of the project, new sites will be initiated in upstate locations (the Rochester and Capital areas) and hopefully in Long Island.

### Implications of SDM for New York Law

#### A. Guardianship

The most obvious area to which SDM applies is that of guardianship, whether under Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act. The former specifically requires consideration of less restrictive alternatives<sup>22</sup> before guardianship may be imposed.<sup>23</sup> While 17-A lacks virtually all the procedural—and constitutionally mandated—protections of Article 81,<sup>24</sup> least restrictive alternatives should apply equally to guardianships for persons with intellectual and developmental disabilities as a constitutional imperative, premised in substantive due process,<sup>25</sup> and courts have so held.<sup>26</sup> SDM is clearly a less restrictive alternative, and is increasingly recognized as such in both case law<sup>27</sup> and in revisions to guardianship statutes, as with the revised UGCOPAA, and state statutes, like Maine's,<sup>28</sup> that have since followed UGCOPAA's lead.

As a less restrictive alternative, SDM derives conceptually from the statutory requirement that the state may not intervene in an "incapacitated" person's life, or deprive that person of liberty and/or property interests, unless such intervention is "necessary" to protect the person from harm.<sup>29</sup> Where a functioning system of supports for the "incapacitated" person's decisions is in place, there is adequate protection, and the necessity for more restrictive state intervention disappears. But, SDM also functions to interrogate and overcome the required finding that a person is "incapacitated."<sup>30</sup>

Article 81 deliberately adopted a "functional" test of incapacity, rejecting the diagnosis-driven determination that characterized New York's previous conservator and committee statutes<sup>31</sup> and that still controls guardianship under Article 17-A. Historically, in evaluating capacity, a person's ability to "understand and appreciate" the nature and consequences of a decision has been seen as occurring in a vacuum; the operative model is that of an isolated "rational" individual examining relevant facts and independently reaching her/his decision. Yet both our personal experience and new findings in psychology and neuroscience<sup>32</sup> demonstrate how problematic this underlying premise really is. People without disabilities

do not generally make "rational decisions," and, as already discussed, seldom if ever make them entirely alone.

SDM provides the lens for a different and more realistic understanding of how most people make decisions, and thus the meaning of their "capacity" to make them. Instead of asking solely whether someone can "understand and appreciate" a decision entirely on her or his own, the better inquiry is whether that individual can "understand and appreciate" *with appropriate and adequate supports*. That is, capacity is not a singular capability possessed and exercised by a lone individual. Rather, capacity is grounded in relationships, inviting a new legal formulation: that the individual's own capability, *plus* the support of others, equals capacity. This re-conceptualization of capacity has important implications for other areas of health law and practice.

#### Surrogate Health Care Decisions in the Family Health Care Decisions Act and SCPA Article 1750-b

One example comes from current New York statutes and regulations providing for surrogate health care decision-making when a patient "lacks capacity." In another article in this special issue, Robert Swidler discusses efforts to harmonize New York's two separate laws, one specifically for persons with intellectual and developmental disabilities,<sup>33</sup> the second for all other adults who "lack capacity" to make health care decisions for themselves and who do not have advance directives or court appointed guardians.<sup>34</sup>

Putting aside the differences—and complexities in application—in the two statutes, and the arguments for consolidation of some sort, both depend on a determination of "incapacity" to make health care decisions. For example, for major medical decisions not involving end of life treatment<sup>35</sup> for persons receiving services from the Office of Persons with Developmental Disabilities (OPWDD), surrogate decision-making is authorized "when the adult lacks capacity to understand appropriate disclosures required for proposed professional medical treatment,"<sup>36</sup> a determination dependent on the written opinion of a psychologist or psychiatrist.<sup>37</sup> Under the FHCDA, and where end of life decisions are to be made for persons with I/DD, that determination is made by the attending physician, who must confirm, to a "reasonable degree of medical certainty," that the person currently lacks capacity to make health care decisions.<sup>38</sup> Surely, given the move to a functional rather than medically/diagnosis-driven assessment in guardianship generally, and the abandonment of a medical model for a social model of disability, it is at the very least problematic to hold that decision-making capacity is something that can be determined by a physician with "medical certainty."<sup>39</sup>

More to the point of this article, SDM and the reconceptualization it creates may be relevant to a determination of incapacity here in two different but complementary ways. First, as a practical matter, any statute(s) dealing with this issue should provide that, in addition to health care directives, the existence of a valid SDMA which specifically includes health care decisions<sup>40</sup> should preclude inquiry into incapacity and should be honored by the health care provider. Second, in the absence of an SDMA, but drawing from SDM's more generous and realistic understanding of capacity, the determination of "capacity to make health care decisions" should not be made in a vacuum, but rather should take into consideration the person's ability to make those decisions with support.

For example, imagine a person with I/DD, who does not communicate verbally, in an emergency room by herself or himself. Imagine that the attending doctor has no special training in I/DD and cannot communicate with the patient. Determination of lack of capacity is almost certain, yet if the patient had or were given appropriate communicative supports, her or his ability to make the necessary decisions might look very different. And it's not just about communicative supports; a trusted person who knows the patient well could explain the medical situation in ways the patient could understand, and help her or him weigh alternatives and reach her or his own decision.

There is also an argument, not specifically related to SDM, that the Americans with Disabilities Act (ADA)<sup>41</sup> may require provision of such supports, both for persons carrying an I/DD diagnosis and for adults in a hospital setting<sup>42</sup> whose "capacity" is in question. Both<sup>43</sup> may be entitled to have the health care provider offer appropriate accommodations to enable the patient to be treated equally with all others in making her or his own health care decisions and communicating her or his medical needs in order to receive necessary treatment.

Allowing trusted persons in the patient's life to support her or him in making the health care decision (especially if the person is a "supporter" under an SDMA), rather than insisting the patient may only do so on her or his own, is arguably a "reasonable accommodation" to enable the individual to participate in health care decision-making. Allowing a friend or supporter to remain in the recovery room with a patient with I/DD to enable that patient to communicate her or his choices and/or needs effectively would be a modification to a policy keeping third parties out that, as required by the ADA, neither imposes an undue burden on the hospital or health care provider nor represents a fundamental alteration to the nature of their services. Similarly, the hospital or health care provider may be required to provide

support by, for example, furnishing information slowly and in plain language, the same way that they may be required to provide sign language interpretation to ensure effective communication with deaf or hard of hearing patients.<sup>44</sup> Through its commitment to removing societally imposed barriers to equal treatment for persons with disabilities, the ADA resonates, and is consistent with, SDM as an "accommodation" for support that allows persons with disabilities to make their own health care decisions and articulate their health care needs like any other "competent adult."

### Involuntary Administration of Antipsychotic Drugs

For more than three decades our courts have recognized that the state may not involuntarily administer antipsychotic drugs to persons with mental illness committed to psychiatric facilities. In *Rivers v. Katz*,<sup>45</sup> the Court of Appeals reiterated the general principle that competent adults have a right to control their own medical treatments, including refusing prescribed medication. The Court held that, without a finding of incapacity, persons with mental illness retain that right. Only a finding, by clear and convincing evidence, "that the individual to whom the drugs are to be administered lacks the capacity to decide for himself whether he should take the drugs" permits the court to consider and decide whether administration of those drugs is in the patient's best interest.<sup>46</sup>

In this situation, the lens of SDM can provide a new and additional perspective. Here, it could be argued, "capacity" should be determined by assessing the ability of the person with mental illness to make a decision, not entirely alone, but *with the support* of a trusted person or persons in his or her life. When a psychiatric patient has an SDMA, honoring that agreement would both preserve her or his rights and integrity, and also avoid costly and unnecessary litigation.<sup>47</sup> In the absence of an SDMA, appropriate supports might also be offered as an ADA-required or inspired "accommodation."

The use of SDM—and a model for facilitating SDMA for persons with psychosocial disabilities—is, at this moment, undeveloped in the US. Such individuals often have a dearth of natural supports, including family members, from whom they may be estranged. Accordingly, SDM may operate somewhat differently for this cohort than it does for persons with I/DD. Peer support, which has been used for SDM by persons with psychosocial disabilities in other countries, seems a promising alternative.<sup>48</sup>

Because SDM is also understood to include advance directives,<sup>49</sup> it also potentially encourages use of psychiatric advance directives (PADs)<sup>50</sup> and/or so-called "Ulysses

# GUARDIANSHIP AND SURROGATE DECISION-MAKING

agreements.”<sup>51</sup> The latter involve choices/decisions/instructions about treatment and medication that a person with a psychosocial disability makes, often with peer support, which are specifically intended to override his or her objections to such treatment or medication when he or she is in “crisis.”<sup>52</sup> Honoring such agreements would avoid litigation and, as well, potentially preserve a respectful physician-patient relationship.

## Conclusion

Supported decision-making is not only a process currently in use by, or being piloted for, persons with I/DD as an alternative to guardianship. It is also a new way of thinking about fundamental issues of “mental capacity” and “legal capacity” as those characterizations affect other groups of vulnerable people for whom substitute decision-making, with its concurrent denial of rights, has long been a default position. Where health law confronts and/or requires decision-making by adults with intellectual and developmental disabilities, psychosocial disabilities, traumatic brain injury (TBI) or older persons with progressive cognitive decline, dementia, and Alzheimer’s, SDM challenges the existing paradigm of substitute decision-making and rights deprivation. Instead, SDM presents an exciting opportunity both to promote self-determination and dignity and, at the same time, “to do no harm.”

## Endnotes

1. Robert Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: the Difficult Road from Guardianship to Supported Decision-Making, 19 Hum. Rts. Brief 8, 10 (2012).
2. For examples of how persons with intellectual and developmental disabilities make health care decisions with supports, see the informative video, *Making Healthcare Choices: Perspectives of People with Disabilities*, available at <http://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library>.
3. G.A Resolution 61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006), available at [www.un.org/disabilities/documents/convention/convoptprot-e.pdf](http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf) (CRPD).
4. CRPD, *id.*, Article 3, General Principles (a).
5. CRPD, General Comment No. 1 (2014) Para. 11, available at <https://wgnusp2013.files.wordpress.com/2014/article-12-general-comment-1-11-april-2014-pdf>. The General Comment is a product of the Committee on the Rights of Persons with Disabilities, the body created under the Convention to interpret it, and to issue reports on compliance or noncompliance by member states that have ratified the Convention and its Optional Protocol.
6. General Comment, *id.*, Para. 17.
7. ACL is an agency within the U.S. Department of Health and Human Services (HHS) that includes the Administration on Aging and the Administration on Intellectual and Developmental Disabilities. It was an early supporter of SDM, partnering with two ABA Commissions in the first National Roundtable in 2012.

See <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>.

8. ARC of the United States is the national organization representing numerous ARC (formerly, the Association for Retarded Children) chapters around the country, and is the preeminent organization of parents of children with I/DD.
9. The Center’s website is available at <https://www.supporteddecisionmaking.org>.
10. The Arc, Position Statement, Autonomy, Decision-Making Supports and Guardianship (2016), available at <https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship>.
11. National Guardianship Association, Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making (2017), available at <https://guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf>
12. UGCOPPA, available at <http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>.
13. National Council on Disability, Beyond Guardianship: Toward Alternatives That Provide Greater Self-Determination (March 22, 2018), available at [https://www.ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://www.ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)(NCD Report).
14. For example, there were presentations on SDM at the Association of American Law Schools (AALS) in 2014, the Law and Aging Section of the Law & Society Association in 2015, Cardozo Law School’s Symposium, Personhood and Civic Engagement by Persons with Disabilities in 2017, Columbia Law School’s Symposium, Localizing Human Rights in the New Era in 2017, etc.
15. SDM was the subject of a presentation at the NYSBA Elder Law and Special Needs Section Fall Meeting in 2017, at an evening forum of the New York City Bar Association on June 14, 2018, and will be featured at a CLE at the NYSBA Annual Meeting in January, 2019.
16. Tex. Est. Code Ann. §§ 1357.001–.003 (2015); Del. Code Ann. tit. 16, §§ 9401A–9410A (2017); D.C. Code §§ 21-2001 to 2077 (2018); Wis. Stat. §§ 52.01-.32 (2018).
17. For the most recent updates, see <http://sdmny.org/sdm-state-map/>.
18. For more information on the model see Kristin Booth Glen, *Piloting Personhood: Reflections From the First Year of a Supported Decision-Making Project*, 39 Cardozo L. Rev. 495 (2017)
19. SDMNY is experimenting with Occupational Therapy Assistant (OTA) students at La Guardia Community College and Bachelor of Social Work (BSW) students at Hunter’s Silberman School of Social Work.
20. There is precedent for this as the D.C. Board of Education has regulations specifically requiring recognition of SDMA’s; see Supported Decision-Making, D.C. Pub. Schools, <https://dcps.dc.gov/page/supported-decision-making>.
21. It is particularly moving that one of these decision-makers in the Restoration Pilot, is a Willowbrook survivor.
22. Under 81.02(a)(2), the court is mandated to consider the sufficiency of other vehicles set out in 81.03(e), which lists, without limitation, “available resources.” Notably, Article 81 was passed a quarter of a century ago, when SDM, as an articulated concept or process, was entirely unknown.
23. See MHL 81.01 MHL (“The Legislature finds that it is desirable ... for persons with incapacities to make available to them the least restrictive form of intervention...”) 81.09(5)(xii), directing the court evaluator to report on “least restrictive form of intervention”

## GUARDIANSHIP AND SURROGATE DECISION-MAKING

- and MHL 81.15(b)(4 and 5), requiring a showing of necessity and requiring a guardian's powers to be limited to the "least restrictive." Although specific language requiring guardianship to be the least restrictive alternative is not used in the statute, the Law Revision Commission made clear that that imperative was fundamental to the entire statutory scheme ("The Legislature recognized that the legal remedy of guardianship should be the last resort for addressing a person's needs because it deprives the person of so much power and control over his or her life") (emphasis added), Rose Mary Bailly, *Practice Commentaries*, McKinney's Cons. Law of N.Y. Book 34A, Mental Hygiene Law Sec. 81.01 at 7 (2006 ed.).
24. See discussion in the Report of the NYC Bar Association Committees on Mental Health Law and Disability and the Law, reprinted as Karen Andrieasian *et al.*, *Revisiting S.C.P.A. 17-A: Guardianship for Persons with Intellectual and Developmental Disabilities*, 18 CUNY L. Rev. 287,301-317 and 301, n.65 (collecting comments on the statute's constitutional infirmities) (2015) and n. 65 (NYC Bar Committees Report)
  25. See, e.g., *Kesselbrenner v. Anonymous*, 33 N.Y.2d 161, 165(1973); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D.2d 189, 197-98 (1st Dept. 2001)
  26. See, e.g., *In re D.D.*, 50 Misc. 3d 666, 668 (Sur. Ct., Kings Co. 2015); *In re Dameris L.*, 38 Misc. 3d 570, 578 (Sur. Ct., N.Y. Co. 2012)
  27. *Id.*
  28. Maine, "An Act to Recodify and Revise the Maine Probate Code," LD 123 (HP 91) signed 4/20/2018, [www.legislature.maine.gov/LawMakerWeb/summary.asp?ID=280062616](http://www.legislature.maine.gov/LawMakerWeb/summary.asp?ID=280062616).
  29. See MHL 81.02(a)(1) and (b).
  30. See MHL 81.02(a)(2) and (b)(2).
  31. Unfortunately, and almost certainly unconstitutionally, Article 17-A, unchanged in this respect since enactment in 1969, retains this outmoded reliance on diagnosis as the basis for imposing a guardian. NYC Bar Committees Report, *supra* n. 24 at 303.
  32. See discussion of the recent work in behavioral economics, including that of the 2017 Nobel prize winner in economics, that "undermines the fundamental belief that our decisions are based in reason," NCD Report, *supra* n. 13 at 77.
  33. N. Y. Sur. Ct. Proc. Act Art. 17-B.
  34. FHCDA, N.Y. Pub. Health L. § 2994-a *et seq.*
  35. End-of-life decisions for persons with I/DD are covered by S.C.P.A. 1750-b, which provides a whole series of additional protections for that population.
  36. 14 N.Y. Comp. Codes R. & Regs. Sec. 633.11(a)(1)(iii)(b).
  37. *Id.* at 633.11(g)(2).
  38. FHCDA, *supra* n. 24 at Sec. 2994-c (2); SCPA 1750-b(4)(a).
  39. See NCD Report, *supra* n. 13 at 78 ("Medical doctors are simply not trained in the legal, functional and medical assessments that could lead to a reliable determination of an individual's "capacity").
  40. Because each SDMA specifies the areas/domains in which support is to be given, the existence of an SDMA per se would not take the patient out of the statute's purview.
  41. Americans With Disabilities Act, 42 U.S.C. Secs. 12161 *et seq.* (1990).
  42. Unlike 1750-b, the FHCDA only applies in hospital, hospice and nursing home situations. The ADA covers public hospitals under Title II, See 42 U.S.C. 12131(2), 28 C.F.R. 35.130, and private hospitals, under Title III, 42 U.S.C. 12181(7)(F); the latter also covers the professional office of a health care provider.
  43. Under Title II's "qualified individual" standard, both would be covered because they are eligible for the health care services they are seeking, while under Title II they are "individuals who are discriminated against on the basis of a disability in the full and equal enjoyment of the goods, services, facilities, privileges...of any place of public accommodation."
  44. The obligation to provide reasonable accommodations to enable communication with people with disabilities derives from the language of the ADA, Sec. 12132, and from DOJ regulations on auxiliary aids and services, specifically 28 CFR 35.160. The communication obligation has been applied to people with I/DD in, e.g. *Folkerts v. City of Waverly*, 707 F.2d. 975, 984 (8th Cir. 2017) and *Brooklyn Center for Independence of the Disabled v. Bloomberg*, 980 F. Supp. 2d 588, 650 (S.D.N.Y. 2013).
  45. 67 N.Y.2d 485(1986)
  46. *Id.* at 496-97
  47. Involuntary medication litigation is costly to the institution in the time of its employees, and, of course, to the court system. It is also often counterproductive to the patient's long-term relationship with health care providers and the use of potentially helpful medications.
  48. See Kristin Booth Glen, *Introducing a "New" Human Right: Learning From Others, Bringing Legal Capacity Home*, 49 Colum. Human Rts. L. Rev. 1, 38 (2018) ("Introducing").
  49. CRPD, General Comment No. 1, *supra* n. 3, at para.15.
  50. For a discussion of the status of PADs and the use of health care agents in New York, see Ronna Blau, Lisa Volpe, Christy Coe and Kathryn Strodel, *Psychiatric Advance Directives: A New York Perspective*, NYSBA Health Law Journal 25 (Spring 2017) and see Disability Rights New York, Mental Health Advance Directives Fact Sheet, *available at* <http://new.drny.or/docs/factsheet/mental-health-advance-directives-fact-sheet.pdf>.
  51. See, e.g., Judy A. Clausen, *Making a Case for a Model Mental Health Advance Directive Statute*, 14 Yale J. Health Pol'y L. & Ethics 1,3 (2014); Cuca, *infra* n. 52, at 1153.
  52. It should be noted that there is some debate about whether Ulysses agreements can appropriately be considered SDM as they privilege a "former self" over a "present self" in times of crisis, thus depriving that "present self" of legal capacity. For an example of SDM/peer support in making and utilizing Ulysses agreements in a pilot project in Nairobi, Kenya, see *Introducing*, *supra* n. 48, at 38. See Roberto Cuca, *Note: Ulysses in Minnesota: First Steps Toward a Self-Binding Psychiatric Advance Directive Statute*, 78 Cornell L. Rev. 1152,1152-53 (1993) (Cuca).