

Health Law Journal



A publication of the Health Law Section
of the New York State Bar Association

A JOINT ISSUE: GUARDIANSHIP AND SURROGATE DECISION-MAKING



Inside

- Guardianship for People with Intellectual Disabilities
- Restoring Rights in 17A Guardianships
- Health Care Decisions Act and End-of-Life Treatment
- LST Decisions for Unbefriended Nursing Home Residents

HEALTH LAW JOURNAL

Fall 2018

Vol. 23, No. 2

THE HEALTH LAW SECTION
NEW YORK STATE BAR ASSOCIATION

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Table of Contents

	Page
Message from the Section Chair	4
<i>Robert Hussar</i>	
A Joint Issue: Guardianship and Surrogate Decision-Making	5
<i>Tara Anne Pleat and Brendan Parent</i>	
Regular Features	
In the New York State Courts	6
Legislative Update	13
In the New York State Agencies	20
New York State Fraud, Abuse and Compliance Developments	23
In the Law Journals	30
For Your Information	32
Special Edition: Guardianship and Surrogate Decision-Making	
Overview of Guardianship for Individuals with Intellectual Disabilities: Changes on the Horizon	33
<i>Tara Anne Pleat, Edward V. Wilcenski and Katy Carpenter</i>	
Restoring Rights in 17A Guardianships: Myths and Strategies	36
<i>Jennifer J. Monthie</i>	
Chapter 1: Guardianship Basics	41
<i>An Excerpt from Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination</i>	
Guardianship: A Civil Rights Perspective	52
<i>Sheila E. Shea and Carol Pressman</i>	
New York's "Black Hole" of Surrogate Decision-Making for Individuals with Intellectual and Developmental Disabilities Without Capacity	59
<i>Kathryn Jerian and John Dow</i>	
The Family Health Care Decisions Act Should Apply to End-of-Life Decisions for Persons Who Are Intellectually Disabled	64
<i>Robert N. Swidler</i>	
Life-Sustaining Treatment Decisions For Unbefriended Nursing Home Residents: Application of a Clinical Ethics Algorithm	80
<i>Howard J. Finger, James Zisfein, Khoi Luong, Cheryl A. Dury, Ravindra Amin, Steven Hahn, Albina Shkolnik, and Nancy Neveloff Dubler</i>	
Why Not "Act Now": Can a Simpler Health Care Proxy Advance the Goal of Supported Decision-Making?	90
<i>Paul Kietzman</i>	
Supported Decision-Making: What You Need to Know and Why	93
<i>Kristin Booth Glen</i>	
Section Matters	
Newsflash: What's Happening in the Section	99
Section Committees and Chairs	101

Message from the Chair

I am very honored and excited to serve as Chair of the Health Law Section. One of the primary benefits of our Section is the ability of our membership to keep abreast of rapidly developing legal issues in our field through regular education and communication by and between our members. I am committed to continuing this Section's tradition of camaraderie and collaboration that has allowed our members to remain on the cutting edge of our ever-evolving discipline.



Recently, I was reminiscing about my early exposure to the practice of health law and involvement in the Health Law Section. I fondly recall meeting with Barry Gold shortly after our Section was formed. Barry shared with me some of his experiences as a health law attorney. His passion for the practice of health law was evident from his voice and he was thrilled that NYSBA had created a Section devoted to our practice. We all owe a debt of gratitude to Barry, as one of the founding members of our Section and its first Chair, and all of the esteemed former leaders of our Section, for creating an environment in which our members regularly share their experiences and knowledge to improve the level of service our membership can provide.

While I won't individually recognize all of our Section's past leaders, I must thank Larry Faulkner for all of his efforts over the past five years, and particularly the past year in both leading the Section and ensuring the seamless transition of the leadership of the Section. I would also like to express my gratitude to two other former Chairs, Robert Swidler and Jim Lytle, for their mentorship and guidance over the years and their encouragement to become more involved in Section activities and leadership opportunities. My goal over the next year is to follow their lead and encourage and facilitate even greater participation in our Section's activities and committees. I hope that our membership will collectively inspire the next generation of health care attorneys and leaders of this Section with the same infectious passion that Barry, Robert, Jim, and so many others, have infused into our Section over the years.

As is true with any group of individuals, no matter how formal or informal their bond or association, the group is only as productive or successful as the sum of the individual efforts. As Barry pointed out to me over 20 years ago, the breadth and depth of diverse areas of health law leads to a multitude of practice specialties and opportunities. However, I have witnessed over the past few years that it is this same variety that also chal-

lenges our Section in consistently engaging and meeting the diverse interests of our members. I am convinced that no one individual, committee or even the collective executive leadership can effectively manage or lead all of the Section's interests. Rather, it can only be accomplished through the combined efforts of the Section members, including law students, newly admitted and experienced attorneys, and those in between, to develop programs and initiatives focused on these interests.

I recognize that our members are at different places in their careers and personal lives, which may influence their level of involvement. However, the diversity of our members, in terms of areas and years of practice, creates great opportunities to share and develop our unique experiences. I implore everyone to engage, reengage or more fully engage, as your personal situation permits. As you plan your year ahead, please consider incorporating one or more of the following opportunities to participate with our Section:

- Join a committee or offer to lead one;
- Mentor a student or new attorney;
- Author an article or serve as special editor for our *Health Law Journal*;
- Post to our online forum;
- Organize or present at an in-person or web-based CLE;
- Organize or host a networking event;
- Attend a conference; and
- Share an idea on ways to grow and/or improve our Section.

Please also share these opportunities with your colleagues and encourage them to get involved as well.

I look forward to the year ahead and welcome any thoughts and/or assistance to grow our ranks and further enhance our programs, activities and initiatives. Please feel free to reach out to me personally or our Section leadership or committee chairs with any ideas you have to increase the value of membership in our Section. Finally, I want to remind all of you that our Annual Section meeting will be on January 16, 2019 at the New York Hilton in Midtown. This is one of our Section's premier events and I encourage all members to attend and bring along a colleague to introduce them to our Section and one of its first-class programs.

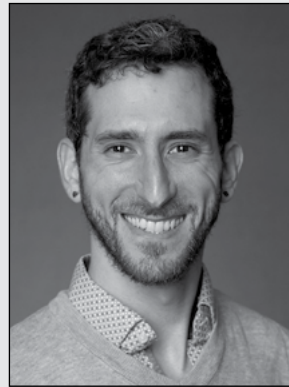
Warmest regards,
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A Joint Issue: Guardianship and Surrogate Decision-Making

The leadership of the Health Law and the Elder Law and Special Needs Sections thought it both timely and important to provide a joint edition of our respective *Journals*. Both Sections have tremendous interest and insight into the representation of individuals with disabilities and their families. The issues and procedures involving Article 17-A and Article 81 guardianships for individuals with developmental and intellectual disabilities have received a significant amount of focus over the last two years. This edition of our *Journals* provides in-depth analysis of these and other statutes concerned with personal decision-making, an area that requires thoughtful attention from practitioners, the judicial system, and the legislature. Decision-making for individuals who need assistance affects families,



Tara Anne Pleat, Immediate Past Co-Editor
Elder and Special Needs Law Journal



friends, health care practitioners, mediators, advocates, educators, and the individuals themselves. Potential changes to the laws discussed in this edition will affect the ease, efficiency, nuance, and oversight of guardianship and surrogate decisions. While guardianship advocates have strong and at times conflicting opinions regarding legal and regulatory changes, they are united by a desire to promote the well-being of people who often find themselves in positions of vulnerability. We are hopeful that this edition represents the range of positions and issue complexity, and will assist readers in counseling their clients on the status of guardianship in New York and surrogate decision-making statutes, and alternatives to guardianship that can be sought out.

Brendan Parent, Editor,
Health Law Journal

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In the New York State Courts

By Leonard M. Rosenberg

Appellate Division Upholds Punitive Damages Award Against Physician for Intentional Destruction of Medical Records

***Gomez v. Cabatic*, 159 A.D.3d 62, 70 N.Y.S.3d 19 (2d Dep’t 2018)**

Appellant, the administrator of his deceased child’s estate, commenced a medical malpractice action contending that his child was misdiagnosed by her pediatrician and endocrinologist, resulting in her death from diabetic ketoacidosis. Following a trial, the jury awarded the estate \$500,000 in compensatory damages, and \$7.5 million in punitive damages. The Appellate Division, Second Department, held that the father could recover punitive damages against the endocrinologist based on her destruction of the child’s original treatment records, and the evidence supported the jury’s decision to award punitive damages, but the \$7.5 million punitive damages award was excessive.

The court framed the main issue as whether a plaintiff may recover punitive damages for a medical professional’s act of altering or destroying medical records in an effort to evade potential medical malpractice liability. The court unanimously answered that question in the affirmative.

The case arose from the death of a 6-year-old child who developed diabetic ketoacidosis after the defendant endocrinologist failed to diagnose the child’s Type I diabetes. The endocrinologist testified that although she saved her original, handwritten notes memorializing her first visit with the child, after receiving a letter from the plaintiff’s attorney requesting the child’s medical records, she destroyed the original, handwritten notes memorializing her two subsequent visits with the child. The evidence at trial further established that although the



endocrinologist’s notes from the first visit indicated that the child would return in four weeks for a follow-up visit, the endocrinologist instructed the person scheduling

appointments to make an appointment for the child approximately nine weeks later. The child died approximately six weeks after that appointment. At trial, the plaintiff’s expert explained the differences between Type I and Type II diabetes, explaining that although a growing number of children were being diagnosed with Type 2 diabetes, the chance that a 5-year-old child would have Type II rather than Type I diabetes is less than half a percent. Based on this data, the expert concluded that the endocrinologist departed from the accepted standard of care by assuming the child was developing Type 2 diabetes and not teaching the child’s family about diabetic symptoms and recommending the family to perform home-testing measures.

Based on this testimony, the jury found that the endocrinologist departed from accepted medical practice in the diagnosis, care and treatment of the child and that this departure was a substantial factor in causing the injury that resulted in the child’s death. The jury awarded damages in the sums of \$400,000 for the child’s pain and suffering, \$100,000

for monetary loss, and following a separate trial, \$7.5 million in punitive damages for the endocrinologist’s destruction of the child’s records. Thereafter, upon motion by the endocrinologist, the trial court ordered a new trial on punitive damages unless the plaintiff stipulated to a reduction of the punitive damages award from \$7.5 million to \$1.2 million.

The endocrinologist appealed, arguing, among other things, that the trial court erred in submitting the issue of punitive damages to the jury, that the jury’s verdict on punitive damages was not supported by legally sufficient evidence and was contrary to the weight of the evidence, and that the award of punitive damages, even as reduced, was excessive. The father cross-appealed, arguing that the jury’s award of punitive damages should not have been reduced.

Rejecting the endocrinologist’s contention that her act of destroying the child’s original medical records cannot support a punitive damages award, the court concluded, “...we now hold that where, as here, a plaintiff recovers compensatory damages for a medical professional’s malpractice, a plaintiff may also recover punitive damages for that medical professional’s act of altering or destroying medical records in an effort to evade potential medical malpractice liability.” As the court explained, allowing such award “will serve to deter medical professionals from engaging in such wrongful conduct, punish medical professionals who engage in such conduct, and express public condemnation of such conduct.” Based on this reasoning, the court held that the trial

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court did not err in submitting the issue of punitive damages to the jury.

The court likewise rejected the endocrinologist's contention that her destruction of the records did not contribute to the cause of the child's death. The court held that because the endocrinologist destroyed the original records after the child died does not mean that punitive damages were awarded for conduct unconnected to the malpractice. The award of compensatory damages for the endocrinologist's departure from the standard of care was a substantial factor in causing the injury that resulted in the child's death and served as a foundation for the award of punitive damages. As for the fact that the plaintiff was still able to prove medical malpractice despite the endocrinologist's destruction of the original medical records, the court held that such fact should not insulate the endocrinologist from liability. As the court indicated, any other result may "embolde[n]" medical professionals to alter or destroy medical records, knowing that they will face no added liability in tort." The court, however, ordered a new trial on the amount of punitive damages to be awarded unless plaintiff stipulated to reduce the punitive damage award to \$500,000.

Court of Appeals Holds That New York City Board of Health's Flu Vaccination Rules for Children Do Not Violate Separation of Powers Doctrine and Are Not Preempted by State Law

***Garcia v. New York City Dept. of Health & Mental Hygiene*, 31 N.Y.3d 601 (June 28, 2018)**

New York City and New York State share regulatory authority over child care facilities and programs in New York City. The NYC Department of Health and Board of Health regulate health and safety standards for school-based programs for children ages three through five, and also group day care services for children under age six. New York State oversees smaller day care programs as

well as child care services for school-age children.

Public Health Law § 2164 requires particular vaccinations for children between two months and 18 years of age. Historically, the New York City Health Code §§ 43.17 and 47.25 required that children attending certain programs under the NYC Department of Health's jurisdiction must be immunized in accordance with the Public Health Law, and also have additional immunizations as required by the Department. In December 2013, the Board amended Health Code §§ 43.17 and 47.25 to require children between six and 59 months of age attending child care or school-based programs to receive annual flu vaccinations. The Board's amendment provided that non-compliance with the flu vaccine rules rendered child care providers and schools subject to fines for each unvaccinated child allowed entry.

Petitioners, parents of children subject to the flu vaccine amendment, commenced a hybrid CPLR Article 78 proceeding and declaratory judgment action to enjoin Respondents from enforcing the flu vaccine directives, or alternatively, to have the court declare the directives invalid. Petitioners argued that the Board's promulgation of these rules exceeded its regulatory authority, violating the separation of powers doctrine, and also that the Public Health Law preempted the flu vaccine rules because only the state legislature may mandate vaccines for school-age children. Respondents cross-moved to dismiss the petition.

The Supreme Court, New York County granted Petitioners' motion, denied Respondents' cross motion, and permanently enjoined Respondents from enforcing the flu vaccine directives, holding that the state legislature retains the authority to mandate vaccinations not delineated in the Public Health Law. The Appellate Division affirmed, but solely on the basis that the particular regulatory scheme here exceeded the scope of the Board's authority, involving

improper policy decisions under the analysis of *Boreali v. Axelrod*, 71 N.Y.2d 1 (1987) and its progeny. The Appellate Division found, however, that because the state has not assumed full regulatory responsibility over the entire field of disease control and vaccination, the Public Health Law did not preempt the Board's flu vaccine rules.

The Court of Appeals reversed, holding that the Board acted within its legislatively delegated, long-exercised authority to regulate vaccinations, and also that the Public Health Law did not preempt the Board's rules.

The Court's analysis centered on the four factors it articulated in *Boreali*, which clarify the boundary between administrative rule-making and legislative policy-making. These factors are whether (1) the agency balanced costs and benefits according to preexisting guidelines or made value judgments involving complex choices between broad policy goals to resolve social problems; (2) the agency merely filled in details of a broad policy or "wrote on a clean slate," creating its own comprehensive set of rules without legislative guidance; (3) the legislature has unsuccessfully attempted to enact laws pertaining to the issue; and (4) the agency used special technical expertise in the applicable field. The Court noted that these factors should not be rigidly applied, and are merely related considerations designed to ascertain whether an agency has transgressed the bounds of permissible action.

As to the first *Boreali* factor, the Court found that the legislature had chosen the "end" of public health and the "means" to promote that end by empowering the board to implement necessary additional provisions to the health code to prevent the spread of communicable diseases. The Court held that there is an explicit connection between the flu vaccine rules and the preservation of public safety, and that the Board's decision to implement fines for non-compliance is a necessary part of its exercise of regu-

latory authority. In so holding, the Court noted that the limited scope of the flu vaccine rules did not amount to policy-making.

As to the second factor, the Court held that the legislature delegated significant power to the Board to promulgate public health regulations and that, here, it cannot be claimed that, in enacting the flu vaccine rules, the Board created its own set of rules without legislative guidance. The Court noted that the legislature has consistently reaffirmed the authority of the Board to regulate vaccinations, which the Board has exercised previously, including by mandating immunizations beyond those required by the legislature.

As to the third factor, the Court held that the parties had not identified any attempt by the legislature to enact influenza vaccine mandates for children attending child care programs of the NYC Department of Health. The Court also held that while the state legislature has sought to encourage that children receive the influenza vaccination through incrementally increasing requirements, such efforts do not amount to repeated failures by the legislature to reach agreement on a debated subject matter, as contemplated by *Boreali*.

The Court held that the fourth factor, which assesses whether the agency used special expertise in the field to develop the regulation at issue, does not weigh in favor of invalidating the flu vaccine rules. Specifically, the Court held that the Board's health expertise was essential to its decision regarding the flu vaccine mandate and that, while the Board's selection of financial penalties for non-compliance was less reliant on its health-related competency, such selection was consistent with the Board's authority to choose among various enforcement methods to maximize compliance.

Next, the Court addressed Petitioners' arguments regarding field and conflict preemption, holding that the flu vaccine rules do not conflict with the Public Health Law and,

likewise, do not encroach upon the legislature's regulation of the school vaccinations field.

As to conflict preemption, the Court held that the language of Public Health Law § 2164 does not suggest that the statute's list of required vaccinations is exhaustive or not to be expanded by localities to which the authority to regulate vaccinations has been delegated. The Court emphasized that on multiple occasions, the legislature has overtly expressed recognition of the Board's independent authority to issue immunization regulations. The Court also held that the flu vaccine rules do not conflict with Public Health Law §§ 206 and 213, which are plainly directed to the powers of the Commissioner of the New York State Department of Health, and not the Board.

As to field preemption, the Court held that while the state has enacted a comprehensive statutory scheme for school vaccinations, the relevant statutes, and also the legislature's explicit recognition of the Board's independent mandates, reflect the legislature's recognition that municipalities play a critical role in vaccination programs. In so holding, the Court noted that it is not atypical for the state to set a "floor" for public health regulations while allowing localities to adopt stricter measures.

Appellate Division Holds That New York Court Has Jurisdiction Over New Jersey Based Radiologist, After He Provided Remote Radiology Services to Patients in New York

***Allen v. Inst. for Family Health*, 159 A.D.3d 554, 74 N.Y.S.3d 15 (1st Dep't 2018)**

Plaintiff, a cancer patient, filed a medical malpractice action against various defendants, including a radiologist, alleging that the radiologist's negligent reading of her sonogram led to a delay in diagnosis and treatment of breast cancer. New York Supreme Court denied the radiologist's motion to dismiss the complaint for

lack of personal jurisdiction, which was premised on the fact that the radiologist was a New Jersey resident and worked only at an office in New Jersey. The First Department upheld the Supreme Court's denial of the radiologist's motion to dismiss.

The court explained that a New York court could exercise jurisdiction over the radiologist under CPLR 302(a)(1), notwithstanding his lack of physical presence in New York, because he was licensed to practice medicine in New York, contracted with co-defendant's practice group where Plaintiff's sonogram was performed in New York, relayed his diagnostic findings to New York, and the New York-based practice issued a report based on the radiologist's findings that were allegedly relied upon by the Plaintiff and her doctors. The court noted that the radiologist "project[ed] himself into the State by electronically or telephonically transmitting his diagnostic findings." The court noted that it also could exercise jurisdiction over the radiologist under CPLR 302(a)(3) because, as alleged in the complaint, the radiologist's negligent misdiagnosis resulted in a delay in Plaintiff's treatment, thereby causing injury to Plaintiff in New York, which the radiologist should reasonably have expected that his out-of-state misdiagnosis in Plaintiff's case might have consequences in New York.

Psychiatric Facilities Required to Provide a Complete Copy of Each Patient's Medical Record Prior to Any Proceeding to Retain the Patient for Involuntary Psychiatric Care

***Mental Hygiene Legal Service v. Daniels*, 158 A.D.3d 82, 67 N.Y.S.3d 147 (1st Dep't 2017)**

Mental Hygiene Legal Services (MHLS) commenced an Article 78 proceeding seeking a writ of mandamus to compel Bronx Psychiatric Center (BPC) to provide a complete copy of each patient's medical record prior to any proceeding to retain the patient for involuntary psychiatric

care. Affirming the decision of the trial court, the Appellate Division held that MHLS had organizational standing to commence the proceeding, and that MHLS established its clear right to mandamus relief.

MHLS contended that the language of Mental Hygiene Law 9.31(b) requires that BPC, in a proceeding to retain a patient in a hospital for involuntary psychiatric care, must provide MHLS with a copy of the patient's "record" as defined in MHL 9.01, 14 NYCRR 501.2(a) and MHL 33.16(1). Because BPC's "pattern and practice" was to provide MHLS with only the admission, transfer or retention application papers and orders, but not the patient's complete clinical record, MHLS averred that BPC failed to perform its duty imposed by law. BPC contended that because MHLS has not suffered injury by the alleged conduct, MHLS lacked standing to bring the proceeding, that MHL 9.31(b) does not require the broad disclosure alleged by MHLS, and that MHLS always has full access to medical charts, 24 hours a day, seven days a week, pursuant to MHL 47.03(d).

The trial court held that MHLS possessed "organizational standing" based on its statutory mandate. Specifically, the trial court held that MHL 9.31(b) and its disclosure mandate is intended to protect the rights of patients in proceedings pursuant to MHL 9.31(a) by ensuring that they are provided with the very records that generally form the basis of any retention application. The petition, the court noted, is an "extension of that duty." The trial court held that by not providing MHLS with a complete copy of the patient's medical chart, BPC is violating the clear language and legislative intent of MHL 9.31(b), which requires facilities to provide the entire chart and not portions thereof prior to a hearing.

On appeal, the Court held that MHLS has organizational standing to bring the action given that: (i) the injury that MHLS asserts falls within the interests or concerns sought to be provided or protected by the statu-

tory provisions that it invokes; and (ii) MHLS has alleged a specific and genuine burden on its resources given that BPC's refusal is pervasive and affects each and every one of MHLS's clients and their respective retention hearings.

Reading MHL 9.31(b) together with MHL 9.01, MHL 33.16(1) and 14 NYCRR 501.2(a), the court agreed with the trial court that when read together, these statutory duty and regulatory provisions impose upon BPC a compulsory duty to provide MHLS with a copy of its client's complete medical charts before their respective retention hearings under MHL 9.31 and 9.33.

In reaching its decision, the court explained that while it was mindful of BPC's justifiable cost concerns in producing copies of its patients' complete medical records, the court "cannot turn a blind eye to the clear legislative mandate that each and every one of the individuals, whom MHLS represents and whom are subject to involuntary retention, receive the representation that the legislature has mandated they receive." Disagreeing with the dissent's position, the court held that the detriment that these patients may experience in not having copies of their charts is plainly higher and more compelling than the detriment to the hospital in having to undertake additional photocopying responsibilities.

The court also expressly disagreed with the dissent's position that neither 14 NYCRR 501.2(a) nor the MHL should be used to derive the definition of "accompanying data" within the meaning of MHL 9.01. According to the dissent, while MHL 9.01 defines a client's "records" to mean his or her "accompanying data," it defers to the Office of Mental Health (OMH) regulations to provide, if any, the meaning of "accompanying data." Thus, as the Court noted, "the dissent would have us interpret the statute to give the Department of Hygiene the absolute discretion to obviate the statute's requirement to provide a patient with "accompa-

nying data" at a retention hearing. The court rejected that approach, holding that it is inconsistent with the purpose of Mental Health Law 33.16, which requires BPC to provide an indigent patient with his or her medical records upon request. As the court held, it would be "incongruous" to conclude that "while indigent patients who are treated by mental health facilities generally have the right to access and to copies of their clinical records, they surrender such rights when the mental health facility seeks to retain the patient for involuntary psychiatric care."

The court also disagreed with the dissent's position that BPC would be unduly burdened if it were required to provide a copy of the patient's medical record ahead of every retention hearing. As the court held, in order to ensure that the medical testimony adduced against its clients at the retention hearings is accurate, MHLS must be able to review the medical record prior to the proceeding. The court rejected the dissent's contention that such duties could easily be accomplished by the MHLS lawyer's ability to personally inspect the medical records at the health facility, contending that with an unlimited case load and limited staff of lawyers, MHLS can ill afford to spend the extra time and effort required to review and copy such records. The court also held that MHLS's endeavor to ensure that medical testimony adduced against its client is accurate is not rendered wasteful by the fact that many retention proceedings never reach the hearing stage. As the court explained, MHLS's legal duties are triggered immediately upon MHLS receiving notice of BPC's intention to voluntarily retain its patients, and MHLS cannot safely predict the eventual outcome of each proceeding at its inception.

Finally, the court rejected the dissent's conclusion that, because MHLS has around-the-clock access to patient records, copying is not required for its attorneys to review the charts before the hearings. As the court noted, medical charts are a fluid set of documents that the medical staff

are constantly updating during the continuing constant treatment and care of the patient. Thus, MHLS's attorneys' right to access the charts "at any given time" would not assure the attorney that he or she is looking at the very same documents that BPC relies on at the retention hearing.

Appellate Division Rules That Patient Who Underwent a Procedure Without Consent Had No Right of Action Against a Hospital or a Physician Under 10 NYCRR § 405.7 and Public Health Law § 2803-c

***Dray v. Staten Island University Hospital*, 160 A.D.3d 614, 75 N.Y.S.3d 59 (2d Dep't 2018)**

Plaintiff alleged that her physician and the hospital's director of obstetrics delivered her child by caesarean section despite her insistence on a vaginal birth and refusal to consent. Plaintiff sought damages for, *inter alia*, battery and negligence based on defendants' alleged failure to summon a patient advocacy group and bioethics panel. The patient also alleged violations of the 10 NYCRR § 405.7 and New York Public Health Law § 2803-c, both of which establish certain patient rights, including the right to refuse treatment. 10 NYCRR § 405.7, in particular, instructs hospitals to ensure that all patients are afforded their rights, and Public Health Law § 2803-c outlines the rights of patients in certain medical facilities.

The hospital and its director moved to dismiss portions of the complaint. The motion court, in relevant part, (1) converted portions of the motion to a motion for summary judgment, (2) denied dismissal with respect to the first claim insofar as it alleged negligence based on defendants' purported failure to summon a patient advocacy group and bioethics panel, and (3) denied dismissal with regard to the fourth claim, which alleged violations of 10 NYCRR § 405.7 and Public Health Law § 2803-c for purportedly depriving the patient of the right to refuse treatment. Plaintiff

appealed, and the hospital and its director cross-appealed.

The Appellate Division affirmed in part and reversed in part. Notably, the court held that the motion court properly sustained the first cause of action to the extent it was based on defendants' alleged failure to summon a patient advocacy group and bioethics panel. The court rejected the defendants' arguments that these allegations were duplicative of the allegations sounding in battery, explaining they were not based on intentional conduct but on negligence.

The court reversed the decision to sustain the alleged violations of 10 NYCRR § 405.7 and Public Health Law § 2803-c, specifically the alleged deprivation of a patient's right to refuse treatment. The court examined the statutory scheme of Public Health Law § 2803-c and ruled the statute was not intended to apply to hospitals. Rather, the statute only applies to, and creates a private right of action for, patients of residential health care facilities, such as nursing homes. Accordingly, the plaintiff could not sustain a claim under this statute.

The court also ruled that 10 NYCRR § 405.7 does not create a private right of action. The court explained that, even though it applies to hospitals, it is merely a regulation promulgated by the New York State Department of Health. It can be cited to support a medical malpractice claim based on a separate violation of standard of care, but it cannot, in and of itself, form the basis for a claim.

In a companion decision *Dray v. Staten Island University Hospital*, 160A.D.3d 620, 74 N.Y.S.3d (2d Dep't, 2018), the court held that the plaintiff could not sustain a claim against her treating physician or his medical practice under either 10 NYCRR § 405.7 and Public Health Law § 2803-c. Rather, 10 NYCRR § 405.7 applies to hospitals, and Public Health Law § 2803-c applies to residential health care facilities. The court reiterated that 10 NYCRR § 405.7 does not give rise to an independent cause of action.

Appellate Division Holds That Notice Requirement of Labor Law § 741(3) Is Satisfied in the Absence of Affirmative Objection to Employer Practices Where Objection Would Have Been Futile

***Skelly v. New York City Health & Hosps. Corp.*, 161 A.D.3d 476, 75 N.Y.S.3d 178 (1st Dep't 2018)**

Plaintiff, a physician formerly employed in Lincoln Hospital's Department of Infectious Diseases, alleged that he was terminated in retaliation for his objection or refusal to comply with the hospital's practice of not testing the residential drinking water of Legionnaire's disease patients. Plaintiff disagreed with the New York City Department of Health and Mental Hygiene's position that *Legionella* bacteria was found only in cooling towers, and believed that the practice of not testing patients' residential drinking water constituted "improper quality of patient care" under the New York Labor Law. Plaintiff alleged that his supervisors directed him to stop testing the residential drinking water of patients, and to not associate with the hospital any longer if he insisted on continuing to do so.

The Supreme Court, Bronx County, granted defendants' motion to dismiss the complaint under CPLR 3211(a)(7). The Appellate Division reversed, holding that plaintiff had sufficiently pled the notice requirement of Labor Law § 741(3), which provides that an employee may not bring an action "unless the employee has brought the improper quality of patient care to the attention of a supervisor and has afforded the employer a reasonable opportunity to correct such activity, policy or practice."

The court held that although the statute expressly contemplates an affirmative act or objection to an employer's practice, here, strict compliance with that requirement would not serve the statute's purpose. Specifically, the court held that Plaintiff's express objection to the hospital's practice would have been futile given the allegations that his supervisors

had directed him to stop testing the drinking water, and if he would not, to discontinue his affiliation with the hospital.

The court also rejected defendants' alternative argument that plaintiff could not demonstrate improper quality of patient care (another required element of § 741), holding that discovery should proceed regarding whether the failure to test patients' drinking water qualifies as sub-par patient care under the Labor Law. The court noted that, even if the Department of Health and Mental Hygiene is the sole entity entrusted with testing residential drinking water, that did not establish that the hospital has no independent obligation to do so.

Appellate Division Upholds Hospital's Decision to Deny Psychiatrist's Application for Reappointment to Medical Staff Based on Her Failure to Disclose a Previous Application Denial

***Meyer v. Zucker*, 160 A.D.3d 1243, 75 N.Y.S.3d 325 (3d Dep't 2018)**

Plaintiff, a psychiatrist licensed to practice in New York, commenced an Article 78 proceeding asserting that North Shore University Hospital (NSUH) violated Public Health Law § 2801-b (PHL) by seeking revocation of her privileges and denying her reappointment application. NSUH moved to dismiss for improper commencement of an Article 78 proceeding, failure to state a cause of action, and based on documentary evidence. The motion court held that the Article 78 proceeding was improperly commenced, exercised its discretion pursuant to CPLR 103(c), and converted the matter to an action for solely injunctive relief pursuant to PHL § 2801-c. The motion court dismissed plaintiff's claims for compensatory damages because plaintiff's sole remedy under PHL § 2801-c is injunctive relief, and thereafter dismissed the complaint in its entirety, as the record established that NSUH's reasons for terminating plaintiff's privileges and for not reappointing her to its medical staff were in good faith - and nothing in NSUH's bylaws entitled Plaintiff to

maintain her clinical privileges after they expired. The Third Department affirmed.

Plaintiff was appointed to the NSUH medical staff in 2004. Four years later, in July 2008, plaintiff applied for appointment at Forest Hills Hospital (FHH) for clinical privileges, but was advised that a recommendation would be made to deny her application. In September 2009, plaintiff was notified that her application to FHH was denied. That decision was upheld on administrative review. In August 2010, plaintiff's application for reappointment to NSUH was approved for a two-year cycle, but Plaintiff did not disclose, as asked on that reapplication, that she had been previously denied clinical privileges at FHH. After NSUH became aware of the omission, NSUH requested corrective action to terminate plaintiff's clinical privileges. While the request for corrective action was pending, plaintiff's privileges at NSUH expired, and her application for reappointment was denied. NSUH's Hearing Committee upheld the request for corrective action and termination of plaintiff's clinical privileges, as well as the decision denying her request for reappointment to the medical staff. That decision was upheld by NSUH's appellate review committee. Plaintiff thereafter commenced an improper practice complaint with Public Health and Health Planning Council (PHHPC), alleging that NSUH's request for corrective action and denial of her application for reappointment to the medical staff at NSUH violated PHL § 2801-b. The PHHPC did not credit plaintiff's complaint, finding that the request for corrective action was consistent with PHL § 2801-b. Plaintiff then commenced an Article 78 proceeding.

Under PHL § 2801-b, it is an improper practice for a hospital to deny privileges unless it gives reasons, and those reasons must relate to "standards of patient care, patient welfare, the objectives of the institution or the character or competency of the applicant." In this context, judicial review of an alleged violation of PHL § 2801-b is "limited to whether the purported

grounds were reasonably related to the institutional concerns set forth in the statute, whether they were based on the apparent facts as reasonably perceived by the administrators, and whether they were assigned in good faith." Applying this standard, the Third Department found that there was no basis in the record upon which to find that NSUH's decisions to seek corrective action and to deny plaintiff's application for reappointment were made in bad faith or impermissible reasons, where plaintiff omitted on multiple occasions her denial at FHH. The court also found that plaintiff properly abandoned her claim for monetary damages under the PHL, because no cognizable claim for damages exists under PHL § 2801-b, as plaintiff was only entitled to seek injunctive relief under PHL § 2801-c.

Appellate Division Affirms That Hospital's Internal Report Was Exempt From Disclosure Under Education Law 56527(3) and PHL § 2805-j

***Pasek v. Catholic*, 159 A.D. 3d 1553, 72 N.Y.S.3d 720 (4th Dep't 2018)**

Plaintiff brought a medical malpractice action seeking damages based on a surgical incident that occurred at defendant Mercy Hospital of Buffalo (the "Hospital"). Plaintiff's husband went into cardiac arrest during a mitral valve repair surgery and required emergency surgery, which left him with permanent physical and cognitive impairments.

Plaintiff learned that the hospital had been cited by the New York State Department of Health for failing to inform the patient or his family that his heart-lung machine unintentionally disconnected while he was being transported to an operating room for emergency surgery. Plaintiff then moved to compel the hospital to produce any reports pertaining to the incident.

Following an *in camera* review, the trial court denied the motion with respect to an "occurrence event summary report." The Appellate Division held that the trial court did not abuse

its discretion in denying disclosure of the “occurrence event summary report” because the hospital established that the information was generated in connection with a quality assurance review function under New York Education Law § 6527(3), or a malpractice prevention program pursuant to New York Public Health Law § 2805-j. Accordingly, the information in the report was privileged and exempt from disclosure under both the Education Law and the Public Health Law.

The court also rejected plaintiff’s argument that the privilege was negated because the report purportedly contained information that had been improperly omitted from the patient’s medical record. The court noted that privileged information is not subject to disclosure regardless of its relevance or importance. The privilege that applied to the “occurrence event summary report” served to improve the quality of medical care by enhancing the objectivity of the quality assurance process and ensuring the frank exchange of information.

First Department Holds That Two-and-a-Half Year Statute of Limitations Applies to Incident Where Patient Falls From Hospital Stretcher While Being Positioned for An X-Ray

***Lang-Salgado v. Mount Sinai Med. Ctr., Inc.*, 157 A.D.3d 532, 69 N.Y.S.3d 292 (1st Dep’t 2018)**

On June 25, 2015, plaintiff filed an action to recover damages for injuries she allegedly sustained as a result of her fall from a hospital stretcher while she was being positioned by an x-ray technician. The date of the accident was July 5, 2012. Defendant moved to dismiss the case as barred by the two-and-a-half year statute of limitations for medical malpractice actions. Plaintiff argued that she alleged an ordinary negligence cause of action, which has a three-year statute of limitations. Plaintiff also cross-moved to include three additional causes of action for (1) negligent hiring; (2) failure to promulgate regulations on the use of stretchers/hospital beds in the x-ray room; and (3) failure to follow

the procedures promulgated for the use of such stretchers/hospital beds, and to have the additional claims relate back to date of the complaint. The trial court dismissed the case as time-barred and denied the motion to amend. The Appellate Division affirmed.

The first issue was whether the trial court correctly applied the two and a half year statute of limitations. In determining whether an action sounds in medical malpractice or in ordinary negligence, the critical factor is the nature of the duty owed to the plaintiff which the defendant is alleged to have breached. When the duty arises from the physician-patient relationship or is substantially related to medical treatment, the breach gives rise to an action sounding in medical malpractice. Thus, the court held that the trial court was correct to hold that the x-ray technician’s conduct was linked to the medical treatment of the patient, and that the medical malpractice statute of limitations should apply.

The court also held that the trial court was correct in holding that the additional claims did not relate back to the original medical malpractice claim. The issue before the court was whether the proposed causes of actions were time barred and thus lacked merit. The additional claims would be time barred unless the claims related back to the original complaint under CPLR 203(f). Under CPLR 203(f) a claim in an amended pleading “is deemed to have been interposed at the time the claims in the original pleading were interposed, unless the original pleading does not give notice of the transactions, occurrences, or series of transactions or occurrences, to be proved pursuant to the amended pleading.” The court reasoned that the proposed negligent hiring and failure to promulgate regulations claims arose from different facts and implicate different duties based on conduct that is separate and apart from the alleged medical malpractice. In other words, plaintiff’s original complaint, asserted one cause of action which arose from her x-ray on July 5, 2012, whereas the transac-

tions and occurrences relating to the proposed causes of action presumably took place before that date.

Appellate Division Dismisses Medical Malpractice Action Against Surgical Resident Who Performed Procedure but Did Not Exercise Independent Medical Judgment

***Blendowski v. Wiese*, 158 A.D.3d 1284, 71 N.Y.S.3d 274 (4th Dep’t 2018)**

Plaintiff suffered nerve damage during knee replacement surgery. She filed a medical malpractice action against the surgeon, the surgeon’s private medical practice, a third-year orthopedic resident, and the hospital where the surgery took place. The hospital was named on the basis that the resident was an officer, agent, and/or employee of the hospital. The resident performed the procedure under the supervision of the surgeon. During the procedure, the resident severed plaintiff’s nerves by drilling into her femur. The resident and hospital moved for summary judgment on the medical malpractice claim. The trial court denied the motion. The Appellate Division reversed.

The court held that the resident and the hospital met their burden on summary judgment with respect to the medical malpractice claims because they established that the resident did not exercise “independent medical judgment” during the procedure. The court noted that a “resident who assists a doctor during a medical procedure, and who does not exercise any independent medical judgment, cannot be held liable for malpractice so long as the doctor’s directions did not so greatly deviate from normal practice that the resident should be held liable for failing to intervene.” The court reasoned that plaintiff was the surgeon’s patient and that the resident was acting under the surgeon’s direction. Specifically, the court noted that the surgeon supervised the resident’s selection of the location and angle to drill, and made the decision to stop the drill during the procedure.

Legislative Update

By James W. Lytle

Six-hundred-six bills passed both houses during this legislative session, 34 more than last year. The bills passed this year included some reasonably significant new laws, including one that broadens the paid family leave benefit to include bereavement leave, a number of bills relating to animal welfare, criminal justice reforms and civil procedure revisions, along with a host of statutory changes made as part of the 2018-19 budget, that are not summarized below.



The bills catalogued below are among those likely to be the most relevant to the health care law practitioner and reflect the very substantial amount of legislative activity that touches upon health and related topics. As of this writing, while all of these bills passed both houses, many of them have not yet been acted upon by Governor Cuomo—who, based on past years, may defer action on many of these bills until near the end of 2018.

Public Health

Required Newborn Testing for Cytomegalovirus (A.587-C Rosenthal / S.2816-B Hannon): This bill would require hospitals to perform, upon the consent of the parents, a test for cytomegalovirus on any newborn who is identified as having a hearing impairment. This bill would also require that information on cytomegalovirus be included within the health and wellness education outreach program overseen by DOH. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Grants for Local Blood Drives (A.2381 Gottfried / S.2701 Parker):

This bill would authorize the Commissioner of Health to make grants to not-for-profit organizations and schools to help pay for the costs of conducting a local blood donation drive. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Smoking Prohibition Near Public Libraries (A.330-B Dinowitz / S.169-B Rivera): This bill would prohibit smoking within 100 feet of the entrances and exits of any public library, unless on residential property. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect 180 days after becoming a law.

Access to Tanning Facilities (A.7218-A Jaffee / S.5585-A Boyle): This bill would update the Public Health Law to prohibit anyone under the age of 18 from using the ultraviolet radiation devices available at tanning facilities. Currently, New York State law allows 17- and 18-year-olds to frequent tanning facilities after obtaining a written consent form from a parent or legal guardian. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Public Health Law Extenders (Chapter 106 of the Laws of 2018; S.8093-A Hannon / A.10221-A Gottfried): This law extends a number of provisions in the Public Health and Social Services Laws, including those governing the State Board of Professional Medical Conduct, providing immunity from liability for individuals involved with hearings before the Board, and establishing the physician committee for referral of physicians suffering from alcoholism, drug abuse or mental illness through July 1, 2023; authorizing DOH to conduct energy audits and disaster preparedness reviews of residential health care facilities through July 1, 2021; establishing limited home care services

agencies and providing for their reimbursement through June 30, 2019, and governing fair hearings for Medicaid beneficiaries enrolled in FIDA through January 1, 2021. The law was signed by the Governor on July 1, 2018 and took effect on that date.

Electronic Cigarettes (Chapter 4 of the Laws of 2018; S.1223 Akshar / A.8014 Rosenthal): This law prohibits the free distribution of electronic cigarettes to anyone under 18 years of age. The law was signed by the Governor on April 18, 2018 and took effect on that date.

Lead Poisoning (Chapter 20 of the Laws of 2018; S.7295 Alcantara / A.8992 Dinowitz): This law allows the Department of Health to take appropriate enforcement actions to address lead paint abatement violations. The law was signed by the Governor on April 18, 2018 and took effect on that date.

Crohn's Disease and Colitis Fairness Act (Chapter 42 of the Law of 2018; S.7327 Hannon / A.8989 Paulin): This law reenacts the Crohn's Disease and Colitis Fairness Act, which allows for access to bathrooms in places of business for persons with those diseases, in the General Business Law rather than the Public Health Law. The law was signed by the Governor on April 18, 2018, and took effect on April 17, 2018.

Newborn Safe Sleep Study (Chapter 46 of the Laws of 2018; S.7408 Hannon / A.8957 Simotas): This law amended a 2017 statute to require DOH to undertake a study on the effectiveness of existing safe sleep practices, including a review of "baby boxes" and other products aimed at encouraging safe newborn sleep.

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Within 12 months of the study, DOH must conduct a pilot program aimed at improving caregiver education and safe sleep practices, particularly in counties with high rates of infant mortality. The law was signed by the Governor on April 18, 2018 and is deemed to have taken effect on October 23, 2017.

Drinking Water Contaminant Levels (S.6655 Hannon / A.10927 Gottfried): This bill would amend the current obligation of DOH to establish notification levels for any emerging drinking water contaminants by requiring DOH to make those notification levels easily accessible to the public on its website. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Impact Study on Tick-Borne Diseases (A.9019-A Gunther / S.7171-A Serino): This bill would require the Commissioner of Health to develop a report that studies the mental health impact of tick-borne diseases and the correlation between blood-borne pathogens and mental illness in particular areas of the state. The report would be due to the Legislature by October 1, 2019. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Lyme and Tick-Borne Diseases Working Group (S.7170-A Serino / A.8900-A Hunter): This bill would establish a working group to review current best practices for and provide recommendations related to the diagnosis, treatment, prevention, reduction, elimination and tracking of Lyme and other tick-borne illnesses. The working group would be required to issue a report on its findings by May 1, 2019. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect 90 days after becoming law.

Sepsis Awareness (Chapter 10 of the Laws of 2018; S.7280 Marcellino / A.9001 Nolan): This law requires that currently mandated quadrennial education for dentists, nurses, podiatrists,

optometrists and dental hygienists on sepsis include information on infections that could lead to sepsis. The law was signed by the Governor and took effect on July 1, 2018.

Physical Activity Awareness Campaign (A.4426 Cusick / S.8716 Sepulveda): This bill would require DOH to establish the New York State physical fitness and activity outreach and education campaign. The purpose of the statewide campaign would be to increase public awareness among youth, seniors and other high-risk populations of the importance of and the health benefits derived from physical fitness and activity. DOH would select individuals to promote the campaign who may be fitness experts or celebrity advocates. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Aging/Long-Term Care

Long-term Care Ombudsman Program (A.11050 Lupardo / S.9002 Dilan): This bill would amend the statute governing the long-term care ombudsman program to bring the program into compliance with recent changes to federal regulations by adding additional eligibility requirements and conflict of interest standards for individuals or entities serving as an ombudsman, defining the roles and responsibilities of the state long-term care ombudsman. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately.

Adult Care Facility Reporting (Chapter 64 of the Laws of 2018; A.9034 Gottfried / S.7282 Alcantara): This law adds to reporting requirements applicable to operators of an adult care facility with respect to deaths, attempted suicides and any incident believed to be a felony crime. This law was signed by the Governor on June 1, 2018 and took effect on that date.

Residential Off-Site Facility Demonstration Project (Chapter 101 of the Laws of 2018; A.10758 Morelle / S.8926 Robach): This law provides a

three-year extension for the residential off-site facility demonstration project until 2021. The project enables three residential health care facilities to provide various therapies and educational services at non-medical off-site locations. This law was signed by the Governor on July 1, 2018 and took effect on that date.

Alzheimer's and Dementia Locator Technology Information (S.5221-A Stavisky / A.1118-A Rosenthal, L.): This bill would require DOH, in conjunction with the SOFA, local Departments of Social Services and the State Police, to develop a list of all businesses and other entities that manufacture, distribute or offer locator technology or services designed to assist in locating individuals with Alzheimer's disease or dementia, post the list on the DOH website and notify all practicing physicians of the list. This bill passed both houses and was signed by the Governor. This bill takes effect on January 1, 2019.

Access to Hospice Services for Assisted Living Program Residents (A.10459-A Lupardo / S.8353-A Hannon): The bill would permit residents of assisted living programs (ALP) to access hospice services without having to leave the ALP. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Consumer-Directed Personal Assistance Program Clarification (Chapter 41 of the Laws of 2018; S.7326 Hannon / A. 9035 Gottfried): This law amends a 2017 law governing the authorization of fiscal intermediaries for the Consumer-Directed Personal Assistance Program to clarify its effective date as January 1, 2018 and to allow fiscal intermediaries operating prior to April 1, 2017 to have a year to become authorized. This law was signed by the Governor on April 18, 2018.

Notices to Residents in Adult Homes, Residences for Adults, Enriched Housing and Assisted Living Programs of Appointment of Temporary Operators (A.8159 Wright / S.766 Stewart-Cousins): This bill would require DOH to provide written notification

to residents of adult homes, enriched housing programs, residences for adults and ALPs of the appointment of a temporary operator. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Applicability of Cybersecurity Regulations to Continuing Care Retirement Communities (A. 10486-B Cahill / S. 7940-B Seward): The bill would exempt Continuing Care Retirement Communities (CCRCs) from the Department of Financial Services' cybersecurity regulations, provided that the CCRCs self-certify as to its compliance with applicable HITECH, HIPAA and other cybersecurity requirements that otherwise govern nursing homes and similar facilities. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Informal Caregivers in the Workplace (A.3958 Dinowitz / S.8739 Sepulveda): This would require the State Office for the Aging (SOFA) to develop and to update yearly a guide for employers on current best practices for retaining employees who are also informal caregivers. The guide would be available on the SOFA, the Department of Labor and the Department of State websites. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Hospitals and Health Care Facilities

Hospital Standing Orders for Newborn Care (A.9950-B Gottfried / S.8774-B Hannon): This bill will allow a hospital to establish non-specific patient orders for the care of healthy newborns by an attending nurse. The legislation sets forth certain requirements for the use and approval of such standing orders and allows DOH to promulgate regulations. The bill would also outline procedures for circumstances that would require a deviation from the standing order. This bill has passed both houses, but has not yet been delivered to the Gov-

ernor. This bill would take effect 120 days after becoming a law.

Lymphedema Information (A.8819-B Rosenthal / S.7765-B Golden): This bill would require the Commissioner of Health to design and make available to all general hospitals informational materials about lymphedema. Hospitals would be required to distribute the materials to patients identified as being at high risk of developing lymphedema; the bill provides a description of those patients who would be deemed high risk. This bill has passed both houses, but has not yet been delivered to the Governor. This bill would take effect 120 days after becoming a law.

Pharmacy

Drug Take Back Act (Chapter 120 of the Laws of 2018; A.9576-A Gunther / S.9100 Hannon): This law creates a statewide pharmaceutical take-back program and requires pharmaceutical manufacturers to pay for the costs related to the collection, transport, disposal and destruction of drugs, and public awareness and education. This law was signed by the Governor on July 10, 2018 and will take effect on January 6, 2019.

Pharmacy Interns as Immunizers (A.2857-D McDonald / S.1043-D Funke): This bill would allow pharmacy interns who receive specific training to administer immunizations under the immediate personal supervision of a licensed pharmacist certified to administer vaccines, with the understanding that persons receiving the vaccine will be informed that an intern is administering it and that they have the option of receiving the vaccine from a pharmacist. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Pharmacy Benefit Management ("PBM") Gag Clauses and Copayments (A.8781 Rosenthal / S.6940 Hannon): The bill would preclude PBMs from preventing pharmacists from disclosing information relating to the cost of prescription medication and would prohibit the imposition of copay-

ments that exceed the total submitted charge by the pharmacy. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would be effective 90 days after becoming a law.

Behavioral Health

Maternal Depression Treatment and Support Resources (Chapter 62 of the Laws of 2018: A.8953 Richardson / S.7409 Krueger): This law requires the Commissioner of Health to consult with the Commissioner of Mental Health and to make available on the DOH website information regarding how to access mental health professionals and other community resources that provide treatment or support for maternal depression. It would also require both commissioners to communicate to providers the need to raise awareness about maternal depression. This law was signed by the Governor on June 1, 2018 and took effect on that date.

Notification for Service Reductions by State-Operated Hospitals and Research Institutes (S.7207 Ortt / A.9563-A Gunther): This bill would amend the Mental Hygiene Law to set an outer limit—24 months—for the minimum notice that must be provided when OMH anticipates that a state-operated hospital or research institute will have a significant service reduction. This bill passed both houses, but has not yet been delivered to the Governor. The bill would take effect immediately, but would cause any notice issued pursuant to this section prior to the effective date to expire 12 months after the effective date.

Educational Resources Regarding Suicide Prevention (A.3210-A Ortiz / S.5860-A Ritchie): This bill would require the Commissioners of Mental Health and Education to publish educational materials on: suicide prevention measures; identifying signs of depression; understanding how depression manifests in different cultures; and noting the warning signs of suicide. These materials would be available to the faculty and staff at any university or community col-

lege. Such materials would need to be made available within 90 days of the bill becoming a law. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Special Education Services for Patients in OMH Hospitals (Chapter 89 of the Laws of 2018; A.10471 Nolan / S.8325 Marcellino): This law extends a pilot program allowing students residing in OMH psychiatric hospitals to receive appropriate special education services. The law was signed by the Governor on July 1, 2018 and took effect on that date.

Geriatric Service Demonstration Expansion (A.10938 Gunther / S.8632 Ortt): This bill would authorize collaboration between mental health providers and home care providers for the purposes of improving access to and integration of services in the community. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Substance Abuse

Prohibition of Patient Brokering by Substance Use Disorder Providers (A.7689-A Rosenthal, L. / S.6544-B Akshar): This bill would prohibit substance use disorder providers from engaging in "patient brokering," such as providing, soliciting or accepting remuneration for referrals, and makes such activities a misdemeanor. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Directory of Substance Abuse Providers (A.8151 Rosenthal / S.8552 Golden): The bill would require the Office of Alcoholism and Substance Abuse Services (OASAS) to maintain a directory of all providers licensed, certified or operated by the agency, that would include the following information: location, contact information, services provided, populations served, insurance accepted, availability of beds and services and any other information the Commissioner deems necessary. The bill passed both

houses, but has not yet been sent to the Governor. This bill would take effect 180 days after becoming law.

Substance Abuse Education (A.7470 Davila / S.8318 Comrie): This bill would require OASAS to develop or utilize existing educational materials to provide to school districts to supplement drug and alcohol related curriculum regarding abuse of alcohol, tobacco, prescription medications and any other relevant substances. Each school district would designate an employee to serve as an educator and a resource to students, parents and staff. The bill has passed both house, but has not yet been sent to the Governor. This bill would take effect 120 days after becoming a law.

Developmental and Other Disabilities

Early Childhood Screening (A.9868 Santabarbara / S.8955 Ortt): This bill would require the Commissioner of Health to develop a standardized screening approach for the early identification of autism spectrum disorders in children under the age of three. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Identification Cards for Individuals with Developmental Disabilities (A.249-C Santabarbara / S.249-C Helming): This bill would direct the Commissioner of the Office of People with Developmental Disabilities (OPWDD) to develop an identification card indicating that a person has been diagnosed with a developmental disability. The identification card would provide the bearer's name, address, age and the name of an emergency contact. The card is intended to be presented to first responders, law enforcement officials and others unfamiliar with the individual's diagnosis. An identification card could be obtained for a fee by all eligible individuals, as determined by OPWDD. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect 180 days after becoming a law.

Report on the Early Diagnosis and Long-Term Treatment of Autism Spectrum Disorder (A.261 Abinanti / S.3895 Parker): This bill would require the Commissioners of the Office of Mental Health, OPWDD, SED, DOH and OCFS to submit a report to the Governor and the Legislature on the projected future cost to the state of providing services related to diagnosis and care of individuals with autism spectrum disorder. The report would be due April 1, 2021 and would include the legislative recommendations deemed necessary by the Commissioners. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Use of the Proceeds from the Sale of Property Previously Used by OPWDD (S.8633 Ortt / A.10951 Lentol): This bill would require that 85 percent of the proceeds from the sale of any property previously used by OPWDD be used exclusively to increase funding for state-operated residential services or community based services provided by OPWDD. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately and would apply to the sale of any property on or after April 1, 2018.

Extension of Authority for DASNY Funding for NYSRA (A.10674 Gunther / S.8815 Ortt) and *NYSARC* (S.8074 Ortt / A.10332 Gunther): The first bill would extend Dormitory Authority of State of New York (DASNY) financing for the New York State Rehabilitation Association and to the Alliance for Inclusion and Innovation, the newly formed successor organization, for an additional five years. The second bill likewise allows NYSARC to obtain DASNY financing for another five years, through 2023. Both bills passed both houses and the NYSRA bill was signed by the Governor on July 31, while the NYSARC bill has not yet been delivered to the Governor.

Expands the Role of the Autism Spectrum Disorders Advisory Board (A.7976 De La Rosa / S.5534-A Ham-

ilton): This bill would add to the duties of the autism spectrum disorders advisory board by requiring the board to improve outreach and coordination of services for minorities. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect 60 days after becoming a law.

OPWDD Care Demonstration Program (S.7291 Ortt / A.8990 Gunther): The bill would provide that certain services *may* (rather than *shall*) be included in the Care Demonstration Program operated by the OPWDD and would provide for the expiration of the program on March 31, 2020, instead of 2021. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Transportation of Individuals with Disabilities (A.10708 Gunther / S.8592 Ortt): This bill would allow an individual with a developmental disability receiving services within the OPWDD service system to request to be transported by a staff person of the same gender. This bill has passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately.

Tax Credit for Home Improvements for Persons with Disabilities (A.5333-A Weprin / S.2829-A Parker): This bill would authorize a 30 percent tax credit for expenditures related to improvements to a residence, including ramps, widening of interior doors, reinforcements of bathroom walls to allow installation of grab bars, and moving light switches and outlets to be more accessible. The tax credit would be subject to a \$5,000 lifetime maximum per taxpayer and the aggregate amount of tax credits in any single year could not exceed \$1 million, which would be allocated based on date of filing. This bill does not limit the credit to persons or household members with disabilities. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately and would apply to all tax years

commencing on or after January 1, 2019.

Revises Statutory References to "Hearing Impaired" (A.7178 Englebright / S.6128 Murphy): This bill would replace all references to "hearing impaired" within New York State law with "deaf or hard of hearing." The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Notice of Eligibility for Medicaid for Persons with Disabilities (S.7328 / A.9004 Gottfried): The bill would repeal provisions added last year relating to notices of eligibility for Medicaid to require that written notice be provided to person applying for Medicaid who may be eligible for Medicaid, except for exceeding the income limits. The notice would advise the applicant that certain income may be disregarded if it has been placed in trust for an applicant with a disability. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Health Care Personnel and Professions

Clinical Laboratory Supervision Requirements (A.10781-A Gottfried / S.7521-A Hannon): This bill would clarify that requirements governing the supervision of clinical laboratories may be satisfied by individuals who are not on the premises of the laboratory, but are available by phone or synchronous two-way electronic audio visual communication. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Provisional Permitting of Clinical Laboratory Technologists (A.9966-A Magnarelli / S.8140-A DeFrancisco): This bill would replace limited license options for clinical technologists with the option to obtain a provisional permit. The provisional permit would provide technologists trained outside of New York State with additional time to complete required course

work needed to meet New York licensure requirements. The bill has passed both houses and was delivered to the Governor on July 19, 2018, but has not yet been acted upon. This bill would take effect immediately.

Emergency Technicians Re-Certification (Chapter 102 of the Laws of 2018; A.10830 Stern / S.8158-A Seward): This law provides a five year extension for the emergency technician five-year re-certification demonstration program. This law was signed by the Governor on July 1, 2018 and took effect on that date.

Licensure Exemption for Physicians Treating Members of a Team (S.4375-A Funke / A.7237-B Cusick): This bill would provide that physicians, who maintain a license in good standing in another state or territory and have a written agreement to provide medical services to Olympic athletes, an out-of-state secondary or postsecondary school or a professional athletic organization, do not need a license when providing medical services to such athletes or team at a sporting event, including up to five days prior and three days after the event occurs. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect 180 days after becoming law.

Physical Therapy Assistants (Chapter 107 of the Laws of 2018; S.8217 LaValle / A.10381-A Pichardo): This law extends the authority for physical therapy assistants providing care in the home through June 30, 2022. This law was signed into law by the Governor on July 1, 2018 and took effect on that date.

Continuing Education for Psychologists (S.7398-A Valesky / A.9072-A Fahy): This bill would require psychologists to complete a minimum of 36 hours of continuing education, with at least three of those hours focusing on the subject of professional ethics, every three years in order to receive a triennial registration certificate from the Education Department. The bill has passed both houses, but has not yet been sent to the Governor.

This bill would take effect on January 1, 2021.

Pathologists' Assistants Licensure (Chapter 85 of the Laws of 2018; A.10174 Bichotte / S.8088 LaValle): This law changes the effective date of a 2016 statute establishing licensure for pathologists' assistants to July 1, 2018. This law was signed by the Governor on July 1, 2018 and took effect immediately.

Continuing Education for Accountants (A.10648 Stirpe / S.8522-A Helming): The bill would eliminate an exemption on the mandatory continuing education requirement for newly licensed CPAs. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect on January 1, 2020.

Ebola Virus Volunteers (A.11020 Rules (Epstein) / S.8757 Hannon): The bill would extend the right of health care professionals to take unpaid leaves of absence to assist in addressing Ebola virus outbreaks. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Nurse Practitioners and Healthcare Proxies (S.7713-B Hannon / A.10345-A Gottfried): The bill would allow nurse practitioners in various settings to witness the execution of healthcare proxies and to determine the lack of capacity of a person to make a healthcare decision. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect 90 days after becoming law.

Civil Service Report on Nurse Practitioners (Chapter 17 of the Laws of 2018; S.7290 Hannon / A.8928 Gunther): This law directs the Director of Classification and Compensation within the Department of Civil Service to prepare a report on the current compensation and classifications of nurse practitioners employed by New York State. This law was signed by the Governor on April 18, 2018 and

was deemed to have taken effect on November 29, 2017.

Rural Health Council Review of Rural Healthcare Personnel Shortages (Chapter 43 of the Laws of 2018; S.7329 Hannon / A.8988 Jones): In addition to increasing the number of members appointed by the Governor to the 21-member Rural Health Council from seven to 10, the law also requires the Council to recommend ways to obtain timely data on the status of the health care workforce in rural areas and would require that its report to the regional economic development councils on the status of healthcare workforce supply be done every three years, rather than annually. The law was signed by the Governor on April 18, 2018 and took effect on that date.

Health Care Finance

Nursing Home and Hospital Project Bonds (S.8648 Hannon / A.10673 Paulin): This bill would increase the maximum aggregate principal amount for projects eligible for bonds and notes from the New York State Medical Care Facilities Finance Agency from \$15.8 billion to \$16.6 billion. The bill passed both houses and was delivered to the Governor on July 19, 2018, but has not yet been acted upon. This bill would take effect immediately.

Maintenance of Effort Requirements for SUNY Health Care Science Centers (S.7259-A LaValle / A.10620 Glick): This bill would clarify that SUNY health care science centers are part of the State's maintenance of effort requirements and that salary increments, fringe benefits and other non-personal services costs and inflationary expenses must be included in the maintenance of effort for SUNY schools and health care science centers. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately.

Dormitory Authority Financing for the New York Academy of Medicine (S.8414 Benjamin / A.10656 Rodriguez): This bill would make the New York Academy of Medicine eligible

for financing and construction services through the Dormitory Authority of the State of New York. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately.

Insurance

Mental Health and Substance Abuse Disorder Parity Reporting (A.3694-C Gunther / S.1156-C Ortt): This bill would require insurance plans to report to the Department of Financial Services certain information related to mental health and substance abuse services claims, for the purposes of ascertaining plan compliance with parity laws. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect 60 days after becoming a law.

Coverage of Enteral Formula (A.11043 Stern / S.8924 Seward): This bill expands the conditions for which enteral formula and modified solid food products must be reimbursed by insurers. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect on the first of January next succeeding the date on which it shall have become a law.

Cost-sharing for Prostate Cancer Screening (S.6882-A Tedisco / A.8683-A Gottfried): This bill would provide that screening for prostate cancer cannot be subject to cost sharing or annual deductibles and requires the DOH to produce written materials notifying patients of the availability of such insurance coverage. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately; however, the provisions relating to insurance coverage would apply only to policies and contracts issued, renewed, modified and amended on or after January 1, 2019.

Worker's Compensation Coverage of Acupuncture (S.6666 Amedore / A.2023-A Bronson): This bill would provide coverage for acupuncture services by Worker's Compensation and sets parameters for acupuncturists participation in and reimburse-

ment by the program. The bill passed both houses, but has not yet been delivered to the Governor. This bill would take effect immediately.

Excess Medical Malpractice Extender (Chapter 99 of the Laws of 2018; A.10613 Cymbrowitz / S.8499 Seward): This law extends through 2023 the elimination of a requirement on the Medical Malpractice Insurance Pool that it offer a second layer of excess medical malpractice insurance coverage. The law was signed by the Governor on July 1, 2018 and took effect on that date.

Health Savings Accounts Pilot Program Extender (S.5890-B Seward / A.8176-A Woerner): This bill would extend for five years—until 2021—the current demonstration program allowing managed care plans to offer a group high deductible health plans in conjunction with a health savings account. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Not for Profit Organizations

Not for Profit Corporation Membership (A.10336-A Paulin / S.8699 Gallivan): This bill would provide that,

on and after July 1, 2019, every not-for-profit corporation (except a corporation that has no members) shall have at least three members. The bill provides that such corporation may have a corporation, joint-stock association, unincorporated association or partnership as a sole member, if such corporation, joint-stock association, unincorporated association or partnership is owned or controlled by no fewer than three persons. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately.

Audit Committee Membership for Not-For-Profit Corporations (A.10534 Paulin / S.8638 Gallivan): The bill would allow independent directors who serve on “controlled corporations” (i.e., those entities controlled by another not-for-profit corporation) to serve on the audit committee of the controlling or other controlled corporations. The bill has passed both houses, but has not yet been submitted to the Governor. This bill would take effect immediately.

Charities to Identify Attorney General Website in Solicitations (A.2688-B Steck / S.3780-B Ranzenhofer): This bill would require that any charitable

organization soliciting donations, including a professional fundraiser for such organization, to provide a statement identifying the website and telephone number of the New York State Attorney General where an individual can receive information on charitable organizations. Such information would include information as to how much of each donated dollar is used for the charitable purpose, as opposed to administrative costs. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect 90 days after becoming a law.

Decouple New York State UBIT From New Federal Tax Changes (A.11051 Paulin / S.8831 Ranzenhofer): This bill would relieve not-for-profit organizations from having to pay New York State Unrelated Business Income Tax (UBIT) on pre-tax commuting and parking employee benefits, as would be otherwise required by the recent federal tax legislation. The bill has passed both houses, but has not yet been sent to the Governor. This bill would take effect immediately and would apply to tax years beginning on and after January 1, 2018. (Also noted under Tax Law Section).

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In the New York State Agencies

By Francis J. Serbaroli

Operation of Licensed Housing Programs for Children and Adolescents with Serious Emotional Disturbances



Notice of withdrawal of proposed rulemaking. The Office of Mental Health withdrew its proposal to repeal and replace section 594.8 to Title 14 NYCRR to clarify the regulation. *See* N.Y. Register March 7, 2018.

Problem Gambling Treatment and Recovery Services

Notice of proposed rulemaking. The Office of Alcoholism and Substance Abuse Services proposes to repeal Part 857 and add a new Part 857 to Title 14 N.Y.C.R.R. to update gambling regulations. *See* N.Y. Register March 21, 2018.

SNAP Benefit Offset

Notice of adoption. The Office for People with Developmental Disabilities amended Parts 671 and 686 of Title 14 NYCRR to update the SNAP benefit offset and the amount that each individual must pay to providers. *See* N.Y. Register March 28, 2018.

Continuing Care Retirement Communities

Notice of expiration. A notice related to continuing care retirement communities originally proposed in March 2017 has expired and cannot be reconsidered unless the Department of Financial Services publishes

a new notice of proposed rulemaking in the N.Y.S. Register. *See* N.Y. Register April 4, 2018.

Early and Periodic Screening, Diagnostic and Treatment Services for Children

Notice of revised rulemaking. The Office of Mental Health amended Part 511 of Title 14 NYCRR to promote the expansion of behavioral health services for children and youth under 21 years of age. *See* N.Y. Register April 4, 2018.

Clarification of Assessment of Functional and Health-Related Needs

Notice of adoption. The Office for People with Developmental Disabilities amended Subpart 636-1 of Title 14 N.Y.C.R.R. to clarify requirements for an Assessment of Functional and Health-Related Needs in Person Centered Planning regulations. *See* N.Y. Register April 11, 2018.

Minimum Standards for Form, Content and Sale of Health Insurance, Including Standards of Full and Fair Disclosure

Notice of emergency rulemaking. The Department of Financial Services amended Part 52 (Regulation 62) of Title 11 N.Y.C.R.R. to ensure coverage for essential health benefits in all individual, small group, and student accident and health policies. *See* N.Y. Register May 9, 2018.

Lead Testing in School Drinking Water

Notice of adoption. The Department of Health amended Subpart

67-4 to Title 10 N.Y.C.R.R. to require lead testing and remediation of potable drinking water in schools. *See* N.Y. Register May 9, 2018.

Trauma Centers

Notice of adoption. The Department of Health amended Parts 405 and 708 of Title 10 N.Y.C.R.R. to require hospitals to be verified by the American College of Surgeons Committee to be designated trauma centers by the department. *See* N.Y. Register May 16, 2018.

Public Water Systems—Revised Total Coliform Rule

Notice of adoption. The Department of Health amended Subpart 5-1 of Title 10 N.Y.C.R.R. to increase public health protection by reducing exposure to contaminants in drinking water. *See* N.Y. Register May 16, 2018.

Credentialing of Addictions Professionals

Notice of proposed rulemaking. The Office of Alcoholism and Substance Abuse Services proposes to repeal Part 853 and add a new Part 853 of Title 14 N.Y.C.R.R. to repeal obsolete rules and update process of credentialing addictions professionals. *See* N.Y. Register May 23, 2018.

Appeals, Hearings and Rulings

Notice of proposed rulemaking. The Office of Alcoholism and Substance Abuse Services proposes to amend Part 831 of Title 14 N.Y.C.R.R. to protect patient confidentiality, update due process provisions, technical amendments. *See* N.Y. Register May 23, 2018.

COMPILED BY FRANCIS J. SERBAROLI. Mr. Serbaroli is a shareholder in the Health & FDA Business Group of Greenberg Traurig's New York office. He is the former Vice Chairman of the New York State Public Health Council, writes the "Health Law" column for the *New York Law Journal*, and is the former Chair of the Health Law Section. The assistance of Caroline B. Brancatella and Katharine J. Neer, respectively of counsel and associate of Greenberg Traurig's Health and FDA Business Group, in compiling this summary is gratefully acknowledged.

Certificate of Incorporation

Notice of proposed rulemaking. The Office for People with Developmental Disabilities proposes to amend Part 681 of Title 14 N.Y.C.R.R. to remove a requirement for certificate holders that is no longer required under Mental Hygiene Law section 16.07. *See* N.Y. Register May 23, 2018.

Criminal History Record Checks and Advanced Home Health Aides

Notice of proposed rulemaking. The Department of Health proposes to amend Parts 402, 403, 700, 763, 765, 766, 793, 794 and 1001 of Title 10 N.Y.C.R.R. to implement statutory changes related to criminal history records checks and advanced home health aides. *See* N.Y. Register May 30, 2018.

Early Periodic Screening, Diagnostic and Treatment Services for Children

Notice of adoption. The Office of Mental Health amended Part 511 of Title 14 N.Y.C.R.R. to promote the expansion of behavioral health services for children and youth under 21 years of age. *See* N.Y. Register May 30, 2018.

Medical Use of Marijuana

Notice of adoption. The Department of Health amended sections 1004.3, 1004.4, 1004.22 and 1004.23 of Title 10 N.Y.C.R.R. to allow certain defined facilities to become a designated caregiver for a certified patient in N.Y.'s Medical Marijuana Program. *See* N.Y. Register June 6, 2018.

Procedure for Treatment and Hospitalization of Certain Mentally Ill Prisoners in Jail

Notice of adoption. The Office of Mental Health amends section 18.7 of Title 14 N.Y.C.R.R. to conform implementing regulations with a change in the authorizing statute. *See* N.Y. Register June 6, 2018.

Update Standards for Adult Homes and Standards for Enriched Housing Programs

Notice of emergency rulemaking. The Department of Health amends sections 487.4, 488.4, 489.7, 490.4 and 494.4 of Title 18 N.Y.C.R.R. to prohibit residential providers from excluding an applicant based solely on the individual's status as a wheelchair user. *See* N.Y. Register June 13, 2018.

Rate Rationalization—Intermediate Care Facilities for Persons with Developmental Disabilities

Notice of emergency rulemaking. The Department of Health amends Subpart 86-11 of Title 10 N.Y.C.R.R. to amend rate methodology effective 7/1/16 and include the addition of an occupancy adjustment and revision to 4/1/15 2 percent compensation calculation. *See* N.Y. Register June 13, 2018.

Managed Care Organizations

Notice of adoption. The Department of Health amended section 98-1.11(e) of Title 10 N.Y.C.R.R. to maintain the contingent reserve requirement applied to the Medicaid Managed Care, HIV SNP and HARP programs. *See* N.Y. Register June 13, 2018.

Respite Services

Notice of emergency and proposed rulemaking. The Office for People with Developmental Disabilities amends Subpart 635-10 of Title 14 N.Y.C.R.R. to remove language that conflicts with respite services related to the new 1115 waiver. *See* N.Y. Register June 13, 2018.

Minimum Standards for Form, Content, and Sale of Health Insurance, Including Standards for Full and Fair Disclosure

Notice of emergency and proposed rulemaking. The Department of Financial Services amends Part 52 (Regulation 62) of Title 11 N.Y.C.R.R. to establish minimum requirements for policies of volunteer firefighter

enhanced cancer insurance. *See* N.Y. Register June 20, 2018.

Plan of Conversion by Medical Liability Mutual Insurance Company

Notice of proposed rulemaking. The Department of Financial Services proposes the approval of a plan by the Medical Liability Mutual Insurance Company to convert from a mutual property and casualty insurance company to a stock property and casualty insurance company. *See* N.Y. Register June 20, 2018.

Medical Staff—Sepsis Protocols

Notice of proposed rulemaking. The Department of Health proposes to amend section 405.4 of Title 10 N.Y.C.R.R. to update definitions and guidelines of sepsis and associated protocols for treatment to align with the latest evidence-based practices. *See* N.Y. Register June 20, 2018.

Inpatient Psychiatric Services

Notice of proposed rulemaking. The Department of Health proposes to amend section 86-1.39 of Title 10 N.Y.C.R.R. to enhance reimbursement mechanisms for inpatient psychiatric services. *See* N.Y. Register June 20, 2018.

Authorization for Physicians to Use Controlled Substances for Treatment of Chemical Dependence

Notice of adoption. The Office of Alcoholism and Substance Abuse Services repealed Part 829 of Title 14 N.Y.C.R.R. to repeal an obsolete regulation. *See* N.Y. Register June 27, 2018.

Charges for Professional Health Services

Notice of emergency and proposed rulemaking. The Department of Financial Services amended Part 136 (Regulation 85) of Title 11 N.Y.C.R.R. to ban the use of placement agents by investment advisers engaged by the State employees'

retirement systems. *See* N.Y. Register June 27, 2018.

Site-Based and Community Based Prevocational Services

Notice of emergency and revised rulemaking. The Office for People with Developmental Disabilities amends Subpart 635-10 of Title 14 N.Y.C.R.R. to clarify site-based and community-based services and clarify reimbursement requirements. *See* N.Y. Register July 3, 2018.

Telephone Service

Notice of adoption. The Office for People with Developmental Disabilities amended Part 635 of Title 14 N.Y.C.R.R. to require providers to have and maintain active telephone service at all times. *See* N.Y. Register July 3, 2018.

Minimum Standards for Form, Contest and Sale of Health Insurance, Including Standards for Full and Fair Disclosure

Notice of emergency and revised rulemaking. The Department of Financial Services amended Part 52 (Regulation 62) of Title 11 N.Y.C.R.R. to ensure essential health benefits coverage in all individual, small and large group, and student accident and health policies. *See* N.Y. Register July 11, 2018.

Hospital Policies and Procedures for Individuals with Substance Use Disorders

Notice of adoption. The Department of Health amended Parts 405 and 407 of Title 10 N.Y.C.R.R. to require hospitals to establish policies and procedures to identify, assess and refer individuals with substance use disorders. *See* N.Y. Register July 11, 2018.

Care Coordination Organizations

Notice of emergency rulemaking. The Office for People with Developmental Disabilities amended Subpart 635-11 of Title 14 N.Y.C.R.R. to allow

individuals to be enrolled in a CCO when individuals are unable to enroll themselves. *See* N.Y. Register July 11, 2018.

Enrollment in Medicare Prescription Drug Plans and Fully Integrated Duals Advantage Plans for IDD

Notice of emergency and proposed rulemaking. The Office for People with Developmental Disabilities amended Subpart 635-11 of Title 14 N.Y.C.R.R. to allow individuals to be enrolled in a FIDA-IDD plan when individuals are unable to enroll themselves. *See* N.Y. Register July 11, 2018.

Minimum Standards for Form, Content, and Sale of Health Insurance, Including Standards for Full and Fair Disclosure

Notice of proposed rulemaking. The Department of Financial Services proposes to add section 52.1(r) and amend sections 52.17(a)(36), (37), 52.18(a)(11) and (12) of Title 11 N.Y.C.R.R. to clarify requirements regarding coverage and disclosure of information for contraceptives. *See* N.Y. Register July 25, 2018.

Prescription Contraceptive Drugs

Notice of proposed rulemaking. The Department of Health proposes to amend section 505.3(d) and (e) of Title 18 N.Y.C.R.R. to allow for a written order of prescription contraceptives for family planning purposes to be filled 12 times within one year. *See* N.Y. Register July 25, 2018.

Voluntary Foster Care Agency Health Facility Licensure

Notice of proposed rulemaking. The Department of Health proposes to add Parts 769 and 770 to Title 10 N.Y.C.R.R. to license Voluntary Foster Care Agencies to provide limited

health-related services. *See* N.Y. Register July 25, 2018.

Establishment and Operation of Market Stabilization Mechanisms for Certain Health Insurance Markets

Notice of emergency rulemaking. The Department of Financial Services amended Part 361 of Title 11 N.Y.C.R.R. to allow for the implementation of a market stabilization pool for the small group health insurance market. *See* N.Y. Register August 1, 2018.

Medical Use of Marijuana

Notice of emergency and proposed rulemaking. The Department of Health amended section 1004.2 of Title 10 N.Y.C.R.R. to add additional serious conditions for which patients may be certified to use medical marijuana. *See* N.Y. Register August 1, 2018.

Newborn Screening for Phenylketonuria and Other Diseases

Notice of proposed rulemaking. The Department of Health proposes to amend Subpart 69-1 of Title 10 N.Y.C.R.R. to support timely collection and submission of specimens for the detection of diseases in newborn infants in New York State. *See* N.Y. Register August 1, 2018.

Early Intervention Program

Notice of revised rulemaking. The Department of Health proposes to amend Subpart 69-4 of Title 10 N.Y.C.R.R. to conform existing program regulations to Federal regulations and State statute. *See* N.Y. Register August 1, 2018.

New York State Fraud, Abuse and Compliance Developments

Edited by Melissa M. Zambri

New York State Department of Health Medicaid Decisions

Compiled by Margaret Surowka Rossi

Richard Saline, D.M.D. (DOH Administrative Hearing decision July 6 2018, John Harris Terepka, ALJ). This audit involved a \$21,250 incentive payment from Medicaid to the dentist to upgrade to an electronic health records (EHR) system. After hearing, the ALJ found that the appellant failed to meet criteria to receive the incentive payment, the adoption of a certified system and volume of Medicaid patients. The appellant conceded that he never adopted, implemented or upgraded the system that he reported on his attestation. He did claim, however, that the office where he worked had an uncertified version of the system he reported and his prior office where he worked in 2012 did have a certified system. He was unable to document the system was used by him in 2013. As such, the ALJ determined that he failed to meet the first criteria. The appellant was also unable to document his Medicaid patient volume. He attempted to do so by presenting his billing information that consisted of a utilization report from the office in which he worked in 2012. The ALJ determined that these records alone failed to establish the volume of his patient encounters as they did not identify what dentist in the office treated the patients. Although he offered other arguments to establish patient volume, he had no other documentation, thereby failing to establish the second requirement for the incentive. The ALJ upheld the OMIG's determination to recover overpayments in the amount of \$21,250.

Dr. Rony Mashihi/Brooklyn Dental (DOH Administrative Hearing Decision May 14, 2018, James F. Horan, ALJ). This audit involved a \$21,500 incentive payment from Medicaid to

the dentist and his practice to upgrade to an electronic health records (EHR) system. After hearing, the ALJ found that the appellant failed to meet the criteria to receive the incentive payment and affirmed the recovery of the overpayments. As an initial matter, in order to qualify for the incentive payment, a provider with a Medicaid patient volume of 30 percent or more of the provider's practice must purchase a certified EHR. The provider's only defense was that he never received an explanation about what it meant to adopt an EHR system. Acting *pro se*, the provider stated that he purchased the most advanced dental software, Dentrrix, but also said that the system does not sync with any of the acceptable EHR systems. Accordingly, the ALJ found that the appellant conceded that he did not adopt accepted software and did not meet the criteria for receiving the incentive payment. The provider also tried to argue that since he gave part of the incentive to his prior employer, he should not be responsible for the entire amount. The ALJ rejected this argument since it was only the appellant who signed the attestation and received the incentive payment. As such, the ALJ upheld the OMIG's determination to recover overpayments in the amount of \$21,500.

Every Boro Ambulette Service Inc. & Jaycinth Blackman (DOH Administrative Hearing Decision February 5, 2018, Ann H. Gayle, ALJ). The providers challenged a Notice of Final Agency Action that censured them and sought overpayments in the amount of \$202,377 for claims in a period in which OMIG asserted that the provider did not have its liability insurance.



Based on evidence and testimony produced at hearing, the ALJ found that the original Notice of Suspension from the Department of Transportation (DOT) had not been received and therefore the period of time for which OMIG sought overpayments was improper and the amount of overpayments was significantly reduced. The issue in this matter involved the filing of a "Notice of Cancellation" or "Form K" by the Insurance Company with DOT. The Form K was filed by the insurance company prior to receiving the provider's payment. The provider contended that payment was in fact sent and that there was no lapse in insurance despite the filing of the Form K. The record showed that there were several notices of cancellation and reinstatement during the relevant time period. The record also showed that a Form E (the required document that a carrier must file with DOT notifying it that the company has insurance coverage) was faxed to the number designated by the DOT but the fax was broken and the DOT did not receive the Form E. Thereafter, DOT prepared a Notice of Suspension. OMIG claimed that the overpayment amount should be calculated from that date. The ALJ disagreed, noting that the Notice was stamped "Original" not "Served," as the Notice of Revocation had been, and that the provider denied ever receiving the Notice of Suspension. As such, the ALJ said that the calculation of the number of claims could only be for the revocation period—that is, the time after the receiving of the Notice of Revocation until the provider had filed the proper form, and not from the time of the Notice of Suspension. The ALJ also upheld the censure but reduced the amount of overpayments to \$49,935.75 for claims paid within the revocation period only.

Residential Health Care Facility (RHCF) Minimum Data Set (MDS) Audits

There are several recent decisions arising out of hearings involving MDS audits. Many of these have been before ALJ Terepka and a few others before ALJ Lynch. We refer you to each decision, which has been decided on fact specific grounds and summarized briefly below. The main issue involves the assessment of the residents' functional capacities in the resident assessment instrument (RAI). A common thread is whether there is sufficient documentation for the reasonableness and necessity of skilled therapy services such as Occupational Therapy (OT) and Physical Therapy (PT) or the residents' need for assistance with activities of daily living (ADL). A finding that there is not sufficient documentation or that the services are not necessary or reasonable would result in a lower resource utilization group (RUG) category, which would result in a recalculation of the reimbursement rate and yield an overpayment.

Elderwood at Cheektowaga (Administrative Hearing Decision April 11, 2018, John Harris Terepka, ALJ). This matter involved two MDS audits and the main issue was the sufficiency of the documentation for skilled therapy. The ALJ affirmed the audit findings, as the provider had failed to substantiate the need in the resident record. The ALJ found that therapy evaluations alone did not suffice to meet the requirements. As such, the audit findings were affirmed.

Garden Care Center (Administrative Hearing Decision February 15, 2018, William J. Lynch, ALJ). This matter involved two MDS audits and the main issue was the sufficiency of the documentation for ADLs. The ALJ affirmed the audit findings relating to Skilled Therapy and Special Treatment, Procedures and Programs for certain residents, but reversed the findings relating to Functional Status-ADL Self Performances and Support for many residents. The reason for the reversal is that the ALJ found, as in the *Avon* case below, the preprinted

ADL Assessment Forms were intended to meet the minimum documentation requirements to support the MDS submissions. As such, the audit findings were only partially affirmed and the overpayments reduced.

The Grove at Valhalla Rehabilitation and Nursing Center (Administrative Hearing Decision January 30, 2018, William J. Lynch, ALJ). This matter involved an MDS audit and the main issue was the sufficiency of the documentation for ADLs. The ALJ affirmed the audit findings based on the insufficiency of the documentation. In this matter, the provider did not have an ADL flow sheet. The provider argued that OMIG rejected the ADLs merely because of the absence of the ADL flow sheet, but the ALJ disagreed, indicating that OMIG was open to accepting any documentation that complied with the CMS RAI Manual and federal regulations. The ALJ rejected the contention that the MDS code sheet itself was sufficient. Also rejected was the care plan, as that is developed after the MDS process is completed and the focus is on the seven-day look-back period. ADL flow sheets and notes in the record that were not in the look-back period were also rejected. Notes in a resident's medical record alone during the look-back period were ruled not enough to meet the requirements. As such, the determination to recover overpayments was affirmed.

Avon Nursing Home (DOH Administrative Hearing Decision January 15, 2018, John Harris Terepka, ALJ). This matter involved two MDS audits and the main issue was the sufficiency of the documentation for ADLs. The ALJ completely reversed the audit findings based on the summary documentation forms provided by the appellant. Specifically, the provider relied upon Nursing Interim Review forms that summarized information received from other shift nurses. OMIG contended that these forms "simply did not pass muster." The ALJ disagreed, citing the CMS Resident Assessment Instrument (RAI) Manual which provides: "[n]ursing homes are left to determine . . . how

the assessment information is documented . . . CMS does not impose specific documentation procedures." The ALJ found that "[t]he appellant has clearly attempted, by means of the preprinted nursing interim review form, to simplify and streamline the documentation to the point where, for ADL scores, all that is necessary is for a nurse to fill in the numbers and sign the form. . . . There is no good reason to conclude, however, that the appellant's nursing interim reviews do not reflect a performance of the assessments required by the CMS Manual, or were not understood and intended to comply with minimum documentation requirements to support the MDS submissions." The ALJ concluded that the Department would be well advised to issue clarification of its requirement if the documentation provided by appellant is not to be accepted. As such, the determinations to recover overpayments were reversed.

New York State Attorney General Press Releases

Compiled by Bridget Steele, Angela Sicker, Gaity Hashimi, Jennifer Cruz

Indictment of New York Doctor For Manslaughter in Opioid Death— June 26, 2018—A D.O. was indicted for Manslaughter in the Second Degree for recklessly causing the death of a patient, a Manhattan resident who died at the age of 36 from a fentanyl overdose. State data used in the indictment shows Barry Sloan, D.O., prescribed oxycodone 30 mg tablets over 26,000 times to approximately 2,000 patients totaling over four million pills, with an estimated street value of over \$100 million. Among New York Medicaid's 17,000 prescribers of oxycodone 15 mg and 30 mg pills, Sloan was the 18th highest prescriber. In addition, Sloan was the fourth highest prescriber in New York of "Subsys," a narcotic approved by the FDA that contains fentanyl, which the Centers for Disease Control and Prevention (CDC) states is 100 times more powerful than morphine and 50 times more powerful than heroin. Sloan also faces a total of 74 counts of felony

criminal offenses. <https://ag.ny.gov/press-release/ag-underwood-announces-indictment-new-york-doctor-manslaughter-opioid-death>.

Registered Nurse Who Stole Over \$390,000 From Medicaid Sentenced— June 25, 2018—A Registered Nurse (RN) was sentenced to one year in jail for stealing over \$390,000 from Medicaid. On November 2, 2017, the RN pleaded guilty to Grand Larceny in the Third Degree, a Class D felony, after an investigation conducted by the Attorney General's office revealed that, over the course of nearly five years, he submitted false claims for private duty nursing services that he never provided to severely disabled patients. In addition to his one-year jail sentence, the RN has agreed to pay full restitution. <https://ag.ny.gov/press-release/ag-underwood-announces-indictment-new-york-doctor-manslaughter-opioid-death>.

New York And Massachusetts Attorneys General: We Will Sue the Federal Government Over Association Health Plans— June 20, 2018—The New York and Massachusetts Attorneys General issued a joint statement indicating they would sue the Federal Government for expanding the footprint of Association Health Plans (AHPs) under the U.S. Department of Labor's Proposed Rule. The Attorneys General claim the Proposed Rule seeking to expand AHPs is unlawful, "invite[s] fraud, mismanagement, and deception," and will not help ease the health care challenges of the country. <https://ag.ny.gov/press-release/ny-attorney-general-underwood-and-ma-ag-healey-we-will-sue-trump-administration-over>.

NY Attorney General And Comptroller DiNapoli Announce Guilty Plea of Queens Pharmacy Owner For \$1.5 Million Medicaid Fraud Scheme— June 8, 2016—A Queens pharmacy owner and its related pharmacy entered felony guilty pleas in Supreme Court, Queens County, based on an illegal kickback arrangement. In papers filed in court, the State alleged

the pharmacy had a kickback arrangement with a former employee of Nassau University Medical Center (NUMC) who earlier in the investigation pleaded guilty to unlawfully accepting kickbacks related to Medicaid services. The pharmacy entered a guilty plea to Grand Larceny in the First Degree, a class B felony, and the pharmacy owner will be sentenced to six months incarceration, five years' probation, and will be required to pay \$1.5 million as restitution. <https://ag.ny.gov/press-release/ag-underwood-and-comptroller-dinapoli-announce-guilty-plea-queens-pharmacy-owner-15>.

Settlement With CityMD of \$883,000 for Submitting False Claims to a Government Health Plan— June 5, 2018—City Practice Group of New York, LLC (CityMD) agreed to a \$883,000 settlement for causing the submission of false claims to New York State's Empire Plan, which provides health care to state and local government employees and their dependents. The AG's investigation revealed that from December 2010 to September 2013, CityMD knowingly caused its affiliates to overbill the Empire Plan for facility fees they were not entitled to, which resulted in \$197,390.52 in overbilling. As part of the settlement, CityMD admitted that despite the prohibition in the manual and United Health Care's instructions to refrain from submitting facility fee bills, CityMD continued to cause its practice affiliates to bill for facility fees. CityMD also admitted that it violated the New York False Claims Act and paid \$706,400 to the State—including the \$37,363.10 that was overbilled and not yet repaid, and over \$669,000 in additional damages, fees, and costs. <https://ag.ny.gov/press-release/ag-underwood-announces-883000-settlement-citymd-submitting-false-claims-government>.

Settlement With Ageless Men's Health for Misleading Patients in Diagnosing and Treating Low Testosterone— June 1, 2018—Ageless Men's Health, P.C. ("Ageless") and its affiliates provide testosterone

replacement therapy (TRT) to men at 36 clinics across the United States, including three in New York City. Ageless failed to inform patients that in diagnosing low testosterone and addressing potential side effects of treatment, it was not following evidence-based practices recommended by leading medical organizations. Additionally, Ageless prominently featured a deceptive "Low T Quiz" on its website that misled patients regarding the diagnosis of low testosterone—if any question was answered in the affirmative on the quiz, the participant was told they could be a "candidate for TRT." Under the agreement with New York, Ageless has committed to (1) remove the misleading "Low T Quiz" from its website; (2) inform patients that according to medical guidelines, blood tests for purposes of diagnosing low testosterone should be performed in the morning, and two morning tests should be performed before starting TRT; (3) inform patients about the thresholds for treatment set out in the relevant medical guidelines; and (4) inform patients in writing about the fertility-related side effects of TRT. <https://ag.ny.gov/press-release/ag-underwood-announces-settlement-ageless-mens-health-misleading-patients-diagnosing>.

New York Attorney General Releases Report Highlighting Office's Work Enforcing Mental Health Parity Laws, Protecting New Yorkers— May 31, 2018—In 2013, after receiving consumer complaints regarding health plans' coverage of behavioral health treatment, the New York Attorney General's Office launched a mental health parity initiative and began investigations into various health plans. Since then, the office has entered into eight national settlement agreements with: MVP, EmblemHealth, Beacon Health Options, Excellus, HealthNow, Anthem, and two settlements with Cigna. Four of the settlements required health plans to implement sweeping reforms in their administration of behavioral

health benefits, in particular relating to medical management practices, coverage of residential treatment, and co-pays for outpatient treatment; and to submit regular compliance reports. The A.G.'s report showed that plans are imposing fewer barriers to necessary mental health treatment by, for example, covering the continuum of care; allowing more consumers to access needed mental health care; and denying care at a lower frequency than in previous years. Since 2014, when the Health Care Bureau initiated its investigations, the number of consumer complaints to the Health Care Bureau Helpline regarding mental health and substance abuse issues diminished by nearly 60 percent. <https://ag.ny.gov/press-release/ag-underwood-releases-report-highlighting-offices-work-enforcing-mental-health-parity>.

New York's Attorney General Joins 17 Attorneys General to Condemn Federal Action—May 30, 2018—The New York Attorney General and 17 other Attorneys General sent a joint letter to the United States Department of Health and Human Services (HHS) and its Centers for Medicare and Medicaid Services (CMS) condemning federal actions that would delay the enforcement of protections for Medicare and Medicaid beneficiaries who receive care in skilled nursing facilities (SNFs). In 2016, a set of CMS long-term care reforms were instituted to prevent the spread of infections in nursing homes; improve training for staff; provide protections against abuse, neglect, and exploitation of Medicare and Medicaid beneficiaries; and ban arbitration agreements. These standards were scheduled to take effect in three phases. The second set of reforms was scheduled to take effect on November 28, 2017. However, CMS delayed the implementation of certain penalties by 18 months and lowered the frequency and amount of penalties for past violations. In the letter to HHS, the Attorneys General warned that CMS' recent actions to roll back protections, if allowed to advance, would not

only threaten the mental and physical security of seniors in nursing homes, but also would potentially create additional challenges for New York's Medicaid Fraud Control Unit (MFCU). <https://ag.ny.gov/press-release/ag-underwood-joins-17-attorneys-general-condemning-federal-action-rolling-back>.

Arrest and Indictment of Licensed Nurse for Allegedly Stealing Over \$550,000 From Brooklyn Hospital and Defrauding Medicaid—May 21, 2018—A licensed nurse was arrested for allegedly defrauding Medicaid and stealing over \$550,000 from Interfaith Medical Center, a Brooklyn not-for-profit community-based hospital. From 2013 to 2016, the nurse conspired with a former Interfaith employee, providing kickbacks to several others, to falsify timesheets in order to make it appear as if she was working at the hospital. During this time, she also allegedly applied for Medicaid and failed to file nearly \$40,000 worth of personal income taxes. If convicted, the nurse faces a maximum of five to 15 years in prison. <https://ag.ny.gov/press-release/acting-ag-underwood-announces-arrest-and-indictment-licensed-nurse-allegedly-stealing>.

Statement by New York Attorney General and Governor on Status of New York's Opioid Investigations—May 16, 2018—The New York Attorney General stated that after a lengthy investigation, the Attorney General's office will be filing a lawsuit against Purdue Pharma for allegedly exploiting New Yorkers' addictions, deliberately, by pushing health care providers to increase patients' use and dependence on opioids. The Governor stated that this will be a significant step forward in holding corporations accountable and ending the opioid crisis. <https://ag.ny.gov/press-release/statement-acting-ag-underwood-and-governor-cuomo-status-new-yorks-opioid>.

Jamestown Taxi Driver Charged With Defrauding Medicaid—April 23, 2018—A Jamestown taxi driver was arrested for allegedly stealing over

\$7,500 from Medicaid. The taxi driver allegedly paid an individual, who was working with the Attorney General's investigators in "Operation Ghost Ride," to notify the State's Medical Answering Services that his taxi service was the individual's preferred provider for medical transportation. It is also alleged that the taxi driver submitted false reports to the company, stating that he provided daily rides to that individual, which he did not. <https://ag.ny.gov/press-release/ag-announces-arrest-jamestown-taxi-driver-charged-defrauding-medicaid>.

New York Attorney General To Congress: Protect World Trade Center Health Program—April 11, 2018—The New York Attorney General wrote a letter to Congress, urging that it protect the World Trade Center Health Program (WTCHP) by opposing Trump's budget proposal, which would separate the WTCHP from the National Institute of Occupational Safety and Health. The Attorney General stated that separating the two would be "unnecessarily disruptive and potentially dangerous" for the first responders and victims of Sept. 11 who need critical health treatment and medical monitoring from their exposure to the tragedy. <https://ag.ny.gov/press-release/ag-congress-protect-world-trade-center-health-program>.

Attorneys General Move to Intervene in Defense of Affordable Care Act Against a Federal Lawsuit Filed in Texas—April 9, 2018—The New York Attorney General, working with a coalition of 16 other Attorneys General, filed a motion to intervene in defense of the Affordable Care Act in *Texas et al. v. United States et al.*, a lawsuit in the federal district court in Texas. The Texas lawsuit seeks, among other things, to dismantle the ACA by petitioning the federal government to stop Medicaid expansion, end incentives that help people afford health care, and allow insurance companies to deny coverage to those with pre-existing conditions. Texas and a coalition of other states allege that the ACA is no longer constitutional due to the passage of

the Republican tax bill in December 2017; meanwhile, in their motion to intervene, the Attorneys General assert that the ACA's constitutionality has been upheld by the Supreme Court. <https://ag.ny.gov/press-release/ag--part-coalition-16-ags-moves-intervene-defense-affordable-care-act>.

Binghamton Transport Owner Charged With Stealing Over \$100K From Medicaid—March 30, 2018—The owner of a transportation company was arrested for allegedly stealing over \$100,000 from the Medicaid program. The felony complaint alleges that the owner knowingly operated his company without Workers' Compensation Insurance or a valid taxi business license, and falsely filed that the company was in compliance with all federal and state laws and regulations. <https://ag.ny.gov/press-release/ag--announces-arrest-binghamton-transport-owner-charged-stealing-over-100k>.

A Joint State-Federal Settlement With CenterLight for \$10.3 Million Over False Medicaid Billing—March 28, 2018—CenterLight Healthcare entered into its second settlement agreement with the Attorney General since 2016, regarding the operation of CenterLight Managed Long Term Care Plan (MLTCP), for \$10.36 million. The settlement resolves the current allegations, initiated by a whistleblower, that CenterLight submitted false claims for monthly Medicaid premiums and knowingly failed to repay Medicaid for falsely obtained payments, violating the New York and federal False Claims Acts. <https://ag.ny.gov/press-release/ag--announces-103-million-joint-state-federal-settlement-centerlight-over>.

New York Attorney General Leads a Coalition of 19 Attorneys General Opposing an HHS Proposed Rule—March 27, 2018—According to the New York Attorney General, the Department of Health and Human Services (HHS) has proposed to unlawfully allow businesses and employers to object to providing insurance coverage for procedures

they consider objectionable. The HHS Proposed Rule could potentially impose burdens on already marginalized patients under the guise of religious freedom, increasing the risk of harm to patients in a manner that is inconsistent with several federal and state laws as well as the Constitution. As such, the New York Attorney General is leading a coalition of 19 Attorneys General that has filed comments opposing the HHS Proposed Rule. <https://ag.ny.gov/press-release/ag--leads-coalition-19-ags-opposing-trump-administrations-attempt-give>.

State Prison Sentence for Long Island Man Convicted of Stealing From Medicaid Funded Charity—March 23, 2018—A 63-year-old man from Bronx County was convicted of Grand Larceny in the Second Degree, a class C felony, and will serve 2 to 6 years in state prison for using a "no-show" job to steal more than \$800,000 from a Bronx County substance use treatment provider. Over a five-year time period, the man collected \$500,000 in salary and benefits as part of his "no-show" job and obtained over \$300,000 by submitting fake invoices to the provider for services never provided. In addition to being sentenced, the Bronx man was ordered to pay \$840,000 in restitution to the New York State Medicaid Fraud Restitution Fund. <https://ag.ny.gov/press-release/ag--announces-state-prison-sentence-long-island-man-convicted-stealing>.

New York Reaches a \$375,000 Settlement With Specialty Pharmacy Over Failure to Provide Basic Services—March 22, 2018—The New York Attorney General announced a settlement with specialty pharmacy Accredo Health Group, Inc. ("Accredo") after an investigation determined that Accredo failed to timely deliver life-sustaining medications, appropriately respond to after-hour calls, and provide sufficient language access for non-English speaking consumers. The Attorney General's office began to investigate Accredo after the Health Care Bureau Helpline received consumer

complaints related to Accredo's services. Under the settlement terms, Accredo has agreed to address delivery delays for life-sustaining medications, improve non-English language services, and better handle consumer complaints. <https://ag.ny.gov/press-release/ag--announces-375000-settlement-specialty-pharmacy-over-failure-provide>.

Health Care Helpline Recovers Nearly \$2 Million in Restitution and Savings for Consumers—March 19, 2018—The Attorney General released a report on its Health Care Bureau's Helpline (HCB Helpline), a free investigative helpline that has investigated and resolved over 2,500 consumer complaints representing \$2 million in cost savings to consumers. The HCB Helpline is accessible at 800-428-9071 to allow New Yorkers to report health care complaints, including incorrect medical billing, wrongful health plan rejection, improper processing of health insurance claims, and wrongful termination of health insurance. The released report describes how the HCB Helpline has helped consumers resolve complaints and details examples of cases the Health Care Bureau has handled, including a case where a consumer was wrongly billed \$24,000 by a hospital for after birth care. <https://ag.ny.gov/press-release/ag-s-health-care-helpline-recovers-nearly-2-million-restitution-and>.

Joint Settlement for \$750,000 With a Long Island Pediatrics Practice Resolving Allegations Company Submitted False Claims to Medicaid—March 7, 2018—The settlement with the Long Island pediatrics practice resolved allegations asserted in a qui tam action brought by a whistleblower that the practice failed to enroll employee providers treating Medicaid patients in the Medicaid program and instead billed under partner physicians' Medicaid identification numbers. As part of the \$750,000 settlement agreement, the New York Medicaid program will receive \$450,000. <https://ag.ny.gov/press>

release/ag--announces-750000-joint-settlement-long-island-pediatrics-practice.

EmblemHealth Pays \$575,000 Settlement for Data Security Breach—March 6, 2018—

EmblemHealth, one of the largest health plans in the United States, admitted a mailing error that resulted in 81,122 social security numbers being disclosed on a mailing. On October 13, 2016, the company mailed 81,122 policy holders, including 55,664 New York residents, a paper copy of their Medicare Prescription Drug Plan Evidence of Coverage, that included a mailing label with the policyholder's social security number on it. This was a violation of the federal Health Insurance Portability Accountability Act (HIPAA) and New York General Business Law. As a result, EmblemHealth settled with New York for a \$575,000 penalty, implemented a Corrective Action Plan and conducted a comprehensive risk assessment. This incident prompted the Attorney General to emphasize the importance of the Stop Hacks and Improve Electronic Data Security Act ("SHIELD Act"), which was introduced in November 2017, affording heightened protection from data breaches to New York residents. <https://ag.ny.gov/press-release/ag-schneiderman-announces-575000-settlement-emblemhealth-after-data-breach-exposed>.

Three Quarter Housing Operators Plead Guilty for Conducting a Medicaid Fraud Scheme—February 15, 2018—Two individuals pled guilty on two counts each of Grand Larceny in the Third Degree. They operated three-quarter homes in New York City, providing housing to formerly homeless individuals and prisoners. They administered a kickback scheme and defrauded Medicaid, whereby in exchange for money, they mandated that the residents attend substance abuse treatment at specific drug treatment centers, regardless of their medical need. If the residents had refused, they would have been evicted. The Medicaid program paid over \$2 million to these groups, which

passed on a portion of the proceeds to the individuals' five corporations. The individuals also executed a civil settlement agreement to forfeit assets—the sale of which will amass between \$1.5 and \$2.5 million in civil restitution for the State Medicaid program. <https://ag.ny.gov/press-release/ag-schneiderman-announces-guilty-pleas-three-quarter-housing-operators-yury-baumblyt>.

Owner of Albany Transportation Company Convicted and Sentenced for Medicaid Fraud—February 14, 2018—A co-owner of an Albany transportation company was sentenced to two to four years in prison for a class E felony. He conducted a scheme between October 2016 and January 2017, billing Medicaid for patient transportation to physical therapy appointments, which in fact never occurred. The scheme generated over \$50,000 in fraudulent claims. <https://ag.ny.gov/press-release/operation-ghost-ride-ag-schneiderman-announces-sentencing-owner-albany-0>.

New York Brings Lawsuit Against Insys Therapeutics Inc. for Dangerous and Deceptive Promotion of Prescription Opioid Subsys—February 1, 2018—The Attorney General filed a lawsuit against Insys Therapeutics Inc., a company that sells a highly addictive fentanyl drug called Subsys. The Attorney General is seeking disgorgement of revenues up to \$75 million. The complaint stated various allegations, including: Insys recklessly marketed the drug for much wider use than the FDA's approved use to treat extreme cancer-related breakthrough pain, downplayed the drug's risk of addiction, bribed doctors to prescribe the drug, lied to health care providers to avoid the authorization process, urged its sales representatives to convince providers to prescribe the more expensive, higher doses, and targeted medical offices that employed providers who had been arrested for illegal opioid distribution. In addition to this lawsuit, the New York Attorney General's Office

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The Editor would like to thank Barclay Damon's Law Clerks Angela Sicker, Gaity Hashimi and Jennifer Cruz for their assistance with this edition.

Angela Sicker is a Summer Associate at Barclay Damon. She attends Vermont Law School and plans to graduate in May 2019 with a JD and Masters in Energy Regulation. Previously, she worked at the RAND Corporation as a research assistant, focusing on substance abuse issues in teens and tobacco regulatory policy. Gaity Hashimi is a second year law student at the Syracuse University College of Law, expected to graduate in 2020. She is a Summer Associate at Barclay Damon LLP in the firm's 1L Diversity Program. In her second year of law school, she will be an editor on the Syracuse Law Review and a member of the Advocacy Honor Society. Jennifer Cruz is a second year law student at Albany Law School, estimated to graduate in May of 2020. Currently, she is a Summer Associate with Barclay Damon and is interested in litigation and healthcare law.

is implementing various other strategies to combat the opioid crisis including: obtaining settlements with major health insurers to remove barriers to treatment of opioid use disorder; improvements to New York's prescription drug monitoring program; allowing state and local-law enforcement officers to carry naloxone; an agreement with a pharmaceutical company which led to a reduction in the price of naloxone; enforcement of mental health parity laws; and a crackdown on drug networks trafficking opioids into communities. <https://ag.ny.gov/press-release/ag-schneiderman-sues-fentanyl-maker-insys-therapeutics-inc-dangerous-and-deceptive>.

New York State Office of the Medicaid Inspector General Update

Compiled by Eric Dyer

UPDATE: Doctor Who Participated in \$30 Million Health Care Fraud Scheme Sentenced in Federal Court—August 2, 2018—<https://omig.ny.gov/latest-news/1102-update-doctor-who-participated-in-30-million-health-care-fraud-scheme-sentenced-in-federal-court>.

OMIG Participates in 2018 National Healthcare Fraud Takedown, Efforts Help to Uncover \$163 Million in Alleged Fraud Schemes—June 28, 2018—<https://www.omig.ny.gov/latest-news/1099-omig-participates-in-2018-national-healthcare-fraud-takedown-efforts-help-to-uncover-163-million-in-alleged-fraud-schemes>.

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In the Journals

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For Your Information

By Claudia O. Torrey

At this writing, I hope you are enjoying the Summer; however, the first day of Autumn (September 22, 2018) may have come and gone by the time you read this brief column. Thus, best wishes for Fall 2018! As we moved toward the “dog days” of Summer, the week of July 30, 2018 proved interesting! During that week:

- The Trump Administration rolled out the Final Rule on short-term health insurance plans¹ that are being “pitched” as a cheaper alternative (basically amends the definition of short-term, limited duration insurance for purposes of its exclusion from the definition of individual health insurance coverage) to buying individual insurance via the Affordable Care Act (ACA) Exchange. This announcement comes on the heels of an earlier Trump Administration announcement regarding Association Health Plans (which this author acknowledged in an earlier edition of the *Health Law Journal*), and none of these plans will be offered on HealthCare.gov.

According to Kaiser Family Foundation Senior Fellow Karen Pollitz, “cheap insurance is cheap for a reason—these plans are less expensive because they are offering you less protection!” The short-term plans do not have to cover pre-existing medical conditions or the “essential” benefits required by the ACA, whereas Association plans *do* have to accept people with pre-existing conditions, but do not have to cover all of the essential benefits (such as wellness visits, prescription drugs, mental health needs, and maternity care). While these new short-term policies may be issued for 364 days and extended up to three years (the ACA short-term plans can only be sold for a coverage period of 90 days), some of these plans may not even cover hospitalization(s) or have very limited hospitalization coverage.

- On his way out the door of the U.S. Supreme Court, Associate Justice Anthony Kennedy, in a four-sen-

tence order,² denied an attempt by the Trump Administration to stay/stop a climate change lawsuit brought by 21 children in *Juliana v. United States*; the ruling was unanimous! This action allows plaintiffs to preserve their October 29, 2018 trial date in the U.S. District Court of Oregon. Plaintiffs’ allege that the federal government has failed to protect our earth from the effects of climate change, in particular as such relates to the federal government’s move to dismantle the controls for vehicle emissions of greenhouse gases. The Trump Administration puts itself in the position of “doing battle” with several states that followed California’s lead to enact higher fuel standards, including New York State.³

- Before the “dog days” of Summer, the N.Y. State Court of Appeals unanimously decided on June 28, 2018 that the 2013 Rule enacted by the New York City Department of Health & Hygiene, mandating the flu vaccine for children attending school-based programs and/or city-regulated child care, *will stand* (needless to say, exceptions will be made for those children with a physician’s order or those children whose family have a sincere religious concern); the decision was written by Judge Stein.⁴

Endnotes

1. Final Rule: Department of the Treasury (via Internal Revenue Service), 26 CFR Part 54; Department of Labor (via Employee Benefits Security Administration), 29 CFR Part 2590; and the Department of Health & Human Services (via Centers for Medicare & Medicaid Services), 45 CFR Parts 144, 146, and 148. All effective 60 days post publication in the *Federal Register*.
2. Order List, 585 U.S. __; Order in pending case *U.S. et al. v. USDC Oregon*.
3. NYS Department of Environmental Conservation Title 6, Chapter III (Air Resources), Subpart 218-8.5; 6 CRR-NY 218-8.5.
4. *Garcia et al. v. New York City Department of Health & Mental Hygiene*, <https://www.nycourts.gov/ctapps/Decisions/2018/Jun28/64opn18-Decision.pdf>.

CLAUDIA O. TORREY is a Charter Member of the Health Law Section.

Overview of Guardianship for Individuals with Intellectual Disabilities: Changes on the Horizon

By Tara Anne Pleat, Edward V. Wilcenski and Katy Carpenter

In New York State, individuals are assumed to be legally competent to make their own personal, medical and financial decisions upon attaining the age of 18.¹ But what happens when an individual is not capable of making these decisions due to an intellectual or developmental disability? Many parents assume that they will continue to make decisions for their child even after the child reaches the age of 18, but this is not the case.

The good news is that New York's Surrogate's Courts offer an accessible guardianship process which authorizes parents and other caregivers to make important life decisions for individuals with disabilities after reaching the age of majority and continuing throughout the duration of the disability. This proceeding is commonly referred to as a "17A Guardianship" (referring to the Article of New York's Surrogate's Court Procedure Act (SCPA) where the procedure for securing this type of guardianship can be found). The 17A Guardianship proceeding can be brought on behalf of any individual with an intellectual or developmental disability having an onset prior to age 22, or on behalf of individuals with a traumatic brain injury sustained at any age.²

Ideally, guardianship should be in place prior to the individual reaching 18 years of age so that there is no disruption in the parent's or other advocate's ability to make important life decisions for the person with the disability. If you believe an Article 17-A Guardianship is appropriate for your child, we recommend that you begin the process six months prior to your child's 18th birthday.

There are three main steps in the process. The first step is to prepare the written request to the court (referred to as the "Petition") and accompanying documents. The documents required in an Article 17-A Guardianship proceeding are sufficiently "user-friendly" such that most families will not need to hire an attorney unless the Petition will be asking for more complicated relief from the court. For example, if the person with the disability recently received a financial windfall (such as a surprise inheritance or a personal injury settlement), it may be necessary for the court to approve the establishment of a special (supplemental) needs trust as part of the guardianship proceeding. This type of request is more complicated, and assistance from an attorney experienced in the area is strongly recommended.

In most cases, individuals who have just reached the age of majority do not own property of their own, and so families are able to handle the 17A Guardianship proceed-

ing on their own. The checklist of information needed to complete the forms is available online (<http://www.nycourts.gov/courthelp/DIY/guardianship17A.shtml>). The online program collects the required information and prints out all forms, including the Petition. Most of the forms will require notarization, and Notary Publics are available at most banks or financial institutions.

If you are uncomfortable working online, you can call your County's Surrogate's Court and request an "Article 17-A Guardianship packet," which will contain the forms and directions on how to complete them.

The Petition will ask for fairly detailed information about the petitioners (i.e., the parents of the child with a disability or the individual petitioning to become guardian) and any individual over the age of 18 who resides in the home of the proposed guardian. Everyone will need to provide their addresses for the past 28 years so that the New York Statewide Central Register of Child Abuse and Maltreatment can conduct a search for past abuse, neglect or maltreatment.³

The third step is to secure proof of the disability using two forms produced by the online program or contained in the packet—a physician's affirmation and a licensed psychologist's affidavit (or two physicians' affirmations).⁴ These forms are intended to certify that the person with the disability is in need of guardianship, and ask the professionals to provide a detailed basis for their opinion along with a specific determination as to whether the person has the capacity to make health care decisions.⁵

Once these steps are complete, the documents are filed with the Surrogate's Court (including the form for the New York Statewide Central Register of Child Abuse and Maltreatment) and a modest filing fee is paid (usually \$20). The court will schedule a hearing, which the individual with the disability will attend. The court will issue a "Citation" (which is the written notice of the date and time of the hearing), and the Citation will need to be "served" (given to) the person with the disability, that person's spouse (if applicable), the other parent (if a joint guardianship is not being sought) and any adult siblings.⁶ If the person with the disability resides in a residence

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certified by the New York State Office for Persons with Developmental Disabilities (OPWDD), the Executive Director of the agency operating the residence and the Mental Hygiene Legal Services will also need to be notified of the proceeding.

In most cases a Guardian *Ad Litem* (GAL) will be appointed by the court to represent the interests of the person with a disability.⁷ The GAL reviews the file, meets with the person with the disability and the proposed guardian and files a report with the court. The GAL is typically an attorney, and is entitled to a fee for his or her work. The fee will be the responsibility of the petitioners unless the person with the disability has assets of his or her own that can pay the fee.

At the hearing the court will review all the documentation, including the GAL's Report, and will issue a decision (referred to as a Decree) which confirms the appointment of Guardians of the Person, of the Property, or (most commonly) both.⁸ The court will also issue "Letters of Guardianship"—a certificate which serves as evidence of the appointment.

A Guardian of the Property has ongoing property management and reporting responsibilities. A Guardian of the Property must:

- Confirm that all of the property of the person with the disability has been collected and deposited into a court-supervised account;
- Request court approval for any withdrawal from such account; and
- Prepare and file annual reports of account activity. Note that Social Security Disability and Supplemental Security Income payments are not subject to these reporting and oversight responsibilities. These programs are federal benefits and are subject to a separate oversight system—the Representative Payee system - which governs the appointment of individuals to manage those benefits for individuals with disabilities.⁹

While a Guardian of the Person in a 17A Guardianship does not have an annual reporting requirement under current law, it is important to remember that a Guardian of the Person nonetheless has a fiduciary relationship to the individual with the disability. This means that the Guardian of the Person has an ongoing obligation to remain informed, involved, and to make decisions in the best interest of the individual with the disability. Some courts have initiated their own "personal needs accounting," which is an annual report providing information about the location and well-being of the person with a disability.¹⁰

Changes on the Horizon?

The relative ease by which parents and other caregivers can become Article 17A guardians has been one of its advantages since its enactment nearly 50 years ago. On the other hand, in recent years the law has been subject to criticism by a number of disability advocates, the concern being that the process for establishing guardianship does not sufficiently protect the due process rights of the individual with the disability.

These advocates raise some very important issues, not the least of which is that the 17A statute is designed to grant guardianship based on a diagnosis, and does not require the court to determine whether there are certain powers that the guardian should NOT be granted. The advocates argue that the approach taken by New York's other, newer guardianship statute—Article 81 of the Mental Hygiene Law—is the better approach, as it requires the court to concentrate on the person's functional abilities rather than diagnosis. If the Article 81 court finds that a person is able to handle certain responsibilities—despite the individual's disability—then the guardian should not be granted any authority in those areas, thereby preserving the individual's independence and right to self-determine as much as possible.

Most people agree with this approach as a matter of principle. The reason why many families do not utilize the Article 81 statute—which is available to individuals with disabilities of any age—is that the process is much more involved and as a result is often significantly more expensive than the 17A guardianship process. An attorney is needed to commence an Article 81 Guardianship proceeding, the hearing itself is longer and more extensive, and the annual reporting requirements are substantial.

The issue recently came to a head when Disability Rights New York (DRNY)—a non-profit organization which advocates for individuals with disabilities—filed a lawsuit in federal court arguing that Article 17A violates the due process and equal protection rights of individuals with disabilities.¹¹ New York's Attorney General filed a "motion to dismiss" the lawsuit on procedural grounds, and some advocates are urging New York State to change some of the language of the statute to address the issues laid out in the lawsuit. The matter was dismissed and Disability Rights New York appealed that decision. Oral argument was held at the Second Circuit Court of Appeals on August 16, 2018. A decision is expected later this fall.

What to Do in Light of the Lawsuit?

Article 17A remains good law in New York, at least for now. And while people on both sides of the issue con-

GUARDIANSHIP AND SURROGATE DECISION-MAKING

tinue to advocate their positions in court and with their legislators, parents and other advocates will still be faced with the dilemma of having a child or other loved one reach the age of majority without having the capacity to make important life decisions.

When we discuss this issue with our clients, we try to educate them on the differences between the Article 81 and Article 17A statutes, and we also remind them that for individuals with mild cognitive disabilities, Advance Directives (Power of Attorney, Health Care Proxy and Living Will) may be an appropriate means of achieving the same end. There is also a movement in New York to enable Supported Decision Making. Information on these efforts can be found at www.sdmny.org.

Different clients approach these delicate issues in different ways. For our part, we simply want to ensure that our clients wrestle with this issue before a family member with a cognitive disability reaches the age of majority.

Endnotes

1. SCPA 1751; *see also* <https://www.nycourts.gov/CourtHelp/Guardianship/17A.shtml> (last visited Aug 30, 2018).
2. SCPA 1750-a(1).
3. SCPA 1706(2), §1761.
4. SCPA 1750-a(1).
5. SCPA 1750-b.
6. SCPA 1753.
7. SCPA 1754(1).
8. SCPA 1754(5).
9. 20 CFR § 404.2035, § 404.2065.
10. In the author's experience, a couple of upstate counties—Albany and Rensselaer—have created a simple personal needs accounting form which is required to be filed on an annual basis.
11. *DRNY v. Unified Court System of NYS, et al.*, S.D.N.Y., Case #1:16-cv-07363.



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Restoring Rights in 17A Guardianships: Myths and Strategies

By Jennifer J. Monthie

Introduction

Guardianship under Article 17A of the Surrogate's Court Procedure Act ("Article 17A") is almost always permanent¹—a court transfers the decision making rights of a person to another and those rights are rarely regained over the lifetime of the person. What happens to a person who is placed under a guardianship and does not need a guardian? Most guardianship statutes, including Article 17A, allow for the modification or termination of the guardianship, but there is limited data on how frequently guardianships are actually terminated. Data on the number of cases where Article 17A guardianships have been terminated and the individual's rights were restored is not currently being collected. Reported decisions of restoration of rights under Article 17A are rare.² Those seeking restoration under Article 17A can even face initial opposition to the petition to terminate the guardianship. In two separate Surrogate's Courts, a person seeking to terminate a guardianship was initially turned away by the court's clerk. They were told that they could not seek a termination of the guardianship because their disabilities were adjudicated as permanent.

This article aims to address the myth that restoration of rights is not possible under Article 17A by following the restoration stories of three people, Michael, Junior and Kelly, who sought the termination of their Article 17A guardianships. Junior was placed under guardianship at the age of 25 because of a diagnosis of intellectual disability. He began exploring restoration after he was told that he could not consent to his photograph being used when he was made employee of the month. Kelly was also placed under guardianship because of her diagnosis of intellectual disability. A disagreement about medical care prompted her to seek legal advice about removing her guardian. Michael lived his entire life with his parents who sought guardianship because of his intellectual disability. It was only as his parents health declined and they were unable to serve as his guardian that Michael started to consider whether he needed or wanted a guardian.

Michael, Junior and Kelly struggled to regain their independence and in the process have helped define a practice of restoration under Article 17A. Their cases highlight the impact of limited procedural protections within Article 17A³ and the lack of a defined process for restoring the rights of someone under guardianships.

History of Article 17A⁴

Before exploring restoration it is important to understand the history of Article 17A. In 1969, spurred by parents and parent organizations seeking to protect the interests of people with intellectual disabilities,⁵ a bill was enacted which authorized a Surrogate's Court judge to appoint a guardian over the person, property or person and property of a person with intellectual disability. Article 17A has remained nearly identical today. Article 17A is a plenary guardianship statute that does not direct the tailoring of the powers of the guardian to the specific needs of the person under guardianship. Article 17A does not require any specific factual allegations about the person's ability to understand the nature and consequences of his or her ability to provide for personal needs or property management. Instead, Article 17A requires that the petition be filed with the court on forms prescribed by the Unified Court System of the State of New York.⁶ The petitioner is required to submit certifications of two physicians or one licensed psychologist and one physician with the petition. The physician or psychologist must opine whether the person is incapable of managing himself or herself and/or his or her affairs by reason of an intellectual or developmental disability and whether such condition is permanent in nature or likely to continue indefinitely.

In 1990, the Office of Mental Retardation and Developmental Disabilities⁷ was directed by the New York State Legislature to study and re-evaluate Article 17A. The legislature sought this study because of "momentous changes [which have occurred] in the care, treatment, and understanding of" individuals with disabilities.⁸ The final study

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GUARDIANSHIP AND SURROGATE DECISION-MAKING

was to be submitted to the legislature by December 1, 1991, but the study was not made public and ultimately no amendments to Article 17A were made.

Nearly two decades later, a renewed examination of Article 17A began after a Surrogate's Court decision criticized the statute for its procedural shortcomings.⁹ This decision was followed by several others and a body of reported decisions on Article 17A have emerged.¹⁰

Then in 2013, the New York State's Olmstead Cabinet¹¹ took a position on Article 17A. The Olmstead Cabinet called for Article 17A to be "modernized in light of the Olmstead mandate...with respect to appointment, hearings, functional capacity, and consideration of choice and preference in decision making."¹² In response to this plan, the Office for People With Developmental Disabilities proposed a departmental bill to the legislature that sought to redress the discrimination criticized in the Olmstead report.¹³ The Bill was not enacted.¹⁴ Other bills have been introduced to amend Article 17A but each has not passed by both branches of the state's legislature.¹⁵

On September 21, 2016, Disability Rights New York¹⁶ (DRNY) filed a suit in the United States District Court for the Southern District of New York seeking to enjoin the State of New York¹⁷ from appointing guardianships pursuant to Article 17A, because the statute violates the Fifth and Fourteenth Amendments of the United States Constitution, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973 (Section 504).¹⁸ On August 16, 2017, the Southern District of New York dismissed the action on the sole ground that abstention is warranted pursuant to *Younger v. Harris*.¹⁹ The court concluded that "[t]he New York State courts are an adequate venue for plaintiff to ventilate its constitutional concerns, and plaintiff's challenge will receive the full benefit of appellate review, and if needed, review in the Supreme Court of the United States...Accordingly, plaintiff's challenge is not prejudiced by my decision today."²⁰ On September 11, 2017, DRNY appealed and the appeal is pending before the U.S. Court of Appeals for the Second Circuit.²¹

Restoring Rights an Evolving Process

As Article 17A is being examined by the legislature and challenged in federal court, people who have been placed under guardianship have started to return to Surrogate's Courts to demand restoration of their rights. These restoration cases are challenging because of the way Article 17A is structured. Under Article 17A, a guardianship continues over the entire life of the person; there is no limit on duration or subsequent review of the need for continued guardianship.²² Modification or termination of an Article 17A guardianship requires the person under guardianship or another person on behalf

of the person under guardianship to petition the court to modify, dissolve, or amend the guardianship order.²³ As one Surrogate's Court judge described it, "[a]lthough article 17-A provides for a proceeding by which a guardianship may be terminated (SCPA 1759), commencing such a proceeding is unquestionably daunting, and may be impossible for someone who is immobile or illiterate. Of equal concern, there is no proceeding by which changes in the ward's condition or situation can be addressed."²⁴

The lack of an easy to understand and accessible process for terminating or modifying an Article 17A guardianship impacts those under guardianship. Kelly's mother obtained an Article 17A guardianship over her when she was 27 years old. Now, in her 40s she lives in her own apartment where she cooks, cleans and shops for herself. Despite her daily independence, and limited interaction with her guardian, Kelly remained under a guardianship for 15 years.

Access to legal advice and representation is often an insurmountable barrier for a person seeking to terminate a guardianship. Article 17A makes no provision for the appointment of an attorney to represent the individual. Instead, Article 17A states that a court, "may in its discretion appoint a guardian ad litem, or the mental hygiene legal service²⁵ if such person is a resident of a mental hygiene facility... to recommend whether the appointment of a guardian as proposed in the application is in the best interest of the person who is intellectually disabled or person who is developmentally disabled."²⁶ This provision does not provide for an attorney-client relationship.²⁷ One Surrogate's Court has held that in light of the severe deprivation of liberty that results from a 17A guardianship, and the inability of the respondent to afford counsel, assignment of counsel was constitutionally mandated when a petition for guardianship is made.²⁸ This right has not been extended to all Surrogate's Courts across the state or to those seeking a modification or termination of a guardianship under Article 17A.

People under Article 17A guardianship and those who support them are often unsuccessful in securing representation on their own. Clients report contacting several legal advocacy organizations and being denied legal representation because restoration under guardianship was not within the organization's practice area. This is not surprising as the legal practice of restoring the rights of people under Article 17A guardianship is limited. An attorney engaging in this type of representation is given very little guidance from the statute. The process can differ depending on the Surrogate's Court. For one client, even after finally securing legal representation, clerks at the Surrogate's Court refused to accept the petition to terminate the guardianship claiming that because the person was placed under guardianship the person lacked the le-

GUARDIANSHIP AND SURROGATE DECISION-MAKING

gal standing to petition the court. In another Surrogate's Court, a clerk told the attorney that since two physicians signed certifications which swore that the disability was severe and permanent, there is no grounds for seeking a termination.

Another barrier to restoration of rights is the lack of understanding about what guardianship means to the person placed under guardianship. Article 17A does not require that the person with intellectual or developmental disabilities be notified of his or her rights to contest the appointment of a guardianship, or to be fully informed of the nature and implications of the proceeding. Many Article 17A guardianships are obtained by parents and family members when the person reaches the age of majority. Those placed under guardianship are sometimes asked if they want their parents to continue to make decisions for them. During a restoration process some clients report that they did not fully understand the impact of guardianship. Clients often report not knowing what a guardianship is and how it impacts their lives. They confuse their desire for their parents to continue to support them with a need to consent to termination of all decision making rights. Others report not understanding the difference between having support in making decisions and having another person make those decisions for them.

During representation in a restoration proceeding, an attorney is, often for the first time, explaining what guardianship means to their client. During the restoration process a person often is considering how decisions are made for the first time, what supports they want or need to help them make decisions, and how restoration may impact the relationships they have and the choices they make. These concerns and questions need to be addressed by the attorney throughout the representation.

In 2014, when DRNY was asked by Michael to assist him, he had just been removed by Adult Protective Services (APS) from his home where he lived with his parents. His parents had been placed in a nursing home and an APS investigation had uncovered deplorable living conditions, a lack of food and working bathing facilities. The home was eventually condemned. Michael had to, for the first time, consider his decision-making process. He learned about what guardianship is and how it impacts his life. Michael developed relationships with the people who supported him and began making decisions about his living arrangements, daily activities and future goals. Over the two year course of the legal proceeding, Michael established his own decision-making process, and he developed a desire to be in control of his life choices. As a result of Michael efforts, those who worked with him regularly, including his service providers and

psychologist, supported his quest for independence and autonomy.

The attorney providing representation in Article 17A restoration cases also faces the additional challenge of building a case without access to a developed record from the original guardianship proceeding. Article 17A permits the court "in its discretion to dispense with a hearing for the appointment of a guardian" where the application has been made by (a) both parents or the survivor; or (b) one parent and the consent of the other parent; or (c) any interested party and the consent of each parent.²⁹ Since parents often serve as guardians, Article 17A guardianships are often appointed without conducting a hearing. The statute does not require the court to make any findings of fact with regard to the nature or extent to the powers requested by the petitioner, the functional abilities or limitations of the person being subjected to the guardianship, or why it is necessary for a guardianship to be appointed. The lack of a hearing and finding of facts impacts representation in restoration cases. There is little information about why a guardianship was sought, or the functional ability of the person to make decisions at the time of the appointment of the guardianships.

Junior was placed under guardianship at the age of 25. Because his family members petitioned for guardianship, Junior's hearing was waived and there was no findings of fact by the court. The only record Junior's attorney had was the decree and letters of guardianship. Therefore, a full record needed to be developed to petition for restoration. This meant gathering records about Junior, obtaining evaluations or assessments from providers and treating professionals, and preparing Junior to provide testimony in court.

Since Article 17A is silent as to which party has the burden when petitioning for modification or dissolution of the guardianship, the burden is placed on the person petitioning the court. That means the person with a disability must prove that it is in her best interest to remove the guardianship. One Surrogate's Court described the "best interest" standard as amorphous, a standard which is "rarely articulated but frequently assumed."³⁰ Without a record to show why the guardianship was imposed and what the guardianship does to benefit the person, the attorney cannot rely upon a change in circumstances. Instead, the attorney is forced to prove that it is not in the client's best interest to remain under a guardianship.

While Junior's diagnosis had not changed over the course of the guardianship, he had secured competitive employment and was no longer receiving Social Security benefits or Medicaid benefits. His full-time employment afforded him a living wage with health benefits. Even though these life changes could demonstrate that

GUARDIANSHIP AND SURROGATE DECISION-MAKING

a guardianship is not necessary, Junior still needed to demonstrate why the guardianship was not in his best interest. Junior's attorney obtained new functional and psychological assessments to support the removal of the guardianship. Junior's attorney relied upon the lack of contact with the guardian, who lived out of state, and the inability to participate in activities at work to show that the guardianship was not in Junior's best interest. An attorney seeking to terminate an Article 17A guardianship should be prepared to present evidence, which far surpasses the evidence used to impose the original guardianship.

Article 17A also contains no requirement that guardians report annually as to the personal status of the person under guardianship.³¹ Many people go their entire lives without anyone reviewing the continued necessity for the guardianship order.³² The lack of a continued review impacts people who are placed under guardianship seeking restoration of rights.

Kelly sought out legal advice after she could not resolve a three-year dispute with her guardian over her medical care. Kelly's doctor recommended a change in her medication. For over three years Kelly tried to convince her guardian to talk with her doctor about a change in medication but her guardian refused. Kelly did not have a forum for reviewing the guardianship and her guardian was not required to provide a report to the court. As this dispute over medication continued, Kelly's relationship with the guardian became more and more tenuous. When a petition to terminate the guardianship was filed, Kelly and her guardian had not spoken for over nine months.

Kelly's experience is not unique. Most people under Article 17A guardianships do not know that there is legal recourse for challenging a decision of a guardian. Article 17A does not require the guardian to educate the person about their option to restore their decision making rights. Guardians even report not knowing that restoration of rights is possible under Article 17A. This is not surprising as the New York State Unified Court System publishes a detailed checklist and forms for obtaining an Article 17A guardianship but does not provide any resources about the process for removing the guardianship.³³ These barriers to legal knowledge and assistance, coupled with the lack of on-going court review, mean that most guardianships stay in place for a person's entire life even where the person does not want the guardian making decisions. Those few that do locate an attorney often lived under a guardianship for years because they were not aware that they could make their own decisions or of the option to remove the guardianship.

In Michael, Kelly and Junior's cases questions about the necessity of the original appointment of the guardianship arose during the representation. Article 17A only requires a certification of disability and then applies a best interest standard. It does not specifically require a showing of harm, an inability to manage personal needs or property, or an inability to understand and appreciate the nature and consequences of such an inability. It also does not require a showing of unmet needs before a guardianship is imposed. All these factors are required before New York's other guardianship statute (Mental Hygiene Law Article 81) is imposed.³⁴ The lack of consideration of these factors impacts representation in cases to restore the rights of a client under Article 17A guardianship. The standard of review is limited to whether the continuation of a guardianship is in the best interest of the person, instead of whether there is an unmet need that necessitates a guardian's involvement. For Junior, his guardian was living outside the state, had not been in contact with him for several years, and did not oppose the removal of the guardianship. If his attorney had been able to show that there was no unmet need it would have taken far less resources than preparing the case for a best interest standard. Instead, because of the confines of Article 17A, the burden rests on the person under guardianship to show that she has arranged her life to the satisfaction of a court and is capable of making reasoned decisions.

Conclusion

Michael, Junior and Kelly each were successful in having their rights restored.

Kelly was fortunate to have the support of the Guardian Ad Litem who came to court and supported the removal of the guardian. The guardian ultimately agreed to withdraw any opposition and the court terminated the guardianship with a determination that it was not in Kelly's best interest.

Michael had a long two-year legal process to remove his guardians. At trial, the Surrogate's Court found that although Michael has a disability that falls within the jurisdiction of Article 17A, it was not in his best interests to have a guardianship in place. The Surrogate's Court also found that an Article 17A guardianship was not the least restrictive means available because the guardianship was not appropriately tailored to fit his needs. The court concluded that Michael is capable of making reasoned decisions regarding his medical care and treatment and of performing daily living tasks without the need for a guardian.

Junior's guardianship was initially put in place in order to fund a trust with an annuity stemming from a personal injury settlement. The guardian never funded the trust and the annuity remained unclaimed for the du-

ration of the guardianship. For a portion of the guardianship his guardian was out of state and out of contact with Junior. Ultimately, after presenting updated psychological assessments and with Junior's testimony, the court removed the guardianship.

The journey towards restoration was not an easy one. Some have to confront their guardians and others expose themselves to a contentious legal process. In the end, these cases and the struggles these three clients faced should shape the way that we think about Article 17A guardianship. Removal of a guardian is a difficult and emotional process. If our goal is really improving self-determination for all, then as Article 17A is being explored in our legislature and by our courts, the restoration process cannot be an afterthought.

Endnotes

1. SCPA 1759.
2. See, e.g., *Matter of Guglielmo*, 2006 N.Y. Misc. LEXIS 4804; 236 N.Y.L.J. 92 (Sur. Ct., Suffolk Co. 2006); *In re Michael J. N.*, 58 Misc. 3d 1204(A) (N.Y. Sur. 2017).
3. For a "deeper dive" into Article 17A you can reference Karen Andreasian et al., *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. Rev. 287(2015); Jennifer J. Monthie, *The Myth of Liberty and Justice for All: Guardianship in New York State* 80 Alb. L. Rev. 947 (2017).
4. This section provides a brief overview of the history of Article 17A and draws from the research of this author's prior publication *The Myth of Liberty and Justice for All: Guardianship in New York State*, 80 Alb. L. Rev. 947 (2017).
5. The statute was originally titled *Guardianship of Mentally Retarded Persons*. The now outdated term "mental retardation" was replaced in 2016 for the preferred term "intellectual disabilities."
6. SCPA 1752. See <https://www.nycourts.gov/forms/surrogates/guardianship.shtml>.
7. The state agency has since been renamed the Office for People with Developmental Disabilities. MHL § 5.01 (Amended L. 2010, c.168 § 2, eff. July 2010.).
8. McKinney's Cons Laws of N.Y., Book 58A, SCPA 1750, Historical and Statutory Notes, L. 1990, c. 516 § 1.
9. *In re Chaim A.K.*, 26 Misc.3d 837, 885 N.Y.S.2d 582 (Sur. Ct., New York Co. 2009).
10. See, e.g., *In re Mark C.H.*, 906 N.Y.S.2d 419 (Sur. Ct. 2010); *In re Dameris L.*, 956 N.Y.S.2d 848 (Sur. Ct. 2012); *In re D.D.*, 19 N.Y.S.3d 867 (Sur. Ct. 2015); *Estate of Meir*, N.Y.L.J. Sept. 30, 2016 (Sur. Ct. 2016) *In re Zhuo*, 42 N.Y.S.3d 53 (Sur. Ct. 2016); *In re Sean O.*, N.Y.L.J., Oct. 7, 2016 (Sur. Ct. 2016); *In re Leon*, 2016 N.Y. Misc. LEXIS 3493 (Sur. Ct. 2016); *In re Michelle M.*, 2016 N.Y. Misc. LEXIS 2719 (Sur. Ct. 2016); *In re Hytham M.G.*, 2016 N.Y. Misc. LEXIS 2722 (Sur. Ct. 2016); *In re Zachary W.*, N.Y.L.J., Apr. 28, 2017 (Sur. Ct. 2017).
11. In November 2012, New York's Governor ordered the creation of the Olmstead Development and Implementation Cabinet ("Olmstead Cabinet"), charged with developing a plan consistent with New York's obligations under *Olmstead v. L.C. by Zimring*, 527 U.S. 581 (1999). Under Olmstead, a state has an affirmative duty to ensure that the state's services, programs, and activities for people with disabilities are administered in the most integrated setting appropriate to the person's needs.
12. N.Y.S Olmstead Cabinet, Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting 28 (2013).
13. Senate Bill 4983, <https://www.nysenate.gov/legislation/bills/2015/S4983>.
14. In 2016, New York Assembly member Levine introduced A5840 to amend Article 17-A.
15. See New York State Assembly Bill A5840 and A8171. New York Senate Bill S5842.
16. DRNY is the designated federal Protection and Advocacy System (P & A) for individuals with disabilities in New York State and, as such, is authorized by Congress to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of individuals with disabilities. See 42 U.S.C. § 15043(a)(2)(A)(ii); N.Y. Exec. Law § 558(b).
17. The suit also names the New York State Unified Court System, Chief Judge Janet DiFiore and Chief Administrative Judge Lawrence K. Marks.
18. *Disability Rights New York v. New York State, et al.*, 1:16 -cv-07363.
19. *Disability Rights New York v. New York State, et al.*, No. 16 CIV. 7363 (AKH), 2017 WL 6388949 (S.D.N.Y. Aug. 16, 2017).
20. *Id.* at 3.
21. *Disability Rights New York v. New York State, et al.*, 2017 WL 6388949 (S.D.N.Y. Aug. 16, 2017), appeal docketed, No. 17-2812 (2nd Cir. Sept. 11, 2017).
22. SCPA 1759(1) "Such guardianship shall not terminate at the age of majority or ...but shall continue during the life of such person, or until terminated by the court."
23. SCPA 1759(2).
24. *In re Mark C.H.*, 28 Misc. 3d 765, 777-78 (Sur. 2010).
25. The Mental Hygiene Legal Service (MHLS) is a New York State agency operating under the auspices of the Presiding Justice of the Appellate Division in each of the state's four judicial departments, pursuant to 22 N.Y.C.R.R. Parts 622, 694, 823, 1023. MHLS is responsible for representing, advocating and litigating on behalf of individuals receiving services for a mental disability who reside or receive services in mental hygiene facilities. See MHL §47.01.
26. SCPA 1754(1).
27. *In re Zhuo*, 2016 NY Slip Op 26309 (Sur. Ct., Kings Co. 2016).
28. *Id.*; *In re Leon*, 2016 N.Y.Misc. LEXIS 3493 (Sur. Ct., Kings Co.).
- 29.
30. *In re D.D.*, 50 Misc. 3d 666 (Sur. Ct., Kings Co. 2015) citing *In re Udwin*, NYLJ, June 11, 2013 at 31 (Sur. Ct., Kings Co.).
31. The yearly reporting requirements within Article 17A only apply to guardians of the property. See SCPA 1761.
32. Surrogates' Court New York County held that 17A is unconstitutional in the absence of periodic reporting and review and read a requirement of same into the law. *In re Mark C.H.*, 906 N.Y.S.2d 419, 434, 435 (Sur. Ct. 2010).
33. See <https://www.nycourts.gov/courthelp/diy/guardianship17A.shtml>.
34. MHL § 81.02(b)(1)-(2); §§ 81.02(a)(1) and (2); 81.03(d).

Chapter 1: Guardianship Basics

Guardianship Fundamentals

Questioning the Assumptions of Guardianship

According to the National Guardianship Association, Inc.: “Guardianship, also referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable.”⁸

Before we can begin evaluating guardianship or making recommendations for how to improve it, it is important to define and ensure a basic understanding of what guardianship is. Although the previous quote may seem like a reasonable definition from which to start, it contains value judgments—which are worthy of consideration—such as what constitutes “safe or sound decisions”; who gets to make that determination for an individual; and how an individual’s safety

should balance against his or her right to experience the dignity of risk.

Despite the oft-cited proposition that all people have certain inalienable rights, once someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person.

Therefore, although guardianship is largely a

[O]nce someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person.

creature of state law, it nonetheless raises fundamental questions concerning federal civil rights and constitutional due process. An adult usually becomes subject to guardianship when the court finds that:

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

Rights at Risk in Guardianships

Guardianships are typically separated into two categories, guardianships of the person and guardianships of the property (also sometimes referred to as *conservatorship*). When the

Reprinted with permission from the March 2018 National Council on Disability report, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination*. Please note: this excerpt provides general guidance as to guardianship procedures, which vary by jurisdiction. Other articles in this Edition provide guidance specific to New York State. To consider or initiate a guardianship proceeding, please consult an attorney in the relevant jurisdiction.

REMOVABLE RIGHTS UNDER GUARDIANSHIP

...that *cannot* be exercised by another person



Marry



Vote



Drive



Seek or Retain
Employment

...that *can* be exercised by another person



Contract



Sue and Defend
Lawsuits



Apply for
Government
Benefits



Manage
Money or
Property



Decide Where
to Live



Consent to
Medical
Treatment



Decide with
Whom to
Associate
or be Friends

...that can be exercised by another person *only with a court order*



Committing
Someone to
an Institution



Consenting to
Experiments



Filing for
Divorce



Consenting to
Termination of
Parental Rights



Consenting to
Sterilization or
Abortion

When Does an Adult Become Subject to Guardianship?

An adult usually becomes subject to guardianship when the court finds that:

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

guardian controls decisions regarding both person and property, the guardianship is called *plenary*. However, there are really three types of rights that are at issue in guardianships:

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

Types of Rights at Issue in Guardianships

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

A person who is determined *incapacitated* generally can have the following rights removed, but these rights cannot be exercised by someone else. These include the right to:

- marry,
- vote,
- drive, or
- seek or retain employment.

Still, other rights can be removed and transferred to a guardian who can exercise these rights on behalf of the individual, such as the right to:

- contract,
- sue and defend lawsuits,
- apply for government benefits,
- manage money or property,
- decide where to live,
- consent to medical treatment, and
- decide with whom to associate or be friends.

In many states, there are also some rights that a guardian can exercise on behalf of the individual subject to guardianship, but only after the court has issued a specific order allowing the action, such as:

- committing the person to a facility or institution,
- consenting to biomedical or behavioral experiments,
- filing for divorce,
- consenting to the termination of parental rights, and
- consenting to sterilization or abortion.



This list is a general description of the way various rights are treated under guardianship laws across the country; for state-specific information consult the table in Appendix A for a reference to guardianship laws in each state.

A Word on Language

When a petition is filed with the court that alleges that the individual is incapacitated, the individual is often referred to as the *alleged incapacitated person*, or *AIP* for short. If the court finds that the person does lack capacity and appoints a guardian to manage some or all of their affairs, the individual is often referred to as the *ward*. In this report, we will use the term *AIP*, but because the term *ward* is viewed by many as stigmatizing and inappropriate, whenever possible, consistent with NCD's longstanding

commitment of avoiding stigmatizing language, we will refer to individuals for whom a guardian has been appointed as an *individual subject to guardianship*. This is also consistent with the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), which is the latest iteration of the uniform guardianship statute that has been approved by the Uniform Law Commission.⁹ However, it should be noted that the term *ward* will appear when it appears in a direct quote.

Process of Obtaining Guardianship *Overview*

Guardianship petitions may be filed in a wide variety of situations: by parents when a child with an intellectual disability turns 18; by a son or daughter when a parent begins to show

signs of dementia severe enough that there is concern for their safety; for a person with a severe disability due to sudden trauma; or when there is concern that a bad actor is exercising undue influence over a person with a disability in order to exploit the individual in some way. There are also times when guardianship is filed for less altruistic reasons, such as to gain access to the person's assets or public benefits or to exploit the individual. Whether the guardianship is over person, property, or both, or whether it is limited or plenary may be determined, at least in part, by the circumstances that give rise to the perceived need for guardianship. Due to our federalist system of government, guardianship is a creature of state, rather than federal law, and all 50 states and the District of Columbia have revised their statutes regarding guardianship numerous times. However, it is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.

Although the process is different in every state, making it difficult to provide a singular description of the guardianship process, there are certain generalities that are helpful to discuss before examination of whether or not guardianship is working for people with disabilities, their families, and communities. The following steps are generalities that may or may not align with the laws in a given state, so it is important for interested individuals to consult their state's laws for more accurate, detailed information.

[I]t is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.

General Steps to Guardianship

1. Filing the petitions
2. Notice that a guardianship petition has been filed
3. Appointment of an attorney to represent the alleged incapacitated person
4. Capacity evaluation
5. Hearing
6. Letters of guardianship
7. Guardianship plan and initial reports

Steps to Guardianship

Step 1—Filing the petitions

In virtually all states, the guardianship process begins with filing a petition in the court with

jurisdiction that alleges that a named individual is incapacitated and needs a guardian. In some jurisdictions, these are two separate petitions that actually result in two cases going

forward. In Florida, for example, the petition for a determination of capacity commences a confidential proceeding and the court file of the case remains confidential as it invariably contains personal and medical information. However, the guardianship petition commences a public proceeding and the ultimate establishment of the guardianship is necessarily public information since the role of the guardian is to engage with others on behalf of the individual subject to

guardianship. From that point in the process until the person is determined to lack, or not lack, capacity, the named individual is known as the AIP. Once a guardian is appointed, the individual is generally referred to as the *ward*, although, as noted previously, we will use *individual subject to guardianship* throughout this report. Usually the petitioner knows the AIP well, and is often a parent, an adult child, or a social worker for the AIP. Generally speaking, most jurisdictions require that the following basic information be provided to the court in the petition:

- A description of the nature and type of disability of the AIP and how it impacts the individual's decision making
- Any relevant medical documentation to which the petitioner has access
- A statement asserting the need for guardianship and justifications supporting this opinion
- The suggested guardian's name, who must be a person who is willing and statutorily qualified (e.g., over 18, not a felon), with a description of his or her relationship to the AIP

Step 2—Notice that a guardianship petition has been filed

Most states require that certain interested parties such as next of kin, existing “attorney-in-fact,” or health care proxy receive notice that a guardianship or determination of capacity petition has been filed. This notice usually includes:

- the name of the AIP;
- the names of the AIP's closest relative(s);

- the name of the person or facility that is providing care for or has custody of the AIP; and
- the name of the proposed guardian or his or her attorney (some states require the guardian to be represented).

Additionally, many states recognize that someone who is facing guardianship may have difficulty understanding the notice they are given. In these states, there are statutory requirements that attempt to ensure that the person has the best chance of understanding the information. For example, in Virginia, the AIP must receive a brief statement in at least 14-point type of the purpose of the proceedings, his or her right to counsel and to a hearing, and a statement warning him or her in bold capital letters that the hearing may result in the individual losing many of his or her rights and a guardian being appointed to make decisions for him or her.¹⁰ Another example is in Florida, where an attorney is appointed by the court as soon as the petition is filed, and that attorney is required to visit the individual within 24 hours of the filing of the petition to read the petition to him or her and explain exactly what it means.¹¹

Step 3—Appointment of an attorney to represent the AIP

The right to counsel is a basic procedural right of respondents in guardianship proceedings. The Uniform Guardianship and Protective Proceedings Act (UGPPA) and the National Probate Court Standards both require appointment of counsel to represent the AIP, and most states have put these provisions into practice. However, the role of the attorney varies significantly from state to state, “with some states requiring counsel as

vigorous advocate and others specifying that counsel should act as guardian ad litem.”¹²

Legal representation should be seen as necessary in all guardianship proceedings—even under the most benevolent and caring circumstances—because guardianship represents a deprivation of liberty, which implicates due process.¹³ The role of legal counsel in guardianship proceedings raises a number of interesting questions and will be discussed in greater detail later, with a close examination in Chapter 6.

Step 4—Capacity evaluation

The procedures for determining capacity vary a great deal from state to state and sometimes depend on the type of incapacity that is alleged.¹⁴ Generally, the determination that an individual lacks capacity will be informed by an evaluation by an expert; this is discussed in greater detail in Chapter 5. As will be discussed in Chapter 5, some states also have separate procedures for people with developmental disabilities.¹⁵ Additionally, a few states provide examiners who are called upon to make capacity determinations after receiving specialized instruction or training in how to make such a determination under the state law.¹⁶

Step 5—Hearing

Generally, the guardianship hearing occurs within a relatively short period of time following the petition and the capacity evaluation.¹⁷ Because some courts now recognize that capacity may change over time, the information and evidence the court will use to make a decision regarding the need for guardianship should be contemporary in order to serve as relevant evidence.¹⁸ Usually, there is a requirement that all interested parties, including

the AIP, next of kin, and possibly others have received notice and know when and where the hearing will be. Finally, most jurisdictions require the AIP to be physically present at the hearing unless the judge determines there is good cause for them not to be there.

Guardianship hearings can be very brief and uncomplicated if the court determines the capacity evaluation presents clear and convincing evidence that the individual lacks capacity, if the AIP does not dispute or agrees to a guardian, and if the court and AIP agree on who the guardian should be. However, the hearings can also become fairly adversarial with witnesses being called and contradicting evidence presented if there is disagreement about whether the individual is incapacitated or who should be appointed guardian.

Step 6—Letters of guardianship

If the court determines that the individual is incapacitated, the judge generally will enter a judgment describing the incapacity and issue letters of guardianship, which outline the extent of the guardian’s authority and outline his or her duties and responsibilities. At this point, the AIP becomes an individual subject to guardianship. In some states, guardians are required to have completed certain training and certification requirements prior to appointment. There are three broad types of guardians:

- Public guardians, who are publicly funded to provide guardianship services to individuals with no family willing to serve as guardian. In some states a public guardian is only appointed if the individual is indigent.
- Professional guardians, who are paid out of the estate of the individual subject to

guardianship or a court fund to provide guardianship services

- Family guardians, who are usually family members, but may also be unrelated friends who are not acting as guardians for multiple individuals

Generally, guardians—even family guardians—can be reimbursed out of the estate of the individual subject to guardianship for activities on behalf of the individual such as paying bills, consulting with medical professionals, or making living arrangements. As the name suggests, professional guardians provide these services to large caseloads of individuals subject to guardianship and are paid, usually after authorization from the court, out of the individual's assets. Payment is generally only authorized by the court at a rate the court deems "reasonable," which may differ from jurisdiction to jurisdiction within the state depending on prevailing rates for professional services. Additionally, what is reasonable may depend on the task performed and the level of expertise required. This is will be discussed in greater detail in Chapter 6.

Step 7—Guardianship plan and initial reports

There are best practices outlined by organizations such as the National Guardianship Association and a few initial steps that most guardians take—as determined by state law. The specific requirements may depend on whether the guardianship is over person, property, or both. One of the first steps of a guardian of the property is to determine what assets and liabilities the individual subject to guardianship has and to make an initial report to the court providing a summary of their finances. In many jurisdictions,

annual reports, including a detailed accounting of how the money of the individual subject to guardianship is being spent, are required as long as a guardianship of the property is in place.

For guardians of the person, many jurisdictions require the guardian to submit a plan soon after appointment that describes his or her proposed plan of care for the individual subject to guardianship as well as history of past care. These plans may be reviewed by the judge overseeing the case, by the clerk of the court, or by a court monitor appointed to assist the court with oversight. This provides a baseline that enables the court to measure the guardian's future performance. Some jurisdictions require that a guardian be represented by an attorney who ensures that the annual accountings and reports are filed accurately and timely. A guardian's attorney may work at the direction of the guardian, but he or she has a fiduciary responsibility to the individual subject to guardianship and can be held accountable for mismanagement of funds, misrepresentations to the court, or any action that is contrary to the best interest of the individual subject to guardianship.¹⁹

Court Determination of Incapacity

Generally speaking, a person who is incapacitated has been determined by a court to be "unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care."²⁰ It should be noted that the word *incapacitated* is essentially interchangeable with the word *incompetent*, which used to be the preferred term. This change in parlance occurred largely due to reforms that began in the 1980s and

continue to this day.²¹ Although there is quite a bit of debate in scholarly circles about the semantic differences in the two terms, it is enough to understand that being declared incompetent is associated with a time when the law declared an individual to be an “idiot,” “lunatic,” “person of unsound mind,” or “spendthrift,” and therefore generally “incompetent” and unable to exercise any rights.²² *Incapacitated*, on the other hand, is the current term used by most courts that employ a combination of medical and functional criteria to reach a determination that a person cannot exercise specific rights. The court generally applies a two-pronged legal test to determine whether an individual is incapacitated.²³ The court must make two findings:

1. The existence of a disabling condition, such as “mental illness,” “mental disability,” “intellectual disability,” “mental condition,” “mental infirmity,” or “mental deficiency.”
2. That such condition causes an inability to adequately manage one’s personal or financial affairs.²⁴

Capacity and Scope of the Guardian’s Authority

Although it used to be the case that guardians were appointed to exercise virtually all the rights of the individual subject to guardianship, it is now possible for judges to decide that a person can exercise some rights but not others on their own.²⁵ For example, a person may be able to understand medical information and make

Two-Step Legal Test to Determine Incapacity

The court must make two findings:

1. The existence of a disabling condition, such as “mental illness,” “mental disability,” “intellectual disability,” “mental condition,” “mental infirmity,” or “mental deficiency.”
2. That such condition causes an inability to adequately manage one’s personal or financial affairs.

informed decisions based on that information but not be able to remember to pay their bills on time. Such a person may retain the right to make medical decisions but lose the right to manage property or sign contracts. This arrangement is called a *limited guardianship*. As one woman who has guardianship over her adult daughter with

[I]t is enough to understand that being declared incompetent is associated with a time when the law declared individuals “idiot,” “lunatic,” “person of unsound mind,” or “spendthrift” . . .

disabilities put it, “[s]he doesn’t really understand the concept of money but as far as decisions [about] where to live, what to eat, where to go, what entertainment to do, she makes all those decisions.” Conversely, when an individual is determined to lack capacity to exercise *any* of the rights described at the beginning of this chapter, the guardianship is considered *plenary* or *general*.

In many states, there is an explicit statutory preference for limited guardianship that only gives the guardian the right to make decisions

the individual is truly incapable of making. Unfortunately, as we will explore in Chapter 4, empirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.²⁶

Lawyers and judges who work in the area of guardianship will also sometimes refer to a *guardian of the person* or a *guardian of the property*. In some states, guardianship of the property is sometimes referred to as *conservatorship*, but we will continue to use the more generic and descriptive term *guardianship of the property* to refer to these arrangements throughout the report.

All these terms simply indicate whether or not the guardian has been given authority to manage any personal affairs or make medical decisions for the

individual subject to guardianship, the authority to manage the individual's property, or both.²⁷ A *plenary guardian* is generally considered the guardian of both person and property.²⁸

Although a determination of incapacity is a legal decision made by a judge, "[t]he court customarily evaluates the medical condition of the proposed individual subject to guardianship by considering the individual's medical history, any diagnosis of mental illness [or other impairment], and a psychological evaluation."²⁹ In many cases, the determination of incapacity and the need for a guardian (as opposed to using a less restrictive alternative) must be proved by clear and convincing evidence.³⁰ One final factor that can impact the scope of the guardian's authority is whether the guardian makes

decisions on behalf of the individual based on a "substituted judgment or best interest" standard; in some jurisdictions the statute or case law will specify which standard should be used and under what circumstances. The substituted judgment standard takes into account the individual's preferences, beliefs, and patterns of behavior as well as the individual's wishes, which may have been expressed when the individual had capacity. While the "best interest" standard should also include a consideration of these factors, it is generally more geared toward making decisions the guardian believes are in the individual's

best interest with the person's well-being, health, and safety being the central concerns. These standards not only impact how the guardian makes decisions, but also how a court might

review those decisions.

Ending a Guardianship

Once a guardianship is put in place, in most circumstances, it lasts either until the individual subject to guardianship dies, until all of his or her rights are restored, or until it is determined by the court that, although the person continues to lack capacity with regard to one or more of the rights that had been removed, there is a less restrictive alternative that will protect the individual's property and/or health and welfare without the need for a guardian. If the guardian dies and a court has not restored the individual's rights or found a less restrictive alternative appropriate, a successor guardian is appointed to replace him or her.

[E]mpirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.

Unfortunately, restoration of rights is an alarmingly rare occurrence. This will be discussed at greater length in Chapter 7, but for now, it is enough to understand that all states have a process for restoration of the rights of the individual subject to guardianship. Usually, either the individual or another interested party can ask the court to restore some or all of the rights that were removed when the

guardianship was established. The procedures vary from state to state, but in many cases, the court will convene a hearing regarding restoration and receive evidence, sometimes including an independent capacity evaluation, and make a ruling regarding whether some or all of the individual's rights should be restored. A court order will specify which of the individual's rights were restored. If property

Unfortunately, restoration of rights is an alarmingly rare occurrence.

rights are restored, generally the guardian of the property is required to file a final accounting and "wrap-up" the guardianship by providing any documents the individual will need to regain control of his or her property and assets.

In the event that the guardianship ends because the individual subject to guardianship dies, the guardian will have to file the death certificate with the court within a specified

period of time and relinquish control of the "guardianship estate" to the executor of the individual's will or the individual's next of kin. Finally, the guardian may be required to file a final accounting that identifies how assets in the guardianship estate have been managed since the last accounting as well as where assets are to be found with the court that had overseen the guardianship.

Guardianship: A Civil Rights Perspective

By Sheila E. Shea and Carol Pressman

Introduction

A person's right to determine the course of his or her life is a fundamental value in American law and firmly embodied in New York State jurisprudence.¹ Guardianship is the legal means by which a court appoints a third party, most typically an individual, but in other cases a not-for-profit corporation or government official, to make some or all decisions on behalf of a person determined unable to manage his or her own affairs.² Guardianship can be an important protective device, forestalling personal harm, financial exploitation, and other affronts to the dignity and welfare of people who are alleged to lack decisional capacity.³ The civil liberties of the person subjected to guardianship yield in the process, however, exacting a personal and societal cost that warrants further exploration and consideration.⁴

This article weaves historical context and modern disability theory together to highlight the principle that less restrictive alternatives must be considered before a guardianship is imposed upon any person. Stakeholders in New York are urging modernization of our guardianship statutes at the same time the American Bar Association has resolved that legislatures and courts recognize supported decision-making as a less restrictive alternative before guardianship is imposed. The article closes with an admonition that guardianships should be considered dynamic, rather than static, in nature. Restoration of rights is required when the person subject to the regimen no longer benefits from its boundaries. Guardianship from a civil rights perspective shatters conventional beliefs about surrogacy and is offered for the benefit of people with disabilities who wish to define their own futures.

Guardianship and American Law

Guardianship has been employed since Ancient Rome to protect people who are unable to manage their personal and financial affairs because of incapacity by removing their right to make decisions and transferring legal power to another person, the guardian.⁵ Guardianship is a matter of state law. Before a guardian may be appointed, an individual must be determined to be an incapacitated person, defined in various ways, but codified in uniform acts as:

an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health,

safety, or self-care, even with appropriate technological assistance.⁶

In most states, a single guardianship statute applies to all populations, regardless of the alleged cause of the person's incapacity. New York is one of six states, the others being California, Connecticut, Idaho, Kentucky and Michigan,⁷ that have a separate statute that may be invoked for people with developmental disabilities. Guardianships may be plenary in nature, divesting all autonomy from the person subject to the regimen, or tailored to the individual needs of the person found to lack capacity.⁸ Although virtually all state statutes have an explicit preference for limited guardianships, the empirical evidence that is available suggests that most guardians appointed by courts are authorized to exercise total or plenary authority over the affairs of the person determined to be incapacitated.⁹

A lack of clarity persists concerning the actual number of people who may have guardians appointed for them in the United States. Estimates range from less than 1 million to more than 3 million, but the number will likely increase significantly with the aging of the "baby boomers,"¹⁰ as well as the prevalence of dementia in the population.¹¹

Guardianship and Civil Rights

Given its ancient origins, guardianship laws predate not only modern civil rights laws, such as the Americans with Disabilities Act,¹² but also precede the U.S. Constitution and the Magna Carta.¹³ Often examined through the lens of benevolence, the appointment of a guardian divests autonomy from another person and has severe civil rights implications. As stated in 1987 by the House of Representatives Special Committee on Aging:

By appointing a guardian, the court entrusts to someone else the power to choose where [he/she] will live, what medical treatment [he/she] will get and, in rare cases, when [he/she] will die. It is

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This article originally appeared in the February 2018 issue of the *NYSBA Journal*.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

in one short sentence, the most punitive civil penalty that can be levied against an American citizen . . .¹⁴

The “civil death” characterization of guardianship arises because a person subjected to it loses autonomy over matters related to his or her person and property. Indeed, in many jurisdictions a person with a legal guardian will be deprived of fundamental rights, such as the right to vote, marry and freely associate with others.¹⁵

A powerful counter voice to guardianship as civil death is the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol.¹⁶ Adopted in 2006, the CRPD is the first international human rights treaty drafted specifically to protect the rights of people with disabilities.¹⁷ Legal scholars argue that the CRPD will provide the impetus for reshaping guardianship laws in the United States as “CRPD dictates supported – as opposed to substituted – decision making.”¹⁸ Whereas guardianships involve a third party making decisions for the individual subject to the regimen, supported decision-making focuses on supporting the individuals’ own decisions. As stated by the American Bar Association:

Supported decision-making constitutes an important new resource or tool to promote and ensure the constitutional requirement of the least restrictive alternative. As a practical matter, supported decision-making builds on the understanding that no one, however abled, makes decisions in a vacuum or without the input of other persons whether the issue is what kind of car to buy, which medical treatment to select, or who to marry, a person inevitably consults friends, family, coworkers, experts, or others before making a decision. Supported decision making recognizes that older persons, persons with cognitive limitations and persons with intellectual disability will also make decisions with the assistance of others although the kinds of assistance necessary may vary or be greater than those used by persons without disabilities.¹⁹

One form of assistance is the “Supported Decision-Making Agreement” by which the person with a disability chooses individuals to support him or her in various areas, such as finances, health care, and employment. In turn, “supporters” agree to assist the person in his or her decisions, rather than substituting their own. Supported decision-making agreements are used in pilot projects

around the world and in at least one state, Texas, which enacted its own Supported Decision-Making Agreement Act.²⁰ In New York, it can be expected that recommendations for legislation will emerge as a result of a five-year pilot funded by the Developmental Disabilities Planning Council. The Council has issued a grant to a consortium of faculty members from Hunter College/City University of New York, among others, to study supported decision making as an alternative to guardianship in New York.²¹

Guardianship in New York

The general adult guardianship statute in New York is codified at Article 81 of the Mental Hygiene Law (MHL). The stated purpose of Article 81 is to:

[S]atisfy either personal or property management needs of an incapacitated person in a manner tailored to the individual needs of that person, which takes in account the personal wishes, preferences and desires of the person, and which affords the person the greatest amount of independence and self-determination and participation in all the decisions affecting such person’s life.²²

A discrete statute exists, however, that may be invoked for people alleged to be in need of a guardian by reason of an intellectual or other developmental disability. In contrast, that statute, codified at Article 17-A of the Surrogate’s Court Procedure Act (SCPA), is a plenary statute the purpose of which at its inception in 1969 was largely to permit parents to exercise continued control over the affairs of their adult children with disabilities.²³ In essence, the statute rested upon a widely embraced assumption that “mentally retarded”²⁴ people were perpetual children.²⁵ Under New York law, a person with developmental disabilities can be subject to either guardianship statute, despite the considerable substantive and procedural variations between Article 81 and Article 17-A.²⁶ A conundrum arises, as a result, because a petitioner for guardianship can choose between two statutes and petitioner’s choice will determine the due process protections to be afforded to a respondent with developmental disabilities.

Article 81 of the Mental Hygiene Law

Article 81 of the MHL, proceedings for appointment of a guardian for personal needs or property management, became effective on April 1, 1993.²⁷ Article 81 replaced the former dual structure conservatorship and committee statutes that operated in New York.²⁸ By way of history, the appointment of a committee, pursuant to former Article 78 of the MHL, was the only available legal remedy to address the affairs of a person alleged to be

incompetent. However, the committee statute required a plenary adjudication of incompetence.²⁹ Because of the stigma and loss of civil rights accompanying such a finding, the judiciary became reluctant to adjudicate a person in need of a committee.³⁰ In 1972, the conservatorship statute (former Article 77 of the MHL) was enacted into law as a less restrictive alternative to the committee procedure.³¹ Unlike the committee statute, the appointment of a conservator did not require a finding of incompetence. Rather, the former law authorized the appointment of a conservator of the property for a person who had not been:

[J]udicially declared incompetent and who by reason of advanced age, illness, infirmity, mental weakness, alcohol abuse, addiction to drugs or other cause suffered substantial impairment of his ability to care for his property or has become unable to provide for himself or others dependent upon him for support.³²

However, by design, the statute limited the power of the conservator to property and financial matters.³³ Chapter amendments to the MHL were enacted in 1974 attempting to expand the role of conservators. The first established a statutory preference for the appointment of a conservator.³⁴ A second chapter amendment authorized conservators to assume a limited role over the personal needs of the person who was the subject of the proceeding.³⁵ Cast as reform measures, the amendments actually contributed to the “legal blurring” between Articles 77 and 78.³⁶ In 1991, the Court of Appeals was confronted with a case requiring a construction of the statutory framework to determine the parameters of the authority of a conservator. The question presented to the tribunal was whether a conservator could authorize the placement of his ward in a nursing home. In *In re Grinker*,³⁷ the Court of Appeals determined that such power could be granted only pursuant to the committee statute. The *Grinker* decision “settled the debate” surrounding the authority of a conservator to make personal needs decisions.³⁸ However, the *Grinker* holding also “dramatized the very difficulty the courts were trying to resolve, namely, choosing between a remedy which governs property and finances or a remedy which judges a person completely incompetent.”³⁹

To resolve the difficulties inherent in the conservator-committee dichotomy, the New York State Law Revision Commission proposed the enactment of Article 81 as a single remedial statute with a standard for appointment dependent upon necessity and the identification of functional limitations.⁴⁰ The new statute rejected plenary adjudications of incompetence in favor of a procedure

for the appointment of a guardian whose powers are specifically tailored to the needs of the individual. Going forward, the right to counsel would be guaranteed⁴¹ and monitoring of guardianships would be required.⁴² The objective of the proceeding as declared by the legislature was to arrive at the “least restrictive form of intervention” to meet the needs of the person while, at the same time, permitting the person to exercise the independence and self-determination of which he or she is capable.⁴³

Still, Article 81 may be “more progressive on paper than . . . in practice.”⁴⁴ As stated by scholar and former jurist Kristin Booth Glen:

[G]uardianship cases are generally only a small portion of the mix of cases carried by individual Supreme Court Justices but if done right can be extremely time consuming. The combination of an overburdened judicial system, petitioners who routinely request plenary authority, inadequate resources for independent evaluation, and the likelihood that the [alleged incapacitated person] AIP will be unrepresented, result in far too little of the “tailoring” to specifically proven functional incapacities that is the heart of the statute.⁴⁵

In addition, as noted by Glen, where the person alleged to be incapacitated suffers, or appears to suffer, from a progressive dementia, “petitioners will request – and courts often grant – full plenary powers to avoid the necessity of repeated future hearings as the individual’s capacity (inevitably) deteriorates.”⁴⁶ Protection of individual liberty, however, should not yield to arguments regarding expense of the proceeding or the convenience of parties other than the person alleged to be incapacitated.⁴⁷ While Article 81 is deemed a model statute in many respects, the statute in application is not without critics. From a civil rights perspective, potential areas ripe for reform abound and include improvement of guardian monitoring in New York, promoting alternatives to guardianship and establishing diversion programs.⁴⁸

Article 17-A of the Surrogate’s Court Procedure Act

Under Article 17-A, the basis for appointing a guardian is whether the person has a qualifying diagnosis of an intellectual or other developmental disability.⁴⁹ Current law permits the appointment of a guardian upon proof establishing to the “satisfaction of the court” that a person is intellectually or developmentally disabled and that his or her best interests would be promoted by the appointment.⁵⁰ As a jurisdictional prerequisite, a 17-A petition must be accompanied by certifications of two physicians

or a physician or a psychologist that the respondent meets the diagnostic criteria of an intellectual or other developmental disability.⁵¹ On its face, Article 17-A provides only for the appointment of a plenary guardian and does not expressly authorize or require the surrogate to dispose of the proceeding in a manner that is least restrictive of the individual's rights. Indeed, Article 17-A does not even require the court to find that the appointment of a guardian is necessary, does not guarantee the right to counsel and permits the proceeding to be disposed without a hearing at the discretion of the court.⁵² That said, Article 17-A has been revered by families because of its relative ease in commencing the proceeding, often without the assistance of counsel.⁵³ In contrast, Article 81 proceedings can be very complex and expensive to prosecute.⁵⁴ The convenience of Article 17-A proceedings as compared to Article 81 proceedings causes tension in New York. As aptly stated by Patricia Wright:

If guardianship is made too expensive, incapacitated people who need the protection and assistance of a guardianship may not have those needs met. However, if guardianship fails to protect the rights of respondents, then respondents can be unjustly deprived of their right to autonomy.⁵⁵

Given the many substantive and procedural variations between Article 17-A and Article 81, the Governor's *Olmstead* Cabinet⁵⁶ and commentators have called for reform or "modernization" of Article 17-A.⁵⁷ Surrogate's Courts are bringing enhanced scrutiny to Article 17-A adjudications and dismissing petitions where guardianship is not the least restrictive form of intervention.⁵⁸ Further, a lawsuit was commenced on September 26, 2016 in the U.S. District Court for the Southern District of New York by Disability Rights New York⁵⁹ seeking to enjoin the appointment of guardians pursuant to Article 17-A.⁶⁰ While the lawsuit was subsequently dismissed on *Younger* abstention grounds, the complaint alleged that Article 17-A violates the due process and equal protection clauses of the Fifth and Fourteenth Amendments to the U.S. Constitution, the ADA and § 504 of the Rehabilitation Act.⁶¹ The federal court's decision to abstain does not prejudice the right of the plaintiffs to challenge the statute in state court.

Restoration

Not enough study has been undertaken regarding the restoration of rights of people subject to guardianship.⁶² Nonetheless, a goal of an effective guardianship regime should be to restore the rights of individuals who are capable of making their own decisions individually or with the assistance of others. Article 81 expressly autho-

rizes modification or termination of the guardianship when, among other things, the incapacitated person has become able to exercise some or all of the powers which the guardian is authorized to exercise.⁶³ Parallel remedies are available to Article 17-A respondents, as Surrogate's Court retains jurisdiction over the proceeding and may consider applications to modify or terminate a guardianship.⁶⁴ For example, in *In re Guglielmo*,⁶⁵ Surrogate's Court previously appointed a 17-A guardian for a respondent who suffered a traumatic brain injury and was in a coma or semi-comatose state for approximately nine months. At the time the 17-A proceeding was commenced, the respondent was dependent upon others for assistance in many activities of daily living. Fifteen years later, he sought to restore his civil rights. The respondent's condition had substantially improved from the time of the accident resulting in his brain injury and three years, in fact, had elapsed since he had been in contact with his guardian. Termination of the guardianship was also supported by the certifications of both a neuropsychologist and a neurologist who opined that the injuries suffered by the respondent did not currently render him incapable of handling his own medical or financial affairs. After hearing from the respondent, who testified at a hearing regarding his abilities and persuasive evidence of capacity, the court determined that the guardianship should be terminated.

In an unreported case, the MHLS assisted an Article 17-A respondent in modifying and then terminating a guardianship that had been purportedly imposed upon the respondent's consent when the guardian (a family friend) would not support the respondent's desire to marry after the respondent became pregnant. The respondent had a mild intellectual disability and had been deemed capable of making an array of decisions concerning her treatment and desire to engage in an intimate relationship. Despite the respondent's capabilities, her Article 17-A guardian would not advocate for the respondent's preferences and desires and instead substituted her own judgment for that of respondent. The guardian went so far as to declare her intention to have the respondent's child removed from the respondent's custody upon birth so that the guardian could establish custody and raise the child. Further, because the respondent was subject to a guardianship, her obstetrician would not accept the respondent's own consent for prenatal care and was prepared to accept the guardian's direction that the respondent receive an intrauterine device (IUD) following delivery of her child. The respondent was willing to accept a different form of birth control, but was opposed to an IUD.

The MHLS identified an OPWDD-certified program where the respondent could reside with her child and her child's father, who also had an intellectual disability, but

the guardian would not consent or agree to the placement. When multiple attempts to resolve the respondent's differences with her guardian failed, the MHLS assisted the respondent in filing a petition in Surrogate's Court under the authority of SCPA 1755 and 1759 to terminate the guardianship. Relief was granted in stages with the respondent's mother being appointed as temporary guardian up and until the birth of the child and then the guardianship was thereafter terminated.

In another unreported case, the MHLS assisted a then 67-year-old woman with mild intellectual disability in removing her 17-A guardian, preventing the appointment of a successor guardian – the guardian's daughter – and dissolving the guardianship. The woman's guardian of 30 years, a distant cousin, had never visited her, had called once in those 30 years and only spoke to care providers when inquiries were made because the guardian failed to return documents presented for her signature. The proposed successor guardian had never met the person subject to guardianship. The woman was, in fact, very capable of making her own decisions. She read books, provided her own consent for medication treatment, and exercised her right to vote. As a resident of a state-licensed family care home, the woman consistently maintained that she did not want a guardian and did not know the proposed successor guardian. As counsel, the MHLS argued against the guardianship based on the woman's capacity and because both the guardian and the proposed successor guardian displayed a complete lack of involvement or interest in the woman's life. After multiple reports to the court, which included two medical opinions stating that the woman did not require a guardian, several objections to withdrawing the petition by petitioner's counsel, and repeated adjournments, petitioner's counsel finally consented to a conference, the withdrawal of his application for the appointment of the successor guardian and the termination of the guardianship.⁶⁶

Restoration efforts in New York may experience a revival as a result of the Supported Decision-Making pilot program funded by the Developmental Disabilities Planning Council. A component of the pilot is to refer people to Disability Rights New York for restoration of rights. As illustrated by the case examples above, the MHLS will also assist individuals subject to both Article 81 and Article 17-A guardianships to petition for modification or termination of guardianship in appropriate cases consistent with the MHLS's enabling regulations.⁶⁷

Proposals for Legislative Reform

During the 2017 legislative session, several bills were introduced to reform Article 17-A, but none of them passed.⁶⁸ There are differences among the various pro-

posals. However, in all of the reform measures advanced, Article 17-A would survive as a discrete statute designed for people with developmental disabilities. Common to the various bills are provisions guaranteeing that a guardian will only be appointed where the respondent exhibits significant impairments in specific enumerated domains of intellectual functioning and/or adaptive behavior. Thus, the proposed chapter amendments promote and require an inquiry by the court into the person's actual abilities before a guardian is appointed.

Additionally, as conceived, the reform measures require that petitioners affirmatively plead that alternatives to guardianship were considered, and identify them. Alternatives may include advance directives, service coordination and other shared or supported decision-making models. The reasons for the declination of alternatives to guardianship must also be pleaded. New formulations of Article 17-A would also include the right of all respondents to a hearing and representation by counsel of the respondent's own choosing, the Mental Hygiene Legal Service, or other court-appointed counsel. Ultimately, the vision behind statutory reform is a reduction in guardianship filings and promotion of alternatives to guardianship.

Conclusion

Guardianship law is evolving internationally, nationally and in New York State. For judges and the practicing bar, the time has come to reexamine and apply the fundamental principle that guardianship should be considered only after lesser restrictive alternatives, such as supported decision-making, have proven ineffective or are unavailable. Further, if guardianship is found to be necessary and is imposed upon any person, an essential goal of that guardianship should be retention and eventual restoration of individual rights if at all possible. The time has come for the plenary guardianship of unlimited duration to be relegated to history in recognition of the right of people with disabilities to participate in society on an equal basis with all others.

Endnotes

1. See *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125 (1914).
2. See, e.g., N.Y. Mental Hyg. Law (MHL) § 81.19. Despite its significance, "guardianship is among the least-noticed, least discussed institutions in the legal system" (Lawrence Friedman, Joanna Grossman, Chris Guthrie, *Guardians: A Research Note*, 40 Am. J. Leg. His. 146 (1996)).
3. See *In re Cooper* (Joseph G.), 46 Misc. 3d 812 (Sup. Ct., Bronx Co. 2014).
4. See Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond*, 44 Colum. Hum. Rts. L. Rev. 93 (2012).
5. *Id.* at 102–06.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

6. Uniform Guardianship and Protective Proceedings Act (UGPPA) Art. 1, Definitions § 102 (11) (1997).
7. Cal. Prob. Code § 1801(d); Conn. Gen. Stat. Ann. § 45a-669 *et. seq.*; Idaho Code Ann. § 15-5-301 *et. seq.*; Mich. Comp. Laws Ann. Ch. 330 (Mental Health Code) § 330.1600 *et. seq.*; Ky. Rev. Stat. Ann. § 387.500-.800; N.Y. Sur. Ct. Proc. Act (SCPA) 1750-1761.
8. Proposed Resolution and Report, American Bar Association, Commission on Disability Rights, Section of Civil Rights and Social Justice, Section of Real Property, Trust and Estate Law, Commission on Law and Aging, Report to the House of Delegates (2017) (ABA Report) www.americanbar.org/content/dam/aba/directories/policy/2017_am_113.docx.
9. *Id.* at 2.
10. *Id.* at 2, n. 6, *citing*, Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A "But Guess" National Estimate and the Momentum for Reform in Future Trends in State Courts* (2011); *A Profile of Older Americans* 2015 (Administration on Aging, Administration on Community Living U.S. Department of Health and Human Services).
11. Robert Abrams, *The Dementia Crisis*, 89 Jan. N.Y. St. B. J. 8 (2017).
12. 42 U.S.C.A §§ 12101 *et seq.*
13. Guardianship originally grew out of the 14th century English concept of *parens patriae* – the duty of the King, and later the State, to protect those unable to care for themselves. *See* Jennifer Wright, *Protecting Who from What and Why and How: A Proposal for an Integrative Approach to Adult Proceedings*, 12 Elder L. J. 53 (2004); A. Frank Johns, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Unprotected Older Americans In the Twenty-First Century – A March of Folly? Or Just a Mask of Virtual Reality?* 27 Stetson L. Rev. 1 (1997).
14. H.R. Doc. No. 100-641, at 4 (1987). Subcomm. on Health and Long-term Care of the House Select Comm. on Aging 100th Cong. Abuses in Guardianship of the Elderly and Infirm: A National Disgrace. Prepared Statement of Chairman Claude Pepper.
15. *See* Michael Perlin, "Striking for Guardians and Protectors of the Mind:" *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 Penn. St. L. Rev. 1159 (2013).
16. *See* <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.
17. Arlene S. Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights*, Routledge (2015).
18. Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 161 (2010); Nina Kohn, Jeremy Blumenthal, Amy Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 Penn. St. L. Rev. 1111 (2013).
19. ABA report, *supra* note 8 at 5.
20. Tex. Estates Code Ann § 1357 (West 2015).
21. The New York DDPC Funding Announcement solicited proposals for two pilot projects utilizing supported-decision making to divert persons at risk of guardianship and the other to restore the rights of persons subject to guardianship (<http://ddpc.ny.gov/supported-decisionmaking-0>). Other consortium partners are the Arc of Westchester, NYSARCA and Disability Rights New York. Kristin Booth Glen is the SDM-NY project director.
22. MHL § 81.01.
23. Upon its enactment in 1969, parents and parent organizations primarily voiced the need for an abbreviated guardianship proceeding for individuals with mental retardation when they reached the age of 18. *See* Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine Hermann, Maria Kuns, Aditi Shah, Naomi Weinstein, *Revisiting S.C.P.A. 17-A: Guardianship for People with Developmental Disabilities*, 18 CUNY L. Rev. 287 (2015).
24. The term "intellectual disability" has replaced the term "mental retardation" and its derivatives in the federal government and most states, including New York (*see* 2010 N.Y. Laws ch. 168; 2011 N.Y. Laws ch. 37). In 2016, the legislature removed the term "mentally retarded" from Article 17-A and substituted "intellectually disabled" (2016 N.Y. Laws, ch.198).
25. *See* Bailly & Nick Torak, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Albany L. Rev. 807, 818 (2012) (The statute's emphasis on the continued role of parents is evidenced from several of its features including that Article 17-A is placed in New York's Consolidated Laws immediately following guardianship of minors, codified at Article 17 of the SCPA.).
26. *See, e.g., Guardianship of Derek*, 12 Misc. 3d 1132 (Sur. Ct., Broome Co. 2006).
27. 1992 N.Y. Laws ch. 698.
28. *Id.*
29. *See generally*, Bailly & Nick Torak, *supra* note 25 at 817; *In re Fisher*, 147 Misc. 2d 329 (Sup. Ct., N.Y. Co. 1989).
30. *In re Fisher*, 147 Misc. 2d at 332.
31. 1972 N. Y. Laws ch. 251.
32. MHL § 77.01 (repealed 1992 N.Y. Laws ch. 698).
33. *Id.*
34. MHL §§ 77.04 & 78.02 (repealed 1992 N.Y. Laws ch. 698). Section 78.02 provided that "prior to the appointment of a committee under this article, it shall be the duty of the court to consider whether the interests sought to be protected could best be served by the appointment of a conservator." *See In re Seronde*, 99 Misc. 2d 485 (Sup. Ct., Westchester Co.1979).
35. 1974 N.Y. Laws ch. 623, § 3.
36. Julie M. Solinski, *Guardianship Proceedings in New York: Proposals for Article 81 to Address Both Lack of Funding and Resource Problems*, 17 Pace L. Rev. 445 (1997), *citing* G. Oliver Koppell & Kenneth J. Munnely, *The New Guardian Statute: Article 81 of the Mental Hygiene Law*, N.Y. St. B. J., Feb. 1993, at 16.
37. *In re Grinker (Rose)*, 77 N.Y.2d 703 (1991).
38. Solinski, *supra* note 36 at 450.
39. *Id.*
40. Memorandum of the Law Review Commission Relating to Article 81 of the Mental Hygiene Law Appointment of a Guardian for Personal Needs and/or Property Management, Senate No. 4498, Assembly No. 7343, Leg. Doc. No. 65 [C] (1992).
41. MHL § 81.10; *see In re St. Lukes's Roosevelt Hospital (Marie H.-City of New York)*, 89 N.Y.2d (1996).
42. MHL § 81.30.
43. MHL § 81.01.
44. Kristin Booth Glen, *supra* note 4 at 115, n. 102.
45. *Id.*
46. *Id.*
47. Article 81 proceedings can be expensive, but the cost does not dilute the merit of proceeding in a manner that protects the due process rights of the alleged incapacitated person. *See* Rose Mary Bailly, *Practice Commentaries McKinney's Cons. Laws of N.Y.* Book 34A, MHL § 81.01, p. 9, *citing* Strauss, *Before Guardianship*,

GUARDIANSHIP AND SURROGATE DECISION-MAKING

- Abuse of Patient Rights behind Closed Doors*, 41 Emory L. J. 761, 763 (1992).
48. See *Guardianship in New York: Developing an Agenda for Change, Report of the Cardozo School of Law Conference* (2012). The report is available online: <https://www.cardozo.yu.edu/sites/default/files/GuardianshipReport.pdf>.
 49. SCPA 1750, 1750-a. An Article 17-A proceeding may also be commenced for a person alleged to have a traumatic brain injury (SCPA 1750-a[1]).
 50. *Id.*
 51. *Id.*; but see *Guardianship of Derek*, *supra* note 26, holding that in a contested 17-A proceeding the physician-patient privilege applies and certificates obtained in violation of the privilege would not be considered by the court.
 52. See Bailly & Nick Torak, *supra* note 25 at 821–25.
 53. See Andreasian et al., *Revisiting S.C.P.A. 17-A*, *supra* note 23 at 300 (where the authors note that 17-A procedure is relatively simple and can be typically managed by *pro se* petitioners).
 54. Bailly, *supra*, note 47.
 55. See Jennifer Wright, *supra* note 13 at 62.
 56. The Olmstead Cabinet was created following the U.S. Supreme Court decision in *Olmstead v. LC*, 527 U.S. 581 (1999). The Cabinet's mandate is to recommend law and policy changes to ensure that people with disabilities receive services and supports in settings that do not segregate them from the community, <https://www.ny.gov/programs/olmstead-communityintegration-every-new-yorker-last>.
 57. See Bailly & Nick Torak, *supra* note 25; Andreasian et al., *Revisiting S.C.P.A. 17-A*, *supra* note 23.
 58. See *In re D.D.*, 50 Misc. 3d 666 (Sur. Ct., Kings Co. 2015).
 59. Disability Rights New York is the Protection and Advocacy Agency in New York State acting pursuant to an enabling statute codified at 42 U.S.C.A. §§ 10802 *et seq.*
 60. *Disability Rights New York v. New York State*, 1:16-cv-0733 (AKH) (filed 9/21/16). Complaint is available at <http://www.new.drny.org/docs/art-17a-lawsuit.pdf>.
 61. *Id.*
 62. The Florida Developmental Disabilities Council may be a leader among states in this regard. The Council commissioned a research study to examine guardianship restoration among people with disabilities. The report of the Council's findings, Florida Developmental Disabilities Council, Restoration of Capacity Study and Workgroup Report (2014), is available online.
 63. MHL § 81.36 (a)(1-4).
 64. SCPA 1755, 1759. While there are specific statutory provisions for modification and termination of an Article 17-A decree, they are lacking due process safeguards. For instance, no hearing is required in a modification proceeding and typically applications are brought only to replace a family member with another as successor guardian. The burden of proof for Article 17-A termination proceedings is not codified and there is no indication of what must be proved for a guardianship to be dissolved (Andreasian et al., *Revisiting S.C.P.A. 17-A*, *supra* note 23 at 316–17).
 65. 2006 N.Y. Misc. Lexis 4804; 236 N.Y.L.J. 92 (Sur. Ct., Suffolk Co. 2006).
 66. During its investigation, MHLS discovered that there had been a testamentary trust established by the woman's deceased mother. The 17-A guardian was the trustee, and successfully petitioned in 2010, for the appointment of her daughters to replace her as co-trustees. During the 30 years that the trust was in existence, no funds were ever expended for the benefit of the beneficiary. MHLS subsequently successfully petitioned to remove the co-trustees and reform the trust as a supplemental needs trust.
 67. N.Y. Comp. Codes R. & Regs. tit. 22, §§ 622.2(b)(5), 694.2(b)(5), 823.2(b)(5), 1023.2(b)(5).
 68. See N.Y. Assembly Number 8171 (2017), N.Y. Assembly Number 5840 (2017), N.Y. Senate Number 5842 (2017). See also N.Y. Senate Number 4983 (2015-2016).

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New York's "Black Hole" of Surrogate Decision-Making for Individuals with Intellectual and Developmental Disabilities Without Capacity

By Kathryn Jerian and John Dow

I. Introduction

In the course of providing the full spectrum of medical, residential, and habilitative care to adults with intellectual and developmental disabilities (I/DD), it becomes quickly apparent that despite New York's wide-ranging surrogate decision-making laws and regulations, something is missing. Namely, for the large number of adults without decision-making capacity and no legal guardian or other legally recognized surrogate, "routine" decisions (i.e., those not rising to the level of requiring informed consent) fall into a void. As counsel, we have often come to not so fondly describe this as the "black hole" of decision-making. Despite the complexity of New York State's surrogate decision-making system, the inevitable murkiness of real life readily displays the inadequacy of our laws. Unfortunately, the lack of any (in some cases) or even intermediate options leads to "holes" that are difficult to address without utilizing underpowered tools or overkill methods. For decisions like executing consents to certain routine medical treatments or screenings, or agreements for admission to rehabilitation or nursing facilities and related matters, many individuals without capacity and no legal surrogate or involved family member are left without options.

Providers are not the only ones in search of a solution to this problem. In 2014, the state oversight agency for people with I/DD, the Office for People with Developmental Disabilities (OPWDD), promulgated draft regulations and attempted to construct a legal backdrop for provider agencies to designate an authorized family member for general decision-making. For many reasons, these regulations did not even proceed to the State Register in proposed form, and the problem they attempted to solve remains.

This article will explore the various pockets of decision-making authority that exist in and outside of guardianship—and what remains unaddressed. In New York State there are more than a dozen different scenarios concerning surrogate decision making for adults with intellectual and developmental disabilities without capacity

to make personal, financial, or health care decisions. Some of these scenarios will be described in more detail below.

II. Guardianship

One of the potentially most comprehensive and "official" options is guardianship, either that under Surrogate's Court Procedure Act (SCPA) Article 17-A or Mental Hygiene Law (MHL) Article 81. As 17-A is specific to individuals with intellectual or developmental disabilities, this article will focus primarily on that guardianship option. Article 17-A petitions may be brought by a parent, any interested person over the age of 18, or a corporation on behalf of a person with an intellectual disability, traumatic brain injury, or developmental disability.¹ Of course, this option assumes that the person with I/DD has a willing and able guardian to seek such legal authority. Many individuals do not have such support. This option is often the most plenary and can provide a guardian with near-total authority (at least on paper) over almost any personal, health care, or financial decision that might arise.² Such guardianships have typically been perpetual given the nature of the disability giving rise to the guardianship, but recently some are being tailored to a specific individual's need or to a limited time frame.³ At the time Article 17-A became law (1969) tailoring these guardianships or limiting their duration was not typically considered. Rather, the act was seen as an important step away from the *parens patriae* of the state institution towards allowing caring family members and friends of those with disabilities to advocate for individualized support and care in the community or other settings.⁴ Even these guardianships still underwent an evolution process when it came to healthcare decisions. From approximately 1988 until 2002, developments in case law made it nearly impossible for 17-A guardians to make critical end-of-life decisions concerning the withdrawal or withholding of life-sustaining treatment due to limitations imposed by the Court of Appeals.⁵

The Health Care Decisions Act for Persons with Mental Retardation (HCDA) and the Family Health Care Decisions Act (FHCDA) changed this.⁶ Both acts have been

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amended several times, and the interplay between the two is complicated because of their overlapping subjects. The FHCDA filled some gaps left by the HCDA, Article 17-A, and other laws. Family, friends, and medical professionals were allowed into the decision-making process when guardians or the Surrogate Decision Making Committee (SDMC)⁷ were not present, thereby helping to ensure individuals were not alone in their final days or weeks.⁸ Guardians were also clearly granted the authority to make end-of-life decisions. Article 17-A guardianship of the person now includes the authority to make any and all health care decisions on behalf of the person that such person could make if they had capacity, including decisions to withhold or withdraw life-sustaining treatment, or to withhold or withdraw artificial nutrition and hydration.⁹ The guardian's decision for health care must be guided by the best interests of the person, the person's wishes, the person's moral beliefs, and the person's religious beliefs when known or reasonably ascertainable.

As stated above, guardianship is also available under Mental Hygiene Law (MHL) Article 81.¹⁰ Article 81 guardianships can be used for a person deemed incapacitated under the definition that they are likely to suffer harm because they are unable to provide for their personal needs and/or property management and they cannot adequately understand the nature and consequences of their inability.¹¹ Of course, this can include someone with I/DD but also anyone else who falls under the above definition. Like Article 17-A, Article 81 provides formal authority for a surrogate decision-maker following a legal determination of incapacity in some or all areas. Unlike HCDA and FHCDA, which do not require court approval to use generally, Article 81 is much like Article 17-A in that a court proceeding and decision are necessary for the appointment of a decision-maker for an individual deemed to lack capacity under their various definitions.

III. Advance Directives (Health Care Proxy, Living Wills and MOLST)

Sometimes known as an advance directive, health-care proxies (HCP) are an alternative to guardianship for individuals with capacity who want to make sure their wishes are honored when it comes time to make a health care decision, but they are no longer able to fully advocate on their own. In a health care proxy, a then-competent adult may appoint a health care agent.¹² The health-care agent becomes empowered upon a determination by an attending physician that the principal now lacks capacity to make health care decisions.¹³ It should be noted that in 2008 the Mental Hygiene law was amended to add a new subdivision that stated that the Commissioners of Health and OPWDD were to approve the use of a

simplified advanced health care directive form for use by adults receiving support from authorized service providers.¹⁴ Steps were taken to develop this form, including the creation of a workgroup, but their work product was never advanced for approval because the legislature did not appropriate funds for the required preapproval study of the forms. As a result, OPWDD has not been able to approve the draft form. This variation on the health care proxy would have allowed an individual's proxy to commence decision making by proxy immediately and with nearly the same limitations and powers of a proxy acting under the Public Health Law.¹⁵

Although development of the form has stalled, the Public Health Law does provide for the execution of a health care proxy for individuals with I/DD residing in residential facilities operated or licensed by OPWDD.¹⁶ In these cases, some "extra" requirements include that one witness must be someone who is not "affiliated with" the facility, and the other must be a physician or clinical psychologist with specialized experience.

Unlike the HCP process for those with I/DD an unmodified HCP on its own does not necessarily declare the principal's wishes concerning end of life care in any great detail. So, the second type of advance directive that is commonly (and advisably) used in conjunction with a health care proxy is a living will. A living will can provide the agent appointed by the proxy with the clarity they need to fulfill their charge and to be protected while they do so.¹⁷ The living will serves as a declaration of the individual's wishes as to health care and end of life care. It can list procedures the principal does or does not want, and so is generally considered acceptable evidence of the wishes the principal would like to guide his or her health care agents. New York has no statute governing their form, interpretation, or enforcement. By itself, the living will carries no legal weight making it very important to draft it with specificity and to provide some level of formality when it is executed.¹⁸ However, a living will that is deployed alongside a health care proxy is much more meaningful guidance for the decision-makers. In reality, these are not often executed or considered.

In addition, even if an individual with I/DD has a valid health care proxy *and* a living will, if those documents are not presented at the time of treatment and a MOLST (Medical Orders for Life-Sustaining Treatment) form¹⁹ is not already on file with the medical facility, the chances of such wishes being honored are slim because absent clear evidence of valid orders to limit treatment, medical facilities will err on the side of caution and provide all treatments.

Obviously, an unmodified HCP and living will are not available to adults with I/DD who lack the capacity

GUARDIANSHIP AND SURROGATE DECISION-MAKING

to designate an agent under current law. Until the modified HCP process is revisited by OPWDD adults with I/DD will not be able to make health care plans that utilize this potentially valuable tool.

IV. Surrogate Decision-Making Systems

Outside of guardianship or advance directives, there are several scenarios where the law empowers a surrogate to make medical decisions for someone without the capacity to do so. These scenarios include individuals who reside in the community or who live in an OMH or OPWDD regulated facility. For example, when someone resides in the community, including an OMH-licensed residence, there are clear and easy to follow rules for identifying a surrogate decision maker. If the patient has involved family or a close friend, a surrogate can make a medical decision for them per the FHCDA. These decisions can include consenting to treatment or a decision to

ment can be provided by a surrogate according to the FHCDA.²⁶ However, a decision to withdraw or withhold life-sustaining treatment is governed by the SCPA and other regulations.²⁷ In the same scenario, but without involved family, the SDMC would be empowered to consent to medical treatment or to make a decision to withdraw or withhold life-sustaining treatment.²⁸ When an individual resides in an OPWDD-licensed facility or is temporarily in a hospital or nursing home, the law is a little more straightforward whether or not the person has involved family. Consent to treatment or consent to withdraw or withhold life-sustaining treatment can be given by an involved family member or the SDMC, depending on the circumstances.²⁹

When an individual resides in an OPWDD-licensed facility, or resides in the community but receives services certified by OPWDD, there are several gaps that can arise depending on the circumstances. In the absence of

"Many medical providers want 'someone' to sign their forms and none of the surrogate regulations fill that gap. For many without legal guardians, provider agencies are often looked to for authorization, even though there is no legal backdrop to support it."

withdraw or withhold life-sustaining treatment.²⁰ If the patient does not have involved family or a close friend, then either the SDMC or the attending physician can give consent to treatment. Otherwise, the attending physician or the court decides per the FHCDA.²¹

If a patient is brought to a hospital or nursing home from an OMH-licensed hospital or unit, there are many rules that must be considered. This scenario is much more complex than when the patient resides in the community or an OMH residence. If the patient has involved family or a close friend and was discharged from the OMH-licensed hospital or unit, then a surrogate decides per the FHCDA. If the patient was not discharged, then the spouse, parent, or adult child decides.²² When a decision to withdraw or withhold life-sustaining treatment must be made, not just a decision whether or not to consent to a treatment, a surrogate always decides.²³ If the patient in this situation has no involved family or close friend then consent to treatment may be given by either the SDMC or the court. When a decision to withdraw or withhold life-sustaining treatment must be made the attending physician may give consent if it is only a DNR; otherwise the attending or the court may give consent.²⁴

If a patient resides in the community and not at an OPWDD-licensed residence, and has involved family, several rules may apply.²⁵ In that case, consent to treat-

a guardian, neither New York law nor regulation identifies a decision-maker in such cases. For example, if there is no other authorized person available the CEO of an individual's residential facility can authorize emergency treatment (but then again informed consent is not even necessary in emergencies).³⁰ This language prevents a facility director from having the clear authority to approve an entire universe of routine but otherwise very necessary medical care. Furthermore, another section of the same regulation allows "any person or other party authorized to speak on behalf of that person" to appeal the authorization. Though a facility director is granted certain limited powers to authorize care, they have no standing to appeal a service plan or placement involving their facility. A variety of other parties such as parents, guardians, and "advocates" have that ability.³¹

There are so many decisions that are more "routine" and do not require informed consent, including consents for health screenings, entering rehabilitative treatment for an injury or condition, ambulance transportation, dental care, or authorization to allow electronic data access, and so on. Many medical providers want "someone" to sign their forms and none of the surrogate regulations fill that gap. For the many without legal guardians, provider agencies are often looked to for authorization, even though there is no legal backdrop to support it.

This decision-making structure does not ensure coverage for routine authorizations and consents. Where a statute does directly apply there are still gaps in coverage. Taken together, the legal codes and regulations behind the surrogate decision-making structure differ in terminology, in whether or not they still apply after a change in status, and in the scope of major medical treatments that can be authorized pursuant to their procedures.³² In some cases, decision-makers are utilized entirely by default rather than because a statute actually applies. This can lead to incapacitated patients becoming suddenly without a clear advocate empowered to give consent on their behalf. Providers might also be confused by a change in who can consent on behalf of a patient or that decision-maker's title. Considering these coverage gaps impact OMH service recipients without close family or friends, a vulnerable part of the I/DD community, providers and advocates should be especially wary of slipping into a black hole with little warning.

V. Even More Options

Outside of these organized decision-making systems are myriad other scenarios that are addressed with varying degrees of success by a variety of statutes and regulations. It should also be noted that while the previously described systems allow personal decisions like consent to a medical procedure or financial decisions to be made, many other surrogate decision-making statutes in New York are restricted to medical treatment decisions.³³

Outside of New York law, some crossover exists with federal law. For example, when a recipient of Social Security benefits needs assistance in managing his or her benefits, a representative payee ("rep payee") may be established. A rep payee is an individual or organization that receives certain benefits for someone who cannot manage, or direct someone else to manage, his or her money.³⁴ Rep payees are required to use the funds in the best interests of the beneficiaries, and can be a friend, family member, guardian, financial organization, community based organization, or even a lawyer.³⁵ Individuals must undergo a vetting process prior to being appointed and can be monitored for compliance with the program's directives.³⁶ Even this option has its built-in limitations. Among other things, rep payees are specifically precluded from making medical decisions, managing any funds other than SSI or OASDI, and signing any legal document on behalf of the individual.³⁷

Like the failed legal representative regulations discussed above, a system like the rep payee one where an application is filed and approved could be an alternative to legal guardianship. Among other things, the applying individual or agency provides evidence of incapacity and

why the applicant is in the best position to assist with this particular money management.³⁸ If it could be designed properly, it is possible this could be a low cost and simpler alternative to going through the courts. However, rep payee functions are more transactional in nature and do not involve more personal decisions like those a guardian is typically expected to make.

Another unique option recently proposed via OP-WDD regulation is the ability of certain decision makers to seek health coverage for individuals who lack capacity and a guardian.³⁹ This is done via an emergency enrollment in a specific managed care plan. Though the individual to be enrolled can cancel the application if they have the "ability" to do so, the regulation establishes a priority hierarchy of decision-makers empowered to make the application in lieu of the individual. Family members and guardians are at the top of the hierarchy, but the CEOs of an agency providing "service coordination" are also on the empowered list, albeit at the lowest level of priority. Appeals are possible and utilize a similar hierarchy of empowered individuals.

Very recently, OPWDD put out yet another set of emergency regulations⁴⁰ akin to the managed care enrollment regulations discussed above. These regulations have the stated purpose of allowing individuals to be enrolled in Care Coordination Organizations (CCOs), a new mandatory service that began on July 1, 2018. Again, absent personal capacity, a legal guardian, or other actively involved family member or spouse, the CEO of the facility where the individual resides is granted authority to enroll. Since New York has made enrollment in care coordination mandatory, it was necessary to create this mechanism for creating legal authority to sign up all individuals. It does allow this specific decision to be made for all individuals, even if they do not have a surrogate on the list. The choice between various CCOs will be an important one for individuals or their surrogates to make.

VI. Conclusions

It is clear that a person-centered approach to surrogate decision-making necessitates a multitude of legal and practical options. These options and approaches should be varied and flexible enough to match an individual's unique circumstances. New York State's current system recognizes this, but because it has been built up over time and not generally evaluated as a whole it fails to achieve its full potential. While necessary to accomplish an end, having a host of separate regulations that are situationally based will only serve to further complicate the legal landscape in New York. The current system is like the rungs of a ladder, a single unified system overall but not a smooth continuum of support. Families of those in the I/DD community, and the health care professionals

that support them, need to know the existing system will always provide a decision-maker with clear and meaningful abilities to provide whatever support an individual needs.

The current process of legislating or promulgating regulations that stand alone as patches to the system demonstrates that despite the array of legal and regulatory support available to assist individuals without capacity in having access to decision-making tools, New York agencies, lawmakers, providers, and advocacy organizations are still searching for new and different solutions. This is evident in some recent attempts to address the non-emergency health needs of individuals, such as insurance or managed care enrollment. This trend should continue. One of the biggest black holes in the current system encompasses authorizations that do not require informed consent but that are nonetheless vital to one's health such as consents for health screenings, entering rehabilitative treatment for an injury or condition, ambulance transportation, or dental care. Filling this hole would improve the speed and quality of health care that providers could confidently offer the I/DD community, and deserves policymakers' attention.

Endnotes

1. SCPA 1751.
2. 17-A guardianships, unless created under the recent trend toward tailoring them despite the statute not allowing for it, are plenary and perpetual unless challenged. Even fundamental rights such as marriage, or the power to contract, are removed. *See In re Mark C.H.*, 28 Misc. 3d 765 (Sur. Ct., N.Y. Co. 2010). However, guardians do have certain duties to their person in need of a guardian, and that duty can limit their powers if an action is challenged. *See In re Derek W. Bryant*, 188 Misc. 2d 462 (Sur. Ct., Broome Co.). 17-A guardianships do not trigger Election Law § 5-106(6) and so do not automatically remove a person's right to vote.
3. For a somewhat radical example *see In re Michael J.N.*, 2017 N.Y. Slip Op. 51925(U).
4. 1969 N.Y. Laws ch. 1143. For context *see N.Y. State Ass'n for Retarded Children, Inc. v. Rockefeller*, 357 F.Supp. 752 (E.D.N.Y. 1973) (held that people with mental retardation had a constitutional right to protection from harm).
5. *Rivers v. Katz*, 67 N.Y.2d 485, 504 N.Y.S.2d 74 (1986); *In re Westchester Cnty. Med. Ctr. Ex rel. O'Connor*, 72 N.Y.2d 517, 534 N.Y.2d. 886 (1988) (court held that a surrogate decision maker did not have the authority to withdraw or withhold life-sustaining treatment absent clear and convincing evidence of the individual's intentions).
6. 2002 N.Y. Laws ch. 500.
7. Now housed in the Justice Center for the Protection of People with Special Needs, SDMC provides an alternative to court for individuals who do not have capacity to give informed consent, but who also have no authorized surrogate available. Again, SDMC will only tackle "major" decisions and specifically excludes routine diagnosis and treatment decisions. *See generally* <https://www.justicecenter.ny.gov/services-supports/sdmc>.
8. *See* PHL § 2994-b(3)(c), § 2994-b(4), § 2994-g(5).
9. PHL § 2980(6); SCPA 1756. *See* SCPA 1750-b(1).
10. 1992 N.Y. Laws, ch. 698, effective April 1, 1993.
11. MHL § 81.02.
12. PHL § 2980-81.
13. A candidate for agent is disqualified if the conditions in PHL § 2981(3) are met. PHL § 2983, PHL § 2982, SCPA 1750-b(2), PHL § 2985.
14. 2008 N.Y. Laws ch. 210, section 4.
15. NY Reg, Jan. 24, 2018 at 61-63.
16. PHL § 2981(2)(c).
17. Where an advance directive would have been helpful but does not exist you have to examine the past statements of the patient. It is advisable to consult the following case in such an instance: *In re O'Connor*, 72 N.Y.2d 517 (NY Court of Appeals, 1988).
18. *See Haymes v. Brookdale Hospital Medical Center*, 287 A.D.2d 486 (2d Dept 2001).
19. N.Y. State Department of Health, MOLST Form, <https://www.health.ny.gov/forms/doh-5003.pdf> (last visited, July 23, 2018).
20. PHL § 2994-d(1)(a).
21. *See* PHL §§ 2994-b(3)(c)-b(4), § 2994-g, MHL art. 80.
22. 14 N.Y.C.R.R. § 27.9.
23. PHL Art. 29-B or 2010 N.Y. Laws ch. 8.
24. *Id.*
25. But a domestic partner might not qualify.
26. *See* PHL § 2994-b(3). Here, the FHCDA might route decision makers to the SCPA or OPWDD regulations depending on the circumstances, but will not itself provide the mechanism by which a decision can be made.
27. SCPA 1750-b, 14 N.Y.C.R.R. § 633.10(a)(7)(iv)(c), MHL art. 80.
28. MHL Art. 80, SCPA 1750-b.
29. Here only 14 N.Y.C.R.R. § 633.10, § 633.11, or SCPA 1750-b governs regardless or the presence of involved family.
30. 14 N.Y.C.R.R. § 633.11(a)(1)(ii).
31. 14 N.Y.C.R.R. § 633.12(a)(4).
32. *Compare* MHL art. 80 with 2010 N.Y. Laws ch. 8.
33. An option which would appropriately be in this section, but that is not discussed in this article, is supported decision-making (SDM). For now, SDM is still in its infancy in New York; however, a promising pilot program is underway. SDM is best thought of as a process by which individuals with disabilities choose a trustworthy person or persons to support them in making their own decisions and exercising their legal capacity.
34. 42 U.S.C. §§ 401-34, 405(j), 1007, 1381-83(f). The mechanics of each program are beyond the scope of this article.
35. 20 C.F.R. §§ 404.2001-.2065, 416.601-.732.
36. 42 U.S.C. § 405(j)(2)(B)(ii).
37. Social Security Administration, Guide For Organizational Representative Payees, https://www.ssa.gov/payee/NewGuide/toc.htm#Limits_Payee (last visited June 6, 2018).
38. Social Security Administration, Program Operations Manual System (POMS), <https://secure.ssa.gov/poms.nsf/lnx/0200502115> (last visited July 23, 2018).
39. N.Y. Reg, Feb. 14, 2018 at 11-13.
40. N.Y. Office for People with Developmental Disabilities, Memorandum, <https://opwdd.ny.gov/taxonomy/term/1401> (last visited July 23, 2018).

The Family Health Care Decisions Act Should Apply to End-of-Life Decisions for Persons Who Are Intellectually Disabled

By Robert N. Swidler

The following scenario is sad, but quite familiar to experienced doctors and nurses in hospitals, nursing homes and hospice: A patient is dying, and a decision must be made about whether to enter a DNR (do-not-resuscitate) order or to make some other life-sustaining treatment decision. The dying patient lacks capacity and did not leave instructions or appoint a health care agent. As a result, the attending physician follows the rules of the Family Health Care Decisions Act (FHCDA).¹ Those rules cover:

- (i) a bedside process to determine patient incapacity;²
- (ii) a priority list to identify a surrogate decision-maker;³
- (iii) the clinical criteria needed to support a life-sustaining treatment decision;⁴
- (iv) the ethical decision-making standard that a surrogate should follow;⁵ and
- (v) documentation and other administrative requirements.⁶

The FHCDA rules are clear, familiar and practical for staff to follow in most cases. And invariably, the rules are embodied in standard, frequently used facility forms. End-of-life decisions are never easy, but typically experienced staff understand the FHCDA process and requirements.⁷

But if the dying patient is intellectually disabled, this is not the case. The FHCDA does not apply.⁸ Rather, such decisions are governed by the Health Care Decisions Act for Persons With Intellectual Disabilities, codified as Surrogate Court Procedure Act 1750-b.⁹ (hereinafter “Section 1750-b”). Section 1750-b is similar to the FHCDA—indeed it preceded and influenced the FHCDA.¹⁰ But Section 1750-b has *slightly different rules in every category listed above*, and additional requirements seen as needed to protect the intellectually disabled population. In practice, this can lead to confusion, disruption, delay, liability concerns, calls to hospital counsel and worst, disparate treatment. Section 1750-b’s differences and additional requirements demand that hospital staff treat incapable patients with intellectual disabilities differently at the end of life from all other patients—and different is not necessarily better.

“Section 1750-b has slightly different rules in every category listed above, . . . In practice, this can lead to confusion, disruption, delay, liability concerns, calls to hospital counsel and worse, disparate treatment.”

There is a compelling need to reconcile the FHCDA and Section 1750-b; to identify and examine in detail all of the specific disparities between the statutes; to consider in each instance whether there is an important rationale for a separate end of life care rule for persons with intellectual disabilities; and where there is no such rationale to establish a common rule.

Fortunately, the difficult groundwork has already been accomplished. Pursuant to a legislative mandate,¹¹ the New York State Task Force on Life and the Law formed a Special Advisory Committee (SAC) to consider whether to extend the FHCDA to persons with intellectual disabilities.¹² The SAC conducted an intensive review of the two laws, including their history, purpose, language and practical application; it heard testimony from numerous interested parties and organizations. It concluded that “for most disparities between the laws that are not necessary to serve differences between populations, the FHCDA will serve all patients without medical decision-making capacity in all settings equally well, with only a few minor modifications.”¹³

The Task Force’s report includes a table that is especially valuable: it is a catalog of the differences among the FHCDA, Section 1750-b, and pertinent OPWDD regulations.¹⁴ Each row includes the SAC’s recommendation for a common rule or adaptation. For example, the table notes these slight differences in the priority lists for the identification of a surrogate, and proposes a reconciliation.¹⁵ (This table can be found at the end of the article.)

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GUARDIANSHIP AND SURROGATE DECISION-MAKING

In this manner, the SAC painstakingly charted a course to amend the FHCDA, a course that would iron out differences, supplying the preferred standard in each case, and thereby enable the FHCDA to apply to this population.

In many instances the SAC recommended retaining a Section 1750-b safeguard for intellectually disabled persons. As one notable example, the SAC called for preserving an important role for Mental Hygiene Legal Services (MHLS) in such cases. Indeed, in one respect it called for enhancing MHLS' role by encouraging providers to bring MHLS into the decision-making process earlier, as opposed to providing a later notification.¹⁶ However, the SAC also recommended requiring MHLS to provide support before it could block a DNR order, "recognizing the primary authority of the surrogate, in consultation with the attending physician, to make decisions based on the patient's wishes and interests."¹⁷

Extending the FHCDA to cover persons with intellectual disabilities, with some special protections adapted from Section 1750-b, would accomplish three broad public policy objectives.

First and foremost, it would serve the interests of persons with intellectual disabilities. They and their families are the ones who suffer from the confusion, delay and uncertainty that results when hospital staff must obtain and carry out an end of life decision based on unfamiliar procedures. To be sure, many families of intellectually disabled persons and residential providers will be familiar with Section 1750-b and comfortable with its requirements. But in most instances end of life decision will be implemented in hospitals and nursing homes. When the emergency room, ICU or cancer unit staff are faced with a nonstandard, unfamiliar process for an infrequently seen patient subpopulation, quality end of life decision-making can be compromised.

Second, extending the FHCDA to this population helps and respects health care professionals. They should not have to learn and apply a separate set of complex legal procedures for a subset of patients—except in those limited instances where there is a compelling rationale for the difference. And the law must strike a better balance, one that protects persons with intellectual disabilities without assuming that health care professionals will violate their oaths by devaluing and discriminating against them.

Third, extending the FHCDA to this population is consistent with the broader principle of seeking more equal treatment under the law for persons with intellectual disabilities. This same principle drives the broader debate regarding SCPA Article 17-A guardianship procedures. Advocates are asking whether SCPA 17-A should

be (or constitutionally must be) amended to resemble more closely the MHL Article 81 guardianship procedures that apply to everyone else who needs a personal or property guardian due to incapacity. They should also call for a process for end of life decisions for persons with intellectual disabilities that resembles more closely the FHCDA procedures that apply to every other person who needs end of life decision making.

The principal objections to extending the FHCDA to decision for persons with intellectual disabilities appear to be:

- **Family/advocate satisfaction with SCPA 1750-b.** Reportedly, families of and advocates for persons with intellectual disabilities have been satisfied with that law, are familiar with it, and are rightfully proud of the advocacy efforts that achieved it. They see no reason to "fix it" when it is not broken, and no reason to learn new slightly different rules. But that view understates the real problems, confusion and delays that occur when decisions have to be made at the end of life in hospital settings for persons with intellectual disabilities. Conversely, the view overstates the difficulty of learning the FHCDA requirements, which are on the whole simpler than the 1750-b requirements. For example, if the proposed change is made, OPWDD's complex MOLST Checklist for persons with intellectual disabilities can either be eliminated or trimmed considerably.
- **Loss of safeguards.** Family and advocates may fear that extending the FHCDA to decisions for persons with intellectual disabilities will mean the loss of special safeguards for that population. But as explained in this article, the Task Force proposal would incorporate key safeguards from SCPA 1750-b.
- **Loss of SCPA 1750-b's application in all settings.** Currently, SCPA 1750 does not specify any limitations on where it applies, while the FHCDA applies only to patients in hospital, nursing homes and hospice. It is rare for life-sustaining treatment decisions to be carried out in non-FHCDA settings. But in any event, the Task Force proposal addresses this by applying FHCDA principles to decisions for persons with intellectual disabilities in settings outside of hospitals, nursing homes and hospice.

The FHCDA should apply to end of life decisions for persons with intellectual disabilities, with key safeguards adapted from Section 1750-b. Doing so will improve care for these persons at the time end of life decisions are made and implemented.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Endnotes

1. NY Public Health Law (PHL) Article 29-CC. *See generally*, Robert N. Swidler, *New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues*, N.Y. St. B.J. (June 2010).
2. PHL § 2994-c.
3. PHL § 2994-d.1.
4. PHL § 2994-d.4-5.
5. PHL § 2994-c.4-5.
6. PHL § 2994, *passim*.
7. Admittedly, this is the impression of this author, and not based on a survey or other data. But it is based on my experience as in-house counsel for a system with five hospitals, seven nursing homes and hospice, and hundreds of discussions with clinicians, administrators and lawyers who work in health care facilities over the eight years since the FHCDA was enacted.
8. PHL § 2994-b.3(b).
9. Chapter 500, L. 2002. *See generally*, Christie A. Coe, *Beyond Being Mortal: Developmentally Disabled and End of Life Treatment*, N.Y. St. B.J. (Oct. 2016). Section 1750-b was enacted in response to a 2001 case in Syracuse in which the family of a dying patient with a severe life-long intellectual disability was not allowed to authorize the withdrawal of medically provided nutrition and hydration and antibiotics. Advocates for the bill emphasized that a surrogate decision-making law was needed for adults who lack capacity due to lifelong intellectual disabilities because, unlike other adults, they have no opportunity to leave advance directives or other evidence of their wishes. Initially called the "Health Care Decisions Act for Mentally Retarded Persons," the term "mentally retarded" was changed to "intellectually disabled" throughout the section in 2016. Chapter 198, L. 2016.
10. *See* NYS Task Force on Life and the Law, Special Advisory Committee, *Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities* June 21, 2016 ("TF/SAC Recommendations"), available at https://www.health.ny.gov/regulations/task_force/reports_publications/.
11. Chapter 8 of the Laws of 2010 § 28. This is an uncodified section of the chapter law that enacted the FHCDA.
12. TF/SAC Recommendations, p.54.
13. *Id.*, p.36.
14. *Id.*, pp. 38-51. Appended to this article.
15. *Id.*, p.41.
16. *Id.*, p. 31.
17. *Id.* p.32

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

Appendix A - Surrogate Decision-Making Laws in New York

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
Who does it cover?	<p>THE FHCDA covers incapable patients in general hospitals, nursing homes, and hospice². PHL § 2994-b</p> <p>This includes patients with Mental Illness located in the above settings.</p> <p>It does not include:</p> <p>(1) patients with a health care agent (§ 2994-b(2));</p> <p>(2) patients with a court-appointed guardian under SCPA Article 17-A;</p> <p>(3) patients for whom decisions about life-sustaining treatment may be made under SCPA § 1750-b;</p> <p>(4) patients for whom treatment decisions may be made pursuant to OMH or OPWDD surrogate decision-making regulations. PHL § 2994-b</p>	<p>HCDA covers:</p> <p>(1) persons with mental retardation or DD who have a guardian appointed under SCPA § 1750 or § 1750-a;</p> <p>(2) persons with mental retardation or DD without a guardian appointed pursuant to SCPA Article 17-A who have a qualified family member (SCPA § 1750-b(1)(a) and (b));</p> <p>(3) members of the Willowbrook class, without a guardian appointed pursuant to SCPA Article 17-A or qualified family member, who are represented by the Willowbrook Consumer Advisory Board (SCPA § 1750-b(1)(a));</p> <p>(4) persons with mental retardation or DD, without a surrogate in categories 1-3 above, whose decisions are made by a surrogate decision making committee (SCPA § 1750-b(1)(a)).</p>	<p>14 NYCRR § 633.10(a)(7)(iv) contains the list of qualified family members to implement the provision of SCPA § 1750-b(1)(a) related to persons with mental retardation or developmental disabilities without a guardian appointed pursuant to SCPA Article 17-A.</p>	<ul style="list-style-type: none"> Amend FHCDA to cover persons now covered by HCDA and OPWDD and OMH regulations (continue current exception for psychiatric treatment decisions for persons in psych hospitals/units and in facilities licensed or operated by OMH and behavioral intervention decisions for people in facilities or programs licensed, operated or funded by OPWDD). Repeal existing HCDA (1750-b) language and replace it with language that would continue to cover persons with DD in FHCDA covered and non-FHCDA covered settings. Amend HCDA to continue to cover persons in non-FHCDA settings, but incorporate FHCDA standards and procedures.
Is there a presumption that the patient has capacity?	<p>Yes. (Unless there is a guardian pursuant to Art. 81) PHL § 2994-c</p>	No	No	<ul style="list-style-type: none"> Amend FHCDA to provide that an adult with a SCPA 17-A guardian is not presumed to have capacity,

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
				<p>but FHCDA procedures to determine incapacity are still required before a surrogate decision to withdraw or withhold life-sustaining treatment.</p> <ul style="list-style-type: none"> • Apply amended FHCDA provision to all.
Who makes capacity determinations?	<p>Attending physician. Such determination shall include an assessment of the cause and extent of the patient's incapacity and the likelihood that the patient will regain decision-making capacity. PHL § 2994-c(2)</p> <p>Before executing withholding/withdrawing treatment decision, a concurring determination from a health or social service practitioner is required. PHL § 2994-c(3)(b)</p> <p>For patients who lack capacity as a result of mental illness or developmental disability (DD), either the attending physician must have special credentials in mental illness or DD, or another physician with such credentials, must concur in the determination. PHL § 2994-</p>	<p>Attending physician must confirm to a reasonable degree of medical certainty that the person with DD lacks capacity to make health care decisions. Such determination shall contain the attending's opinion regarding the cause and nature of the person's incapacity as well as its extent and probable duration. SCPA § 1750-b(4)(a)</p> <p>Before executing withholding/withdrawing treatment, the attending must consult with another physician or licensed psychologist to further confirm the person's lack of capacity.</p> <p>The attending or concurring physician or licensed psychologist must (i) be employed by a developmental disabilities services office named in MHL § 13.17 or</p>	<p>The OPWDD regulation in 14 NYCRR § 633.10(a)(7)(i)(a) and (b) contains the requirements for physicians and licensed psychologists to seek approval of the commissioner to serve as the concurring physician or licensed psychologist regarding capacity determinations under the HCDA.</p>	<ul style="list-style-type: none"> • Amend FHCDA to expand qualifications of persons who can determine incapacity based on DD. • Apply amended FHCDA provision to all.

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	<p>c(3)(c) The professional who determines incapacity based on a DD must be a physician or clinical psychologist who either is employed by a development disabilities services office (DDSO) named in section 13.17 of the mental hygiene law, or who has been employed for a minimum of two years to render care and service in a facility operated or licensed by OPWDD, or has been approved per OPWDD regulations, which must require that a physician or clinical psychologist possess specialized training or three years' experience in treating DD.</p> <p>An attending physician must confirm the adult patient's continued lack of decision-making capacity before complying with health care decisions made pursuant to the FHCDA, other than those decisions made at or about the time of the initial determination. A concurring determination of the patient's continued lack of decision-making capacity shall be</p>	<p>employed by OPWDD to provide treatment and care to people with DD, or (ii) have been employed for a minimum of 2 years to render care and service in a facility or program operated, licensed or authorized by OPWDD, or (iii) have been approved by the commissioner of OPWDD in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or 3 years experience in treating individuals with DD. SCPA § 1750-b(4)(a)</p>		

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	required if the subsequent health care decision concerns the withholding or withdrawal of life-sustaining treatment. PHL § 2994-c(7)			
Notifications of capacity determinations?	<p>Notice of a determination that a surrogate will make health care because the patient lacks decision-making capacity must be given to:</p> <p>(1) to the patient, where there is any indication of the patient's ability to comprehend the information;</p> <p>(2) to at least one person on the surrogate list highest in order of priority, pursuant to § 2994-d(1);</p> <p>(3) if the patient was transferred from a mental hygiene facility, to the director of the mental hygiene facility and to the Mental Hygiene Legal Service. PHL § 2994-c(4)</p>	N/A	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.
Objections to capacity determinations?	If an attending physician has determined that the patient lacks decision-making capacity and if the health or social services practitioner consulted for a concurring determination disagrees with the attending physician's determination, the	N/A	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	<p>matter shall be referred to the ethics review committee if it cannot otherwise be resolved. PHL § 2994-c(3)(d)</p> <p>If the patient objects to the determination of incapacity, the patient's objection or decision shall prevail unless:</p> <p>(1) a court of competent jurisdiction has determined that the patient lacks decision-making capacity or the patient is or has been adjudged incompetent for all purposes and, in the case of a patient's objection to treatment, makes any other finding required by law to authorize the treatment, or</p> <p>(2) another legal basis exists for overriding the patient's decision. PHL § 2994-c(6)</p>			
Who makes withhold/withdraw decisions?	<ul style="list-style-type: none"> • An MHL Article 81 court-appointed guardian (if there is one); • The spouse or domestic partner (as defined in the FHCDA); • An adult child; • A parent; • A brother or sister; or • A close friend. 	<ul style="list-style-type: none"> • A guardian appointed pursuant SCPA Article 17-A; • A qualified family member pursuant to OPWDD regulations; • The Consumer Advisory Board for the Willowbrook Class (only for class 	<p>List of qualified family members is contained in OPWDD regulation 14 NYCRR § 633.10(a)(7)(iv)</p> <ul style="list-style-type: none"> • An actively involved spouse; • An actively involved parent; • An actively involved adult child; 	<ul style="list-style-type: none"> • Amend FHCDA to add to the end of the priority list the Willowbrook Consumer Advisory Board, and the SDMC "in cases where such article is applicable". • Apply amended FHCDA decision to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
		members it fully represents); or • A surrogate decision-making committee (SDMC).	<ul style="list-style-type: none"> • An actively involved adult sibling; • An actively involved adult family member. 	
Standard by which decisions should be made?	(1) “in accordance with the patient’s wishes,” or (2) “if the patient’s wishes are not reasonably known and cannot with reasonable diligence be ascertained,” in the best interests of the person. PHL § 2994-d(4)(a)(ii)	The best interests of the person and, when reasonably known or ascertainable with reasonable diligence, on the person’s wishes, including moral and religious beliefs. SCPA § 1750-b(2)(a)	N/A	<ul style="list-style-type: none"> • Amend FHCDA to clarify that the “wishes standard” refers to the patient’s wishes “held when the patient had capacity.” • Prohibit certain presumptions about patients with development disability or mental illness, and certain financial considerations.
What constitutes “best interest?”	An assessment of the patient’s best interests shall include: <ul style="list-style-type: none"> • consideration of the dignity and uniqueness of every person; • the possibility and extent of preserving the patient’s life; • the preservation, improvement or restoration of the patient’s health or functioning; • the relief of the patient’s suffering; and any medical condition and such other concerns and values as a reasonable person in the patient’s circumstances would wish to consider. 	An assessment of the person’s best interests shall include consideration of: <ul style="list-style-type: none"> • the dignity and uniqueness of every person; • the preservation, improvement or restoration of the mentally retarded person’s health; • the relief of the mentally retarded person’s suffering by means of palliative care and pain management; • the unique nature of artificially provided nutrition or hydration, and the effect it may have on the mentally retarded person; and 	N/A	<ul style="list-style-type: none"> • Apply FHCDA provision to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	PHL § 2994-d(4)(a)(ii)	<ul style="list-style-type: none"> the entire medical condition of the person. SCPA § 1750-b(2) 		
What standards must be met for a guardian/surrogate to make a decision to withhold/withdraw LST?	<p>If the treatment would be an extraordinary burden to the patient; and attending and concurring physician determine with reasonable certainty:</p> <p>(1) the treatment would be an extraordinary burden to the patient and (a) the patient's illness or injury will cause death within 6 months; <i>or</i></p> <p>(b) the patient is permanently unconscious, <i>or</i></p> <p>(2) the provision of treatment would involve such pain or suffering that it would be reasonably deemed inhumane or extraordinarily burdensome AND the patient has an irreversible or incurable condition. PHL § 2994-d(5)</p>	<p>If the attending with the concurrence of another physician determines to a reasonable degree of medical certainty that:</p> <p>(i) the person with DD has a medical condition as follows:</p> <p>A. a terminal condition expected to cause death within one year defined by PHL § 2961; <i>or</i></p> <p>B. permanent unconsciousness; <i>or</i></p> <p>C. a medical condition other than such person's DD which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and</p> <p>(ii) the life sustaining treatment would impose an extraordinary burden on such person, in light of:</p> <p>A. such person's medical condition, other than the person's DD; and</p> <p>B. the expected outcome of the life sustaining treatment, notwithstanding the person's DD.</p>	N/A	<ul style="list-style-type: none"> Amend FHCDA to replace the six month definition for terminal illness with the HCDA's one year definition. Apply the amended FHCDA standard to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
Does LST include artificial nutrition and hydration?	Yes. Standards for this are the same as for all withholding and withdrawing decisions. Where a physician objects to a withhold/withdraw decision for artificial nutrition/hydration based on “inhumane” criteria, requires ethics review committee (ERC) review. PHL § 2994-d(5)(c) [Note: providing nutrition and hydration orally, without reliance on medical treatment, is not “health care” under this law.]	SCPA § 1750-b(4)(b)(i)-(iii) Yes. However, in the case of a decision to withdraw or withhold artificially provided nutrition or hydration there is an additional requirement that: (1) there is no reasonable hope of maintaining life; or (2) the artificially provided nutrition or hydration must pose an extraordinary burden. SCPA § 1750-b(4)(b)(iii)	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.
Is CPR a LST ?	Yes. PHL § 2994-a(19). A surrogate decision to consent to a DNR order must be based on the FHCDA’s clinical criteria.	Yes. SCPA § 1750-b(1) Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. FHCDA made SCPA § 1750-b applicable to DNR orders for persons with developmental disabilities.	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.
Grounds for DNR	<i>Same as for all withhold/withdraw decisions under FHCDA</i> No standard specifically relating to the medically futility	Same as for other decisions regarding withholding or withdrawing of life sustaining treatment under the HCDA.	The FHCDA amended SCPA § 1750-b to include CPR within the definition of life sustaining treatment. As a result, a DNR order is issued in compliance with the HCDA process, and	<ul style="list-style-type: none"> Apply FHCDA provision to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	of resuscitation (although all or most such cases would meet the “inhumane or extraordinarily burdensome” standard).		the DNR regulation in 14 NYCRR § 633.18 is no longer applicable.	
Must anyone approve guardian/surrogate’s decision to withhold/withdraw LST?	<i>In a residential healthcare facility</i> , the Ethics Review Committee or court of competent jurisdiction reviews and approves a surrogate’s decision to <i>refuse</i> life sustaining treatment based on the “inhumane or extraordinarily burdensome” standard” (not required in the case of CPR). PHL § 2994-d(5)(b). For decisions in other locations, not unless an objection is made to the decision. PHL § 2994-f(1) and (2)	Although approval is not specifically required, certain parties must be provided notice of a decision to withhold or withdraw LST and can file objections. Specific requirements are included in notification section below.	N/A	<ul style="list-style-type: none"> • Apply FHCDA provision relevant to residential healthcare facilities. • Apply FHCDA provision for objection resolution with amendment for persons with developmental disability outside of institutional settings (see section below on Objections).
What is the proper method for the guardian/surrogate to express a withhold/withdraw decision?	The surrogate shall express a decision to withdraw or withhold life-sustaining treatment either orally to an attending physician or in writing. PHL § 2994-d(5)(e)	The guardian shall express a decision to withdraw or withhold life-sustaining treatment either: (1) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and presented to the attending physician...; or (2) orally, to two persons eighteen years of age or older,	N/A	<ul style="list-style-type: none"> • Apply FHCDA provision to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
		at least one of whom is the mentally retarded person's attending physician. SCPA § 1750-b(4)(c)(i-ii)		
Notification of decision to withhold/withdraw life sustaining treatment (LST)?	No notification requirement for decision to withhold/withdraw LST. After a physician has determined that a patient is incapacitated, the FHCDA requires that notice must be given to: the patient; a person in the highest available category of the surrogate decision-making hierarchy; and to the Director of the Mental Hygiene facility and Mental Hygiene Legal Service (MHLS) if the person is transferred from a mental hygiene facility. PHL § 2994(c)(4)	At least 48 hours before the implementation of a decision to <i>withdraw</i> LST, or at the earliest possible time prior to the implementation of a decision to <i>withhold</i> LST, the attending physician shall notify: (1) the patient (unless the attending physician determines with confirmation that the individual would suffer immediate and severe injury from such notification); (2) if the person is in or was transferred from a residential facility operated, licensed, or authorized by OPWDD, the CEO of the agency or organization operating such facility and MHLS; (3) if the person is not in and was not transferred from such a facility or program, the Commissioner of OWPPD or his or her designee. SCPA § 1750-b(4)(e)(i)-(iii)	Upon receipt of notification the CEO of the agency shall confirm that the person's condition meets all of the criteria set forth in SCPA § 1750-b(4)(a) and (b). In the event that the CEO is not convinced that all of the necessary criteria are met, he or she may object to the decision and/or initiate a special proceeding to resolve such dispute in accordance with SCPA § 1750-b(5) and (6). 14 NYCRR § 633.10(a)(7)(ii) For purposes of communicating the notification required by § 1750-b(4)(e)(iii) the commissioner designates the directors of each of the DDSOs to receive such notification from an attending physician. In any such case, the DDSO director shall confirm that the person's condition meets all of the criteria set forth in SCPA § 1750-b(4)(a) and (b). In the event that the director is not	<ul style="list-style-type: none"> Amend FHCDA to include, in the case of patient with developmental disabilities (DD), HCDA notifications to facility director and MHLS. Include requirement that MHLS be available to receive notice at any time, and can waive its right to receive notice. For patients with DD, amend FHCDA to establish that MHLS's attendance at a clinical team meeting with the physician, surrogate, and other relevant health care providers satisfies the notice requirement. Apply amended FHCDA provision to all.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
What if there is an objection to the Guardian/surrogate withhold/withdraw decision?	<p>If patient objects to a health care decision by a surrogate, the patient's objection shall prevail unless a court makes any finding required by law to authorize the treatment. PHL § 2994-c(6)</p> <p>If attending physician objects to the surrogate's decision to provide life-sustaining care, the physician must first make the surrogate aware of the objection and then either: transfer the case to another doctor; or make sure the matter is referred to the ethics review committee (ERC) or a court of competent jurisdiction. PHL § 2994-f(1)</p> <p>In a general hospital, if an attending physician objects to surrogate's decision to withdraw/withhold nutrition or</p>	<p>The decision to withhold or withdraw LST is suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the person, in the event of an objection to such decision at any time by:</p> <p>(i) the person with developmental disabilities on whose behalf the decision was made; or</p> <p>(ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person with developmental disabilities; or</p> <p>(iii) the attending physician; or</p> <p>(iv) any other health care practitioner providing services to the person with developmental disabilities, who is licensed pursuant to</p>	<p>convinced that all of the necessary criteria are met, he or she may object to the decision and/or initiate a special proceeding to resolve such dispute in accordance with SCPA § 1750-b(5) and (6). 14 NYCRR § 633.10 (a)(7)(iii)</p> <p>N/A</p>	<ul style="list-style-type: none"> Amend FHCDA to impose stay of DNR order on objection by MHLs or Director only if their objection provides a basis for the objection, and if the basis is a medical objection, that it is written by a physician, physician's assistant, or nurse practitioner. Apply FHCDA standard allowing for ERC resolution to all persons, except, for persons with developmental disabilities outside of institutional settings (i.e. private home), empower Commissioner of OPWDD to promulgate regulations to establish dispute resolution body. Exempt decisions made by surrogate decision making committees (SDMC) from ERC review.

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	<p>hydration, then the ERC or a court of competent jurisdiction must review the decision. PHL § 2994-d(5)(c)</p> <p>If any other party, including the surrogate or another on the surrogate hierarchy list, makes an objection to the decision and this objection is known to the physician, the physician must refer the matter to the ERC. PHL § 2994-f(2)</p>	<p>Education Law Article 131, 131-B, 132, 133, 136, 139, 141, 143, 144, 153, 154, 156, 159 or 164; or</p> <p>(v) the Chief Executive Officer; (vi) the Mental Hygiene Legal Service if the person is in or was transferred from a residential facility or program operated, approved or licensed by OPWDD</p> <p>(vii) the Commissioner of OPWDD, or the Commissioner's designee, if the person is not in and was not transferred from such a facility or program.</p> <p>SCPA § 1750-b(5)(a)</p> <p>While the decision is suspended, the parties may try to resolve the issue through nonbinding dispute mediation. SCPA § 1750-b(5)(d)</p> <p>However, only certain parties are authorized to initiate a special proceeding with respect to any dispute. They are the surrogate, the attending physician, the CEO of the OPWDD operated or certified residential agency, MHLS, and</p>		<ul style="list-style-type: none"> Amend FHCDA to explicitly allow all parties to bypass dispute resolution in favor of a court proceeding, or to initiate a court proceeding at any time during ethics committee review.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
Are there special rules/procedures for the unbefriended patient (i.e., a patient without capacity and without a surrogate)?	Yes. A decision to withdraw or withhold life-sustaining treatment can be made either: (1) by a court, in accordance with the FHCDA surrogate decision-making standards, or (2) if the attending physician and a second physician determine that the treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided, and the provision of the treatment would violate accepted medical standards. PHL § 2994-g(5)	the OPWDD commissioner or designee. SCPA § 1750-b(6) Yes. Under the HCDA, if the individual does not have someone who is available to serve as a surrogate, then a surrogate decision-making committee (SDMC) decides. SCPA § 1750-b (1)(a). The SDMC is a panel of people with health care, advocacy, and legal experience to make investigation-based decisions for the patient's life-sustaining treatment. MHL § 80.05(c).	See SCPA § 1750-b(1)(a) regarding the SDMC's authority.	<ul style="list-style-type: none"> Preserve FHCDA standard and SDMC availability for relevant populations.
Are dispute resolution bodies' decisions binding?	Only binding for: (1) decisions made in nursing homes based on the inhumane and extraordinary burden standard (not applicable to DNR). PHL § 2994-d(5)(b) (2) artificial nutrition/hydration. Where a physician objects to a withhold/withdraw decision for artificial nutrition/hydration. PHL § 2994-m(2)(c) (referring to § 2994-d(5)) (3) For an emancipated minor who seeks to withdraw or	No. SCPA § 1750-b(5)(d)	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.

Recommendations for Amending the Family Health Care Decisions Act to Include Health Care Decisions for Persons with Developmental Disabilities and Patients in or Transferred from Mental Health Facilities

	FHCDA – PHL Article 29-CC	HCDA – SCPA § 1750-b	OPWDD REGULATION 14 NYCRR § 633.10(a)(7) (implements § 1750-b)	TASK FORCE PROPOSAL
	withhold LST and who the attending physician determines has decision-making capacity and is making a decision that accords with surrogate standards for adults PHL § 2994-m(2)(c) (referring to § 2994-e(3)(a))			
Is there a requirement for the provision of “Full and Efficacious Treatment?”	No.	Yes. SCPA § 1750-b(4)	N/A	<ul style="list-style-type: none"> Apply FHCDA provision to all.

Life-Sustaining Treatment Decisions for Unbefriended Nursing Home Residents: Application of a Clinical Ethics Algorithm

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Abstract

Background: Due to fear of running afoul of regulations, clinicians are reluctant to make decisions to withhold or withdraw life-sustaining treatment (LST) when patients cannot express treatment preferences and also lack available surrogate decision-makers. For these *unbefriended* patients, the resulting failure to make LST decisions can lead to medically inappropriate treatments of great burden and little benefit. To assist clinicians with making LST decisions, New York City's public hospitals and nursing homes developed an Algorithm for the Unbefriended in 2016, which is intended to serve as a quality improvement aid, delineating a procedural method that provides a framework for clinical ethics consultations and is compliant with applicable laws and regulations, including New York's Family Health Care Decisions Act (FHCDA).

Methods: From June 2016 through December 2017, the Algorithm was applied by the clinical ethics consultant (CEC) at Coler Rehabilitation and Nursing Care Center (a NYC Health + Hospitals nursing home) for 25 nursing home residents in order to help make end-of-life (EOL) care decisions which involved LST. In each of these 25 cases, LST decisions were endorsed by a multidisciplinary ethics panels assembled for the case discussions. From these initial 25 cases, aggregate outcome results were

Table 1. New York City Health + Hospitals Clinical Ethics Consultation Guidelines: Algorithm for the Unbefriended

AN ALGORITHM FOR DECISIONS REGARDING WITHHOLDING OR WITHDRAWING LIFE SUSTAINING TREATMENT FOR ADULT PATIENTS WITHOUT DECISIONAL CAPACITY AND WITH NO SURROGATE

Attending physicians may use the process described below to develop a plan of care when making a decision whether to withhold or withdraw life sustaining treatment from unbefriended patients without decisional capacity. If an attending physician seeks an ethics consultation for such a plan of care for an unbefriended patient, the clinical ethics consultation process should include the following elements:

1. Convene a multidisciplinary group, including primary care providers, major consultants, nursing and social work staff and the Palliative Care team to explore the medical/ethical issues related to options for care;¹
2. Explore and decide if the patient had any advance directives; advance words, ideas, documents; or communicated values before considering the "best interest" standard;
3. Identify potential therapeutic interventions. Then identify those interventions that are unlikely to provide benefit, highlighting those that might increase suffering for no medical or health gain;
4. Consider national guidelines, NIH consensus statements and end-of-life standards developed by medical and specialty societies;
5. Specify the comfort and palliative interventions that are appropriate given the patient's condition. Consider all options for comfort and palliative care; itemize those elements of the condition of the patient that would qualify the patient for palliative care;
6. Articulate the recommendation of the multidisciplinary group;
7. Prepare a Clinical Ethics Consultation Report documenting the meeting, including the issues discussed, and the recommendation that the multidisciplinary group reached in a form that reflects: 1. Ethically Relevant Medical Facts, 2. Ethically Relevant Social Facts, 3. Ethical Analysis of Treatment Options and 4. Ethics Recommendation;

8. Circulate the Clinical Ethics Consultation Report to the multidisciplinary; and
9. In the event that the multidisciplinary group recommends withholding or withdrawing life-sustaining treatment, the attending physician with the independent concurrence of a second physician,² must determine whether the criteria below are satisfied to a reasonable degree of medical certainty before entering an order implementing the recommendation:
 - (i) life-sustaining treatment offers the patient no medical benefit because the patient will die imminently,³ even if the treatment is provided; and
 - (ii) the provision of life-sustaining treatment would violate accepted medical standards.

This paragraph shall not apply to any treatment necessary to alleviate pain or discomfort.

- 1 NYC Health + Hospitals/Legal Affairs and/or Risk Management of the subject facility are available for consultation if necessary.
- 2 In a residential health care facility, the medical director of the facility, or a physician designated by the medical director, must be the second physician that provides the independent concurrence.
- 3 The standard for the unbefriended patient is designed to be more rigorous than that for a patient with a surrogate. For a patient with a surrogate the patient will be projected to die within 6 months. Thus, "imminent" must be somewhat of a shorter time but need not be immediate, which is not the term used.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

compiled and analyzed by the Coler CEC, who presided over each of these case discussions.

Results: In all 25 cases, the ethics panel, based upon the algorithm, endorsed withholding cardiopulmonary resuscitation (CPR), along with intubation and mechanical ventilator support. In 14 out of the 25 cases (56 percent), the panel endorsed no tube feeding orders. 6 out of the 25 residents (24 percent) were placed on a fully palliative care plan, and 10/19 (53 percent) of the remaining residents were placed on limited medical interventions/ mainly palliative care plan. In 17 out of the 25 cases (68 percent), the panel endorsed either no acute care transfers or limited acute care transfers. As of 12/31/17, 12 out of the 25 residents (48 percent) died with all but one death occurring at Coler. Based upon the results of a satisfaction survey later performed, there was widespread agreement among the users that the algorithm was very effective in helping to address the residents' EOL advanced care planning needs.

Conclusions: Based upon the outcome results achieved at Coler and a satisfaction survey, the algorithm has proven to be a very useful measure to help address the EOL care needs of this highly vulnerable population in an ethical and compassionate manner, with built-in safeguards that greatly minimize the likelihood that arbitrary decisions are made. It has de-emphasized solo decision-making by the attending physician and empowered the interdisciplinary care team with the lead of the ethics consultant to fully address the goals of care for the vulnerable unbefriended adult. The algorithm has provided guidance in addressing burdensome life-sustaining treatment with limited clinical benefit to individuals at the EOL. At Coler, EOL care planning has transitioned from prescriptions of aggressive treatment to palliative measures aimed at increasing comfort. The authors attribute the success of the algorithm to a transparent interdisciplinary panel approach, allowing each care team member to participate in decision-making for the patient's best interest while adhering to evidence-based best practices.

Introduction

The decision to withhold or withdraw life-sustaining treatment (LST) can be difficult when patients cannot express treatment preferences and also lack available surrogate decision-makers. For these *unbefriended* patients, clinicians are understandably reluctant to withhold or withdraw LST for fear of running afoul of policies, regulations, or laws. The resulting failure to make LST decisions can lead to medically inappropriate treatments of great burden and little benefit.

To assist clinicians with making LST decisions, New York City's public hospitals and nursing homes have developed an *Algorithm for the Unbefriended*. The algorithm

(Table 1, see page 80) is intended to serve as a quality improvement aid as it delineates a procedural method that provides a framework for clinical ethics consultations and is compliant with applicable laws and regulations, including New York's Family Health Care Decisions Act (FHCDA).¹

According to the algorithm and the FHCDA, life-sustaining treatment² (LST) can be withheld or withdrawn if it (1) offers no medical benefit because the patient would die imminently (even if the treatment is provided) and (2) would violate accepted medical standards.³ The duration of "imminently" is undefined in the FHCDA. Ethics consultants and legal advisors at NYC Health + Hospitals (the organization comprising New York City's public hospitals and nursing homes) have concluded that "imminently" is longer than "immediately" but should be no longer than a few weeks or months (Table 1, footnote 3).

LST decisions are dependent on the treatment in question and on the medical condition and prognosis of the hospital patient or nursing home resident. For example, cardiopulmonary resuscitation (CPR) in the nursing home setting is almost invariably associated with imminent death. Decisions to not perform CPR therefore would meet the requirements of the algorithm. In contrast, antibiotic treatment of pneumonia can materially prolong life. The withholding of antibiotics would therefore require the patient to have an underlying condition that is predictive of imminent death.

It is also important to determine that the treatment in question is LST. For example, tube feeding in advanced dementia has not been demonstrated to prolong life, let alone decrease morbidity or provide symptomatic benefit.⁴ Therefore, it can be argued that the withholding of tube feeding for patients with advanced dementia, in accordance with the evidenced-based medical literature, should not be considered an LST decision, and, thus, it would not violate the requirements of the algorithm.

Usage of Algorithms in Medicine

Checklists in medicine, the forerunner to algorithms, were borrowed from the aviation industry, in which their initial usage was to prevent accidents or errors by establishing a systematic tool that describes a series of actions for a particular process. These methods include action and verification steps to ensure that each action was performed with the intended goal of improving the quality of production. The most widely used checklist in medicine is the World Health Organization Surgical Safety Checklist, which is organized in a logical sequence of events that involves participation by the surgeon, anesthetist, and surgical nursing team for successful completion.⁵ Clinical ethics consultations, however, do not easily fit into the world of "checklists," which direct and constrain linear

procedures; they require a more complex decision support tool. The Algorithm for the Unbefriended presented here is reflective of the deep complexity of the decisions about EOL patient care which are often the reason for calling a clinical ethics consultation. The purpose of this algorithm is to serve as a quality of care improvement aid to allow patients to die with dignity and to be spared at the EOL medically inappropriate treatments of great burden and little benefit in keeping with the current standards for end-of-life care.

General Requirements to be Met Prior to Application of the Algorithm for the Unbefriended

Before we describe the actual experience of Coler Rehabilitation and Nursing Care Center (a NYC Health + Hospitals nursing home) in using the algorithm, it is important to take note of two general requirements that must be met, the first of which is that a diligent, good faith search was made to establish that the patient has no viable surrogates. The second is that a determination was properly made to establish that the patient lacks the capacity to make informed medical decisions.

Diligent Search to Establish That the Patient Has No Viable Surrogates

A good faith effort must be undertaken to determine that there are no potential surrogates and/or advanced directives (oral and/or written). As nursing home residents at Coler are routinely referred for admission by short-term acute care hospitals (STACHs), the initial determination that the individual is unbefriended is made by the STACH, which utilizes all reasonably available modalities for searching for patient information. Upon admission to Coler, a further diligent search is conducted by key personnel including social workers, patient account representatives and members of the care team to corroborate the determination made at the STACH. This process is exhaustive as new information is always sought by the social workers and care team members, and is discussed at care team meetings and documented in the medical record. Lastly, prior to the actual application of the algorithm by the ethics multidisciplinary panel, a discussion is held about potential surrogates as a determination must be made, based upon the available evidence, that the resident is unbefriended.

Determination of Decisional Capacity

As the Algorithm for the Unbefriended applies specifically to those without decisional capacity,⁶ this key element must also be determined prior to its application. Under the direction of the chief of psychiatry at Coler, the methodology for determination of decisional capac-

ity since 2009 has been based upon the model described by Appelbaum,⁷ which utilizes the following four key factors: (1) the consistency of the decision; (2) an understanding of the given information in terms of risks vs. benefits of accepting/rejecting the choice; (3) the ability to manipulate the information presented in a rational manner; and (4) the ability to appreciate the impact of the decision on his or her health and life. In addition to his consultant psychiatrists, the chief of psychiatry educated the attending physicians on how to apply this model, which has been utilized continuously since the Algorithm for the Unbefriended was initially applied at Coler in June 2016.

In July 2017, NYC Health + Hospitals released the *Clinical Ethics Consultation [CEC] Guidelines Concerning Management of Patients with Possibly Compromised Decisional Capacity* (Table 2). This algorithm was developed by the NYC Health + Hospitals Ethics Council for the express purpose of assisting the attending physicians and clinical ethics consultation services in assessing patients' decisional capacity. The methodology described in this algorithm is largely based upon the Appelbaum model, which was already in effect at Coler.

Application of the Algorithm for the Unbefriended Nursing Home Residents

From June 2016 through December 2017, the algorithm has been applied at Coler for 25 nursing home residents in order to help make LST decisions. In each of these 25 cases, LST decisions were endorsed by multidisciplinary ethics panels assembled for the case discussions. In some cases, there were multiple consults on the same resident. A chart of the aggregate outcome results (Table 3) was compiled by the Coler Clinical Ethics Consultant who presided over each of these case discussions.

DNR and DNI

In 25 out of 25 cases in which a clinical ethics consultation was requested to aid in making an LST decision, the multidisciplinary ethics panel (described in table 1, step 1), with the approval of the attending physician and the concurrence of a second attending physician designated by the nursing facility medical director, endorsed withholding cardiopulmonary resuscitation (CPR), along with intubation and mechanical ventilator support, with resulting orders to "do not resuscitate" (DNR) and "do not intubate" (DNI). The withholding of CPR and intubation were necessary to help shape palliative EOL care plans. In the very unlikely event that the patient somehow managed to survive CPR, then an ICU level of care in an acute care hospital would have been necessary. Without orders for DNR and DNI, the door would have been left open to a broad array of aggressive medical treatments with an exceedingly poor likelihood of success.

Evidence-Based Rationale for DNR

Nursing home residents undergoing CPR have survival rates to discharge from the acute care hospital of 0 percent to 5 percent.⁸ Nursing home residents with dementia have a CPR survival rate of 3 percent.⁹ Not surprisingly, CPR is three times less likely to succeed in dementia patients in an acute care hospital, as opposed to cognitively intact patients, with success rates nearly as bleak as those with metastatic cancer.¹⁰ In a sample of 114 elderly nursing home residents who underwent CPR, no one with an unwitnessed cardiac arrest was successfully resuscitated.¹¹ With such dismal survival rates in the evidence-based medical literature for this population in regard to the success of CPR, attending physicians generally have no difficulty in making this determination in accordance with the algorithm.

Evidence-Based Rationale for DNI

The authors of a recent study that utilized the national repository of Minimum Data Set (MDS) assessments from 2000 to 2013 pertaining to the use of mechanical ventilation for hospitalized persons with advanced dementia and severe functional impairment noted that the usage of this modality increased significantly over time without evidence of substantially improved survival.¹² Based upon the lack of evidence-based medical data to support improved survival of such individuals near the end of life who are put on mechanical ventilators, the same rationale for withholding CPR can be applied to the withholding of intubation and mechanical ventilator support. In the algorithm outcome chart in Table 3, it is noteworthy that in all 25 cases, the attending physician withheld both CPR and intubation.

No Tube Feeding

In 14/25 (56 percent) of the nursing home residents, the multidisciplinary ethics panels endorsed orders for no tube feedings. It should be noted that four of 25 (16 percent) of these nursing home residents were already receiving tube feedings for various reasons, including one who just required it to receive essential medications. As these four residents seemed to tolerate the feeding tube well, the multidisciplinary ethics panel chose to not recommend withdrawal of the tube feedings. It should be noted that in all 14 cases in which the ethics panels endorsed orders to withhold tube feedings, none was considered to involve the withholding of LST. Thus, step 9 of the Algorithm for the Unbefriended was not applied as all of these residents were in the advanced stage of dementia.

Tube Feeding in Advanced Dementia Should Not Be Considered LST

Unlike CPR and intubation, tube feeding in individuals who are in the advanced stage of dementia should not be classified as LST, as there is no clinical evidence to support any benefit in terms of survival outcomes, prevention of aspiration pneumonia, prevention or improvement of pressure sores, improved overall functioning or even palliation.^{4, 13} The current standard of medical care for patients with advanced stage dementia is to avoid tube feeding and to instead offer oral assisted feeding.^{14, 15}

Tube Feeding In Terminal Cancer Should Not Be Considered LST

Similar to the lack of efficacy of tube feeding in cases of advanced dementia, the evidence-based literature does not support the use of artificial nutrition in terminally ill cancer patients with anorexia and cachexia in terms of improved survival, which is an important and easily measurable clinical outcome.¹⁶ The Lundholm *et al.* study carefully looked at the potential benefits to terminally ill cancer patients of both enteral (tube feeding) and parenteral nutrition. No evidence of a survival advantage was found in an intent-to-treat analysis.¹⁷

Fully Palliative Plan of Care

The multidisciplinary ethics panels endorsed a *fully palliative plan of care* for six of 25 (24 percent) of these nursing home residents. All aggressive treatment modalities were withheld for these individuals in the terminal stage of their illness as orders for DNR, DNI, no tube feeding, no vasopressors, no central lines, no hemodialysis, no blood transfusions, no acute care transfers, and no further diagnostic testing were issued by the attending physician. This was accomplished mainly by applying step 9 of the algorithm. By 12/31/17, 5/6 (83.3 percent) of these residents had expired in their Coler nursing unit. The algorithm clearly provided a basis for the care team, in concert with the multidisciplinary ethics panel, to perform advanced care planning on these frail, elderly individuals, most of whom were in the advanced stage of Alzheimer dementia. According to the evidenced-based medical literature, advanced care planning is crucial to the effective management of this population with advanced dementia, as it is regarded as the single most consistent and modifiable factor linked to the avoidance of unnecessary and unwanted treatments.^{18, 19, 20, 21}

Limited Medical Intervention Plan of Care

The multidisciplinary ethics panels endorsed a *limited medical intervention plan of care*, which was considered mainly palliative, for 10/25 (40 percent) of these nursing home residents. This plan consisted of DNR, DNI, no cen-

tral lines, no vasopressors, no hemodialysis, along with either no acute care hospital transfers or a limitation on acute care hospital transfers for short-term treatments which could not be provided in the nursing facility. In such cases, the algorithm enabled more conservative, alternative medical treatments to be utilized in the nursing facility as more aggressive, but potentially burdensome treatments were withheld by the clinician. As viable alternative treatments existed, the attending physician in such circumstances was not withholding LST, and, thus, did not have to apply step 9 of the algorithm.

During these multidisciplinary ethics meetings, in accordance with steps 3 through 5 of the Algorithm, potential therapeutic interventions were identified which were unlikely to provide benefit as well as others that likely might increase suffering for no medical or health gain. For example, in many cases, central lines were withheld in those severely ill residents who were placed on DNR and DNI, as less aggressive but viable alternatives were used, such as inserting a peripheral intravenous line was utilized for the short-term, from which these residents could be administered intravenous fluids and antibiotics should the need arise. When feasible, in many situations oral antibiotics were used, which spared these residents painful needle sticks. By doing so, these nursing home residents at the EOL could be spared the burden of undergoing acute care hospital discharges, which would offer them little if any benefit, and which more likely would cause them further pain and suffering. Instead, the primary goal of the care plan was to provide palliation for these elderly, severely debilitated nursing home residents, many of whom were in the advanced stage of dementia, which is now widely recognized as a terminal condition.²²

When treatments at the EOL were felt to not be clinically indicated, they were withheld in accordance with steps 3 through 5 of the algorithm as such were not considered beneficial, with the burdens outweighing the benefits. This was usually the case for hemodialysis in these residents, and consistent with the recommendations of the Committee for the Study of the Medicare ESRD Program, regarding the lack of benefit of dialysis for those with very limited survival potential and poor overall quality of life.²³

Vasopressors are a powerful category of drugs that cause blood vessels to constrict and help to elevate or maintain arterial blood pressure.²⁴ Usage of such agents necessitate insertion of a central line and require an ICU level of care. For those frail, elderly and debilitated residents in the advanced stage of dementia, such agents would not offer any benefit and are routinely withheld at these multidisciplinary ethics panel discussions. A good case can also be made that such individuals would die

imminently with or without such treatment, in keeping with step 9 of the algorithm.

Finally, in regard to blood transfusions for such individuals in the advanced stage of dementia who require total nursing care and who are being hand fed, such is not generally considered to be beneficial. In cases of massive gastrointestinal hemorrhage, the clinical determination is generally made that with a reasonable degree of medical certainty, such individuals will die imminently with or without blood transfusions.

Discussion of Outcome Results

The Algorithm for the Unbefriended was developed by bioethics consultants and legal advisers at New York City's public hospitals and nursing homes to serve as a quality improvement aid, aimed at helping clinicians make LST decisions for hospital patients and nursing home residents who lack decisional capacity and lack surrogate decision-makers. At Coler Rehabilitation and Nursing Care Center, the algorithm has improved the quality of care at the EOL by decreasing the use of medically inappropriate treatments (e.g., CPR) of great burden and little benefit. By using the algorithm, the care teams and CEC have gained confidence that their LST decisions not only conformed to best medical practices but also conformed to applicable policies, regulations, and laws.

What is quite noteworthy is that in 17/25 (68 percent) of these elderly, frail and debilitated nursing home residents, the multidisciplinary ethics panel endorsed either no acute care hospital discharges or limitation of acute care hospital discharges for short-term treatments that could not be provided in the nursing facility. As a result, unnecessary and unwanted treatments were largely avoided. In only 1/25 (4 percent) of these cases was the resident discharged to acute care at the very end of life. In that particular case, it was due to complications of hemodialysis which the resident's dialysis clinic chose to continue in accordance with his prior wishes. However, it should be noted that CPR and intubation with mechanical ventilator support were withheld at the time of death, in accordance with the prior advanced care planning determination made via the application of the algorithm.

In regard to tube feeding, in 14/25 (56 percent) of these residents, all of whom were in the advanced stage of dementia, the multidisciplinary ethics panel endorsed the decision to withhold tube feeding in keeping with the current standard of care, which recommends enhanced oral feedings as the more compassionate alternative.^{15, 16}

One of the major goals in developing the algorithm to serve as a quality improvement aid was to help avoid unnecessary acute care hospitalizations at the very end of life, and to allow these nursing home residents to die

with the appropriate palliative advanced care planning measures in place, in relative peace and comfort, in the familiar surroundings of their nursing home units while being attended by dedicated and compassionate caregivers who know them best. Based upon the outcome results, such clearly appears to have been the case, as 11/25 (44 percent) of these nursing home residents expired at Coler as of 12/31/17, with CPR, intubation, and mechanical ventilator support withheld.

As for those residents who were still alive as of 12/31/2017, in all of the cases, appropriate palliative measures were put in place to help avoid burdensome and unnecessary treatments in their final days. Such was in stark contrast to earlier days when nursing home residents in the advanced stage of dementia commonly endured uncomfortable or aggressive interventions in their final days of life.²² What perhaps is most telling from these results is that the algorithm appears to have facilitated advanced care planning, which is considered crucial to the effective management of such nursing home residents, many of whom are in advanced stage of dementia.^{18, 19, 20, 21}

Satisfaction Survey and Observations

Based upon the results of a satisfaction survey (Table 4) of care team members who participated in these multidisciplinary panel discussions, which were intended to gauge user feedback as to its effectiveness as a quality improvement aid, there was widespread agreement that the algorithm was, indeed, successful in its intended goals. Prior to implementation of the algorithm, members of the care team often felt uneasy and were reluctant to address such concerns on their own, without a supportive mechanism in place. The survey bore out that care team members felt that they were empowered by the algorithm to finally address EOL advanced care planning issues for this highly vulnerable population.

Among the observations of the ethics consultant at Coler and the director of social work is that the plight of these frail, elderly and debilitated residents, without any family or friends to comfort them in their time of greatest need, has a major impact upon the members of the interdisciplinary care team who are their caregivers. They note that these caregivers are often the only ones there to offer them comfort and emotional support over the long term, which serves to create a deep bond between them. They feel that in the eyes of these residents, the members of the care team, at times, seem almost like family, and that over the long haul, the caregivers, too, grow accustomed to being there for them. As a result, they surmise that these caregivers often become staunchly protective of these unbefriended residents, sometimes making it quite difficult to let go when their health declines. In their view, the algorithm, which relies on an inclusive, transparent, inter-

disciplinary process, allows the caregivers to act as stakeholders, which seems befitting as no one else knows these individuals better. The net effect, both strongly believe, is that it helps to ensure that the recommendations offered are truly in the best interests of these residents.

Applicability of the Algorithm for the Unbefriended elsewhere

Whether or not the utility of the Algorithm for the Unbefriended as a quality improvement aid would be as beneficial, if applied elsewhere, remains to be seen. Its design was tailored to New York City's public hospitals and nursing homes which have a significant unbefriended population. The fact that it worked so well as a quality improvement aid at Coler, a very large nursing home with many unbefriended residents, does not necessarily imply that it will succeed elsewhere. Nevertheless, the fact that it was so effective at Coler is noteworthy and may encourage other facilities with a similar problem to consider such an approach.

Conclusions

Based upon the experience at Coler, the authors view the algorithm as a very useful quality improvement aid to help address the EOL care needs of this highly vulnerable population in an ethical and compassionate manner with built in safeguards that greatly minimize the likelihood that arbitrary decisions are made. Prior to the implementation of the Algorithm for the Unbefriended, the medical staff at Coler was inclined to make EOL medical treatment decisions for the unbefriended without collaborating with the other members of the interdisciplinary care team. Due to the vulnerable nature of this population, the EOL care process tended to result in delayed decision-making, as more aggressive and burdensome medical treatments were initiated, resulting in multiple acute care hospitalizations with eventual death out of the facility. This all changed with the implementation of the Algorithm as evidenced by the outcome results and satisfaction survey.

According to the chief medical officer at Coler, the algorithm is aligned with the Patient Centered Care Model, which is a core value at Coler. It has proven to be an invaluable tool in de-emphasizing solo decision-making by the medical attending and in empowering the interdisciplinary care team with the lead of the ethics consultant to fully address the goals of care for the vulnerable unbefriended adult. The algorithm had provided guidance in addressing burdensome life sustaining treatment with limited clinical benefit to individuals at the EOL. At Coler, EOL care planning for this population has transitioned from prescriptions of aggressive treatment to palliative measures aimed at increasing comfort. The success of the algorithm can be attributed to a transparent interdisciplinary-

ary panel approach, allowing each care team member to participate in decision-making geared to the patient's best interest while adhering to evidence-based best practices.

Table 2. New York City Health + Hospitals Clinical Ethics Consultation Guidelines:

GUIDELINES CONCERNING MANAGEMENT OF PATIENTS WITH POSSIBLY COMPROMISED DECISIONAL CAPACITY

1. There is an ethical imperative to respect and enhance patients' decisional capacity to promote their autonomy and to ensure that they have a meaningful choice in their health care. Failing to detect impaired decisional capacity when it exists risks abandoning the patient and may leave the patient without the benefit of effective surrogate decision makers.
2. Many of our patients have impaired capacity to understand treatment options and interventions and to evaluate the risks and benefits of treatments. The first task for these patients is to determine their decision-specific decisional capacity. If the patient lacks capacity to make health care decisions, the attending physician with the support of other members of the health care team, must identify and work with surrogate decision makers when available. If there are no surrogates available and there are no known prior wishes of the patient, the care team must make decisions based upon notions of the best interest of the patient. The staff must continue to care for patients who may assent to or refuse care or vacillate between refusal and acceptance of treatment.

The determination of a patient's capacity is the responsibility of the patient's attending physician, the accuracy of whose judgment will be enhanced by consultation with members of the care team.

3. Determination of capacity involves the following considerations:
 - As an initial premise, every adult patient is presumed to have decision-making capacity.
 - Capacity is decision-specific. Complex decisions, consents to or refusals of standard of care, and consents to or refusals of critical or life-saving treatment and high-risk treatments, require a higher degree of capacity.
 - Decisional capacity may fluctuate with time of day, existence of pain, or change in setting.
 - Especially for elderly patients, consistency of a patient's choice with previous choices and

known values may serve as evidence supporting decisional capacity.

- Limited language skills or verbal fluency, limited knowledge of human anatomy and physiology, language barriers which are difficult to overcome, or limited literacy skills are not necessarily, by themselves or in combination, evidence of a lack of decision-making capacity.
4. Decision making capacity to make a health care decisions means the ability to understand and appreciate the nature and consequences of the proposed health care, including the benefits and risks of and alternatives to the proposed health care to reach an informed decision. An attending physician may consider using the following procedure during his or her assessment of a patient's decisional capacity:
 - A. Assess the patient's understanding – (e.g. “Please tell me in your own words what your doctor told you about: medical condition, treatment, benefits, risks, alternatives.)
 - B. Assess the patient's appreciation – (e.g. assess the patient's beliefs, perceptions and attitudes these must be assessed directly, e.g., “What do you believe is really wrong with you? What do you think this treatment will do to you or for you?”)
 - C. Determine what the patient's choice is – (e.g. “Tell me what your decision is ...”)
 - D. Assess the patient's reasoning – (e.g. “Tell me how you reached the decision you have made.” “What things did you consider in making that decision?”)
 5. Mental Illness. If the attending physician makes an initial determination that a patient lacks decision-making capacity because of mental illness, either such physician must be an appropriately trained and qualified psychiatrist or an appropriately trained and qualified psychiatrist must independently determine whether the patient lacks decision-making capacity.
 6. The experience or anticipation of pain may adversely affect decisional capacity and effective pain management can mitigate that effect.
 7. Beyond their role as potential surrogate decision makers, the participation of a supportive family, friend or clinician may improve the patient's ability to participate in decision-making and improve his or her decisional capacity.

GUARDIANSHIP AND SURROGATE DECISION-MAKING

8. Lack of capacity is neither a sufficient ethical reason to treat over the objection of a patient nor (absent an emergency or court order) legally permissible.
9. Clinical Ethics Consultations with patients who have compromised decisional capacity should focus on continuing efforts to improve the patient's decisional capacity and maintain and optimize the patient's role in decision-making. These efforts should be documented in the CEC Chart Note.

July 13, 2017

Table 3. Outcome for 25 Residents with Care Guided by Algorithm for the Unbefriended (6/01/16 to 12/31/17)

End of life care for all residents whose care was guided by the Algorithm for the Unbefriended	Number of Residents (n=25)	Percent of all Residents
DNR and DNI orders	25	100%
Do not use tube feeding orders	14	56%
Already using and tolerating tube feedings	4	16%
Full palliative care plan*	6	24%
Limited medical intervention/mainly palliative plan of care**	10	40%
Residents placed on either a limited medical intervention/mainly palliative or a fully palliative plan of care	16	64%
Residents with do not transfer to acute care orders	10	40%
Residents with limited acute care transfers	7	28%
Number and treatment of residents deceased as of 12/31/2017	Number of Residents (n=12)	Percent of All Residents / Percent of Deceased Residents
CPR, intubation/mechanical ventilator support withheld	12	(48%)/ (100%)
Died at Coler (without transfer); CPR, intubation/mechanical ventilator support withheld	11	(44%)/ (92%)
Died in acute care (receiving hemodialysis at time of death)	1	(4%)/ (8%)
Number and status of surviving residents who remained unbefriended as of 12/31/2017	Number of Residents (n=12) †	Percent of All Residents / Percent of Surviving Residents who Remained Unbefriended
DNR and DNI orders	12	(48%)/ (100%)
Residents on limited medical interventions/ (mainly palliative plan of care)	7	(28%)/ (58%)
Residents on fully palliative plan of care	1	(4%)/ (8%)
*Full palliative care comprises DNR, DNI, no tube feeding, no vasopressors, no central lines, no hemodialysis, no blood transfusions, no acute care transfers, and no further diagnostic testing.		
** Limited Medical Interventions/Mainly Palliative comprises DNR, DNI, no vasopressors, no central lines, no hemodialysis and either no acute care transfers or limited acute care transfers for short-term treatment that can't be provided in the nursing facility.		
† 1 Resident later found to have surrogate and a telephone conference was held with surrogate, who agreed to DNR.		

GUARDIANSHIP AND SURROGATE DECISION-MAKING

Table 4. The Algorithm for the Unbefriended are Team Survey Results_

(Overall - 26 Respondents from NF Medicine, Social Work, Nursing and Food & Nutrition)

1. Was the Algorithm for the Unbefriended beneficial in addressing the resident's end-of-life advanced care planning needs?	Extremely beneficial		Generally beneficial		Sometimes beneficial		Not sure		Not beneficial		Favorable Responses	
	15	57.7%	9	34.6%	2	7.7%	0		0		26	100.0%
2. During the meetings, all major concerns were adequately addressed.	Strongly agree		Somewhat agree		Neither agree nor disagree		Somewhat disagree		Strongly disagree		Favorable Responses	
	18	69.2%	7	26.9%	1	3.8%	0		0		25	96.2%
3. When the resident's prior wishes were unknown, the best interest standard was applied in accordance with the Family Health Care Decisions Act.	17	65.4%	8	30.8%	1	3.8%	0		0		25	96.2%
4. Utilizing the Algorithm for the Unbefriended at the interdisciplinary ethics case meetings helped allay or relieve any apprehensions that you may have had in regard to the type of decisions to be made.	16	61.5%	9	34.6%	1	3.8%	0		0		25	96.2%
5. I would recommend this tool and the process utilized to colleagues in other nursing facilities who care for similar types of residents.	19	73.1%	5	19.2%	2	7.7%	0		0		24	92.3%
6. The Algorithm for the Unbefriended helps to empower the attending physician and other members of the care team to make these difficult types of decisions in a transparent manner, in which all viewpoint may be shared, including the wishes and values of the resident when known, while demonstrating the utmost respect and compassion for these residents.	18	69.2%	8	30.8%	0		0		0		26	100.0%

Endnotes

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Special thanks to Deane Tsuei, M.D., Associate Director of Nursing Facility Medicine at Coler.

Coler Rehabilitation and Nursing Care Center is an affiliate of the New York University School of Medicine.

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Why Not “Act Now”: Can a Simpler Health Care Proxy Advance the Goal of Supported Decision-Making?

By Paul Kietzman

As this issue of the *Journal* explains, much of Article 17-A of the SCPA has been “in play” for a while now. Over three years ago the Governor’s Task Force on Life and the Law drafted and submitted to the governor and legislature a report and a piece of draft legislation that would have [and still might] fold into the Public Health Law¹ the provisions of SCPA 1750-b.² At the same time, the entirety of Article 17-A has been under fire from advocates, surrogates and even the U.S. District Court for the Southern District (which has thus far side-stepped the merits of claims brought by Disability Advocates New York, the designated federal Protection and Advocacy for Individuals with Developmental Disabilities agency for the state).³ Very simply put, critics of 17-A guardianship believe that 17-A lacks fundamental constitutional protections afforded by the general guardianship statute Mental Hygiene Law Article 81. Among the Elder and Special Needs Law practice bar, Article 81 seems to have few enthusiastic supporters. On the other hand, 17-A has much steadfast support chiefly from parents and families of people with developmental disabilities, many of whom have availed themselves of the straightforward procedures provided for in the SCPA and have been 17-A guardians for many years. No legislative resolution appears to be immediately forthcoming, and yet in the discussions around guardianship issues there emerges at least some common ground—the notion that as few adult persons as reasonably possible should have *any surrogate* making health care decision *for them*. This article is intended to suggest an approach that builds on that broad consensus.

In 2008 the legislature passed and the governor signed a bill,⁴ that created a Simplified Health Care Proxy demonstration project for the system of care overseen by the New York State Office for People With Developmental Disabilities (OPWDD). The statute provided that a health care proxy form would be developed (in consultation with a broad spectrum of stakeholders) and approved by OPWDD and the New York State Department of Health (DoH), and would embody the option for the principal to check a box authorizing the appointed agent to “act now.” The statute also provided that a report of the two-year implementation/demonstration period would be provided to the executive and legislature. The state of California had already put into use such a form health care proxy intended for use by all “institutionalized” populations, including the elderly living in supported residences. Like the California form, the New York form was designed for

simplicity, written in 5th grade English (rather than the 12th grade language in PHL 2981), profusely illustrated to help comprehension, and approved by stakeholders and DoH—but not approved to date by OPWDD (which was charged by the legislation with producing the report on outcomes of the demo at a time of significant agency resource reductions, and which is reportedly now re-considering the “act now” option internally for the residentially served developmentally disabled population). In the NYS Assembly there have been several subsequent attempts to provide an “act now” option for the general population.

With impetus from the infamous *Pouliot* case⁵ the legislature in 2003 enacted SCPA 1750-b,⁶ since augmented by several Chapter Laws that broadened its scope and applicability so as to presently *exclude* only incapacitated persons with developmental disabilities with no “qualified family member”⁷ and no prior contact with the OPWDD service system.

In the spring of 2010, the Family Health Care Decisions Act (FHCDA) and a small “compromise” that greased the legislative rails were enacted and signed. That small matter was embodied in Section 28 of the bill.⁸ The state’s two largest providers of services to persons with developmental disabilities could not agree whether their constituencies wanted in or out of the Public Health Law—this section was the result. The section directed the Governor’s Task Force on Life and the Law to form a special advisory committee to study, report on and suggest the incorporation of SCPA 1750-b (end-of-life and general health care decisions for persons with developmental disabilities) into the FHCDA, as well as dealing with the same issues in facilities operated or certified by the Office of Mental Health. Seemingly lost in the midsts of the ensuing six or so years was the sense of the parties at the time of passage that this little pothole in the road needed filling, mostly so that in the State Senate’s 2010 moment of opportunity (an actual Democratic majority) the FHCDA could roll out as it had not (in the Senate) during the preceding 19 years.

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GUARDIANSHIP AND SURROGATE DECISION-MAKING

Over the past 18 months, an ad hoc group of concerned NYSBA legal scholars has been wrestling with the issue referred to, and eventually dealt with by the Governor's Task Force on Life and the Law a couple of years ago, but in the limited realm of persons with mental disabilities only. Although it may be a dangerous generality, I would say that persons served in Office of Mental Health (OMH) facilities have little inclination to have any family member make health care decisions for them under any circumstances. I also believe, as a general matter, that the OPWDD system is pretty well satisfied with SCPA 1750-b, which has been sustained against a broad array of claims of constitutional insufficiency in two separate trips to the Court of Appeals.⁹

tion of loss of capacity by a physician the agent can make health care decisions for the person, but only "in direct consultation with the principal and the attending physician;"¹⁰ if the person disagrees with his or her agent, the person's decision prevails; the "consultation" underlying the decision must be summarized and recorded in his or her medical record; and the usual (for whatever reason they continue to exist...) protections relating to nutrition and hydration by means of medical treatment remain. Also remaining in the scheme¹¹ would have been the person's rights to (a) fire his agent "by any ... act evidencing a specific intent to revoke the proxy;"¹² (b) the right to have his or her objection to *either* a determination of incapacity or a decision made by the agent "*prevail*"¹³ until or unless a

"The two central ideas behind the 2008 health care proxy demonstration legislation were ease of comprehension for a principal and the fact that the threshold capacity to execute a HCP is among the least onerous for the lawful execution of any legal document."

In approaching the limited scope of the 2010 legislative assignment, and given the overarching goal of the interested parties that the number of persons who need surrogates to make health care decisions should be as small as possible, why not consider an "act now" Health Care Proxy as an option for everyone?

The two central ideas behind the 2008 health care proxy demonstration legislation were ease of comprehension for a principal and the fact that the threshold capacity to execute a HCP is among the least onerous for the lawful execution of any legal document. In the process of drafting the "Advance Health Care Directive" authorized by the legislature, it was readily agreed by stakeholders that a person could *lack* the ability to personally grasp the risks, benefits and alternatives of a proposed medical treatment and at the same moment *have* sufficient capacity to designate someone they trust to help make that decision. PHL Section 2981 provides that "every adult person shall be presumed competent to appoint a health care agent" unless adjudicated otherwise. I submit that in reality the world is chock full of adults (present company *included*) without any official mental disability who probably cannot adequately comprehend the risks, benefits and alternatives involved in many modern medical procedures, especially at a time of advanced age, accompanied by the stress and apprehension of a serious illness, when the discussion often takes place.

The 2008 legislation would have worked in this way: The person (principal) checks the "act now" box on the form; at any point in time prior to the formal determina-

court intervenes; and (c) should she or he have appointed a spouse as agent, plug-pulling authority would be revoked by a legal separation or divorce.¹⁴

So in the midst of very important due process, equal protection and other public policy and social justice issues involved in the guardianship debate, it is the author's purpose to simply ask "why not?"—what is the argument on any level against everyone having the opportunity to choose someone they trust to help right now and in the future without having to be deemed in writing to be incapacitated and possibly cut out of the discussion entirely?

It seems to be firmly accepted by all parties to the discussions on health care decision-making that a health care proxy is the preferred vehicle for the making of surrogate end-of-life health care decisions. In the case of people with developmental disabilities, a valid health care proxy obviates (a) the inability to initiate end-of-life decisions by a surrogate until the point at which the person is terminally or chronically and irreversibly ill (or permanently unconscious); (b) the need to be assessed and deemed medically to currently lack "capacity to make health care decisions..."; and (c) the back and forth process involving several parties beyond the patient and his/her family set forth in statute.¹⁵

On a personal note, some of the most heart-wrenching conversations I have had over the past 15 years of state and voluntary agency service have been with parents and siblings of persons with developmental disabilities, whose dying process was lengthened by SCPA

GUARDIANSHIP AND SURROGATE DECISION-MAKING

1750-b, and who learned only after formulating their *own* treatment decision for a loved one that their “decision” merely initiates a potentially days-long process in which attending and consulting physicians, residential providers, the state agency (OPWDD), the Mental Hygiene Legal Service, “any other health care practitioner providing services to the [] person” and possibly even a court all might have a say in the outcome.¹⁶ There should be fewer such conversations involving any New Yorker, with or without a diagnosed disability, in the future.

Endnotes

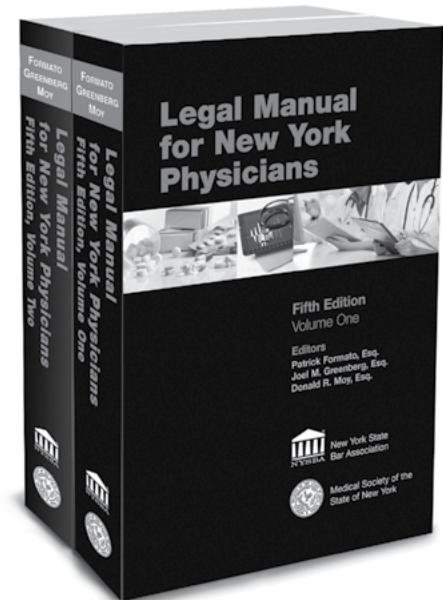
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2. Originally entitled the Health Care Decisions Act for Persons with Mental Retardation.
3. *Disability Rights New York v. New York State, et al.* USDC SDNY 16 Civ. 7363 (AKH).
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5. *See Blouin v. Spitzer*, 213 F. Supp. 2d 184.
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14. PHL § 2985 1 (e).
15. SCPA subsections 1750-b 4 (b) and (e), and subsections 5 and 6.
16. SCPA 1750-b subsections 4, 5, and 6.

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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.”¹

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.²

The second source from which SDM derives is the United Nations Convention on the Rights of Persons with Disabilities (CRPD),³ 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.”⁴ 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.”⁵

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.⁶

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),⁷ the American Bar Association, the Uniform Law Commission (ULC), the National Guardianship Association, and the Arc.⁸ ACL has funded a number of related projects including the National Resource Center on SDM.⁹ The ABA has passed a resolution promoting SDM, and similar official statements have been issued by the Arc¹⁰ and NGA.¹¹ 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.¹²

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

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GUARDIANSHIP AND SURROGATE DECISION-MAKING

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

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.¹⁶ Similar statutes are currently under consideration in a number of additional states.¹⁷

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?

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.

“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.¹⁸ Facilitators, who serve as volunteers (or, in the case of student facilitators, potentially for academic credit)¹⁹ receive a two-day training and are supervised by experienced mentors with expertise in the SDMNY facilitation process.

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.²⁰ 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.²¹ 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 alternatives²² before guardianship may be imposed.²³ While 17-A lacks virtually all the procedural—and constitutionally mandated—protections of Article 81,²⁴ least restrictive alternatives should apply equally to guardianships for persons with intellectual and developmental disabilities as a constitutional imperative, premised in substantive due process,²⁵ and courts have so held.²⁶ SDM is clearly a less restrictive alternative, and is increasingly recognized as such in both case law²⁷ and in revisions to guardianship statutes, as with the revised UGCOPAA, and state statutes, like Maine's,²⁸ 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.²⁹ 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."³⁰

Article 81 deliberately adopted a "functional" test of incapacity, rejecting the diagnosis-driven determination that characterized New York's previous conservator and committee statutes³¹ 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 neuroscience³² 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,³³ 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.³⁴

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 treatment³⁵ 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,"³⁶ a determination dependent on the written opinion of a psychologist or psychiatrist.³⁷ Under the FHCD, 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.³⁸ 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."³⁹

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 decisions⁴⁰ 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)⁴¹ may require provision of such supports, both for persons carrying an I/DD diagnosis and for adults in a hospital setting⁴² whose "capacity" is in question. Both⁴³ 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.⁴⁴ 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*,⁴⁵ 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.⁴⁶

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.⁴⁷ 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.⁴⁸

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

agreements.”⁵¹ 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.”⁵² 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 (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.
8. See <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>.
9. 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.
10. The Center’s website is available at <https://www.supporteddecisionmaking.org>.
11. 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>.
12. 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>.
13. UGCOPPA, available at <http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>.
14. 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 (NCD Report).
15. 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.
16. 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.
17. 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).
18. For the most recent updates, see <http://sdmny.org/sdm-state-map/>.
19. 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).
20. 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.
21. 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>.
22. It is particularly moving that one of these decision-makers in the Restoration Pilot, is a Willowbrook survivor.
23. 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.
24. 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.
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.org/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).

NEWS *flash*

What's Happening in the Section

Upcoming Deadline

The Diversity Summer Fellowship in Health Law was developed in 2011 by the Health Law Section as part of the New York State Bar Association's Diversity Challenge to develop and execute initiatives to increase the diversity of its membership, leadership and programs and to evaluate the results.

The deadline for 2019 applications is December 3, 2018.

The primary goal of the Diversity Summer Fellowship in Health Law is to increase representation of lawyers and students from a diverse range of backgrounds in health law.

Since 2012, the Health Law Fellowship Program has placed law students at NYU Langone Medical Center, Montefiore Medical Center, Mount Sinai Health System and Catholic Health Services of Long Island.

The Fellowship is operated in partnership with and administered by the New York State Bar Foundation.

To be eligible, an applicant must be a law student in a New York State accredited law school. There is a \$5,000 stipend for the eight-week Fellowship. Applications can be mailed to Leigh Dorr, The New York Bar Foundation, One Elk Street, Albany, NY 12207 or emailed to ldorr@tnybf.org (include "Health Law Fellowship" in the subject line).

Visit www.nysba.org/HLS for more information or to download an application..

Recorded Programs Available Online

The Section has three recordings available to purchase and view for CLE credit, any time that is convenient for you:

1. Legal Issues Surrounding Eye, Organ and Tissue Donation

CLE: 1.5 credits in professional practice, non-transitional and accredited for MCLE credit in New York State only.

Cost: Free to Health Law Section Members.

Presented by the Health Law Section in partnership with the New York Alliance for Donation (NYAD), and co-sponsored by the Health Law Committee and Bioethical Issues Committee of the New York City Bar.

New York State is facing a health care crisis: the need for transplantable organs far exceeds the availability. While a single donor can help save the lives of up to eight people, potential donors are rare. It is crucial that all of the participants in the process, legal, clinical, administrative and governmental are knowledgeable about the law and the process surrounding organ and tissue donation.

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Cost: Health Law Section Members: \$175

This program offers a look at innovative programs that are designed to facilitate access to comprehensive, coordinated care to improve patient satisfaction and clinical outcomes. These programs and the use of the technology necessary to support them do not come without legal barriers and challenges. A diverse panel of speakers will describe initiatives that are disrupting the health care system, and the practical ways to overcome the real and perceived barriers to sustained implementation. This program is relevant for attorneys representing all provider types, health systems, in-house counsel, insurance/payor plans and governmental attorneys involved in health care regulation.

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- Medical-Legal Partnerships in Health Care
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- Concierge Medicine/Telemedicine/Direct Primary Care
- Ethics of Health Information Technology Privacy

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Part I of this series is available for free, and does not offer CLE credit. Visit www.nysba.org/ehrs.

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ISSN 1530-3926 ISSN 1933-8406 (online)

HEALTH LAW JOURNAL

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