

Elder and Special Needs Law Journal



A publication of the Elder Law and Special Needs Section
of the New York State Bar Association

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(Jennifer J. Monthie)

Supported Decision-Making: What You Need to Know and Why
(Hon. Kristin Booth Glen)

...and more!

**SPECIAL JOINT EDITION WITH THE HEALTH LAW SECTION
ON GUARDIANSHIP FOR INDIVIDUALS WITH DISABILITIES**

Message from the Chair



Judith D. Grimaldi

Dear Colleagues and Members of the ELSN Section:

Our 2018-2019 Section cycle has started with some exciting activities. First, I wish to welcome my fellow officers, **Tara Anne Pleat**, **Deepkanker Murkerji**, **Mathew Nolfo** and **Christopher Bray** as well as immediate past chair **Martin Hersh**, and the newly appointed Executive Committee Chairs. I am encour-

aged by the projects the committees are taking on. For example, the Elder Abuse Committee Chairs **Julie Stoil Fernandez** and **Debra Ball** are continuing to work on legislation to protect this vulnerable population. The Client and Consumer Issues committee, with Chairs **Linda A. Redlisky** and **Patricia Angley**, will be updating the Legalese brochures and materials on Trustees' roles and the use of POAs for our clients and fellow colleagues

Our Elder Law and Special Needs Section Summer Meeting was a remarkable three day event at beautiful Niagara-on-the-Lake in Ontario, Canada. A giant thank you to the Summer Meeting Co-Chairs **Beth Polner Abrahams** and **JulieAnn Calareso** for organizing and coordinating the 15 extraordinary sessions making 12 CLE credits available to attendees. The topics ranged from elder law and tax law updates, Medicaid strategy sessions, a primer on e-filing in Surrogate's Court, Cultural Competency for the diversity credit, and Advance Planning for Special Needs and Drafting Techniques for Trusts and Powers of Attorneys. We ended with an informative session on cyber security issues for law firms.

The Executive Committee has made a commitment for two special projects. One is the reactivation of the Task Force on Challenges to the Medicaid Planning Practice Area. Committee members **JulieAnn Calareso**, **Salvatore Di Costanzo**, **Rene Reixach**, **Laurie Menzies**, **Robert Kurre**, **Yana Feldman** and **Linda Grear** will focus on understanding first how the Medicaid planning practice area is changing and the impact of the growth of non-lawyer Medicaid planning practices in our state. The task force will be researching what is happening around the nation and how we can develop strategies to preserve our Medicaid planning practice and to protect the interests of our clients who may have been provided substandard Medicaid advice. The committee welcomes new members as we move forward. Please contact me or

any of the committee members if you are interested in this task force.

The ELSN's second opportunity is to host a special symposium on "Innovative Housing Alternatives for Older New Yorkers" featuring international housing advocate **Eloy van Hal**, the founder and director of the Dementia Village called De Hogeweyk in the Netherlands, in late October 2018. See: <https://hogeweyk.dementiavillage.com>. This is a specially designed village that has 23 houses for 152 dementia-suffering seniors. Mr. van Hal's presentation will be followed by a panel discussion to explore ways our city and state can begin to incorporate these housing and care techniques into the way we care for frail or cognitively impaired elders. This symposium will not only be open to our members but also to housing and aging advocates, government policy makers and housing and assisted living developers. Our goal is to start a new conversation on housing options for older persons. We are proud to be working together with NY NAELA and the current NY NAELA Chair, **Ronald Fatoullah**, as co-sponsor of the program and thank the Section Real Estate and Housing Committee Officers who are taking leadership to make this special Symposium happen: **Joseph P. Greenman**, **Neil Rimsky**, **Robert Shaw** and **Martin Petroff**, as well as their committee members.

We enjoyed seeing you all at the Fall Meeting on October 4 and 5, 2018, at the Park Ridge Marriott in New Jersey. The program offered an innovative look at how the aging of our society is impacting the elder law practice area and sought to tackle complex policy and practice issues facing today's elder law and special needs attorneys. The two day program offered a broad perspective on national socioeconomic trends in health care delivery, technology, housing, taxation, and wealth transfer. The overarching conference goal was to promote forward thinking and opportunities to evaluate the practice of law in the broader context of our changing society.

A keynote presentation by social economist, **Professor Anthony Webb** of the New School of Social Research, reviewed the financial challenges facing baby boomers who are retiring without pensions. Our luncheon speaker, **Professor John Jacobi** of Seton Hall Law School, reviewed Medicaid's biases and how they impact minority applicants, especially African Americans (this qualified as a diversity credit). Our Chairs **Moriah Adamo** and **Mary Fern Breheney** also organized a debate on the Aid in dying legislation for our ethics credit. It was a very successful Fall Meeting!

The fall is turning out to be a productive season and I thank all the members for their enthusiasm and support.

Best always,

Judith D. Grimaldi

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Professional Growth Opportunities

Elder Law and Special Needs Section committees address, from the perspective of an elder law practitioner, unique issues facing the elderly, those with disabilities and those in the legal profession.

The Section offers you the opportunity to serve on many committees and to network with attorneys throughout the state. Committees give you the opportunity to research issues, influence legislation that affects the elderly and/or those with disabilities, and achieve professional development and recognition.

Elder Law and Special Needs Section Committees

Please designate in order of choice (1, 2, 3) from the list below, a maximum of three committees in which you are interested. You are assured of at least one committee appointment, however, all appointments are made as space availability permits.

- ___ **Client and Consumer Issues** (ELD4000)
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- ___ **Elder Abuse** (ELD7600)
- ___ **Estates, Trusts and Tax Issues** (ELD1200)
- ___ **Ethics** (ELD7300)
- ___ **Financial Planning and Investments** (ELD4400)
- ___ **Guardianship** (ELD1600)
- ___ **Health Care Issues** (ELD3600)
- ___ **Legal Education** (ELD1900)
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- ___ **Special Needs Planning** (ELD3800)
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- ___ **Technology** (ELD7800)
- ___ **Veteran's Benefits** (ELD6700)



Message from the Co-Editors-in-Chief Regarding Joint Edition



Brendan Parent



Tara Anne Pleat



Katy Carpenter



Patricia Shevy

The leadership of the Elder Law and Special Needs Section and the Health Law Section 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 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 the Article 17-A statute as it currently functions with respect to personal decision making, an area that requires—and is receiving—attention and thought from practitioners, the judicial system and the legislature. If you were not aware of the attention being given to Article 17-A, we are hopeful that this *Journal* will help readers understand the issues and assist them in counseling their clients on the use and status of Article 17-A Guardianships and alternatives to Guardianship that can be sought out.

Brendan Parent, Editor, *Health Law Journal*

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

Katy Carpenter, Co-Editor, *Elder and Special Needs Law Journal*

Patricia Shevy, Co-Editor, *Elder and Special Needs Law Journal*

Request for Articles



If you have written an article you would like considered for publication, or have an idea for one, please contact *Elder and Special Needs Law Journal* Co-Editors:

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Articles should be submitted in electronic document format (pdfs are NOT acceptable), along with biographical information.

www.nysba.org/ElderJournal

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

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



Tara Anne Pleat



Edward V. Wilcenski



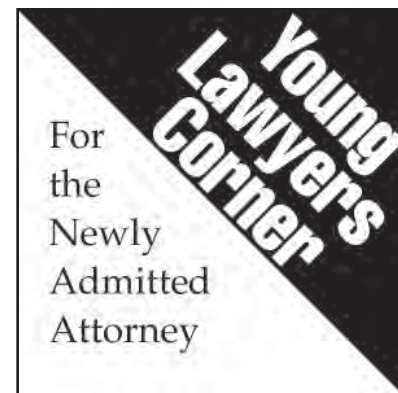
Katy Carpenter

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 Guard-



ianship 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 proceeding 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 pro-

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 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 continue 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.

The authors are practicing with the law firm of Wilcenski & Pleat, PLLC, with offices in Clifton Park and Queensbury, New York. The firm focuses in the areas of Elder Law, Special Needs Planning, and traditional Trust & Estate Planning and Administration.

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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 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 authorizes 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 proposals. 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.
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. Luke’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, 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 Member Spotlight: Kirsten Dunn

Interview by Katy Carpenter

Q Where are you from?

A I was born in New York but my family moved when I was young and I was raised in Colorado. I met my husband in New Mexico, where we had most of our children and then we relocated to Canajoharie, New York, 13 years ago.

Q What brought you to Canajoharie, New York?

A We decided to try to farm, so that we could have more involvement with our children as they were growing up. Since my husband was a baseball player, we discovered the Baseball Hall of Fame in Cooperstown; then we discovered the land was inexpensive in New York compared to the West. We found a beautiful farm in the Fort Plain area, and here we are.

Q What do you enjoy most about practicing law in a rural part of New York?

A I love the variety. Lawyers in rural areas have a hard time specializing, so we have a general civil practice which allows us to take almost every client that walks through our door. There's never a dull moment. The three-minute commute from our farm to the office is nice, too!

Q What is the most memorable and favorite place you have traveled to?

A Hungary. I visited as a child when it was still a Soviet-controlled nation. My dad is Hungarian and I would spend the summers with my grandmother—who did not speak English. I always enjoyed the old architecture, the food, the language and the people—Hungary is so unique.

Q Tell me about your family and kids.

A I'm married with nine children—no twins! Yes, they are all mine and yes, they are all his, too!



Q What's been the most challenging part about being a non-traditional new lawyer?

A I had to readjust my thinking to accept "jumping through the hoops," for things like standardized testing. I had so much life experience by that point in time, the mental discipline was challenging with my life and circumstances as a mom. Life was full of complexities with many children while going to law school in Albany, and remains a challenge as I engage in the law practice.

Q Tell me about a project or accomplishment that you consider to be the most significant in your career.

A Most memorable at this point was handling my first matter truly on my own—it was an accomplishment in and of itself and a "big step" in my career to assure myself that I can do it!

Q Have you had any turning points in your life?

A Many! I'm thankful that my husband enjoys the stimulation of drastic change in our lives—we are a good team in achieving our goals together. To begin, we have 9 kids, so I went from being a high school teacher teaching German and History, to a stay-at-home mom home schooling our children. Then we dropped our lives in New Mexico where my husband was an attorney and bought a farm in upstate New York and began farming. From there I decided to go to law school and work with my husband in our small firm partnership—all while continuing to raise our children—4 of our kids have either graduated or are attending college and 5 are still at home.

All of these turning points were financially, logistically, mentally and physically challenging.

Q What or who inspired you to a career in law?

A The "what" was necessity—after the stock market crash in 2007-2008, we realized that farming would not be

financially lucrative enough to put nine kids through college and recoup our lost savings.

The “who” is my husband who worked as an attorney when we lived in New Mexico and decided to pursue taking the Bar in order to practice and open a firm in New York.

Q How is it working with your husband?

A We are very compatible—while we have distinct differences in work styles, they are not insurmountable. On one hand, it’s a treat because he’s knowledgeable and I feel freer than most new attorneys to ask him for advice and suggestions and on the other hand he is protective, so I need to make efforts to be independent.

Q Where do you see yourself in five years?

A I don’t see my circumstances largely changed, since I will still have children in school and at home. I’m happy to finally be practicing law: law lends itself to longevity and working past age 65—there are fewer physical limitations than there are in farming.

Q What did you want to be when you were younger?
A HA! I wanted to be a single, childless diplomat or in international business somewhere in a German-speaking country.

Q What hobbies do you look forward to on the weekends ... besides driving many miles?

A Sleep and rest, but because I can’t do that I enjoy cooking and baking on the weekends. I like to prepare large breakfasts and bake bread.

Q What is something that most people don’t know about you? Is there anything else you want people to know about you?

A Despite my penchant for bread and other baked goods, I am also physically active, and have enjoyed skiing (I grew up in Colorado, remember!), self-defense, running and playing with my children in the yard. I also make soap, quilt, weave, and have an assortment of odd and unmarketable talents!

Do You Have a Story to Share...

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- Has a pro bono case made a difference in the lives of others?
- Has an individual attorney or firm gone above and beyond to provide pro bono assistance?

We invite you to submit articles showcasing excellence in pro bono service for upcoming editions of the Pro Bono Newsletter. For more information, go to www.nysba.org/probono.



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



Jennifer J. Monthie

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

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changes [which have occurred] in the care, treatment, and understanding of” individuals with disabilities.⁸ The final study 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 legal 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 ap-

plication 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 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 duration 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).

Please note:

The last *Elder and Special Needs Law Journal* listed the 2020 UnProgram on the wrong date. The 2020 date is April 30 - May 1, 2020.

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Format: Submit the article in the form of a Word document. Please do not use Word Perfect or .docx. The article should contain endnotes in Arabic numerals, and all sources should be attributed in *Bluebook* format. Contact the Co-Production Editor for further details or your Office of Student Life or its equivalent.

Judging: The articles will be judged by the *ESNLJ* Editorial Board. Even if one of your students' articles is not chosen as a winner, we may choose to publish it in the *ESNLJ*.

To Enter: Please send all submissions to the following email addresses:

kimtrigoboff@gmail.com &
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Deadline: March 15, 2019 and no extensions will be granted.

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

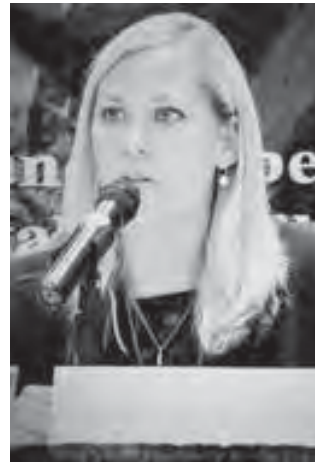
In the course of providing the full spectrum of medical, residential, and habilitative care to adults with intellectual and developmental disabilities (I/DD), it becomes quickly apparent that despite New York's wide-ranging surrogate decision-making laws and regulations, something is missing. Namely, 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



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John Dow

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

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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 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

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 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 treatment 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 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 of 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).

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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



Robert N. Swidler

sions 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.

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

“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.”

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 Deci-

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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.)

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 intellectually 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 intellec-

tual 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.

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,

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>		

...continued on page 37

Recap of the Section's Summer Meeting at Niagara-on-the-Lake

- » Fun location for a Summer Meeting combined with perfect weather and wonderful outdoor activities
- » Outstanding speakers and the highest quality written materials for ongoing reference in our law practices
- » Plenary and break-out sessions covering basics for newly admitted attorneys and cutting edge updates and skills for seasoned practitioners

This summer, our Section's Summer Meeting in Niagara-on-the-Lake, Canada, had it all including plenary sessions and specialized breakout sessions covering an array of essential topics. Beginning with Chair-elect **Tara Anne Pleat's** highlights of changes to the tax code, SSI POMs, and a summary of important cases and fair hearing decisions affecting our elder law and special needs law practices, the Summer Meeting interspersed breakout sessions designed for the newly admitted attorney and the experienced practitioner.

Vincent J. Russo presented a basic overview of tax planning for the elder law practitioner, followed by a breakout session on advanced tax under the new tax laws.

Newly admitted attorneys were in for a treat with **James R. Barne's** breakout session, which reviewed the basics of chronic care Medicaid, including eligibility, transfer of assets, and spousal protections. **Sara Meyer's** breakout session addressed fundamental issues and procedures for the administrative fair hearing when an application is denied or Medicaid benefits discontinued. **Britt Burner** and **Richard A. Marchese** offered a comparison of the operation of upstate and downstate MLTC Medicaid, its impact on our clients, and advocacy tips.

Advanced practitioners chose from break-out sessions including an examination of use of the CPLR in complex Article 81 proceedings led by **Joseph A. Greenman** and **Richard L. Weber**, and **Richard Weinblatt** speaking on creative and helpful clauses for wills, trusts and powers of attorney, and cautioning practitioners about use of clauses which may not achieve our client's goals. **Richard's** materials provide a useful resource culled from our Section's leaders for up to date sample clauses and provisions.

Joan Lensky Roberts' and **Kerry M. McGrath's** breakout session discussed the basics of SSI, SSD, and programs for persons with disabilities, and participants learned the acronyms of special education. Later, **Joan** and **Robert Mascali** reviewed advanced and sophisticated options for special needs planning without the use of the pay back (first party) SNT and the complexities of the Medicare Set Aside Trust.

The practice management and ethics breakout session brought together Erie County Surrogate's Court Chief Clerk **Kathleen D. Drauz** and Chief Court Attorney **Joseph A. Shifflett** with moderator, **Linda Stravalaci Grear**, who shared their insights on e-filing in Erie County Surrogate's Court, and included updates and best practices in e-filing.

Summer Meeting participants were treated to several excellent plenary sessions.

Danielle Pelfrey Duryea, Assistant Dean for international

Affairs and Health Law Initiatives at the University of Buffalo, **Veronica Escobar**, and **Pauline Yeung-Ha** presented on cultural differences and their impact on our legal interactions, legal issues and representation, and which gave participants the newly required Diversity, Inclusion and Elimination of Bias CLE credit. **Michael Burger**, of Neutral Mediation Group, introduced the audience to mediation as an alternative to litigation, and the mechanics of mediation and its use in contested surrogate and guardianship matters, and was followed by **Beth Polner Abrahams'** brief summary of our Section's initiatives to facilitate court-referred mediation programs. **Devika Kewalramani** provided an insightful and informative look at the ethical considerations and duty of confidentiality in the "cyber" world and what attorneys and our offices must comply with, as well as steps to take for implementing internet security. And our final presenter of the conference, **Valerie Bogart**, gave the audience an update on changes implemented in MLTC in May, upcoming changes, and the impact on seniors and persons with disabilities.

No Summer Meeting is complete without social activities and Section Chair **Judith Grimaldi** made sure this happened, starting with wine and dinner at the stunning historic Peller Estates vineyard, theater at the Shaw Festival, and the Trolley Wine Country Tour. For those of us who didn't participate in these the activities, there was the floral beauty of strolling, shopping and dining on the main street in Niagara-on-the-Lake.

JulieAnn Calareso and **Beth Polner Abrahams**, as program co-chairs, together with Section Chair **Judith Grimaldi**, worked collaboratively for several months to create and implement the program and its activities. **Elizabeth Briand** once again met our goals for bringing our wonderful sponsors. If you would like to co-chair a meeting, contact our Section leaders. Get involved, get to know your fellow Section members, and watch the wonderful results.

Beth Polner Abrahams
Polner Abrahams Law Firm

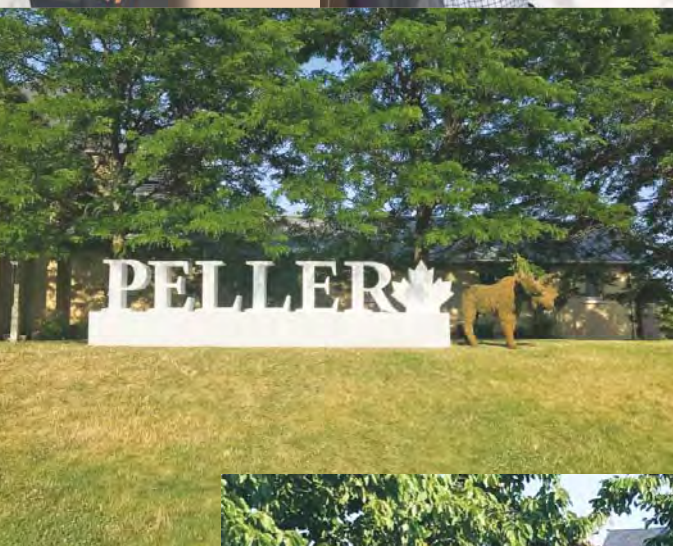
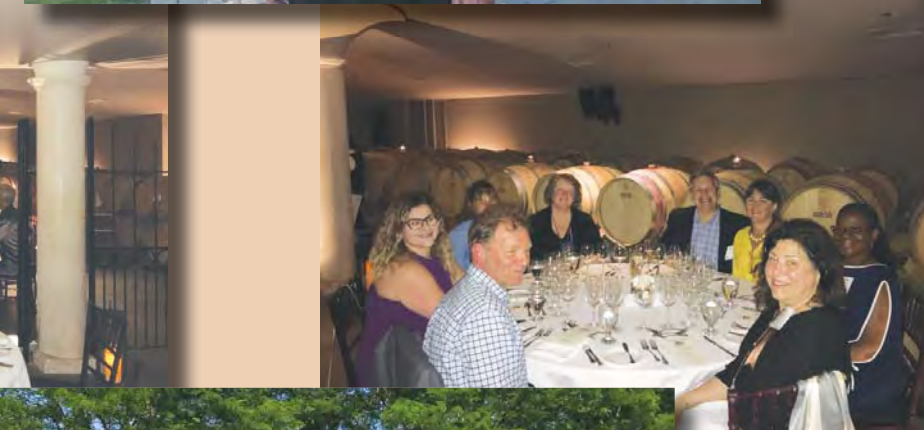
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The Elder Law and Special Needs Section Summer Meeting







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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?	Notice of a determination that a surrogate will make health care because the patient lacks decision-making capacity must be given to: (1) to the patient, where there is any indication of the patient's ability to comprehend the information; (2) to at least one person on the surrogate list highest in order of priority, pursuant to § 2994-d(1); (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)	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.

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>members it fully represents); or</p> <ul style="list-style-type: none"> • 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?	<p>(1) “in accordance with the patient’s wishes,” or</p> <p>(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)</p>	<p>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)</p>	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?”	<p>An assessment of the patient’s best interests shall include:</p> <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. 	<p>An assessment of the person’s best interests shall include consideration of:</p> <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.

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: 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.

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.

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.

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 OWPDD 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.

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
			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)	
What if there is an objection to the Guardian/surrogate 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>	N/A	<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 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, MHL, 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.

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
		the OPWDD commissioner or designee. SCPA § 1750-b(6)		
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)	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.

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

By Hon. Kristin Booth Glen



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

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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 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?

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.

In Phase 1, the facilitator works with the Decision-Maker to determine what kinds of decisions she or he is already making, or is able to make on her or his own, in which areas or domains she or he needs and desires support, and what kinds of support she or he wants in each

area. Some relevant domains include health care, finances, education, employment, relationships, community services, etc. The facilitator also assists the decision-maker in identifying trusted persons in her or his life to serve as her or his supporters.

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

In Phase 3, the decision-maker and supporters come together with the facilitator to negotiate their SDMA. The agreement they reach spells out the areas for support, from whom the support in each area will be given, and the kinds of support to be provided. Each SDMA is individually tailored, but follows a template developed by SDMNY based on review of all existing SDMAs in the U.S. and elsewhere, and consultation with a variety of stakeholders, including self-advocates.

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

There is currently no statute in New York requiring acceptance of SDMAs by third parties, although SDMNY is working on efforts to have state agencies, including the Office of People with Developmental Disabilities (OP-WDD) and the Department of Education, honor them.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 SDMAs.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 consid-

eration 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 FHCDA, and where end of life decisions are to be made for persons with I/DD, that determination is made by the attending physician, who must confirm, to a "reasonable degree of medical certainty," that the person currently lacks capacity to make health care decisions.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. See <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>.
8. ARC of the United States is the national organization representing numerous ARC (formerly, the Association for Retarded Children) chapters around the country, and is the preeminent organization of parents of children with I/DD.
9. The Center's website is available at <https://www.supporteddecisionmaking.org>.
10. The Arc, Position Statement, Autonomy, Decision-Making Supports and Guardianship (2016), available at <https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship>.
11. National Guardianship Association, Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making (2017), available at <https://guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf>.
12. UGCOPPA, available at <http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>.
13. National Council on Disability, Beyond Guardianship: Toward Alternatives That Provide Greater Self-Determination (March 22, 2018), available at https://www.ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf (NCD Report).
14. For example, there were presentations on SDM at the Association of American Law Schools (AALS) in 2014, the Law and Aging Section of the Law & Society Association in 2015, Cardozo Law School's Symposium, Personhood and Civic Engagement by Persons with Disabilities in 2017, Columbia Law School's Symposium, Localizing Human Rights in the New Era in 2017, etc.
15. SDM was the subject of a presentation at the NYSBA Elder Law and Special Needs Section Fall Meeting in 2017, at an evening forum of the New York City Bar Association on June 14, 2018, and will be featured at a CLE at the NYSBA Annual Meeting in January, 2019.
16. Tex. Est. Code Ann. §§ 1357.001–.003 (2015); Del. Code Ann. tit. 16, §§ 9401A–9410A (2017); D.C. Code §§ 21-2001 to 2077 (2018); Wis. Stat. §§ 52.01-.32 (2018).
17. For the most recent updates, see <http://sdmny.org/sdm-state-map/>.
18. For more information on the model see Kristin Booth Glen, *Piloting Personhood: Reflections From the First Year of a Supported Decision-Making Project*, 39 Cardozo L. Rev. 495 (2017).
19. SDMNY is experimenting with Occupational Therapy Assistant (OTA) students at La Guardia Community College and Bachelor of Social Work (BSW) students at Hunter's Silberman School of Social Work.
20. There is precedent for this as the D.C. Board of Education has regulations specifically requiring recognition of SDMA's; see Supported Decision-Making, D.C. Pub. Schools, <https://dcps.dc.gov/page/supported-decision-making>.
21. It is particularly moving that one of these decision-makers in the Restoration Pilot, is a Willowbrook survivor.
22. Under 81.02(a)(2), the court is mandated to consider the sufficiency of other vehicles set out in 81.03(e), which lists, without limitation, "available resources." Notably, Article 81 was passed a quarter of a century ago, when SDM, as an articulated concept or process, was entirely unknown.
23. See MHL 81.01 MHL ("The Legislature finds that it is desirable ... for persons with incapacities to make available to them the least restrictive form of intervention...") 81.09(5)(xii), directing the court evaluator to report on "least restrictive form of intervention" 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.or/docs/factsheet/mental-health-advance-directives-fact-sheet.pdf>.
51. See, *e.g.*, Judy A. Clausen, *Making a Case for a Model Mental Health Advance Directive Statute*, 14 Yale J. Health Pol’y L. & Ethics 1,3 (2014); Cuca, *infra* n. 52, at 1153.
52. It should be noted that there is some debate about whether Ulysses agreements can appropriately be considered SDM as they privilege a “former self” over a “present self” in times of crisis, thus depriving that “present self” of legal capacity. For an example of SDM/peer support in making and utilizing Ulysses agreements in a pilot project in Nairobi, Kenya, see *Introducing*, *supra* n. 48, at 38. See Roberto Cuca, *Note: Ulysses in Minnesota: First Steps Toward a Self-Binding Psychiatric Advance Directive Statute*, 78 Cornell L. Rev. 1152,1152–53 (1993) (Cuca).

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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



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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.

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

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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

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 determination 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 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 au-

thor’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 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

1. Article 29-CC, the Family Health Care Decisions Act.
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).
4. L.2008, Ch. 210.
5. *See Blouin v. Spitzer*, 213 F. Supp. 2d 184.
6. Surrogate’s Court Procedures Act 1750-b, part of SCPA Article 17-A, “Guardians of Mentally Retarded and Developmentally Disabled Persons” SCPA 1750–1761.
7. SCPA 1750-b 1. (a).
8. L.2010, Ch. 8.
9. *See, e.g., In re M.B.* 6 N.Y.3d 437 (2006) and *In re Guardianship of Chantel R.* 6 Misc. 3d 693, aff’d 34 A.D.3d 99, appeal dismissed 8 N.Y.3d 840 (2006).
10. Mental Hygiene Law § 33.03 (e).
11. PHL Article 29-C, generally.
12. PHL § 2985 1 (a).
13. PHL § 2983 5.
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.

Senior Member Spotlight: David Kronenberg

Interview by Katy Carpenter

Q Where are you from?

A I was born in Valley Stream, New York and grew up primarily in West Hartford, Connecticut. My parents are from the Bronx and now I live in Forest Hills in Queens.

Q What do you like about the area and community in Queens?

A It's one of the most diverse places in the world. I enjoy having my kids grow up here and experiencing the culture and diversity. I do miss having a yard and outdoor space but we have many friends and are becoming part of the fabric of the community which makes it hard to leave. My commute isn't bad because I can take the subway or the Long Island Railroad as I'm the last stop before Penn Station.

Q What is the most memorable and favorite place you have traveled to?

A We honeymooned in Italy so that will always be memorable—with kids it's difficult to take trips like that so we've traveled to Yosemite, Big Sur in California and New Orleans, most recently. We are looking forward to a big family trip to Peru next summer!

Q Tell me about your family/kids.

A I'm married—my wife is Jacqueline Flug—and we have two daughters, Abigail who is 11 and Rachel who is 8.

Q Have you had any turning points in your life?

A Yes, I was a musician in a band while living in Oregon after college and we toured all around the West. Luckily, my parents were supportive of my dream to become a professional musician; however, I'm most proud of my transition from a musician to becoming a lawyer.

Q What led you to a career in Elder Law?

A My parents. My father was the President of the Hebrew Home for the Aged in Providence, Rhode Island and then in Hartford, Connecticut; essentially a nursing home administrator. He had a great philosophy about the quality of care and how to treat patients and staff with the utmost respect. My mother was a hospice volunteer coordinator and she has helped guide my philosophy about dying with dignity and end-of-life care issues. I



guess you can say elder care is a “family cause”. I believed that by going to law school, I would learn elder law and be able to advocate for seniors and people with disabilities.

Q Tell me about a project or accomplishment that you consider to be the most significant in your career.

A In my practice, I take the most pride in helping families and clients set up home care services, and we are fortunate because New York has a robust Medicaid home care benefit. Additionally downstate we have many options to offer clients because of the large amount of home care workers. Assisting people to remain in their homes when they need assistance is extremely rewarding.

Q Where do you see yourself in 5 years?

A I don't know where I see myself at 5 o'clock! I imagine our firm will transition a bit by then and I hope to still be doing what I'm doing now.

Q What did you want to be when you were younger?

A Initially I wanted to be a baseball player then in high school my dream transitioned to becoming a touring musician. Being a lawyer is my fall back!

Q Are there hobbies you look forward to on the weekends?

A Music—my daughters play instruments too so I enjoy playing together. Otherwise I enjoy doing things outdoors, playing tennis and fishing.

Q Have you ever been given memorable advice or have advice to offer?”

A Best advice was to get involved in the NYSBA Elder Law Section and go to events. We have great colleagues in our Section. It feels like a family where we all support each other.

Q Is there anything else you want people to know about you?

A Just that I welcome new attorneys to reach out to me if they have any problems or need assistance with anything. I want to offer the same help that was offered to me when I was just starting to practice.

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and often collaborate with non-legal professionals on any matter involving the Public Health Law and public funding for health care

Most recently, the Health Care Issues Committee has been leading our Section with the review, comments and analysis of the proposed New York State Medical Aid in Dying legislation.

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Article 81 of the Mental Hygiene Law (*includes CLE*)

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Wednesday, December 12, 2018 | 9:00 a.m. - 5:00 p.m. | Albany

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#### Elder Law and Special Needs Section Meeting at the NYSBA Annual Meeting

Tuesday, January 15, 2018 | NYC

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This practice guide is currently divided into two parts.

Part One, written by Bernard A. Krooks, Esq., examines the scope and practice of elder law in New York State, covering areas such as Medicaid, long-term care insurance, powers of attorney and health care proxies. Elder law cuts across many distinct fields including benefits law, trusts and estates, personal injury, family law, real estate, taxation, guardianship law, insurance law and constitutional law.

Part Two, written by Jessica R. Amelar, Esq., gives the attorney a step-by-step overview of the drafting of a will, from the initial client interview to the will execution. This section provides a sample will, sample representation letters and numerous checklists, forms and exhibits.

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