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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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Message from the Chair

Tara Anne Pleat

The 2019-2020 Section year is off and running. At the outset, please allow me to convey my sincere gratitude to Judy Nolfo and Jeff Asher for their hard work and seamless handling of the Section's Summer Meeting in Boston. We received tremendous feedback from those who were in attendance regarding the content and structure of the program. Special thanks to Cathy Teeter, Lisa Bataille and Kathy Plog for their work, support and handling of the details for our social events, reception and dinner. For those of you who were in attendance, we hope you enjoy the photos appearing in this edition of the *Journal* recounting our festivities. Equally successful was the Fall Meeting in Saratoga on October 24th and 25th at the Gideon Putnam, which we hosted jointly with the Trusts and Estates Law Section. Ellyn Kravitz and Sal DiCostanzo were our Section's program co-chairs. Together with their Trusts and Estates counterparts, Frank Santoro and Nicole Clouthier, we had a wonderful, sold-out program.

We were most fortunate to have NYSBA President, Hank Greenberg attend and address the Section's Executive Committee and the general session at the Summer Meeting. His comments about the Power of Attorney proposal gave us great hope that we will finally see the passage of the bill in the upcoming legislative session. That said, NYSBA wishes to continue its full court press for the remainder of 2019, with a mind toward getting the legislation passed by the Senate before the state budget process begins. To that end, NYSBA is looking for letters of support from upstate "consumer" groups such as AARP or Alzheimer's Association Chapters to provide relative to the legislation. If you happen to be a member any such consumer groups, please reach out to me at TPleat@WPLawNY.com or David Goldfarb at Goldfarb@Seniorlaw.com and we can provide you a sample memorandum for your organization's consideration and use.

At the Executive Committee Meeting that occurred on July 18th the Section voted to support affirmative legislation proposed by the Task Force on the Unauthorized Practice of Law which would amend the Public Health Law creating a requirement that skilled nursing facilities provide written notice to residents (or their representatives) at the time of admission of their right to legal counsel in securing Medicaid benefits. We have heard countless stories from our colleagues about non-legal service providers providing incorrect or incomplete legal advice when preparing Medicaid applications. Robert Kurre of our Medicaid Task Force and Deborah Ball of our Legislation Committee are working on finalizing the proposal for submission to the NYSBA Executive Committee in time for a vote in April of 2020.

In passing the 2020 Budget, the Section also officially approved a grant proposed by the Medicaid Committee to the New York Legal Assistance Group (NYLAG) in the amount of $25,000, which will primarily pay for a consultant to design an online system for interactive visualization of Managed Medicaid Cost and Operating Reports (MMCOR), which all Medicaid managed care and MLTC plans must file with the New York State Department of Health. These reports contain extensive data about the plan's revenue, operating costs, and the quantity and cost of all services provided. Revenue is broken down to show the monthly "per member per month" capitation rate, collections of spend-down, and other revenue. Administrative expenses reveal everything from executive and staff salaries to rent, advertising and legal fees. These reports reveal not only the total amount and cost of each service provided during the year (number of hours of home care, etc.), but the number of "member months" in which these services were provided. A team of advocates will work with the consultant to identify and prioritize which of the potentially hundreds of data points would be visualized online. The team would be led by Valerie Bogart, Director of the Evelyn Frank Legal Resources Program at NYLAG, and other members of our Section as well as advocates from other coalitions in New York State. While there are a number of moving parts, the end game here is to obtain a clear and easily understandable advocacy piece that shines a light on the deficiencies in the MLTC system in a way that is accessible to the public and will be meaningful to our state legislators. As our budget was approved by NYSBA, we will be making the actual grant payment in January of 2020 so the New York Legal Assistance Group can get started.

The Executive Committee also reviewed and voted on proactive communication to the New York State Department of Health requesting reconsideration of two aspects of the February 4, 2019 General Information System message, "Clarification of Policy for Treatment of Income Placed in Medicaid Exception Trusts" (GIS 19 MA/04), specifically: (1) The creation of a policy requiring gifting authority for an agent acting under a Power of Attorney to establish a pooled income trust, which is contrary to the General Obligations Law; and (2) Form OHIP-0119 "Explanation of the Effect of Trusts on Medicaid Eligibility," which fails to meet the requirements of the "Pooled Trust Notification Act."

The letter, which was drafted by our Medicaid Committee, together with former Section Chair David Goldfarb, keenly and precisely explains the basis for reconsideration, and frankly, where we believe the Department is incorrect on the law. It was sent to the Department on August 7th and we expect to follow-up with the Department prior to the Fall Executive Committee Meeting so we are able to provide an update on what, if any, action the Department is taking (or is considering taking) in response. Our very active Medicaid Committee is led by Co-chairs Naomi Levin and Sara L. Keating, and Co-vice chairs Nina Keilin, Valerie J. Bogart and Deanne M. Eble.

An issue that has received attention by those of us who prepare Supplemental Needs Trusts and give advice regarding Supplemental Security Income, as raised by former Section Chair, Howie Krooks, in our Executive Committee meeting, is the POMS that were issued on June 25, 2019 by the Social Security Administration. On their face, the new POMS suggest that every attorney who drafts Supplemental Needs Trusts must comply with the Social Security Administration's fee authorization procedure or risk being fined and/or convicted of a misdemeanor. The Special Needs Planning Committee, co-chaired by Lisa Friedman and Joan Robert, agreed to provide an education to the Section about this and did so on September 5, 2019 in an hour-long program entitled "What Every Special Needs Planning Attorney Needs to Know About the New POMS." The program was led by attorney Blaine Brockman, Esq. of Hickman Louder in Ohio. Blaine is on the Board of Directors of the National Academy of Elder Law Attorneys (NAELA) and is a member of Academy of Special Needs Planners (ASNP). In his remarks he gave some historical clarity and practical advice on how to approach this pronouncement by the Social Security Administration. We are grateful to the Special Needs Planning Committee for jumping on this issue and making valuable information and insight available to our Section membership. As we all know, these POMS have been rescinded, but Section members remain diligent in advocacy with the Social Security Administration.

As you can see, there is a lot of exciting work happening on our committees. If you are not already involved, I encourage you to get involved and invite you to contact me at TPleat@WPLawNY.com if you have questions about how to do so.

Tara Anne Pleat

Message from the Co-Editors

Katy Carpenter

Patricia Shevy

As the days grow shorter and the temperatures drop, we are beginning to think about the Association's Annual Meeting. It is the perfect time to learn the latest and greatest in long-term care planning and changes to the Medicaid eligibility rules while catching up with friends and colleagues resident throughout the State. We hope that you will be able to join us as the Section program includes an array of relevant topics including a legislative update, advocating for 100 days of Medicare coverage in light of the Jimmo case, and navigating mental health issues in estate planning and administration engagements. We'll be taking photos throughout the meeting, so be sure to take a look for yourself in the Spring *Journal*.

And, we know, the day remains a constant 24 hours, but when we're losing the daylight, it seems like we'll soon be living in a world of darkness. If it is difficult for us, imagine the difficulties for those with Sundown Syndrome and their caregivers. Sundowning is a neurological phenomenon associated the increased confusion and disorientation of an individual with early to moderate dementia or Alzheimer's disease. The cause of sundowning behaviors is unknown. The timing of the individual's confusion coined the term "sundowning" as the individual's behavioral problems begin to occur in the late afternoon or evening while the sun is setting. While we're not physicians or social workers, our clients routinely ask for recommendations when dealing with a loved one's sundowning. Some helpful tips when living with or caring for someone who sundowns include: maintaining predictable routines and maximizing activity earlier in the day; simplifying surroundings and controlling noise; and adjusting light exposure. No one thing helps everyone, and managing sundowning requires flexibility and creativity as well as patience and empathy.

Many of the articles in this edition of the *Journal* focus on the tools available to our special needs practice. Sheila Shea and Mark Brody highlight the use of third party agency trusts as a vehicle to compromise or settle a Mental Hygiene Law Article 43 debt.

Anyone on social media has friends who post links to GoFundMe pages or seek charitable donations. On Facebook, we are now asked to fundraise in honor of our birthdays by selecting a charity to whom our friends may make donations. In this *Journal* edition, Lauren Mechaly discusses the use of crowdsourcing when the beneficiary of the fundraiser is receiving means-tested government benefits. Lauren's article explains how to establish the fundraising account in a way that does not jeopardize government benefits.

Lindsay Webb's article spotlights the creation of the New York State Justice Center for the Protection of People with Special Needs in an effort to combat the lack of adequate and organized responses to the abuse and neglect of persons with intellectual and developmental disabilities, as well as other agencies targeting the protection of these individuals.

This *Journal* includes the winner of our annual law school writing competition, Lisa R. Valente's "Constitutional Challenges to Article 17-A Guardianships." In her article, Lisa provides a summary of the differences between Article 81 and Article 17-A guardianships, focusing on the need for reform to ensure that persons with intellectual and developmental disabilities are not deprived of their rights under the Fifth and Fourteenth Amendments. Our Section and the Legislation and Special Needs Planning Committees continue to closely monitor ongoing efforts to amend SCPA Article 17-A and 1750(b) to ensure protection for persons with intellectual and development disabilities while also providing a reasonable approach to the appointment of guardians.

If you have an idea for an article, please reach out to us. Even if you have never written an article before, we can team you up with a member of our Board of Editors to help you. We look forward to seeing you all at the Annual Meeting.

Tricia and Katy

Does Your Power of Attorney Allow Your Agent to Create and Fund a Pooled Income Trust?

By Samantha Lyons

Young Lawyers Corner
For the Newly Admitted Attorney

On June 25, 2018, a Medicaid Alert was issued by the Medical Insurance and Community Services Administration (MICSA), stating that the Medical Assistance Program (MAP) and the Home Care Services Program (HCSP) will not accept any Medicaid application that includes a pooled income trust that was signed by an agent pursuant to a power of attorney, if the power of attorney does not specifically authorize the agent to create and fund a pooled income trust.[1]

Samantha Lyons

Pooled trust arrangements are commonly used when an applicant for community (home care) Medicaid has income in excess of the Medicaid allowance. For example, for the year 2019, an applicant for community Medicaid is permitted to retain monthly income in the amount of $879. As such, if a client receives monthly income of $3,000, the client has excess income of $2,121. One option (if the client does not have monthly medical expenses that exceed this surplus) is to pay the excess income directly to the local Medicaid agency. Alternatively, the applicant may enroll in a pooled community trust and continue to access those funds for his or her needs. This is because in New York, the income of a disabled individual which is deposited into a pooled income trust is disregarded by Medicaid when calculating the Medicaid budget.[2]

A pooled income trust is administered by a non-profit organization where each member of the trust has their own sub-account and the non-profit acts as trustee of the trust. There are presently over 20 non-profit organizations in New York that offer the use of pooled income trusts.[3]

When counseling clients about home care Medicaid eligibility, the pooled income trust is critical for protecting excess income so that a client may remain at home and receive care through the Medicaid program while also continuing to pay ongoing bills and expenses. However, the client needs to have capacity to set up and fund his or her pooled trust or a legal guardian or agent under power of attorney with the appropriate authority may execute the required documents on his or her behalf.

On July 26, 2017 the MAP Authorized Resource Center (MARC) issued an alert outlining the requirements to establish a valid pooled income trust for Medicaid purposes with a power of attorney.[4]

Pursuant to GIS 19 MA/04, "if a trust is established by an agent acting under a power of attorney, the powers granted under the power of attorney must include the permission to gift assets."[5] As such, in order to establish a pooled income trust utilizing a power of attorney, Section (H) of the New York State power of attorney must be initialed and the Statutory Gifts Rider (SGR) must also be signed and witnessed by two people in compliance with New York General Obligations Law § 5-1514.[6]

As the statutory gifts rider must be executed at the same time as the power of attorney, if a statutory gifts rider does not include the requisite authority to create and fund a pooled trust, the client would need to either execute a new power of attorney with the appropriate language included in the statutory gifts rider or sign the pooled income trust's joinder agreement. The problem arises in many of these cases that the client no longer has the capacity to do so.

The important question that is yet to be answered is how far back local Medicaid agencies will go in reviewing the "validity" of previously submitted pooled income trusts signed by agents pursuant to a power of attorney that lack the specific authority to create and fund a pooled income trust in the statutory gifts rider.

In conclusion, it is of great importance that clients execute powers of attorney simultaneously with the statutory gifts rider that specifically allows the agent to create and fund a pooled income trust. Without said provision the client runs the risk of not being able to utilize a trust arrangement that protects his or her excess income while allowing the client to receive and benefit from Medicaid home care services.

Endnotes

1. http://www.wnylc.com/health/file/658/?f=1.
2. Soc. Serv. L. § § 366.5(f)-(g), as amended June 16, 2018. *See also*, 18 N.Y.C.R.R. §§ 360-2.3, 360-4.3.
3. http://wnylc.com/health/entry/4/.
4. POMS SI 01120.203(E)(2), *available at* https://secure.ssa.gov/apps10/poms.nsf/lnx/0501120203 and http://www.wnylc.com/health/file/627/?f=1.
5. GIS 19 MA/04, dated February 2, 2019, *available at* https://www.health.ny.gov/health_care/medicaid/publications/docs/gis/19ma04.pdf.
6. General Obligations Law § 5-1514, *available at* https://codes.findlaw.com/ny/general-obligations-law/gob-sect-5-1514.html.

Samantha Lyons is a Senior Associate of the Firm Enea, Scanlan & Sirignano, LLP and concentrates her practice on elder law with a focus on Medicaid home care and nursing home care. She is a graduate of Pace University School of Law (2012) and is admitted to practice in New York and New Jersey. Ms. Lyons is a member of NYSBA, the Elder Law and Special Needs Section (Senior Law Day Committee, Medicaid Committee) and a member of the Westchester County Bar Association. She is also a Co-Chair of the Cocktails for a Cause Committee of the Pace Women's Justice Center.

Estate Planning and Will Drafting in New York

Editor-in-Chief

Michael E. O'Connor, Esq.
Costello, Cooney & Fearon, PLLC
Syracuse, NY

Product Description

Estate planning is a diverse, challenging and sophisticated area of practice that requires the technical skills of a tax attorney; a strong understanding of business, real property and decedents' estate law; and the sensitivity and caring of a personal adviser. Estate planning is much more than will drafting - it is a well-recognized specialty that is a prominent part of the legal profession.

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Contents at a Glance

New Member Spotlight: Emily Kahn

Interview by Katy Carpenter

Q Where are you from?

A I'm originally from Brooklyn and later moved to Connecticut. I attended New York University for undergrad, followed by Pace University School of Law in White Plains. I've lived in Westchester for nine years.

Q Where is your favorite place you've traveled to?

A My fiancé's family is from Varberg, Sweden, and our first visit there together was very special. We're currently planning our honeymoon . . . suggestions welcome!

Q Why did you choose to practice in the areas of Trusts and Estates and Elder Law?

A I had a great experience working at Walsh & Amicucci as a Law Clerk during my 1L summer, which inspired me to pursue a career in these practice areas. My work is interesting and very rewarding.

Q Did you have a turning point in your career?

A I made a decision several years ago to continue in a boutique firm environment, allowing me the ability to specialize and develop an expertise. I've worked hard to build a practice and have developed meaningful relationships with other practitioners and the courts.

Q What's your favorite part about your job?

A I love working through complex issues, both with individual clients and the courts. As many areas and types of work fall under the Trusts and Estates umbrella, every day brings something new.

Q Tell me about an accomplishment that you consider to be the most significant in your career thus far.

A I received the 2018 Legal Services of the Hudson Valley Pro Bono Award for mentorship in the area of Trusts and Estates. Recognition from such an incredible organization was very significant to me and the firm.

Q Where do you see yourself in 5 years?

A Among my classmates and colleagues, it's fairly unusual to remain with one firm or even in one area of practice, but I genuinely love what I do and plan to stick around. I enjoy learning from and practicing with our experienced partners, Karen Walsh and Paul Amicucci.

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

A I was very enthusiastic about becoming a judge, which motivated me to pursue a legal career.

Q Tell me a little about your family.

A I met my fiancé, Nick, on our mutual first day of law school just about nine years ago, and we're getting married next October at The Garrison. It's comforting to have a partner who understands the trials and tribulations of practicing law, though frustrating during arguments! We're both lucky to have supportive parents and siblings.

Q Are there hobbies you look forward to outside of work and the law?

A I love long runs in the summer, and hot yoga and skiing in the winter.

Q What is the best piece of advice you have received?

A Both personally and professionally, I'm very meticulous and always try to go the extra mile. I've learned that if you work hard and follow your personal values, it's OK to not be perfect.

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

A I have a black belt in Taekwondo.

Upcoming 2020 Elder and Special Needs Law Section Meetings

April 30 - May 1

The Elder and Special Needs Law Section Spring Unprogram

The Desmond Hotel, Albany, New York

July 16 - 19

The Elder and Special Needs Law Section Spring Meeting

The Equinox Resort, Manchester, Vermont

October 29 - 30

The Elder and Special Needs Law Section Fall Meeting

The Doubletree Hotel, Tarrytown, New York

Winner of the 2019 *Elder and Special Needs Law Journal* Writing Competition

Constitutional Challenges to Article 17-A Guardianships

By Lisa R. Valente

Constitutional flaws in Article 17-A of the Surrogate's Court Procedure Act ("Article 17-A"), such as substantive and procedural due process deficiencies, including, but not limited to, lack of reporting by a guardian and lack of monitoring by the court, demand that this New York State statute be reformed. Changes in the legal, medical and social landscape surrounding persons with intellectual and developmental disabilities (PWIDD) since the enactment of Article 17-A in 1969 support the need for reevaluation and reform.

The population of PWIDD is rapidly increasing, making their needs and rights an increasingly controversial legal topic. Through medical advances, and social and cultural initiatives designed to increase the independence, autonomy and self-determination of PWIDD, intellectual and developmental disability is no longer a static diagnosis. Article 17-A fails to recognize that PWIDD can live full and independent lives with the support of family, friends and other resources, without the need for a plenary guardianship.

The diagnosis-oriented Article 17-A statute no longer comports with the social, legal and medical advances of today, and, more importantly, violates fundamental constitutional rights of PWIDD. A comparison of Article 17-A's statutory provisions with provisions from New York's other guardianship statute, Mental Hygiene Law Article 81 ("Article 81"), demonstrates how Article 17-A fails to provide substantive and procedural due process rights to which PWIDD are entitled.

History of Article 17-A

In 1969, New York State enacted Surrogate's Court Procedure Act Article 17-A ("Article 17-A") authorizing a Surrogate to appoint a guardian over the person and/or property of a person with mental retardation.[1] A mentally retarded person, now known as an intellectually disabled person, is defined as a person who has been certified as being incapable of managing him or herself and/or his or her affairs by reason of intellectual disability and that such condition is permanent in nature or likely to continue indefinitely.[2] Article 17-A was the result of various organizations, including parents and parent organizations, voicing the need for an abbreviated court proceeding for individuals with mental retardation when they reached the age of 18.[3] At that time, Mental Hygiene Law Article 81 (to be further discussed below) did not exist, and the only mechanisms available for substituted decision-making were Mental Hygiene Law Articles 77 and 78 committee and conservator proceedings. The ideology was that mentally retarded persons are perpetual children[4] and the legal rights that parents have over persons under

Lisa R. Valente

18 years of age should be continued indefinitely for the parents of mentally retarded persons.[5] In 1989, Article 17-A was amended to include other "developmental disabilities."[6] A developmentally disabled person is a person who has been certified as having an impaired ability to understand and appreciate the nature and consequences of decisions to such an extent that he or she is incapable of managing him or herself and/or his or her affairs by reason of such disability, and such condition must be permanent in nature or likely to continue indefinitely, and must be attributable to cerebral palsy, epilepsy, neurological impairment, autism, traumatic brain injury, or any condition found to be closely related to intellectual disability.[7] The condition must have originated before age 22, except for traumatic brain injury, which has no age limit.[8]

Current Issues with Article 17-A

Under Article 17-A, the basis for appointing a guardian relies entirely on whether the person has a qualifying diagnosis of an intellectual or other developmental disability,[9] a diagnosis-driven definition of incapacity. The statute allows the appointment of a guardian upon

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Lisa is a member of NYSBA and its Elder Law and Special Needs and Young Lawyers Sections. She is also a member of the Nassau County Bar Association, the Nassau County Women's Bar Association and the Portuguese American Bar Association. In addition, Lisa is an active member of St. Raphael's R.C. Church and enjoys teaching religious education to the children of the parish.

Lisa Valente is the winner of the 2019* Elder and Special Needs Law Journal *Writing Competition.

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 of a guardian.[10] In most cases, the only proof needed to appoint a guardian is the certifications of two physicians or of a physician and a psychologist showing that the person has an intellectual or developmental disability.[11] In some courts, no hearing in an Article 17-A proceeding is held. The statute does not require the court to find that the appointment of a guardian is necessary, nor does it guarantee PWIDD the right to counsel.[12] In some courts, the Surrogate may make a determination based solely on the papers submitted without meeting the PWIDD.

In addition, Article 17-A guardianship is plenary; the person under guardianship loses the right to make any and all decisions. The appointment of a guardian has no time limit and continues indefinitely.

Furthermore, unless otherwise ordered by the court, there is no requirement that a guardian of the person ever report on the status of PWIDD, and there is no review of the necessity for continuation of the guardianship by the court.

> should be exercised by such persons to the fullest extent possible.[15]

In September 2016, due to Article 17-A's alleged unconstitutional provisions, a lawsuit was brought by Disability Rights New York, a protection and advocacy agency in New York, seeking to enjoin the appointment of guardians under Article 17-A.[16] Even though the case was dismissed on abstention grounds, the complaint alleged that Article 17-A violated the due process and equal protection clauses of the Fifth and Fourteenth Amendments to the U.S. Constitution, the Americans with Disabilities Act, and § 504 of the Rehabilitation Act.[17]

As one court noted, the extreme remedy of guardianship should be the last resort for addressing an individual's needs because "it deprives the [individual] of so much power and control over his or her life."[18]

A comparison of the differences between New York State's Surrogate's Court Procedure Act Article 17-A and Mental Hygiene Law Article 81 guardianship statutes will assist in highlighting the flaws and failings of Article 17-A, and the need for reform.

"Even though Article 81 proceedings are typically more expensive than Article 17-A proceedings, the benefit of Article 81 proceedings is protection of due process rights of the alleged incapacitated person."[23]

In light of recent constitutional challenges to the provisions of Article 17-A and its lack of providing for the least restrictive form of intervention, Surrogate's courts have been scrutinizing petitions for guardianship and dismissing them if guardianship is not the least restrictive form of intervention.[13] Surrogate's courts have begun to acknowledge that there is a wide range of functional capacity found among PWIDD, and that understanding the functional capacity of an individual with disability is necessary in determining the best interest and necessity of guardianship.[14] In fact, the New York State Legislature recognized this when it amended Article 17-A in 1990, noting

> [S]ince this statute was enacted in 1969, momentous changes have occurred in the care, treatment and understanding of these individuals. Deinstitutionalization and community-based care have increased the capacity of persons with mental retardation and developmental disabilities to function independently and make many of their own decisions. These . . . rights and activities which society has increasingly come to recognize

Mental Hygiene Law Article 81

In or around 1991, the New York State Law Revision Commission examined adult guardianship issues and proposed Mental Hygiene Law Article 81 ("Article 81"), which was enacted in 1992 and which became effective in 1993.[19] The stated purpose of Article 81 is to

> satisfy 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.[20]

DIFFERENCES BETWEEN ARTICLE 17-A AND ARTICLE 81

Article 17-A has received positive feedback from families because of its relative ease in initiating the proceeding, often without the need of legal counsel.[21] The 17-A procedure is far simpler than an Article 81 proceed-

ing. Article 17-A proceedings are more affordable than Article 81 proceedings since there is no court evaluator appointed by the court, as is the case in Article 81 proceedings.[22] However, protection of individual rights should not be sacrificed for convenience or expense. Even though Article 81 proceedings are typically more expensive than Article 17-A proceedings, the benefit of Article 81 proceedings is protection of due process rights of the alleged incapacitated person.[23]

A. Petition

Article 81 requires its petition to include "a description of the alleged incapacitated person's functional level including that person's ability to manage the activities of daily living, behavior, and understanding and appreciation of the nature and consequences of any inability to manage the activities of daily living."[24] If a proposed guardian is seeking personal needs powers, Article 81 also requires that the petition include specific factual allegations that demonstrate that the alleged incapacitated person is likely to suffer harm because he or she cannot adequately understand and appreciate the nature and consequences of his or her inability to provide for his or her personal needs.[25] Furthermore, if a proposed guardian is seeking property management powers, Article 81 requires the petition to include specific factual allegations that demonstrate that the alleged incapacitated person will likely suffer harm because he or she cannot adequately understand and appreciate the nature and consequences of his or her inability to provide for property management.[26]

In contrast, Article 17-A does not require that its petition contain any specific factual allegations about the person's ability to understand the nature and consequences of his or her ability to provide for personal or property management needs. Rather, Article 17-A only requires that the petition be prepared and filed on prescribed court forms.[27] Article 17-A simply requires that a licensed physician and/or licensed psychologist certify that the PWIDD is an intellectually or developmentally disabled person.[28] The physician or psychologist is not directed to describe how the existence of an intellectual or developmental disability makes the person incapable of managing himself or herself or his or her affairs. Furthermore, Article 17-A does not require a petitioner to state why the person would likely suffer harm if the court did not appoint a guardian.

B. Court Investigation

Article 81 requires the appointment of an independent court evaluator to investigate and make recommendations to the court.[29] One of the court evaluator's duties is to explain to the alleged incapacitated person, in a manner which the person can reasonably understand, the nature and possible consequences of the proceeding, the general powers and duties of a guardian, and the rights to which the person is entitled, including the right to counsel.[30]

Article 17-A, on the other hand, only provides that the court, *in its discretion,* can appoint a guardian ad litem to perform a similar function.[31] Article 17-A makes no provision to ensure that the PWIDD is fully informed of the nature of the proceeding and its possible consequences.

C. Grounds for Appointment of Guardian

Article 17-A relies entirely on a diagnosis-driven definition of incapacity[32] as opposed to Article 81 which focuses on a functional analysis of the alleged incapacity.[33] Article 81 mandates that a guardianship can only be imposed when it is necessary to provide for the personal needs and/or property management of the alleged incapacitated person and such person either consents to the appointment, or it has been shown that: 1) the person is likely to suffer harm; *and* 2) the person is unable to provide for personal needs and/or property management; *and* 3) the person cannot adequately understand and appreciate the nature and consequences of such inability.[34]

In contrast, Article 17-A only provides that when it shall appear to the satisfaction of the court that a person is an intellectually disabled or developmentally disabled person, the court is authorized to appoint a guardian of the person or property, or both, if the appointment of a guardian or guardians is in the best interest of the intellectually disabled or developmentally disabled person.[35] The Article 17-A statute allows all of a person's decision-making to be permanently removed based on a medical diagnosis and on the subjective decision of a surrogate. Such a standard does not comport with constitutional liberty and substantive due process rights.

D. A Hearing

Article 81 requires that "a determination that the appointment of a guardian is necessary for a person alleged to be incapacitated shall be made only after a hearing."[36] On the other hand, in some courts, there is no hearing in an Article 17-A proceeding. No hearing is required where the petition is made by or on consent of both parents, or the surviving parent.[37] The Surrogate may make a determination based solely on the papers submitted.

In addition, Article 81 provides that the person for whom guardianship is sought must be present at the hearing, even if it means that the judge must travel to where the person resides or some other place outside the courtroom "so as to permit the court to obtain its own impression of the person's capacity."[38] Exceptions are limited. By contrast, Article 17-A allows the presence at a hearing to be dispensed with where, upon medical evidence, presence "is likely to result in physical harm" or the person is "medically incapable" of attendance, or "such other circumstances which the court finds would not be in the best interests of the mentally retarded or developmentally disabled person."[39] As a result, if there

is a hearing, the person for whom guardianship is sought may not be present.

E. Burden of Proof

Article 81 requires proof of clear and convincing evidence of all three criteria—likely harm, inability to provide, and inability to understand and appreciate.[40] Article 17-A does not provide a standard for burden of proof. Article 17-A's language only provides that it must appear to the satisfaction of the court that *the best interests* of such person will be promoted by the appointment of a guardian.[41] In fact, one New York court held that "the decision to appoint a guardian of the person or property, or both, under N.Y. Surr. Ct. Proc. Act § Art. 17-A is based upon a less stringent standard of proof, namely, the best interests of the mentally or developmentally disabled person."[42]

F. Right to Counsel and Right to Cross-Examine

Article 81 provides that the alleged incapacitated person has "the right to choose and engage legal counsel of the person's choice,"[43] and also requires the appointment of counsel in various circumstances, such as when the alleged incapacitated person contests the proceeding.[44] Article 17-A makes no provision for the appointment of an attorney to represent the person for whom guardianship is sought. Rather, Article 17-A states that the court *may, in its discretion,* appoint a guardian *ad litem* or the mental hygiene legal service (if the person resides in a mental hygiene facility), to recommend whether the appointment of a guardian is in the best interest of the PWIDD.[45]

In addition, Article 81 specifically provides a party opposing guardianship with the right to cross examine.[46] Article 17-A has no similar provision.

G. Findings on the Record

Article 81 provides that in order to appoint a guardian of the person and/or property, the court must make specific findings on the record.[47] Even with the consent of the alleged incapacitated person, the court must still find on the record the person's functional limitations, necessity for a guardian to deal with those limitations, the specific powers granted to the guardian, and the duration of the appointment.[48] Additional findings are required when there is no consent. These findings must show, on the record, that the petitioner has met its burden, by clear and convincing evidence; that the alleged incapacitated person lacks understanding and appreciation of the nature and consequences of his or her functional limitations; and the likelihood of harm resulting from the lack of understanding and appreciation. Furthermore, the findings must show the specific powers granted to the guardian, and that the powers are the least restrictive form of intervention necessary.[49] Article 17-A has no provision requiring findings on the record. In fact, there can be no record of findings if there is no hearing in an Article 17-A proceeding, as can be the case.

H. Qualifications of Guardian

Article 81 provides detailed provisions regarding who should be appointed as guardian, including the alleged incapacitated person's preferences and/or nomination.[50] The court must consider the social relationship between the proposed guardian and the alleged incapacitated person, and between the proposed guardian and "other persons concerned with the welfare of the incapacitated person."[51] The court must further consider the care and services being provided to the incapacitated person,[52] the unique requirements and needs of the incapacitated person,[53] and whether there are any conflicts of interest between the incapacitated person and the proposed guardian.[54] Article 17-A has no provisions with regard to what specific considerations are to be taken into account by the court if a guardian is to be appointed.

I. Guardian's Powers – Plenary v. Tailored

One of the most controversial issues with Article 17-A guardianships is that the statute provides that upon the diagnosis and "best interest" finding, the Surrogate's only remedy is to appoint a plenary guardian, thus removing that individual's legal right to make decisions over one's own affairs and vesting in the guardian "virtually complete power over such individual."[55] Specifically, the statute provides that "if the court is satisfied that the best interests of the intellectually disabled person or developmentally disabled person will be promoted by the appointment of a guardian of the person, or the property, or both, *it shall make a decree naming such person or persons as guardians*."[56] Article 17-A does not require the Surrogate to consider "least restrictive alternatives" and it does not provide for a limited or tailored guardianship. This was illustrated in *In re Chaim A.K.*, where the court found that although the person for whom guardianship was sought may have required a guardian to make medical decisions, he did not need, nor was it appropriate, to appoint a guardian "with total, unfettered power over his life, the only choice available under 17-A."[57]

On the other hand, Article 81's provisions show a strong preference against a plenary guardianship, and appear to favor a more closely tailored guardianship designed to meet the specific functional limitations that might result in harm to the incapacitated person. The statute specifically states that if the court has found the person to be incapacitated and that the appointment of guardian is necessary, "the order of the court shall be designed to accomplish the least restrictive form of intervention by appointing a guardian with powers limited to those which the court has found necessary to assist the incapacitated person in providing for personal needs and/or property management."[58] Furthermore, Article 81 imposes an obligation on the guardian to "afford the incapacitated person the greatest amount of independence

and self-determination with respect to personal needs and/or property management—in light of that person's wishes, preferences and desires…."[59] In fact, Article 81 specifically provides that a person for whom a guardian is appointed "retains all powers and rights except those powers and rights which the guardian is granted."[60] In addition, Article 81 provides for single purpose transactions as an even less restrictive means than appointing a full guardian.[61]

J. Reporting and Review

Article 17-A only requires that the guardian of the property file a yearly report with regard to the person under guardianship's finances.[62] A guardian of the person is not required to file any report or provide any information about the well-being of the person under guardianship, or whether there is any continuing necessity for a guardian. This lack of monitoring is a violation of the PWIDD's constitutional rights. Without periodic review, there is no way for the court to know if the guardianship is still necessary, or if it should be terminated or modified (if allowed), or whether it continues to serve the PWIDD's best interests.[63] In light of today's longer life expectancies and advances in medical knowledge, and where the appropriate treatment is likely to change frequently, "the absence of any continuing judicial oversight raises another red flag about the suitability of Article 17-A."[64] As one court held, in the absence of periodic reporting and review, Article 17-A is unconstitutional, and the Surrogate administratively imposed the requirement of yearly reporting on all guardians of the person in that court.[65]

By contrast, Article 81 provides detailed reporting requirements for guardians of both the person and property, including an initial report, to be filed within 90 days of the issuance of a commission to the guardian,[66] and annual reports thereafter,[67] which are reviewed by court examiners. These reports describe "the social and personal services that are to be provided for the welfare of the incapacitated person"[68] and information concerning the social condition of the incapacitated person, including the social and personal services currently utilized by the incapacitated person, and the social skills and social needs of the incapacitated person.[69] In addition, Article 81 requires court-appointed guardians to visit the person under guardianship a minimum of four times per year.[70]

K. Termination or Modification of Guardianship

Article 81 recognizes that a person's functional capacity or incapacity can change and therefore, specifically provides for modification or termination of a guardian's powers.[71] Under Article 81, there is a broad range of persons who can initiate a proceeding for modification or termination, including "the guardian, the incapacitated person, or any person entitled to commence a proceeding under this article."[72] A hearing is required, and a jury trial is available on demand by the incapacitated person and his or her counsel.[73] Where the relief sought is termination of the guardianship, the party opposing such relief must prove, by clear and convincing evidence, that the grounds for guardianship continue to exist.[74] These provisions illustrate Article 81's principle of least restrictive intervention.

Unlike Article 81, Article 17-A fails to recognize that PWIDD's functional capacities can change and that a guardian may no longer be needed. The statute provides for the presumptive continuation of the guardianship for the entire life of the person, unless terminated by the court.[75] Article 17-A does permit modification "to protect the intellectually disabled or developmentally disabled person's financial situation and/or his or her personal interests."[76] This provision, however, is typically used only to replace one family member guardian with another.[77] Moreover, the statute does not indicate who has the burden of proof or the proof needed in order to terminate the guardianship. Hence, many Surrogate courts place the burden on the moving party. Applications brought by a person under guardianship for termination of guardianship appear to be rare.[78]

"Unlike Article 81, Article 17-A fails to recognize that PWIDD's functional capacities can change and that a guardian may no longer be needed. The statute provides for the presumptive continuation of the guardianship for the entire life of the person, unless terminated by the court."[75]

Constitutional Challenges to Article 17-A

The Fifth and Fourteenth Amendments of the U.S. Constitution provide that neither the federal nor state government shall deprive any person "of life, liberty, or property without due process of law." Fundamental liberty interests protected by the U.S. Constitution include "not merely freedom from bodily restraint but also the right of the individual to contract, to engage in any of the common occupations of life, to acquire useful knowledge, to marry, establish a home and bring up children … and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men."[79] In cases involving deprivation of personal liberty, courts are required to impose only the

least restrictive form of intervention consistent with the clinical condition of a given individual.[80]

Unlike Article 81, Article 17-A lacks constitutionally protected procedural guarantees such as a right to a mandatory hearing; a right to be present at the hearing; a right to call witnesses and cross-examine; a right to a higher standard of burden of proof, specifically, the standard of clear and convincing evidence; a right to conclusive findings on the record; a right to routine reporting and review; a right to a proper and justified means for modification and/or termination of guardianship; and most importantly, a right to the least restrictive means of intervention, which should include tailored powers to a guardian, if a guardian is needed.

Substantive due process has been understood to include a requirement that when the state interferes with an individual's liberty on the basis of its police power, it must utilize the least restrictive means available to achieve its goal of protecting the individual and the community.[81] New York has embraced this idea of least restrictive alternatives. For example, in *Kesselbrenner v. Anonymous*, the court stated that "to subject a person to a greater deprivation of his personal liberty than necessary to achieve the purpose for which he is being confined is, it is clear, violative of due process."[82] This was the rationale behind the enactment of Article 81 where the Law Revision Commission described the goal of the statute as "requiring a disposition that is the least restrictive form of intervention."[83]

By contrast, Article 17-A is unnecessarily broad. Article 17-A's imposition of a plenary guardianship of the person and/or property which terminates all decision-making authority, without an assessment of the person's functional abilities and without narrowly tailoring the guardian's powers, serves no compelling government interest. In addition, there is no compelling or legitimate government interest for applying more protections for appointment of a guardian in an Article 81 proceeding than in an Article 17-A proceeding.

Attempts to Reform Article 17-A

In 2013, New York's Olmstead Cabinet issued a report concluding that Article 17-A's diagnosis-driven basis for appointing a guardian, rather than a basis requiring review of the functional capacity of the person with disability, did not comport with the State's responsibility under the American with Disabilities Act, and thus, the Olmstead Cabinet recommended that Article 17-A be amended to include an examination of the functional capacity and consideration of choice and preference in decision making.[84] To date, Article 17-A has not been so amended.

During the 2017 legislative session, several bills were presented to reform Article 17-A, but none of them passed.[85] A common theme in the proposed bills were provisions guaranteeing that a guardian will only be appointed when the respondent shows significant specific intellectual functioning impairments; thus, requiring the court to conduct an inquiry into the person's actual abilities before a guardian is appointed.[86] The proposed measures also require that petitioners affirmatively plead that alternatives to guardianship, such as advance directives, service coordination and other shared/supported decision-making models, were considered, and identified.[87] Furthermore, the proposals call for the right of all respondents to a hearing and representation by counsel, either by the respondent's choosing, or by Mental Hygiene Legal Service, or by other court-appointed counsel.[88]

A. Least Restrictive Means

As the U.S. Supreme Court held in *Jackson v. Indiana*, where personal liberty is being deprived, courts must apply only the least restrictive form of intervention consistent with the clinical condition of a given individual.[89]

As Article 81 provides, alternate, least restrictive legal means should be examined in all guardianship cases before a guardian is deemed necessary. Legal tools, such as powers of attorney, may be utilized to handle financial matters, and advance directives, such as a health care proxy, may be utilized to allow family members to make medical decisions for the PWIDD when he or she is no longer able to do so.[90] Furthermore, services are provided by the Office for People with Developmental Disabilities to support individuals with intellectual disabilities. These alternative resources enable persons with disabilities to maintain as much control over their own life decisions as they are capable to make in the least restrictive setting.[91]

B. Supported Decision-Making

There has been a movement away from the traditional guardianships involving substituted decision-making to more supported decision-making guardianships allowing the a person alleged to be in need of a guardian to retain autonomy and self-determination. In fact, support systems may be so beneficial and helpful to PWIDD that they may eliminate the need for a guardian. Such was the case in *In re Dameris L.* where the court terminated an Article 17-A guardianship on the finding that a support network had developed around the person under guardianship such that she was able, with their support, to make her own decisions, thus, no longer needing a guardian.[92] The *Dameris* court held that:

> [T]o avoid a finding of unconstitutionality, N.Y. Surr. Ct. Proc. Act. § 17-A must be read to require that supported decision making must be explored and exhausted before guardianship can be imposed or, to put it another way, where a person with an intellectual disability has the "other resource" of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian.[93]

Also, 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.[94]

As one court stated, guardianship "may be granted only if it is the least restrictive alternative to achieve the goal of protecting a person with a mental disability."[95] This was proven in *In re D.D.*, where the court denied the petitioners, the mother and the brother of the person for whom guardianship was sought, guardianship based on the fact that the person for whom guardianship was sought was benefiting from a network of supported decision-making which had "yielded a safe and productive life where he ha[d] thrived and remained free from the need to wholly supplant the legal right to make his own decisions."[96] The *D.D.* court found that guardianship was not the least restrictive means to address the needs of the person for whom guardianship was sought, where the presence of supported, instead of substituted, decision-making was available.[97]

Conclusion

Article 17-A was enacted with the intent to provide protection for PWIDD who were viewed as vulnerable persons in our society. However, as discussed herein, the statute's provisions are outdated and infringe on the constitutional rights of PWIDD. The statute requires extensive reform in order to be constitutionally sound. The time has come for plenary guardianships with unlimited duration to end, and for PWIDD to have equal rights and to participate in our society on an equal basis. Ideally, reform to Article 17-A will result in a reduction of guardianship filings and will promote exploration and use of alternatives to guardianship, with the idea of preserving the constitutional rights of PWIDD.

Endnotes

1. The term "intellectual disability" has replaced the term "mental retardation" in New York (*see* 2010 N.Y. Laws ch. 168; 2011 N.Y. Laws ch. 37).
2. N.Y. Surr. Ct. Proc. Act § 1750.
3. *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).
4. *See generally*, Janice Brockley, *Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History*, in Mental Retardation in America, 130 (Steve Noll & James Trent, Jr. eds. 2004).
5. *See* Rose Mary Bailly & Charis B. Nick-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Alb. L. Rev. 807, 817-19 (2012).
6. 1989 N.Y. Sess. Laws 675 § 2 (McKinney).
7. N.Y. Surr. Ct. Proc. Act § 1750-a.
8. *Id*.
9. N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-a.
10. *Id*.
11. *Id*.
12. *See* Bailly & Nick Torak, *supra* note 5, at 807, 821-25.
13. *See In re D.D.*, 50 Misc.3d 666 (Surr. Ct. Kings Cnty. 2015).
14. *Id.*
15. L 1990, ch 516, § 1, reprinted in McKinney's Consol. Laws of N.Y., Book 58A, SCPA 1750, Historical and Statutory Notes at 427 (2011 ed.).
16. *Disability Rights N.Y. v. State of N.Y.*, No. 1:16-cv-07363 AKH (S.D.N.Y. Aug. 16, 2017). Complaint available at http://www.new.drny.rg/docs/art-17a-lawsuit.pdf.
17. Sheila E. Shea and Carol Pressman, *Guardianship: A Civil Rights Perspective*, NYSBA Journal 19, 22 (February 2018).
18. *In re Dameris L.*, 38 Misc3d 570, 577-78 (Surr. Ct. N.Y. Cnty. 2012).
19. Bailly, Practice Commentary, McKinney's Consol. Laws of N.Y., Book 34A Mental Hyg. § 81.01.
20. N.Y. Mental Hyg. Law § 81.01.
21. *See* Karen Andreasian, et al., *supra* note 3.
22. *Id*.
23. *See* Rose Mary Bailly, Practice Commentaries McKinney's Consol. Laws of N.Y. Book 34A, Mental Hyg. Law § 81.01, p. 9, *citing* Strauss, *Before Guardianship, Abuse of Patient Rights Behind Closed Doors*, 41 Emory L. J. 761, 763 (1992).
24. N.Y. Mental Hyg. Law § 81.08(3).
25. N.Y. Mental Hyg. Law § 81.08(4).
26. N.Y. Mental Hyg. Law § 81.08(5).
27. N.Y. Surr. Ct. Proc. Act § 1752.
28. N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-a.
29. N.Y. Mental. Hyg. Law § 81.09.
30. *Id*.
31. N.Y. Surr. Ct. Proc. Act § 1754(1) (emphasis added).
32. "[A] person who is developmentally disabled is a person who has been certified by one licensed physician and one licensed psychologist, or by two licensed physicians…" N.Y. Surr. Ct. Proc. Act § 1750-a.
33. "In reading its determination the Court shall give primary consideration to the functional level and functional limitations of the person." N.Y. Mental Hyg. Law § 81.02(c).

34. N.Y. Mental Hyg. Law § 81.02(a)(b)(1)-(2).
35. N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-a.
36. N.Y. Mental Hyg. Law § 81.11(a).
37. N.Y. Surr. Ct. Proc. Act. § 1754(1).
38. N.Y. Mental Hyg. Law § 81.11(2).
39. N.Y. Surr. Ct. Proc. Act § 1754(3).
40. N.Y. Mental Hyg. Law §81.12(a).
41. N.Y. Surr. Ct. Proc. Act § 1754(5) (emphasis added).
42. *In re Jonathan Alan Mueller*, 25 Misc.3d 165, 166 (Surr. Ct., Dutchess Cnty 2009).
43. N.Y. Mental Hyg. Law § 81.10(a).
44. N.Y. Mental Hyg. Law § 81.10(c).
45. Surr. Ct. Proc. Act § 1754(1) (emphasis added).
46. N.Y. Mental Hyg. Law § 81.11(b)(3).
47. N.Y. Mental Hyg. Law § 81.15.
48. N.Y. Mental Hyg. Law §§ 81.15(a)(2-5).
49. N.Y. Mental Hyg. Law §§ 81.15(b)(2-3), (5).
50. N.Y. Mental Hyg. Law § 81.19.
51. N.Y. Mental Hyg. Law § 81.19(d)(2).
52. N.Y. Mental Hyg. Law § 81.19(d)(3).
53. N.Y. Mental Hyg. Law § 81.19(d)(7).
54. N.Y. Mental Hyg. Law § 81.19(d)(8).
55. *In re Mark C.H.*, 28 Misc3d 765, 776 (Surr. Ct. N.Y. Cnty 2010).
56. N.Y. Surr. Ct. Proc. Act § 1754(5) (emphasis added).
57. 26 Misc.3d 837, 847 (Surr. Ct. NY Cnty 2009).
58. N.Y. Mental Hyg. Law § 81.16(c)(2).
59. N.Y. Mental Hyg. Law § 81.20(6)(1), (7).
60. N.Y. Mental Hyg. Law § 81.29(a).
61. N.Y. Mental Hyg. Law § 81.16.
62. N.Y. Surr. Ct. Proc. Act §§ 1761, 1719.
63. *In Re Chaim A.K.*, 26 Misc.3d 837, 847 (Surr. Ct. NY Cnty 2009).
64. *Id*. at 848.
65. *In Re Mark C.H.*, 28 Misc.3d 765 (Surr. Ct. N.Y. Cnty 2010).
66. N.Y. Mental Hyg. Law § 81.30(b).
67. N.Y. Mental Hyg. Law § 81.31.
68. N.Y. Mental Hyg. Law § 81.30(c)(2).
69. N.Y. Mental Hyg. Law § 81.31(b)(6)(iv).
70. N.Y. Mental Hyg. Law § 81.20(a)(5).
71. N.Y. Mental Hyg. Law § 81.36.
72. N.Y. Mental Hyg. Law § 81.36(b).
73. N.Y. Mental Hyg. Law § 81.36(c).
74. N.Y. Mental Hyg. Law § 81.36(d).
75. N.Y. Surr. Ct. Proc. Act § 1759.
76. N.Y. Surr. Ct. Proc. Act § 1755.
77. *See, e.g., In re* Garrett YY, 258 A.D.2d 702 (3d Dept. 1999).
78. *In re* Mark C.H., 28 Misc.3d 765, n.28 (2010).
79. *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923).
80. *Jackson v. Indiana*, 406 U.S. 715, 738 (1972).
81. *O'Connor v. Donaldson*, 422 U.S. 563, 95 S.Ct. 2486, 45 L.Ed.2d 396 (1975).
82. 33 N.Y.2d 161, 165, 350 N.Y.S.2d 889, 305 N.E.2d 903 (1973).
83. Law Revision Commission Comments, 34 A. McKinney's Consol. Laws of N.Y. §81.03.
84. http://www.governor.ny.gov/sites/governor.ny.gov/files/archive/assets/documents/olmstead-cabinet-report101013.pdf.
85. *See* N.Y. Assembly Number 8171(2017), N.Y. Assembly Number 5840 (2017), N.Y. Senate Number 5842 (2017).
86. Sheila E. Shea and Carol Pressman, *Guardianship: A Civil Rights Perspective*, NYSBA Journal 19, 23 (February 2018).
87. *Id*.
88. *Id*.
89. 406 U.S. 715, 738 (1972).
90. *In re D.D.*, 50 Misc.3d 666 (Surr. Ct. Kings Cnty 2015).
91. *Id*.
92. 38 Misc.3d 570 (Surr. Ct. N.Y. Cnty 2012).
93. *Id*.
94. 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) www.americanbar.org/content/dam/aba/directories/policy/2017_am_113.docx.
95. *In re Guardian for A.E..*, NYLJ, Aug. 17, 2015 at 22, col 4 (Surr. Ct. Kings Cnty 2015).
96. *In re D.D.*, 50 Misc3d 666 (Surr. Ct. Kings Cnty 2015).
97. *Id*.

2020 Law Student Writing Competition

Sixth Annual *Elder and Special Needs Law Journal* Writing Competition

The Elder Law and Special Needs Section of the New York State Bar Association continues to strive to achieve a diverse membership body, in hopes of fostering a rich environment within which ideas are cultivated. The current President of the New York State Bar Association, Hank Greenberg, as well as our own Section Chair, Tara Anne Pleat, firmly endorse the cultivation of a diverse atmosphere, as it is necessary to the ongoing success of the Section, the Association, and the bar as a whole.

To further this initiative, we are pleased to announce the Sixth Annual *Elder and Special Needs Law Journal* Writing Competition, for all students attending an accredited ABA law school within New York State. The winners of the Competition will be guaranteed publication within the New York State Bar Association's Elder and Special Needs Law Journal (ESNLJ) in addition two prizes of $1,000 each to the top two entries, and complimentary one-year membership in the ESNL Section (mentioned in the flyer). There will be up to two (2) winners chosen by the ESNLJ's editorial board.

Prior winners have been invited to the Fall Meeting of the Elder Law and Special Needs Section where they were presented with their prize and a copy of the ESNLJ with their published articles. The requirements of the Sixth Annual *Elder and Special Needs Law Journal* Writing Competition are as follows:

- Your article MUST be based on a pertinent topic within the elder and/or special needs law field(s), two historically underserved and diverse populations.
- The article MUST be submitted in the form of a Word document. Please do not use Word Perfect or .docx, since our editing staff does not have tools to support such formats. If you plan on converting your document, please check your formatting.
- Bold the title of your article, include your name directly underneath, single space the text and double space between paragraphs.
- Indent the first line of the paragraph 0.5 (under "Paragraph" see "Special" and choose first line option). All other margins (i.e. right and left margins) should measure "1.0." The NYSBA will re-configure your article for two columns, as per the format of the *Elder and Special Needs Law Journal*; as a result, you need not do so.
- If your article warrants the use of an organizational structure, then please employ A, B, C… for headings, separating the text and bolding the headings. Subheadings should then read as follows: 1, 2, 3… and sub-subheadings a, b, c…. Should you choose to utilize bullet points, numbering, or lettering throughout your article please do so consistently.
- It is important that your source materials, non-original ideas, and references, etc. must be accurately attributed and in the appropriate Bluebook format.
- The article should contain endnotes. Please utilize the automatic endnote function within Word, because it allows for easy editing. Use Arabic numerals (1, 2, 3…).
- Please include a short biography along with your article of about 500 words, as well as a copy of your most recent working resume. Also include a photo of yourself, so that it may appear alongside your article in either the format of a JPEG or TIF file. If you do not wish to include your photo, please state such on a separate piece of paper, as it is not required.
- Each of your submissions must be fully complete, and you may not re-edit, or send additional information subsequent to receipt by the editorial board.
- Submitted articles are due by **March 15, 2020**, and no extensions will be granted.

Please E-MAIL your submissions to BOTH of the following addresses:

jseminara@gylawny.com

-AND-

kimtrigoboff.esq@gmail.com

If you wish to MAIL your submissions, please mail them to BOTH:

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The editorial board of the *Elder and Special Needs Law Journal* is excited to read your articles, and the Elder Law and Special Needs Section is eager to include a new and diverse group of soon-to-be attorneys within its current dialogue. Should you have any questions or concerns regarding the Sixth Annual *Elder and Special Needs Law Journal* Writing Competition, please contact the ESNLJ Assistant Production Editor, Lauren Enea, at the following email address: l.enea@esslawfirm.com.

Good luck!
Joanne and Kim

Member Spotlight: Deborah Slezak

Interview by Katy Carpenter

Q Where are you from?

A Amsterdam, New York.

Q Tell me about your family.

A I am one of eight children in my family of origin (6th). My parents did not go to college, so they were adamant that their children go to college. They achieved their goal and all eight of us graduated from college and three of us have advanced degrees. My parents are very proud of all of us.

I am married with three kids and my husband and I live in Hagaman, N.Y. with our children and two dogs. Hagaman is about three miles from where I grew up.

Q Have you had any turning points in your life?

A Going to law school! I never expected to be an attorney. In college I majored in English and my plan was to be an English professor. When I graduated, my first job was as a mortgage officer and I knew that I did not want to be a mortgage officer forever. I had a colleague who talked me in to taking the LSATs with him—we both took it and I went to law school and he did not. We still laugh about it, but he is very happy he did not pursue law school as he is now a vice president with the mortgage firm we had worked at.

Q What led you from real estate to a career practicing in the area of Elder Law?

A It was one client (now deceased): I had been sent to her home to supervise the execution of a Power of Attorney. We started talking about her husband and that led me to helping her obtain Medicaid coverage for her husband. My relationship with her and helping her through began my love for elder law. I enjoy hearing my clients' stories. Every case is different, and I am always learning something new.

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

A I had a difficult case with a young client with frontal temporal lobe dementia. The nursing home was trying to evict him and have him transferred to a home in Massachusetts. Through a series of difficult hearings, we were able to keep him local. This was not an easy lift and the family was so grateful for the advocacy.

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

A I wanted to be three things: a scientist, a cake decorator or a hairdresser. I always believed my creativity would come through in my career and now I use it to solve problems for clients.

Q Do you have any advice for young attorneys?

A Be brave without being foolish: do not be afraid to try something.

I was only a year out of law school when my mentor, Howard Carpenter, Esq., recommended that I interview for the position of Town Attorney in Amsterdam. I served from 1996-2008 and learned so much about municipal law and land use. I went on to be the Town Justice for the Town of Amsterdam from 2008-2016. I also currently serve as the Town Attorney for the Town of Florida, which I find to be an interesting and fulfilling position.

If I had never gone for that interview as a young attorney these other opportunities may have never presented themselves. So my advice: take a chance and grow a little.

Q What is your passion outside of work and the law?

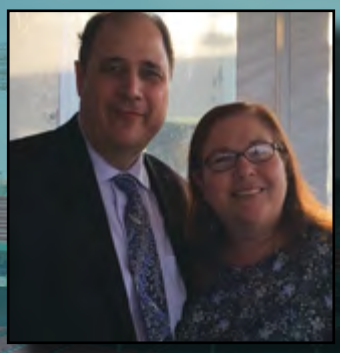
A Being an advocate for the elderly and for those with special needs. I am on the Boards of the Montgomery County's Office for the Aging as well as Liberty ARC. Liberty ARC is special to me and my family as they were my son, Luke's, Medicaid service coordinator. Both of my sons were also part of the Boy Scouts of America, and I continue to volunteer there as well.

Summer Meeting 2019

The Elder Law and Special Needs Section held its annual Summer Meeting July 18 - 20 in Boston, Massachusetts.

New England Aquarium

Fenway Park



Pub Crawl

The Forgotten Facility: The Need to Strengthen New York's System of Response to the Abuse and Neglect of Individuals with Intellectual and Developmental Disabilities

By Lindsay Webb

In a report released by NPR, *The Sexual Assault Epidemic No One Talks About*, investigators reviewed unpublished data by the Justice Department and discovered that individuals with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities. The report goes on to detail the difficulties faced in detecting and prosecuting these crimes.[1] The focus of the investigation was on sexual assault and does not specifically address the multitude of ways that individuals with intellectual disabilities may be victimized—these include physical, emotional, and verbal abuse as well as financial exploitation.

It is difficult for victims of abuse and neglect to leave their abusers for a variety of reasons. Within marriages, for example, reasons for staying may include children, family, friends and financial obligations. In cases involving children who are victimized, the abuser may be the primary caregiver, or is knowingly allowing the abuse to occur by another party, while the caregiver is at the same time legally responsible for the child. In romantic relationships, domestic violence is often described within the Cycle of Abuse. Victims go from periods of tension building, to incidents of abuse, victim blaming, reconciliation and finally a period of calm or a "honeymoon" before the cycle repeats.[2] The *2012 Survey on Abuse of People with Disabilities* was the first national survey to poll advocates, family and individuals with disabilities on their experiences with abuse and neglect. The survey factored in various types of abuse including verbal or emotional, physical, sexual, financial abuse and neglect. According to the study, over 70% of people with disabilities who took the survey reported that that they had been a victim of abuse. And 66.5% of individuals with a diagnosis of autism reported abuse while another 62.5% of individuals with an intellectual or developmental disability reported that they had also been a victim of abuse.[3]

Despite the tremendous hurdles a victim of abuse must face, he or she has the right to break free from such a cycle and seek the supports needed to successfully do so. New York has laws requiring mandated reporting of child abuse and involvement of Child Protective Services (CPS).[4],[5] In New York, adults who lack the cognitive capacity to protect themselves from abuse or neglect may be eligible for services through Adult Protective Services (APS).[6] Additionally, the Protection of People with Special Needs Act[7] governs the reporting and review of instances of abuse, neglect and mistreatment in programs in various state-run and certified agencies including in programs certified by the Office for Persons with Developmental Disabilities (OPWDD).[8] Every individual should have the equal right to actively or passively receive services to assist them in breaking free from abuse and neglect. Unfortunately, persons with intellectual or developmental disabilities (I/DD) who are not recipients of specific OPWDD services are not afforded the same protective scope of oversight which New York has established for other vulnerable individuals. This article will focus on the lack of adequate and organized response to the abuse and neglect of individuals with intellectual and developmental disabilities who are not receiving distinct services through OPWDD. Abuse and neglect cases of individuals residing in private homes in the community are often the cases that fail detection, proper investigation and adequate follow-up. Moreover, abuse at the hands of a legal guardian poses its own additional hurdles in adequately safeguarding the victim. It is arguable that the failure of a state to intervene by continuing to allow a legal guardian, granted authority and power by a Surrogate's Court, to abuse a ward amounts to a violation of the Americans with Disabilities Act.[9]

Lindsay Webb

New York's Mental Hygiene Law Section 16.19 (hereafter MHL 16.19) addresses the Commissioner of OPWDD's responsibility to investigate and take action in order to protect individuals with I/DD from abuse, neglect and mistreatment in general.[10]

> MHL 16.19 (a). *No individual who is or appears to have a developmental disability shall be*

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Special thanks to Lee A. Hoffman, Jr., Esq., of Hoffman & Keating and our Board of Editors, for his contributions to the preparation of Ms. Webb's article.

detained, deprived of liberty or otherwise confined without lawful authority, or inadequately, unskillfully, cruelly or unsafely cared for or supervised by any person.

(b) *If the commissioner has reason to believe that a person is being detained or given inadequate, unskillful, cruel or unsafe care, as described in subdivision (a) of this section, he shall promptly investigate the matter…*

(c) In addition to any other remedies available under this article, the commissioner may bring an action in the supreme court to enjoin any person from unlawfully subjecting a person with a developmental disability to physical, sexual, or emotional abuse, or active, passive or self neglect, or detaining a person with a developmental disability or providing inadequate, unskillful cruel or unsafe care or supervision for such a person.

If the victim of abuse or neglect receives services by OPWDD, or by providers of services authorized by the Commissioner of OPWDD, such as a non-profit, then it is incumbent upon those parties to act to safeguard the individual. Providers of OPWDD certified services (an "agency") required to safeguard the individual include those offering day or community habilitation, care coordination, clinic services or other Home and Community Based Medicaid Waiver Services.[11] 14 N.Y.C.R.R. 625.3 (hereafter 625.3) addresses incidents occurring outside of the auspices of the provider agency itself; for example, within a private home.[12] These incidents may become known to service providers and are thus required to be reported and potentially investigated by the discovering agency. The regulations spell out the duties of the agency to report to law enforcement or APS/CPS when appropriate or mandated, to interview the victim and witnesses, to assess and monitor the individual, and to refer for services. All incidents upon which agencies act pursuant to 625.3 are reportable to OPWDD.[13] MHL 16.19 indicates that a case shall be referred to Adult Protective Services if the individual is *not* known to the Commissioner of OPWDD as having received OPWDD services.[14]

MHL 16.19 (d) (1). *If, upon receiving a report that any adult thought to have a developmental disability has been subjected to physical, sexual, or emotional abuse, or active, passive or self neglect, and the commissioner has reason to believe that such adult is known to the commissioner to have received services from providers duly authorized by the commissioner and has been subjected to such abuse or neglect, the commissioner shall intervene pursuant to this section, or, if such adult has not received services from said authorized providers, the commissioner shall, immediately, or as soon as practicable, notify adult protective services…*

Additionally, 625.3 (d) (3) indicates the agency shall notify APS of abuse or neglect when *"the individual is in need of protective services the agency cannot provide."* These services may include petitioning for an Order of Protection, guardianship, or a court order authorizing involuntary protective services.[15] For example, in the case of a young man with disabilities residing in a home occupied by hoarders which is infected with insects and rodents and whose guardian will not permit assess to the home, APS may be able to act to obtain a court order permitting access to the home.

MHL 16.19 requires that OPWDD and Office of Children and Family Services (OCFS) develop and maintain a Memorandum of Understanding (MOU) which outlines the duties and responsibilities of each entity. These MOUs are created and maintained by local APS units within Department of Social Services agencies and Developmental Disabilities Regional Offices within the OPWDD system.[16] Some counties in New York can readily furnish a copy of the MOU between DSS and local OPWDD offices while other counties may not be able to. This writer has encountered both situations.

MHL 16.19 (d) (2). In order to carry out the provisions of this subdivision, the commissioner and commissioner of the office of children and family services (OCFS) shall develop a model memorandum of understanding which shall be entered into between each developmental disability services office[17] and each local department of social services within its jurisdiction. Such agreement shall define the responsibilities of each developmental disabilities services office and social services district with respect to reports pursuant to paragraph one of this subdivision and reasonable time frames for implementing such responsibilities.

Reports made pursuant to MHL 16.19 concerning incidents of abuse or neglect are to be formally sent within 48 hours to the New York State Justice Center for the Protection of People with Special Needs.[18] [19] In addition, an annual report by OPWDD and OCFS highlighting statistics and cases falling under the MOU requirement had previously been submitted to the Governor, Senate and Assembly pursuant to *Chapter 536 of the Laws of New York 2005 and Chapter 356 of the Laws of New York 2006.*[20],[21] When New York passed the Protection of People with Special Needs Act in 2012,[22] which created the New York State Justice Center, the annual reporting requirement was initially maintained within 16.19 and the Justice Center was charged with assisting OPWDD and OCFS in the creation of the annual report.[23] That annual reporting requirement has subsequently vanished from the law and the language removed from MHL 16.19.[24]

Hospitals, law enforcement agencies and other human service professionals may attempt to contact Adult

Protective Services when they encounter a victim of abuse or neglect with I/DD. However, if the individual is known to OPWDD, Adult Protective Services will refer the case back to the provider agency or OPWDD for investigation and follow-up. For example, consider the case of a young intellectually disabled woman who is found to be pregnant by her primary care physician and who lacks the ability to consent to sexual activity. She is a refugee from another country and is residing with relatives in the United States. The case is initially investigated by APS until the young woman is found eligible for OPWDD services. However, the implementation of such services is delayed as the family is reluctant to allow strangers such as a care manager into the home. Law enforcement fails to conduct an adequate investigation due to the assumption they will be unable to communicate with the young woman and because the family member refuses police involvement. APS closes their investigation once the woman is eligible for OWPDD services. The case is not investigated or further acted upon until an OPWDD certified agency eventually becomes involved with the family almost a year later and follows up on the case upon a report of facial bruising by a school nurse. The young woman may have been continuously abused or mistreated during the time when there was a lapse in services.

"If the victim of abuse or neglect receives services by OPWDD, or by providers of services authorized by the Commissioner of OPWDD, such as a non-profit, then it is incumbent upon those parties to act to safeguard the individual."

In 2012, OPWDD's Developmental Disabilities Regional Office, Region 2 (DDRO) in Syracuse, New York,[25] created a Crisis Mitigation Team in part to address the need for a more proactive response to abuse and neglect in community settings. The team consists of staff that investigate incidents of abuse and neglect in the community. Prior to 2012, the Crisis Mitigation Team was being developed by one passionate social worker employed at OPWDD and could only provide services within Onondaga County. The team eventually grew to expand to cover all eight counties that the DDRO Region 2 office provides services to.[26] The team currently employs three staff with duties very similar to Adult Protective case workers. They may assist an individual or family in obtaining needed OPWDD services or provide respite or residential opportunity referrals. They offer assistance to provider agencies which may lack the adequate resources or training in order to carry out the duties outlined in 14 N.Y.C.R.R. 625.3. The team may collaborate with APS in cases where the MOU may mandate such involvement. The Crisis Mitigation Team is unique to part of Central New York as it was initially created by one since retired employee. This writer is unaware of any other existing similar models throughout New York. If we look back at the unpublished DOJ statistics in the NPR investigation[27] as well as the statistics in the report on the 2012 National Survey of People with Disabilities,[28] we see that the rate of abuse within this population of individuals is of concern. There remain various ways an incident may escape proper investigation and adequate follow-up. Unfortunately, with the abolition of the annual reporting requirement in MHL 16.19, there is virtually no recent data to review for New York's response to its most vulnerable and no appreciable way to monitor the effectiveness of the MOUs between APS and OPWDD across various counties in New York. Along with the repeal of the reporting requirement, the Justice Center was absolved of its duty under MHL 16.19 to *"receive and review reports required pursuant to 16.19 and take any action as required by law."*[29]

The Justice Center retains legal counsel as well as investigators throughout New York who are responsible for investigations of incidents in various programs including those certified by OPWDD. Yet there is no existing framework within the agency for investigating incidents of abuse and neglect in non-certified community settings. The Justice Center has further created Vulnerable Person Task Forces in various counties which include participants from law enforcement agencies, hospitals, DSS offices and OPWDD authorized service providers.[30] The agency is equipped to act as a community investigative liaison with various stakeholders in order to ensure proper cross-system response in cases of abuse or neglect of adults with I/DD in non-certified settings.

Another valuable resource in responding to the abuse of adults with I/DD are Child Advocacy Centers (CAC) in some counties across New York.[31] The centers act to provide a safe and secure environment in which to conduct interviews pertaining to allegations of child abuse and to offer a coordinated medical, social and legal response. Although the mission of a CAC is not centered around an adult population, the forensic interview process for individuals with I/DD may employ similar techniques to interviews used in child abuse cases. This writer has been informed that some Child Advocacy Centers have partnered with the Justice Center in some cases to offer forensic interviews.[32] Additionally, the Bivona Child Advocacy Center in Rochester was the recipient of a $75,000 grant from Golisano Children's Hospital[33] in 2015 to establish the I/DD Alliance.[34] The Alliance is a community partnership consisting of agencies within the Rochester area which work together to investigate, evaluate, treat and prevent abuse of children with I/DD.[35] Ideally, coordinated efforts to investigate and combat abuse of vulnerable adults with I/DD should be distinguished from similar efforts by stakeholders in child abuse cases. However, absent a framework for a coordinated effort in adult abuse cases, a CAC remains a valuable existing tool.

One of the largest barriers to effective advocacy and intervention is abuse by the hands of a legal guardian or the *lack* of a guardian with the legal authority to act in order to obtain necessary services. In New York, there are two distinct types of guardianships: Surrogate's Court Procedure Act 17-A (SCPA 17-A) and Mental Hygiene Law Article 81. Article 81 guardianship court orders are able to be tailored in what powers are awarded to a guardian.[36] However, here I refer to SCPA 17-A guardianships which apply to individuals with intellectual and developmental disabilities.[37] SCPA 17-A has been under scrutiny for years for granting overbroad powers to guardians by not allowing for the tailoring of the guardian's powers to the actual needs of the ward and for not containing provisions to protect the rights of the individual or to monitor many of the activities of the guardian.[38],[39] For example, consider the case of a guardian with a history of alcohol abuse which results in a medical crisis requiring his hospitalization and a subsequent stay at an in-patient physical rehabilitation facility. The guardian is responsible for caring for his autistic son who is non-communicative. The son initially accompanies dad to the hospital. Unfortunately, dad refuses to consent to even a temporary respite placement for his son during the period when he is unable to care for him. As a result, the son remains living in a hospital room with no medical reason for his continued hospital stay for several weeks as the hospital is left without an option for safely releasing him.

It is important to note that SCPA 17-A allows for any interested party, on behalf of the ward, to petition in a guardianship proceeding.[40] It may be necessary to bring such a petition in order to remove a victim of abuse from an unsafe environment and to provide placement in an OPWDD-certified residence. Should the individual's abuser be the legal guardian, then the guardian must consent to the residential placement or the guardian removed by the court. On the other hand, a victim may be cognitively unable to consent to residential placement and may be living with a family member who is coercing the victim to stay or preventing them from leaving, necessitating the need for a guardian to be appointed.

It is not uncommon for Adult Protective Services to petition for a Mental Hygiene Law Article 81 guardianship[41] or to serve as guardian in matters involving individuals who lack decision-making capacity and need a guardian. For example, an individual with dementia who has no involved family or friends may need a guardian to establish Medicaid eligibility, manage finances, or to select appropriate services within the home or a long-term care facility. However, in cases of abuse or neglect handled by OPWDD, the ability to obtain legal counsel to petition in a SCPA 17-A guardianship matter is not as easily established. This writer has experienced variations in these cases:

In some jurisdictions APS may be willing to provide counsel for legal guardianship proceedings involving a victim who is receiving OPWDD services even though APS is not responsible for investigating the allegations of abuse or neglect pursuant to the MOU. In other instances, a county may refuse involvement and indicate that OPWDD must bring a petition in a guardianship matter. This writer has experienced that OPWDD will indicate a conflict of interest to be a petitioner as the agency either provides direct services to the victim or certifies the agency which provides such services. As such, this writer has previously asked that OPWDD consult with the New York State Attorney General's Office[42] in these matters should there be a concern for such conflict.

Another entity which may encounter victims is the Mental Hygiene Legal Service (MHLS), a legal advocacy agency housed in the New York Appellate Courts with four distinct Judicial Departments across the state.[43] The agency advocates for the rights of individuals receiving services through OPWDD and the Office of Mental Health (OMH). The agency's functions are outlined in MHL 47.01 and in 47.03.

> Pursuant to 47.01,[44] MHLS "*shall provide legal assistance to patients or residents of a facility as defined as in section 1.03*[45] *of this chapter or any other place or facility which is required to have an operating certificate pursuant to article 16*[46] *or 31*[47] *and to persons* ***alleged*** *to be in need of care and treatment in such facilities."*

MHL 47.03 (e) contains various duties and specifically outlines that the agency may "*initiate and take any legal action deemed necessary to safeguard the right of any patient or resident from abuse or mistreatment, which may include investigation into any such allegations of abuse or mistreatment."*[48]

MHL 1.03 (6) references the definition of facility as including clinics, wards, psychiatric hospitals and other physical structures but it does not *limit* the definition to such structures. MHL 1.03 rectifies the lack of its ability to encompass all facilities by instead excluding those which offer solely non-residential services and are also *exempt* from specific operating certificates including those pursuant to Article 16 of the Mental Hygiene Law (programs certified by OPWDD). MHL 16.03 outlines the programs requiring operating certificates which includes both residential facilities, clinics, and non-residential services offered through the Home and Community Based Services Medicaid waiver. The waiver program includes services offered in home and community-based settings.[49]

> MHL 1.03 (6). *"Facility" means any place in which services for the mentally disabled are provided and includes* ***but is not limited to*** *a psychiatric center, developmental center, institute, clinic, ward, institution, or building, except that in the case of a hospital as defined in article twenty-eight of the public health law it shall mean only a ward, wing, unit or part thereof which is operated for the purpose of providing services for the mentally disabled. It shall* ***not***

include a place where the ***services rendered consist solely of non-residential services*** *for the mentally disabled* ***which are exempt from the requirement of an operating certificate under article sixteen****, thirty one, or thirty two of this chapter, nor shall it include domestic care and comfort to a person in a home.*

MHLS has authority to assert jurisdiction to provide legal advocacy services in cases involving abuse and neglect of individuals residing in non-certified settings if a victim is receiving Article 16 services or is *alleged*[50] to be in need of care and treatment in a facility defined within MHL 1.03. For example, the agency may assert jurisdiction to petition to remove or modify a guardianship order for a young man with I/DD residing in a private home which his legal guardian owns. The home has no food in the cupboards, the man smears feces on the walls, and his non-residential OPWDD-certified service providers have documented the man has been removed from the hospital against medical advice and has not had proper follow-up medical care. Additionally, his guardian makes threats to "leave him" at DSS but continues to turn down residential opportunities for the man.

"One of the largest barriers to effective advocacy and intervention is abuse by the hands of a legal guardian or the lack *of a guardian with the legal authority to act in order to obtain necessary services."*

However, like OPWDD's expressed concerns about bringing 17A petitions due to a potential conflict of interest, MHLS also faces the potential for conflict in some instances that would require a guardianship petition in Surrogate's Court. The agency generally acts as counsel to the individual with I/DD and represents the individual's wishes. Some individuals may lack the ability to communicate direct opinions about a preferred course of action due to their mental disability and are thus unable to guide their attorneys in a specific course of action. As such, counsel may end up utilizing a best interest standard in representing and potentially protecting an individual with I/DD.[51]

As mentioned previously, there are a variety of reasons people may find difficulty leaving an abusive situation. It is imaginable that someone with I/DD may turn assistance away due to emotional manipulation, isolation and coercion by an abuser or even out of love for a caregiver who may simply be unable to provide adequate care for their loved one. In such situations, attorneys would bear the burden of determining whether their professional role is to advocate zealously for their clients' wishes or to act in the individual's best interests. MHLS could thus take the position that they should not be the legal entity pursuing a petition to terminate, modify or appoint a guardian in such instances. However, the agency may provide an invaluable service representing the individual as counsel once a petition has been brought. MHLS is not entirely excluded in its ability to petition in a guardianship proceeding involving a victim of abuse or neglect with I/DD should the individual request involvement or not be able to advance an opinion due to a lack of capacity and harm is being done. However, due to the potential for a conflict of interest in some cases, MHLS should not be consistently relied upon to seek guardianships or petition to modify or terminate existing guardianships.

Interestingly, one entity that does not hold a Mental Hygiene Law Article 16 Operating Certificate happens to be an office within OPWDD; the Developmental Disabilities Regional Offices (DDRO).[52] While OPWDD as an agency itself maintains state-operated Article 16 programs such as residences and clinics within their Developmental Disabilities State Operations Offices, the DDRO does not. The office houses the Crisis Mitigation Team as well as staff that identify and attempt to place individuals in residential opportunities and programs operated both by the state as well as non-profit entities offering services which are certified by OPWDD. The DDRO attempts to secure services but does not actually offer any services that require an Article 16 operating certificate. It would make sense to allow the DDRO's to have readily available access to counsel who can legally advise field staff as well as prepare any necessary court papers and attend legal proceedings—even those involving crimes against the victim and the issuance of orders of protection. Arguably, it is entirely possible that the office could go further and serve as legal guardian in a limited capacity in such matters and parallel to the role APS plays as guardian in its protective capacity.

Mental Hygiene Law 81.19 addresses eligibility of guardians in Article 81 guardianship proceedings and identifies those who shall *not* serve as guardian, including providers of certain direct or in-direct services. However, MHL 81.19 permits the court to grant an exemption in cases where the court finds that no other corporation is able to serve as guardian or is able to offer needed services to the incapacitated person.[53] Article 17-A does not address the eligibility of guardians directly. Parents and siblings are preferred guardians, but the court can refuse to appoint a family member if the evidence shows a history of inability to meet the needs of the disabled respondent.[54]

Although the DDRO provides linkages, referrals and liaison services to various OPWDD-certified services, they do not maintain any Article 16 services themselves. Furthermore, DSS is often considered a guardian of last resort and may be appointed as guardian in Article 81 proceedings.[55] MHL 81.19 authorizes the appointment as guardian of an indirect services provider absent any other available or willing guardian. At the time of writing this paper, it is not clear to this writer how the eligibility guidelines in

MHL 81.19 might be applicable in SCPA 17-A guardianships. For example, the ARC of New York, a nonprofit agency serving the needs of individuals with I/DD has a large corporate guardianship program[56] and sometimes serves as SCPA 17-A guardian for the individuals they provide services to.[57] Additionally, New York's Social Services law allows for the establishments of community guardianship programs.[58]

There are many ways an individual may receive services which would lessen the burden of decision-making for an appointed guardian of an individual with I/DD. For example, the New York State Justice Center provides Surrogate Decision-Making (SDM) services pursuant to Article 80 of the Mental Hygiene Law.[59] Individuals who are known to OWPDD may be eligible for a SDM Committee to review and grant consent for major medical procedures.[60] Further, there are committees which exist to review and provide consent to psychotropic medications as well as to monitor the appropriateness of rights restrictions within plans written for recipients of OPWDD certified services.[61]

If SCPA17-A- could be amended to permit the tailoring of a court order to fit the needs of the incapacitated person in the same manner as Article 81 allows, then such orders could be tailored to address the situations discussed in this article. The court may grant guardians the authority to authorize investigations and interventions in situations involving abuse or neglect. For example, guardianship orders would be able to grant powers to access medical and social records, pursue residential placement, establish representative payee status, pursue orders of protection, criminal charges, or civil damages and/or establish supplemental needs trusts. Not all powers would need to continue indefinitely if other available resources exist to address the needs of the ward.

New York State already retains the existing tools and resources to strengthen our systemic response to the abuse and neglect of individuals with intellectual and developmental disabilities. We simply must collaborate in our efforts to rectify a system which has forgotten that "facility" encompasses a whole range of non-residential services and that providers of such services are responsible for reporting, investigating and intervening in cases of abuse and neglect. The current laws as written leave far too many gaps in effective system response to these cases as well as too much room for ambiguity in identifying the entity or entities responsible to take legal action when indicated. The Justice Center retains in-house counsel and has existing investigation and advocacy staff. There may be room for a community-based investigations liaison and a guardianship unit within the agency. We could also look to the DDRO to serve as a potential guardian for this specific population as the office does not provide direct services so there is no provider conflict. If anything, the services offered by the Crisis Mitigation Team in these cases mirror those services which APS offers in similar cases. Additionally, New York would benefit from reinstating the annual reporting requirement in MHL 16.19, which monitored the utilization and effectiveness of Memorandum's of Understanding between DSS and OPWDD across the state of New York in efforts to address the needs of individuals with I/DD who are victims of abuse or neglect. Finally, lawmakers should consider the impact of the failure of existing laws to monitor potential abuse or neglect by guardians, who have been empowered by the courts to retain control over the decisions and daily activities of their ward. Victims of abuse and neglect with I/DD should have the same right to escape abusive guardians and should further retain the same protections and services offered to non-disabled children and adult victims of abuse and neglect.

Endnotes

1. NPR (2018). *The Sexual Assault Epidemic No One Talks About.* [podcast] Abused and Betrayed. Available at: https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about.
2. Walker, Lenore E. (1979) The Battered Woman. New York: Harper and Row.
3. Nora J. Baladerian, Thomas F. Coleman & Jim Stream, *Abuse of People with Disabilities: Victims and Their Families Speak Out. A Report on the 2012 National Survey of People with Disabilities.*
4. New York Consolidated Laws, Social Services Law - SOS § 411. Findings and purpose.
5. New York Consolidated Laws, Social Services Law - SOS § 421. Responsibility of the office.
6. New York Consolidated Laws, Social Services Law - SOS § 473. Protective services.
7. NY Exec Law § 551. The Justice Center for the Protection of People With Special Needs.
8. Office for People with Developmental Disabilities, OPWDD https://opwdd.ny.gov/opwdd_about/overview_of_agency.
9. 5 U.S.C. 301; 28 U.S.C. 509, 510; U.S.C. 12134, 12131 and 12205a.

   It is beyond the scope of this paper to dive into the issue of abuse by the hands of a court appointed guardian as being an issue that the ADA may be a remedy for.
10. New York Consolidated Laws, Mental Hygiene Law - MHL § 16.19 Confinement, care and treatment of persons with developmental disabilities.
11. 14 CRR-NY 625.3 Agency involvement in events or situations that are not under the auspices of an agency.
12. 14 CRR-NY 625.2. Events or situations that are not under the auspices of an agency. Definitions: 2) ii *Any event or situation that exclusively involves the family, friends, employers, or co-workers of an individual receiving services (other than a custodian or another individual receiving services), whether or not in the presence of agency personnel or a family care provider or at a certified site*.
13. 14 CRR-NY 625.4 OPWDD involvement in events or situations that are not under the auspices of the agency.
14. New York Consolidated Laws, Mental Hygiene Law—MHL § 16.19 Confinement, care and treatment of persons with developmental disabilities.
15. New York Consolidated Laws, Social Services Law—SOS § 473-a. Short-term involuntary protective services orders.
16. New York Consolidated Laws, Mental Hygiene Law—MHL § 16.19 (d) (2).
17. Now known as Developmental Disabilities Regional Offices.

18. New York Consolidated Laws, Mental Hygiene Law—MHL § 16.19 (d) (1).
19. Formerly known as Commission of Quality of Care and Advocacy for Persons with Disabilities and assumed by the New York State Justice Center for the Protection of People with Special Needs pursuant to NY Exec Law § 551.
20. Chapter 536 of the Laws of New York 2005 and Chapter 356 of the Laws of New York 2006.
21. NYS Office for Mental Retardation and Developmental Disabilities & NYS Office of Children and Family Services, *Progress on Implementation of the Adult Abuse Reporting Law: A Report to the Governor, Temporary President of the Senate and Speak of the Assembly* (2010).
22. Protection for People with Special Needs Act. S. 7749 A. 10721.
23. New York Consolidated Laws, Executive Law—EXC § 553. Powers and duties of the justice center.
24. Repealed by L.2013, c. 56, pt. M, § 4, eff. April 1, 2013.
25. https://opwdd.ny.gov/opwdd_contacts/ddro.
26. This information was provided to this writer by former employees of the Crisis Mitigation Team.
27. NPR (2018). *The Sexual Assault Epidemic No One Talks About*. [podcast] *Abused and Betrayed*. Available at: https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about.
28. Nora J. Baladerian, Thomas F. Coleman & Jim Stream, *Abuse of People with Disabilities: Victims and Their Families Speak Out.* A Report on the 2012 National Survey of People with Disabilities.
29. New York Consolidated Laws, Executive Law - EXC § 553. Powers and duties of the justice center (21)

    > To receive and review reports required pursuant to section 16.19 of the mental hygiene law and take any action as required by law. The justice center also shall assist the commissioner of the office for people with developmental disabilities in developing and preparing recommendations required by paragraph three of subdivision (d) of section 16.19 of the mental hygiene law for submission to the governor, temporary president of the senate and speaker of the assembly.

30. https://www.governor.ny.gov/news/governor-cuomo-announces-regional-task-forces-help-crime-victims.
31. NY Soc Serv L § 423-A. Child advocacy centers established.
32. In speaking with staff of Child Advocacy Centers at the 2019 New York State Police Crimes Against Children Seminar.
33. https://www.urmc.rochester.edu/childrens-hospital.aspx.
34. In conversation with Lindsey Macaluso, LCSW, Director of Mental Health Services at Bivona Child Advocacy Center, Rochester, New York.
35. https://www.bivonacac.org/idd-alliance.
36. New York Consolidated Laws, Mental Hygiene Law—MHL § 81.21. Powers of guardian; property management.

    New York Consolidated Laws, Mental Hygiene Law—MHL § 81.22. Powers of guardian; personal needs.
37. New York Consolidated Laws, Surrogate's Court Procedure Act—SCP § 1750. Guardianship of persons who are intellectually disabled.

    New York Consolidated Laws, Surrogate's Court Procedure Act—SCP § 1750-a. Guardianship of persons who are developmentally disabled.
38. *Disability Rights New York v. New York*, No. 17-2812 (2d Cir. 2019).
39. Rose Mary Bailly and Charis B. Nick-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Alb. L. Rev. 807 (2012).
40. New York Consolidated Laws, Surrogate's Court Procedure Act—SCP § 1751. Petition for appointment; by whom made.
41. New York Consolidated Laws, Mental Hygiene Law—MHL § 81.02 Power to appoint a guardian of the person and/or property; standard for appointment.
42. https://ag.ny.gov/bureau/litigation-bureau.
43. New York Consolidated Laws, Mental Hygiene Law—MHL § 47.01 Mental hygiene legal service.
44. New York Consolidated Laws, Mental Hygiene Law—MHL § 47.01 Mental hygiene legal service.
45. New York Consolidated Laws, Mental Hygiene Law—MHL § 1.03 Definitions.
46. New York Consolidated Laws, Mental Hygiene Law § 16.03 Operating certificate required.
47. New York Consolidated Laws, Mental Hygiene Law—MHL § 31.02 Operating certificate required.
48. New York Consolidated Laws, Mental Hygiene Law—MHL § 47.03 Functions, powers and duties of the service.
49. New York Consolidated Laws, Mental Hygiene Law—MHL § 16.03 Operating certificate required.
50. New York Consolidated Laws, Mental Hygiene Law—MHL § 47.01 Mental hygiene legal service.

    > There shall be a mental hygiene legal service of the state in each judicial department. The service shall provide legal assistance to patients or residents of a facility as defined in section 1.03 of this chapter, or any other place or facility which is required to have an operating certificate pursuant to article sixteen or thirty-one of this chapter, and to persons alleged to be in need of care and treatment in such facilities or places.

51. Rules of Prof. Con., Rule 1.14 McK.Consol.Laws, Book 29 App. Rule 1.14. Client With Diminished Capacity.
52. https://opwdd.ny.gov/opwdd_contacts/ddro.
53. New York Consolidated Laws, Mental Hygiene Law—MHL § 81.19 Eligibility as guardian.
54. *In re Amber M.*, 2016 N.Y, MIsc.LEXIS 3495 (Surr. Ct. NY Cty) (Mella, Surr.), *In re Maselli*, NYLJ, March 29, 2000, at 28, col (4)(Surr. Ct., Nass. Cty) (Radigan, Surr.), *In re Timothy R.R.*, 42 Misc. 3d 775; 977 N.Y.S.2d 877 (Surr. Ct. Essex Cty., 2013) and other cases discussed in the SCPA Article 17-A Collected Cases published by the Second Department Mental Hygiene Legal Services. (This publication is available on the nycourts.gov website on the Guardian and Fiduciary Services page.).
55. New York Consolidated Laws, Mental Hygiene Law—MHL § 81.03 Definitions

    > (a) "guardian" means a person who is eighteen years of age or older, a corporation, or a public agency, including a local department of social services, appointed in accordance with terms of this article by the supreme court, the surrogate's court, or the county court to act on behalf of an incapacitated person in providing for personal needs and/or for property management.

56. New York Consolidated Laws, Surrogate's Court Procedure Act—SCP § 1760. Corporate guardianship.
57. https://delarc.org/our-programs/adult-guardianship-services/.
58. 2012 New York Consolidated Laws, Social Services Article 9-B—ADULT PROTECTIVE SERVICES Title 3, 473-D—Community guardianship.
59. New York Consolidated Laws, Mental Hygiene Law—MHL § 80.05 Surrogate decision-making committees and panels; organization.
60. 14 CRR-NY PART 710. Procedures of the Surrogate Decision-Making Committee of the New York State Justice Center for the Protection of People with Special Needs.
61. 14 CRR-NY 633.16 (f). Person-centered behavioral intervention.

Crowdsourcing: the Benefits, the Pitfalls, and Everything in Between

By Lauren I. Mechaly

Lauren I. Mechaly

Fundraising has always been a fundamental and integral part of for-profit and not-for-profit entities and organizations. Whether the company is seeking to raise capital for a new research project or establish a scholarship fund for future students, the concept of identifying donors and raising money to support a common goal has always been, well, common.

Founded approximately eight years ago, GoFundMe is among the leading crowdfunding options for individuals looking to raise money for themselves or others for everything from life events to challenging circumstances. Other websites, such as Kickstarter, are more popular among those looking to raise funds for their businesses. GoFundMe is available to individuals and smaller entities who do not necessarily have access to large donors. A fundraiser might be for someone who is undergoing a medical procedure or treatment and cannot afford the cost; or to help cover the cost of a birthday party for an underprivileged child. People can turn to family and friends, and even strangers, through their social networks, to raise much-needed funds. This is quite a valiant effort, one often met with tremendous success given the social media platforms available today, including Facebook, Instagram, YouTube and others.

So what happens when the beneficiary of the fundraiser is receiving means-tested government benefits?

Medicaid and Supplemental Security Income (SSI) are two programs upon which disabled and impoverished individuals may rely to meet their daily needs for services and supports, and for income. This article focuses on the effects of crowdsourcing on these benefits only, though the same principles might apply to other means-tested benefits.

As the reader may know, Medicaid is a jointly funded federal and state program. As such, the applicable rules and regulations vary quite a bit from state to state. For example, in New York, an individual is entitled to Medicaid if he or she has resources below $15,450 (in 2019), while in New Jersey, an individual is not eligible for Medicaid if his or her resources exceed $2,000. Individuals who receive SSI are categorically eligible (or categorically linked) for Medicaid benefits; however, the SSI resource threshold for a single person is $2,000 (in 2019). There are also other rules and thresholds (i.e. income and in-kind support and maintenance) that impact eligibility for these benefits.

How Does Crowdsourcing Work?

Fundraisers are not required to be in the name of the beneficiary, but the funds raised are only able to be withdrawn by the person raising the funds and/or the beneficiary. Funds withdrawn are transferred to WePay, and the funds are then sent to the beneficiary's account. Funds deposited into the beneficiary's account can be put back into the WePay account to be redirected but, according to the site, this process is time consuming (it can take 10 business days to recover) and is not always successful.

There is no mechanism in place to monitor how the funds from the fundraiser are used once transferred to the beneficiary. If the beneficiary established the fundraiser on his or her own, then he or she has immediate access to any funds raised and can use these funds for any purpose. Thus, there is no reason why these funds should be considered exempt or in any way unavailable to the beneficiary for purposes of eligibility for means-tested government benefits. It is the author's experience that Medicaid caseworkers in all states are checking these sites upon receipt of new Medicaid applications to determine whether a fundraiser has been initiated. Further complicating the issue is when is unaware that a friend or family member has started the fundraiser. Even though the beneficiary does not have direct access to the funds when it is initiated by a third party, the lack of oversight and lack of regulations surrounding this area make it difficult to predict how a Medicaid case worker or Social Security representative may treat the funds.

If no additional planning is considered, then the beneficiary will need to spend the money down in the

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month received or risk having it considered an available resource in the following month (note: the government agency may consider this money unearned income in addition to an available resource).

Back to the birthday party for a minute. In or about 2015, a fundraiser was launched to raise money for a young girl suffering from cancer whose family could not afford to pay for a Sweet 16. The crowdsourcing campaign set a modest goal, which was very quickly met. Unfortunately, the girl's mother was receiving SSI, and the Social Security Administration (SSA) took the position that these funds were income to her, and therefore, concluded that her benefits should be terminated. The money raised was returned so that the mother could maintain her SSI and Medicaid benefits which cover food, shelter and medical costs for her and her family.[1]

Other case scenarios have been resolved prior to application or while the application is pending. The author had two cases in the past year in New Jersey regarding crowdsourcing.

The first was a disabled individual who was turning 65 when she was awarded a settlement in a personal injury action against a prior nursing home. A first party Supplemental Needs Trust was established and funded with the net settlement, but later it was discovered that a GoFundMe account had been set up for the individual in an effort to assist in the purchase of a motorized wheelchair that was not covered by Medicaid. Because the individual had already turned 65, the funds could not be released to the individual and deposited into the SNT. As such, the funds were released and paid to Medicaid as a partial payment on the lien.

The second was a disabled individual preparing to file a Medicaid application. As part of the spend down, funds were being liquidated and moved into a SNT. Fortunately, the Client knew about the fundraiser and had been withdrawing money through his WePay account. Thus, he was able to easily draw down on the account until the balance was zero and the fundraiser could be shut down.

A third recent example relayed to the author involved an adult disabled beneficiary. A fundraiser was set up to raise money for a handicap vehicle. The caseworker from the Department of Social Services could not confirm to the attorney how the account would be treated once it exceeded the resource allowance, considering there was no guarantee that the money would be raised and then spent in the month received. Thus, the family terminated the fundraiser in the applicant's name and requested that donations be sent to their home, in their names, and the funds were saved in that way instead.

While these crowdsourcing tools have become widely popular, it seems as if practitioners are failing to discuss them with their clients, which means that applicants or recipients of means-tested government benefits are unaware of the implications on benefits.

First Party Fundraising

A disabled individual can use a self-settled first party supplemental needs trust in order to establish or preserve his or her eligibility for Medicaid in the event he or she is launching his or her own campaign or in the event he or she is the beneficiary of a fundraiser set up by a third party. Of course, this will only be an available planning tool if the disabled individual is under the age of 65.[2] A pooled trust may be utilized for the disabled individual; however, if he or she is over the age of 65, there will be transfer penalties associated with the funding of the pooled trust to the extent he or she enters a nursing home (and requires Medicaid coverage for skilled care) within five years of the transfer.[3]

The beneficiary must monitor the fundraiser so that any funds raised are deposited into the beneficiary's account and then spent in the month of receipt. Otherwise, what would be considered income is treated as a resource and will potentially impact the beneficiary's eligibility for government benefits. The fundraiser should ultimately be treated as an available resource, same as any other account to which the beneficiary has complete access. It is important to keep in mind that once the money raised is collected by the beneficiary and deposited into the trust, the fundraiser must be ended. If not, any money raised after the date of the initial withdrawal will be considered available in establishing his or her eligibility for means-tested government benefits.

Self-settled first party supplemental needs trusts include a payback provision which provides that upon the beneficiary's death, any funds remaining will be paid back to Medicaid to the extent medical assistance was provided to the beneficiary during his or her lifetime. Any funds remaining are paid to the estate of the beneficiary and distributed pursuant to the terms of his or her Will. Similarly, if the beneficiary establishes a pooled trust or community trust, upon his or her death the funds remaining in the sub-trust account will be pooled for the benefit of other disabled individuals. For these reasons, a third-party supplemental needs trust may be a more appealable option to the beneficiary or his or her family.

Third Party Fundraising

For those fortunate enough to have a family member or friend hoping to help pay for costs such as medical care, durable medical equipment, or even a vacation with appropriate staff or support, it is recommended to have the fundraiser set up in the name of a third party supplemental needs trust.[4] This way, the disabled beneficiary's eligibility for means-tested government benefits is not jeopardized. Further, since a third party is receiving the funds, a pay-back provision is avoided.

ABLE Account

Depending on the circumstances of the beneficiary and the amount of funds to be raised, an alternative option is to establish an ABLE account for the beneficiary. This is only appropriate with certain facts, and also includes a pay-back provision. In order to establish an ABLE account, the beneficiary must have been disabled prior to the age of 26, and the annual account contribution is limited to $15,000 (in 2019).

Other Fundraising

In addition to the more popular crowdsourcing sites such as GoFundMe, HelpHopeLive (helphopelive.org) is a fundraising site that provides a platform for raising money for medical expenses not covered by health insurance. According to its website, the organization maintains discretion over the funds raised, and so, in theory, means-tested benefits may be preserved. Of course, the practitioner should confirm this with the Social Security Administration and local Medicaid agency directly.

As a special needs planner, it is important to determine whether one of these options might be appropriate and to discuss the benefits and risks regarding crowdsourcing.

Endnotes

1. https://www.foxnews.com/health/when-gofundme-goes-wrong-woman-faced-losing-state-assistance-after-raising-money-for-daughter-with-aggressive-cancer
2. 42 U.S.C. 1396p(d)(4)(A).
3. 42 U.S.C. 1396p(d)(4(C).
4. EPTL 7-1.12.

Birth of a Third Party Agency Trust

By Mark Brody and Sheila Shea

I. Introduction

Mark Brody

Sheila Shea

A supplemental needs trust[1] shelters the assets of a person with a disability for the dual purpose of securing and maintaining eligibility for programs of government benefits and assistance, such as Medicaid,[2] while enhancing the beneficiary's quality of life with supplemental care paid by his or her trust assets.[3] Typically, the supplemental care paid for by the assets of the trust is used to provide additional health care services and equipment, specialized or unique therapy, private health insurance, educational and vocational training, computers and software, case management services, or recreational activities for the benefit of a person with disabilities.[4] The policy of the State of New York encourages the creation of supplemental needs trusts for people with disabilities.[5]

Nonetheless, it may come as a surprise to advocates for people with disabilities that typical Medicaid planning tools, such as supplemental needs trusts, are ineffective in shielding after-acquired property from pre-existing claims by the Department of Mental Hygiene[6] for care and treatment costs. There is an alternative trust device, however, that may lessen the burden of a collection action upon patients,[7] while promoting preservation of funds for the patient's supplemental needs. This article introduces the reader to an innovative remedial device, the Third-Party Agency Trust (TPAT), that was created in 2006 to afford eligible beneficiaries the opportunity to: (a) voluntarily turn over a windfall of money to the state in satisfaction of a statutory debt owed to the state for care and treatment costs; and, in consideration of that voluntary payment, (b) the state would then allocate an agreed-upon sum of money into a trust administered by NYSARC, Inc., a voluntary agency serving people with disabilities; and, (c) upon the death of the beneficiary, the balance of the money, if any, in the trust, would be returned to the state in satisfaction of its statutory claim. The birth of the TPAT represented a collaboration between structural adversaries in plenary actions to recover care and treatment costs, the Office of the Attorney General representing the autonomous offices of the Department of Mental Hygiene and the Mental Hygiene Legal Service. The authors of this article were frequent adversaries in these actions. It became apparent over time that the resources directed at prosecuting statutory claims and defending actions could better be devoted to achieving outcomes benefiting both the state and the individual with a disability.

II. A Primer on Department of Mental Hygiene Collections

A basic familiarity with article 43 of the Mental Hygiene Law (MHL) is crucial to understanding the proper application of the TPAT. MHL § 43.01 establishes that the Commissioners of the Office of Mental Health (OMH) and the Office for People with Developmental Disabilities (OPWDD) shall charge fees for services to patients. Further, MHL § 43.03 (a) imposes liability upon a patient or any fiduciary for the cost of care and treatment.[8] Indeed, in *State v. Patricia II*,[9] the Court of Appeals held that a patient's "ability to pay" at the time services were rendered (or at any time thereafter) is not a condition precedent to the State's article 43 collection action.[10] Patients receiving care and treatment in mental hygiene facilities are often unable to pay for the cost of care either because they are indigent or lack insurance. In addition, Medicaid has long excluded inpatient care and treatment in psychiatric hospitals from its funding scheme.[11] Thus for indigent patients, unexpected cash windfalls, such as inheritances, often become the staple of article 43 collection actions. Since there is a six-year statute of limitations for article

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43 claims, after-acquired property is not insulated from a collection action.[12]

III. Overview of Special Needs Trusts

The Restatement Third of Trusts defines a trust as "a fiduciary relationship with respect to property, arising from a manifestation of intention to create that relationship and subjecting the person who holds title to the property to duties to deal with it for the benefit of . . . one or more persons, at least one of whom is not the sole trustee."[13] In New York, a trust may be created for any lawful reason,[14] so long as there is "(1) a designated beneficiary, (2) a designated trustee, (3) a fund or other property sufficiently designated or identified to enable title of the property to pass to the trustee, and (4) actual delivery of the fund or property, with the intention of vesting legal title in the trustee."[15] Additionally, "[t]o constitute a trust there must be either an explicit declaration of trust or facts and circumstances which show beyond reasonable doubt that a trust was intended to be created."[16]

A supplemental needs trust (SNT) resembles a traditional trust in that there is a transfer of property into the trust, managed by a trustee, for the benefit of the beneficiary. However, the SNT differs from a traditional trust in two significant respects: (1) the beneficiary must have a disability,[17] and (2) the beneficiary has no control over any disbursements from the trust and no ability to revoke the trust.[18] As stated in case law, an SNT is a "discretionary trust established for the benefit of a person with a severe and chronic or persistent disability that is designed to enhance the quality of the disabled individual's life by providing for special needs without duplicating services covered by Medicaid [or other programs of government assistance]" or destroying eligibility for such programs.[19] Supplemental needs trusts may be first party[20] (funded with the assets of the person with a disability) or third-party[21] (established and funded by others for the person's benefit) in nature. In New York, case law recognized third party supplemental needs trust before federal and state enabling laws were enacted recognizing both first and third party trusts.[22]

A. Third Party Trusts

In re Escher[23] is the watershed case in New York that established the legal foundation for the creation of third-party special needs trusts.[24] *Escher* held that the trustee of a testamentary trust established by parents for their adult daughter with severe mental disabilities, which provided that the principal was to be used only "for the payment of expenses necessary for the maintenance and support," was not required to invade the trust principal to pay care and treatment costs incurred at a state hospital. The court further held that "a trustee could properly exercise discretionary powers by declining to make funds available to pay bills which had accrued for decades where payment would (1) have no impact on the present or future needs of the life beneficiary; (2) be unfairly prejudicial to the life beneficiary (by eliminating the trust as a source of income for future needs), and (3) result in "an arrogant disregard of the testator's intent."[25] In its decision, the Surrogate explained that public assistance had evolved from being a gift into an entitlement for people with disabilities, particularly considering the vast cost of institutional care.[26]

In 1993, the New York Legislature codified the holding of *Escher* at section 7-1.12 of the Estates Powers and Trusts Law. A statutory third-party trust is created when the following five statutory elements are satisfied:

(1) the person for whose benefit the trust is established suffers from a severe or chronic or persistent disability;

(2) the trust evidences the intent that the assets be used to supplement, not supplant, government benefits;

(3) the trust prohibits the trustee from using assets in any way that may jeopardize the beneficiary's entitlement to government benefits or assistance;

(4) the beneficiary does not have the power to assign, encumber, direct, distribute or authorize distribution of trust assets; [27]

(5) if an intervivos trust, the creator of the trust was a person or entity other than the beneficiary.[28]

If the requirements of section 7-1.12 are met, "[i]t shall be presumed that the creator of the trust intended that neither principal nor income be used to pay for any expenses which would otherwise be paid by government benefits or assistance."[29] Further and prospectively, the trustee of a conforming 7-1.12 trust shall *not* be deemed liable for care and treatment costs in a mental hygiene facility by operation of MHL § 43.03 (d).

B. First Party Trusts

The defining characteristic of a first party trust is that the person who is providing the legal consideration for the funding of the trust is also the beneficiary of the trust.[30] As a general rule, trusts funded with the beneficiary's property must be considered available resources for purposes of the beneficiary's eligibility for Medicaid and other "means tested" programs, such as Supplemental Security Income.[31] However, both federal and state law provide for an *exception* to the rule that a self-settled trust should be considered an available resource.[32] There are two types of exception trusts for people with disabilities: those with a single beneficiary and those operated by not-for-profit organizations with many disabled beneficiaries each with his or her own account; the "under 65 payback trust" and the latter "pooled trust. "[33] For a self-settled

under 65 payback trust to qualify as an exception trust, the following statutory requirements must be met:

1. The trust must be established by a parent, grandparent, legal guardian or court (as originally enacted) or by an individual with a disability (as amended by the Special Needs Trust Fairness Act);[34]
2. The beneficiary must meet the disability criteria under the Social Security Act;
3. The beneficiary must be under the age of 65 years old at the time the trust is funded with the beneficiary's assets; and
4. The trust must provide that upon the beneficiary's death, the State Medicaid program be repaid for medical assistance provided during the course of the beneficiary's life.[35]

The "pooled trust" has similar statutory elements but does not contain an age restriction and requires that the trustee be a not-for-profit association.[36] Amounts retained in the trust are pooled for purposes of investment and each beneficiary has a sub-account. Also, a pooled trust may be established for a beneficiary over the age of 65 and upon the death of the beneficiary, the trust is permitted to retain the balance in the beneficiary's sub-account for the charitable purposes of the trust.[37]

C. Third Party Agency Trust

The TPAT is third party trust agreement originally executed on January 26, 2006 by and between OMH and OPWDD (then OMRDD) as "grantor" and NYSARC, Inc., as trustee. The trust instrument recognizes two distinct circumstances where the state agency, as grantor, will establish a beneficiary sub-account for a person who has or is currently receiving inpatient care and treatment: (1) when the state agency is presented with a voluntary payment in full or partial satisfaction of a non-Medicaid funded statutory debt; and (2) when the state agency has received a lump sum payment as representative payee and may use the award to pay for future costs of care as authorized by state and federal law.[38] The TPAT expressly provides that upon the death of the beneficiary, the balance of the sub-account shall be paid to the respective grantor state agency in satisfaction of the article 43 debt. The trust also provides that it is the intent of the grantor (the state agencies) to create a supplemental needs trust which conforms with the provisions of section 7-1.12 of the EPTL and that trust assets are to be used to supplement and not supplant any programs of government benefits and assistance.[39]

The TPAT becomes a viable planning device when a person who has accrued an article 43 debt for care and treatment costs, receives a cash windfall of some type, most likely an inheritance, or lump sum Social Security Award. The article 43 liability may vastly exceed the amount of the windfall which jeopardizes the ability of the person to retain any funds for his or her lifetime use and enjoyment. Until the advent of the TPAT, the state agency may have asked the Office of the Attorney General's civil recoveries bureau to proceed with a plenary article 43 action to secure a judgment for the cost of care. A CPLR article 12 guardian ad litem would often be appointed for the person to defend the action if the person was otherwise incapable of defending his or her rights. In some judicial departments, the Mental Hygiene Legal Service was appointed as guardian ad litem or private counsel would be assigned to defend the action. The matter often proceeded to summary judgment and a turnover proceeding would soon follow to secure the property of the patient and satisfy the judgment. The TPAT was conceived between adversaries striving to identify a remedial approach that would enable the state agencies to pursue recoveries, while allowing patients to have the lifetime use and enjoyment of their property.

"The TPAT becomes a viable planning device when a person who has accrued an article 43 debt for care and treatment costs receives a cash windfall of some type, most likely an inheritance, or lump sum Social Security Award."

In practice, once the nature of the patient's liability is established as being within the ambit of article 43 of the MHL and not a Medicaid recovery, the TPAT can be explored. The use of the TPAT as a vehicle to compromise or settle an article 43 debt is initially predicated upon two provisions of article 43 of the Mental Hygiene Law; section 43.07(a) and section 43.03(b). Regarding the former, section 43.07(a) authorizes the Commissioner (either of OMH or OPWDD) to enter into agreements to satisfy article 43 debts. Further section 43.03(b) provides that the Commissioner may "reduce or waive fees" in cases of inability to pay or for other reasons. Thus, these two statutes do not require the Commissioner to waive claims, but they clearly authorize the agency to do so in appropriate cases.[40]

Consequently, the TPAT may be characterized as a combination of section 43.07(a) agreement and section 43.03(b) conditional waiver. The following case example illustrates the steps that result in the creation of a TPAT account under a hypothetical set of facts:

(1) A patient in a state psychiatric hospital has unpaid article 43 care and treatment costs in the amount of $500,000.

(2) The patient or the patient's fiduciary acquires a $100,000 inheritance.

(3) The patient or the patient's fiduciary, such as a guardian, agrees to partially satisfy the article 43 debt by making a voluntary payment to OMH in the amount of $100,000.

(4) In consideration of the voluntary payment, OMH provides a release or satisfaction of claim to the patient or fiduciary in the amount of $100,000.

(5) Pursuant to the section 43.07 settlement agreement, OMH applies an agreed upon portion to the funds (which can be a nominal amount depending on the facts of the case) toward immediate recovery of its statutory claim and agrees to fund the TPAT with the balance received.

(6) Because OMH received the funds in consideration of satisfying or, partially satisfying, an article 43 claim, it is OMH (and not the patient) furnishing the legal consideration for the creation of the trust.

While best understood as a third party trust, the TPAT also borrows from the Medicaid (first party) payback and pooled exception trusts in two respects: (1) similar, but not identical to the payback feature of the Medicaid exception trust, upon the death of the beneficiary, the remainder interest in the trust is "returned" to the State; and (2) the trustee of the TPAT (NYSARC) pools the investments of the (OMH/OPWDD) beneficiaries. Thus, it is proper to refer to the TPAT as a "pooled trust" (but not a Medicaid exception trust) because its purpose is to permit management of funds subject to article 43 claims (not Medicaid claims).

IV. Conclusion

Commentators have observed that SNTs create opportunities for independent living, innovative rehabilitation and therapy, employment and other activities that give life meaning.[41] The TPAT is a unique planning device available to people who obtain a financial windfall but have a pre-existing article 43 debt. Eligible beneficiaries benefit from the lifetime use and enjoyment of a windfall, while deferring until after death satisfaction of the article 43 claim. The authors commend the agencies, the Office of the Attorney General and NYSARC for their vision and continued support of this unique trust device.

Endnotes

1. This article refers to "supplemental needs trusts" or "special needs trusts" interchangeably. Both terms broadly describe a trust designed to benefit a person with a disability (the beneficiary) without jeopardizing the beneficiary's eligibility for public benefits.
2. Medicaid is a joint federal-state program established pursuant to title XIX of the Social Security Act. The primary purpose of the Medicaid program is to enable each state, jointly with Federal government, to furnish "medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services." *See* 42 U.S.C. § 1396-1. *See also Jennings v. Commissioner, N.Y.S. Dept. of Social Serv.*, 71 A.D.3d 98 (2d Dep't 2010).
3. *In re Abraham XX*, 11 N.Y.3d 429, 434 (2008); *In re Tinsman (Lasher)*, __AD3d__, 2019 N.Y. Slip Op. 01471.
4. *Jennings v. Commissioner, N.Y.S. Dept of Social Serv.*, A.D.3d 98, 105 (2d Dept 2010); *citing Joseph A. Rosenberg, Supplemental Needs Trust for People with Disabilities. The Development of a Private Trust in the Public Good*, 10 B.U. Pub. Int. L.J. 91 at 91-95 (2010).
5. *See In re Kamp*, 7 Misc. 3d 615 (2005).
6. The Department of Mental Hygiene is composed of three autonomous offices: Office of Mental Health, Office for People with Developmental Disabilities and Office of Alcoholism and Substance Abuse Services. *See* Mental Hygiene Law (MHL) § 5.01. The TPAT was created by OMH and OPWDD.
7. Patient is a term of art and means a person receiving services for the mentally disabled at a facility. See MHL § 1.03 (23).
8. MHL § 43.03 (a).
9. *State of New York v. Patricia II*, 6 N.Y.3d 160 (2006).
10. Seizing on the six-year statute of limitations for mental hygiene recoveries, the Court of Appeals in *Patricia II* concluded its ruling promoted the statutory scheme in favor of recoveries and enabled the State to obtain judgments that would be subject to collection for 20 years. *See, Patricia II*, 6 N.Y.3d at 164, *citing* CPLR 211 (b).
11. *See* Social Service Law (SSL) § 365(2). However, on November 18, 2018, the Center of Medicare and Medicaid Services announced a demonstration opportunity for states to include short-term stays in institutes for mental diseases within the Medicaid program. *See* https://www.medicaid.gov/federal-policy-guidance/downloads/smd18011.pdf – last accessed April 15, 2019.
12. MHL § 43.07. A peculiarity in the law enables OPWDD to interpose pre-June 1972 claims against people with developmental disabilities who have not been discharged from the agency's care. *In re Piper*, 145 A.D.2d 97 (3d Dep't 1989) holds that the "old law" statute of limitations applies for services furnished before the June 1972 re-codification of the MHL. The "old law" statute of limitations did not begin to run until the patient was discharged or died. Consequently, even a person receiving care and treatment in the OPWDD system may be subject to an article 43 debt if care and treatment costs for services rendered before 1972 remain unpaid.
13. Restatement (Third) of Trusts § 2 (2009).
14. Estates Powers and Trust Law (EPTL) 7-1.4 (2010).
15. *In re Doman*, 68 A.D.3d 862 (2d Dep't 2009).
16. *In re Estate of Fontanella*, 33 A.D.2d 29, 31 (3d Dep't 1969); *see* Matthew M. Shatzkes, *Supplemental Needs Trusts: The Movement Towards Reformation*, 25 J. Civ. Rts. & Econ. Dev. 739 (2011).
17. "An individual shall be considered disabled if he is unable to engage in any substantial gainful activity by means of any medically determinable physical or mental impairment which can be expected to result in death or can be expected to last for a continuous period of not less than twelve months," 42 U.S.C. 1382c(3).
18. Shatzkes, *Supplemental Needs Trusts: The Movement Towards Reformation*, 25 J. Civ. Rts. & Econ. Dev. at 748, *citing Sai Kwan Wong*

v. Daines, 582 F. Supp. 2d 475, 479 (S.D.N.Y. 2008), *aff'd*, 571 F. 2d 247 (2d Cir. 2009).

19. *Cricchio v. Pennisi,* 90 N.Y.2d 296 (1997); *In re Abraham XX.,* 11 N.Y.3d 429 (2008).
20. 42 U.S.C. § 1396p(d)(4)(A), enacted as part of the Omnibus Budget Reconciliation Act of 1993, Pub.L. No. 103-66 (1993)(OBRA 93).
21. *See In re Escher*, 94 Misc. 2d 952; *aff'd* 75 A.D.2d 531 (1st Dep't 1980), *aff'd*, 52 N.Y.2d 1006 (1981) which was later codified at EPTL 7.1.12; *Jennings*, 71 A.D.3d at 105.
22. *In re Escher*, 94 Misc. 2d 952; *aff'd,* 75 A.D.2d 531 (1st Dep't 1980), *aff'd*, 52 N.Y.2d 1006 (1981).
23. *Id.*
24. Edward V. Wilcenski & Tara Anne Pleat, *Administration of Special Needs Trusts*, 91-March N.Y. St. B. J. 13 (March 2019).
25. 94 Misc. 2d at 960.
26. 94 Misc. 2d at 959, stating that because of the high costs involved, programs to pay for the care of people with mental and physical disabilities were now seen as benefits, rather than charity.
27. EPTL 7.12 (a)(5)(i-iv).
28. After the enactment of OBRA'93, E.P.T.L. 7-1.12 was further amended to allow self-settled trusts that conformed to state implementing language. EPTL 7-1.12 (b)(5)(v).
29. EPTL 7-1.12(b)(1).
30. *Jennings v. Commissioner, N.Y.S. Dept. of Social Serv.,* 71 A.D.3d at 105.
31. 42 U.S.C. § 1396p (h)(1); *see* Shatzkes, *Supplemental Needs Trusts: The Movement Towards Reformation*, 25 J. Civ. Rts. & Econ, Dev. at 749; 42 U.S.C. § 1396p (d)(4)(A); § 1396p(d)(4)(C); the text of the federal Medicaid statutes allowing for first party special needs trust were later incorporated into New York's Social Service Law (SSL § 366[2][b][iii][A]; SSL § 366[2][b][2][iii][B]).
32. 42 U.S.C. 1396p(d)(4)(A); *see Sai Kwan Wong v. Doar,* 571 F3d 247,252 (2d Cir. 2009); *In re Kennedy*, 3 Misc. 3d. 907, 909 (2004).
33. *See Rosenberg*, 10 B.U. Pub. Int. L.J. at 131.
34. 21st Century Cures Act, Pub.L. No. 114-255 (2015) Section 5007.
35. 42 U.S.C. § 1396p(d)(4)(A); Social Services Law § 366 (2)(b)(2)(iii)(A). If the first party trust complies with all statutory requirements, the trust will receive the associated protections under federal Medicaid and Supplemental Security Income (SSI) laws. *See* Wilcenski & Pleat, *Administration of Special Needs Trusts*, 91-March N.Y. St. B. J. at 14. Congress extended the OBRA '93 trust rules to SSI in 1999 (*see*, 42 U.S.C. § 3826[e]][1-5]).
36. An unofficial list of the pooled trusts operating in New York State can be found at http://www.wnylc.com/health/entry/4 – last accessed April 15, 2019.
37. The provisions governing pooled trusts plainly state that "amounts remaining...which are not retained by the trust must be paid to the State up to the total value of all [Medicaid] paid on behalf of the individual." *See In re Altshuler*, 169 Misc. 2d 613, 616, *citing*, 18 N.Y.C.R.R. 360-4.5 (b)(5) (i)(b); *see also,* SSL § 366 (2)(b) (2)(iii)(B); 42 U.S.C. § 1396p (d)(4) (C)(iv).
38. A copy of the TPAT is uploaded on the website of the Mental Hygiene Legal Service for the Third Judicial Department, http://www.courts.state.ny.us/ad3/mhls/index.html.
39. *Id.*
40. Additional support for the TPAT may be found in a 2010 chapter amendment to the M.H.L. requiring the commissioners to create three types of trusts of property to the extent permissible by law when receiving property of patients .The three types of trusts are "… qualifying Medicaid exception trust, including a special needs trust or similar device…." The TPAT would be categorized as a "similar device" to the Medicaid exception trust or SNT. *See* L. 2010, c. 111; s*ee* MHL §§ 29.23, 33.07(e).
41. Rosenberg, 10 B.U. Pub. Int. L.J. at 151.

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