

2016

Petitioning for Protection: Without Repeal or Reform of Article 17A, Can Practitioners Maintain Ethical Guardianship Practices While Simultaneously Protecting the Rights of Persons with Intellectual Disabilities

Maria Campigotto

Brian E. Hilburn

Follow this and additional works at: <https://ir.lawnet.fordham.edu/ulj>

Recommended Citation

Maria Campigotto and Brian E. Hilburn, *Petitioning for Protection: Without Repeal or Reform of Article 17A, Can Practitioners Maintain Ethical Guardianship Practices While Simultaneously Protecting the Rights of Persons with Intellectual Disabilities*, 43 Fordham Urb. L.J. 869 (2016).

Available at: <https://ir.lawnet.fordham.edu/ulj/vol43/iss3/10>

This Editorial is brought to you for free and open access by FLASH: The Fordham Law Archive of Scholarship and History. It has been accepted for inclusion in Fordham Urban Law Journal by an authorized editor of FLASH: The Fordham Law Archive of Scholarship and History. For more information, please contact tmelnick@law.fordham.edu.

**PETITIONING FOR PROTECTION: WITHOUT
REPEAL OR REFORM OF ARTICLE 17A, CAN
PRACTITIONERS MAINTAIN ETHICAL
GUARDIANSHIP PRACTICES WHILE
SIMULTANEOUSLY PROTECTING THE
RIGHTS OF PERSONS WITH INTELLECTUAL
DISABILITIES?**

*Maria Campigotto & Brian E. Hilburn**

ABSTRACT

Despite calls for reform of Article 17A guardianships for more than twenty-five years, the statute remains unchanged and New York routinely subjects adults with intellectual disabilities to open-ended, plenary guardianships with few, if any, procedural protections. As non-profit legal service providers working in a medical-legal partnership, hospitals refer to our organization, LegalHealth, clients who seek Article 17A guardianships over their loved ones. In this Essay, we discuss the many ways in which Article 17A fails to protect the rights of our clients' children, and the ethically compromised position practitioners are often put in while trying to both advocate for our clients (the Petitioners) and protect the ward (the Respondent). New York has another guardianship statute, Article 81, that, while not perfect, does a better job of protecting the rights of

* Maria Campigotto, Esq. is a Senior Staff Attorney at LegalHealth, a division of the New York Legal Assistance Group. She runs legal clinics at Bellevue Hospital and Beth Israel Medical Center at which she is a general legal services practitioner for patients with serious health problems and supervises general practice paralegals. Maria earned a Juris Doctor degree at New York University School of Law and BA from Ohio State University.

Brian E. Hilburn, Esq. is a Staff Attorney at LegalHealth, a division of the New York Legal Assistance Group. He runs legal clinics at Harlem Hospital Center and Metropolitan Hospital Center at which he is a general legal services practitioner for patients with serious health problems. He earned a Juris Doctor degree at Northeastern University School of Law and BA from Arkansas Tech University.

people with intellectual disabilities. Contrary to popular belief, Article 81 proceedings are not any more onerous than Article 17A proceedings. We suggest that the legislature either repeal Article 17A, leaving guardianships to proceed under Article 81, or reform Article 17A to align with protections afforded in Article 81. In the meantime, we suggest some solutions and practice guidelines that practitioners should follow in order to prevent undue violations of the civil liberties and due process rights of people with intellectual disabilities.

TABLE OF CONTENTS

Introduction	871
I. Background	875
II. Article 17A's Central Flaw Is Its Adoption of a Diagnosis-Driven Approach to People with Intellectual Disabilities, Resulting in the Unconstitutional Denial of Procedural Protections Throughout the Guardianship Process.....	879
A. Article 17A Fails to Protect People with Intellectual Disabilities by Applying an Unduly Restrictive One-Size Fits All Approach to Guardianship	883
B. Article 17A Violates the Ward's Right to Due Process by Failing to Ensure Her Right to Participate in the Guardianship Proceeding.....	885
C. Article 17A Endangers Persons with Intellectual Disabilities by Providing No Post-Appointment Protections	890
D. Recent Court Attempts to Salvage Article 17A.....	892
1. <i>In re Mark C.H.</i> and Annual Reporting Requirements After Appointment of a Guardian	892
2. <i>In re Dameris L.</i> and the Least Restrictive Alternative to Achieve the State's Goal.....	895
III. Article 17A Does Not Live up to Its Original Purpose of Eliminating the Costs and Complications Involved in Guardianship Proceedings and Is Not, in Practice, Less Onerous Than Article 81 Guardianships	898
IV. Recommendations	901
A. Article 17A Should Be Repealed.....	901
B. While We Wait for Repeal or Reform: Ethical and Practical Considerations.....	906
1. Considerations Prior to Representation.....	906
2. Considerations During and After Representation.....	908

a. Practitioners May Commit to Only Assisting with Article 81 Guardianships.....908

b. Practitioners May Ask the Court to Read Protections Guaranteed under Article 81 Proceedings into Article 17A909

3. Ethical Considerations.....912

Conclusion.....913

“I love to discover potential in people who aren’t thought to have any.”

– Oliver Sachs

INTRODUCTION

Sarah¹ is a twenty-two-year-old woman with intellectual disabilities, specifically cerebral palsy. She needs to have her wisdom teeth removed. Sarah lacks the capacity to provide the requisite informed consent her doctors require to administer general anesthesia and perform the procedure. Because she has reached the age of majority, her parents no longer have legal authority to consent to the procedure on her behalf.

Charlie is a sixty-year-old man from Belize. He was found confused and disoriented wandering the street. EMTs were called and he was taken to a hospital. He suffers from advanced dementia. He requires help with all of his daily activities and constant supervision. He has no family aside from his sister, a lawful permanent resident and single mother of three, who is unable to care for him at home. Due to his immigration status, he is not eligible for Medicaid or other state health insurance,² which would provide either a home health attendant or care in a skilled nursing facility. Therefore, although he has not required acute medical care in more than a year, he remains hospitalized because no safe discharge plan can be implemented.

Both of these patients were referred to LegalHealth, a medical-legal partnership providing free legal services to low-income patients

1. The names of Sarah and all other clients or patients of LegalHealth discussed in this Essay have been changed to protect their privacy.

2. See generally N.Y. STATE DEP’T OF HEALTH, DOCUMENTATION GUIDE, CITIZENSHIP AND IMMIGRANT ELIGIBILITY FOR HEALTH COVERAGE IN NEW YORK STATE (2008), https://www.health.ny.gov/health_care/medicaid/publications/docs/gis/08ma009att.pdf [<https://perma.cc/G6PY-C4UC>]; N.Y. STATE DEP’T OF HEALTH, ADMIN. DIRECTIVE 4 (2004), http://www.health.ny.gov/health_care/medicaid/publications/docs/adm/04adm-7.pdf [<https://perma.cc/77M9-ZD73>].

at over twenty-five hospitals and clinics throughout New York City and Long Island.³ When LegalHealth's partner organizations recognize that a patient has a legal issue, the medical providers refer their patient to LegalHealth onsite at the hospital or clinic. LegalHealth's mission is to improve the health and quality of life for low-income New Yorkers with serious health conditions by addressing the social determinants that affect health.⁴ For example, helping a diabetic man obtain food stamps will increase his ability to comply with his prescribed diet. By assisting the mother of an asthmatic child living in a mold-infested apartment obtain adequate repairs from the landlord, LegalHealth can improve the child's health, decrease her need for inhaled steroids or other medications with potentially harmful side effects, and reduce ER visits, school absences, and instances where our client must call off from work to care for her sick child.

Unsurprisingly, a significant number of referrals to LegalHealth are for family members of mentally "incapacitated" adults like Charlie and Sarah.⁵ Although both of these families are seeking adult guardianships, or the ability to make decisions on behalf of their mentally incapacitated loved one, the legal process for each is quite different. As we will discuss, the legal protections and due process rights afforded to these incapacitated adults are significantly different as well.

Article 17A of the Surrogate's Court Procedure Act (Article 17A) and Article 81 of the Mental Hygiene Law (Article 81) govern the appointment of guardians in New York.⁶ Article 17A is used to obtain guardianship over a mentally retarded or developmentally disabled person whose mental incapacity occurred before the ward obtained the age of twenty-two-years-old, such as Sarah.⁷ Article 81 applies to any other situation.⁸ Since Charlie's "incapacity" is not the result of mental retardation or developmental disability and occurred

3. See LEGALHEALTH, www.legalhealth.org [<https://perma.cc/L7JJ-E5NR>].

4. *About LegalHealth*, LEGALHEALTH, <http://legalhealth.org/about-us> [<https://perma.cc/XK7X-YYN6>].

5. LegalHealth was referred sixty-nine, eighty-four, and ninety-four matters relating to adult guardianship for the years 2013, 2014, and 2015, respectively.

6. See N.Y. SURR. CT. PROC. ACT LAW §§ 1750–61 (McKinney 2016); N.Y. MENTAL HYG. LAW §§ 81.01–81.44 (McKinney 2016).

7. See C. Raymond Radigan & Jennifer F. Hillman, *Article 17-A Proceedings Remain an Important Tool*, N.Y. L.J., Jan. 6, 2010, <http://rmfpc.com/wp-content/uploads/2012/10/Article-17-A-Proceedings-Remain-Impt-Tool-CRR-JFH-1.10.pdf> [<https://perma.cc/JNM4-4BDM>].

8. See N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016).

well after his twenty-second birthday, an Article 81 guardianship would be used for Charlie.

Compared to Article 17A, Article 81 provides many more procedural protections designed to prevent abuse and preserve an alleged incapacitated person's autonomy. One of the problems with Article 81, however, is that there are very few, if any, organizations providing free representation to petitioners in Article 81 proceedings. Non-profit legal service organizations do not assist low-income New Yorkers to pursue Article 81 guardianships, at least in part, because these organizations believe that the expense and time requirements are beyond their resources. Article 17A guardianships were designed to be an easy and accelerated process for parents who need to maintain a continuity of authority over the legal and medical needs of their children with mental disabilities.⁹ Unfortunately, Article 17A sacrifices procedural protections and respect for autonomy for speed and convenience.

Both Charlie and Sarah's families are seeking similar remedies for similar problems: the legal authority to consent to necessary medical care (in the case of Sarah) or legal representation to pursue immigration remedies that will lead to Medicaid eligibility (in the case of Charlie). Both Charlie and Sarah are facing significant legal consequences, namely the loss of some or all of their autonomy, and what some have described as a "civil death."¹⁰ Why should the protections put in place to protect Charlie's autonomy under Article 81 not also be available to Sarah under Article 17A? Is it not arbitrary to make such determinations based solely upon the underlying cause of their intellectual disability? We believe that it is.

LegalHealth handles many Article 17A guardianship proceedings.¹¹ In addition, LegalHealth has partnerships with several law firms in New York City that represent LegalHealth clients on a *pro bono* basis under its guidance and supervision. Our mission is to improve the lives of medically vulnerable low-income New Yorkers by addressing their non-medical needs.¹² For guardianships, our mission is to improve the lives of the patients alleged to be

9. 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, 818 (2012).

10. See Joseph A. Rosenberg, *Routine Violations of Medical Privacy in Article 81 Guardianship Cases: So What or Now What?*, 85 N.Y. ST. B. ASS'N J. 34, 37 (2013).

11. LegalHealth opened 112 cases for Article 17A guardianship from 2013 to 2015.

12. *About LegalHealth*, *supra* note 4.

incapacitated.¹³ Sarah needs a medical procedure that she cannot get without a guardian. Charlie needs representation to address an immigration matter that might lead to Medicaid eligibility, but cannot understand the possible risks and benefits of various immigration options, nor consent to an attorney-client relationship. Theoretically, both Sarah and Charlie's situation would improve with the appointment of a guardian. However, neither Sarah nor Charlie would be LegalHealth clients during the guardianship process. Instead, their family members would be LegalHealth clients. As attorneys, we are professionally and ethically required to represent the interests of our clients, which may be in direct conflict with the interests of their family member with intellectual disabilities.

As legal practitioners serving low-income clients, we find the current statutory framework extremely problematic. We are troubled by the lack of procedural protections provided by Article 17A and the potential for people with intellectual disabilities to be disenfranchised by a guardianship system that does not recognize their unique abilities and limitations. Under these circumstances, representing the families of individuals with intellectual disabilities in Article 17A guardianship proceeding gives us pause. Because Article 81 guardianship proceedings are available and afford numerous procedural protections, the continued use of Article 17A without major changes makes little sense. Article 17A practitioners can both learn and borrow from the protections afforded under Article 81.

Part I of this Essay discusses the legislative history of Article 17A and the evolution of society's treatment of people with intellectual disabilities. Part II, discusses the ways in which Article 17A fails to protect the rights of people with intellectual disabilities. Part III argues that Article 17A does not live up to its original purpose: to reduce the costs and complications involved in guardianship proceedings. In practice, it is not significantly less onerous than Article 81 guardianship proceedings. In Part IV, we recommend policy reforms aimed at correcting Article 17A's deficiencies. Finally, given that policy reform may take many years, this Essay makes recommendations for practitioners currently representing clients in Article 17A proceedings to affirmatively protect the constitutional rights of wards while we wait for policy reform.

13. *About LegalHealth*, *supra* note 4.

I. BACKGROUND

Article 17A of the Surrogate's Court Procedure Act is an outdated law that reflects an antiquated understanding of intellectual disabilities. To understand Article 17A's deficiencies, it is first necessary to put the statute into its historical context.

In many ancient societies, people with disabilities were believed to be possessed by evil spirits.¹⁴ As a result, they were often killed or abandoned.¹⁵ By the early twentieth-century, medicine had replaced religion as the main authority influencing treatment of people with intellectual disabilities.¹⁶ During this time, it was believed that people with intellectual disabilities suffered "from a hereditary, incurable disease that led to criminality, immorality or depraved behavior, and pauperism, all of which constituted an unacceptable drain on society."¹⁷ People with intellectual disabilities were isolated from the rest of society and abandoned to the notoriously poor conditions of asylums and poor houses.¹⁸ Believed to be genetically inferior and at risk of contaminating the gene pool, people with intellectual disabilities were even subjected to forced sterilization as part of the eugenics movement in the early twentieth-century.¹⁹

By the mid-twentieth century, however, society's understanding of people with intellectual disabilities began to shift. During the 1960s, parents and advocates for people with disabilities made a push toward

14. GEORGE HENDERSON & WILLIE V. BRYAN, *PSYCHOSOCIAL ASPECTS OF DISABILITY* 18 (4th ed. 2011).

15. *Id.* at 18–19.

16. See Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 104 (2012).

17. *Id.*

18. *Id.*

19. *Id.* In 1924, the Commonwealth of Virginia passed a law, modeled on the model eugenics law designed by Harry Laughlin, which provided for compulsory sterilizations of individuals found to be "feebleminded, insane, depressed, mentally handicapped, epileptic and other." *Down Syndrome Human and Civil Rights Timeline*, GLOBAL DOWN SYNDROME FOUND., <http://www.globaldownsyndrome.org/about-down-syndrome/history-of-down-syndrome/down-syndrome-human-and-civil-rights-timeline> [<https://perma.cc/T4TP-E3Z8>]. The law was challenged on constitutional grounds and upheld by the Supreme Court in 1927. See *Buck v. Bell*, 274 U.S. 200, 207 (1927). Writing for the majority, Justice Oliver Wendell Holmes, Jr. ruled that forced sterilization was not a violation of the Due Process Clause of the Fourteenth Amendment but necessary "in order to prevent our being swamped with incompetence. It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." *Id.*

deinstitutionalization,²⁰ and there was a realization that people with disabilities deserved basic human rights.²¹ However, at this time, society made little effort to understand someone with an intellectual disability beyond their diagnosis, and guardianship statutes enacted during this time (such as Article 17A)²² were a “medicalized, diagnosis-driven, rights-depriving paradigm of guardianship, justified by the alleged protective benefits of *parens patriae*.”²³

Another great shift in society’s treatment of people with intellectual disabilities started during the 1980s and, arguably, continues today. Society began to understand that people with intellectual disabilities are unique individuals with unique needs and abilities who have an equal right to self-determination as the nondisabled.²⁴ The ideal, according to this shift, is inclusion and preservation of independence.²⁵

Accompanying this shift in understanding intellectual disabilities, the 1980s saw a wave of guardianship reforms. Many of these reforms were partly inspired by an Associated Press (AP) report titled *Guardians of the Elderly: An Ailing System*, which “exposed widespread neglect and malfeasance in the guardianship process throughout the country.”²⁶ In 1988, the American Bar Association held a National Guardianship Symposium that addressed the need for reforms to “produce a guardianship system . . . more fair, just and responsive to the needs of the wards.”²⁷ In particular, the New York State Law Revision Committee reviewed Articles 77 and 78 of the Mental Hygiene Law and recommend reforms.²⁸ Ultimately, the legislature repealed Articles 77 and 78 because they provided for an

20. See Glen, *supra* note 16, at 128 (citing Ruth Colker, *The Disability Integration Presumption: Thirty Years Later*, 154 U. PA. L. REV. 789, 789–90 (2006)).

21. See Glen, *supra* note 16, at 131–32.

22. Bailly & Nick-Torok, *supra* note 9, at 818.

23. Glen, *supra* note 16, at 106.

24. See *id.* at 128–29.

25. See *id.*

26. THE GUARDIANSHIP CLINIC, GUARDIANSHIP IN NEW YORK: DEVELOPING AN AGENDA FOR CHANGE 48 n.1 (2012), <https://www.cardozo.yu.edu/sites/default/files/GuardianshipReport.pdf> [<https://perma.cc/PN65-Y8YH>].

27. *Id.* (citing A.B.A., GUARDIANSHIP: AN AGENDA FOR REFORM: RECOMMENDATIONS OF THE NATIONAL GUARDIANSHIP SYMPOSIUM AND POLICY OF THE AMERICAN BAR ASSOCIATION iv (1989), http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_agda_refrm.authcheckdam.pdf [<https://perma.cc/H7J5-KF8L>]).

28. Julie M. Solinski, *Guardianship Proceedings in New York: Proposals for Article 81 to Address Both the Lack of Funding and Resource Problems*, 17 PACE L. REV. 444, 450 (1997).

outdated “conservator-by-committee” form of guardianship.²⁹ In its place, the legislature enacted Article 81 of the Mental Hygiene Law, which took effect in 1993.³⁰

Article 81 requires limited, tailored guardianships to meet the specific needs of each allegedly incapacitated person (AIP).³¹ The Legislative Findings and Purpose of Article 81 are highly illustrative of the changing mindsets of that time:

The legislature hereby finds that the needs of persons with incapacities are as diverse and complex as they are unique to the individual. The current system of conservatorship and committee does not provide the necessary flexibility to meet these needs. Conservatorship which traditionally compromises a person’s rights only with respect to property frequently is insufficient to provide necessary relief. On the other hand, a committee, with its judicial finding of incompetence and the accompanying stigma and loss of civil rights, traditionally involves a deprivation that is often excessive and unnecessary. Moreover, certain persons require some form of assistance in meeting their personal and property management needs but do not require either of these drastic remedies. The legislature finds that it is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable. The legislature declares that it is the purpose of this act to promote the public welfare by establishing a guardianship system which is appropriate 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.³²

29. See N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016).

30. Solinski, *supra* note 28, at 450.

31. N.Y. MENTAL HYG. LAW §§ 81.01–81.44 (referring to the individual for whom the guardianship is sought as a person with alleged incapacities, commonly referred to as AIP). *But see* N.Y. SURR. CT. PROC. ACT LAW §§ 1750–61 (McKinney 2016) (referring to the individual as a “mentally retarded or developmentally disabled person,” while case law and common practice, as discussed throughout his article, refer to the individual as a “ward” in Article 17A proceedings). We use “ward” throughout this essay when referring to individuals with intellectual disabilities in Article 17A proceedings and “AIP” when discussing them in the context of Article 81.

32. N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2016).

The legislature set forth similar policies when it reviewed Article 17A in 1990:

[S]ince [Article 17A] was enacted in 1969, momentous changes have occurred in the care, treatment and understanding of [intellectually disabled] 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 are rights and activities which society has increasingly come to recognize should be exercised by such persons to the fullest extent possible. While guardians appointed pursuant to article 17-A of the Surrogate Court Procedure Act must have the authority to make decisions to ensure the ward's best interest, such decision-making authority by the guardian should not infringe on the right of the ward to make decisions when he or she is capable. The legislature also notes that there exists a national consensus that guardianship, for all persons, should be subject to review.³³

Twenty-five years later, there have inexplicably been no changes to Article 17A. Nevertheless, New York courts have found that “the need for reconsideration of our scheme for guardianship of persons with mental retardation and developmental disabilities is greater than ever.”³⁴

Society's evolving understanding of people with intellectual disabilities is reflected in the laws governing their care. Through the mid-twentieth century, lawmakers were primarily concerned with protecting the public from people with intellectual disabilities. By the time Article 17A was adopted in 1969, society's objective had switched to a policy of protecting people with intellectual disabilities from themselves, a paternalistic approach. Arguably, Article 81 is equally paternalistic because it also substitutes a person's decision-making authority for that of a guardian. Many scholars and disability rights activists argue that to truly protect the rights of people with intellectual disabilities, society must depart from this “substituted-decision making” model and adopt a “supported-decision making”

33. *In re* Chaim A.K., 26 Misc. 3d 837, 838 n.1 (N.Y. Sur. Ct. 2009).

34. *In re* Mark C.H., 28 Misc. 3d 765, 769–70 (N.Y. Sur. Ct. 2010).

model.³⁵ Several jurisdictions around the world have already started experimenting with this approach.³⁶

In the meantime, however, practitioners in New York have only Article 17A and Article 81 to choose from. In Part II, this Essay discusses the shortcomings of Article 17A, and how to solve, or at least mitigate, them with the more modern approach of Article 81.

II. ARTICLE 17A'S CENTRAL FLAW IS ITS ADOPTION OF A DIAGNOSIS-DRIVEN APPROACH TO PEOPLE WITH INTELLECTUAL DISABILITIES, RESULTING IN THE UNCONSTITUTIONAL DENIAL OF PROCEDURAL PROTECTIONS THROUGHOUT THE GUARDIANSHIP PROCESS

Article 17A is a “diagnosis-driven” statute because it equates a diagnosis of mental retardation or developmental delay with incompetence.³⁷ Article 17A allows a court to determine that a person is incapacitated and in need of a guardian based solely on the person’s medical diagnosis.³⁸ Under Article 17A, a person is “mentally retarded” if at least two licensed physicians (or one licensed physician and one licensed psychologist), with appropriate experience treating persons with intellectual disabilities, certify that the person is incapable of managing him or herself and/or his or her affairs by reason of mental retardation³⁹ or developmental

35. See, e.g., Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010); see also Glen, *supra* note 16, at 115.

36. Glen, *supra* note 16, at 139–53 (discussing “a number of models that provide for supported decision-making, that reserve substituted decision-making for the most extreme cases of incapacity and that change the very definitions of capacity and incapacity” in jurisdictions including Sweden, Germany, Russia, and Canada).

37. See N.Y. SURR. CT. PROC. ACT LAW § 1750-a (McKinney 2016).

38. See *id.*; *id.* § 1750 (“When it shall appear to the satisfaction of the court that a person is a mentally retarded [or developmentally disabled] person, the court is authorized to appoint a guardian of the person or of the property or of both if such appointment of a guardian or guardians is in the best interest of the mentally retarded [or developmentally disabled] person.”).

39. *Id.* § 1750(1).

disability,⁴⁰ and that the condition is permanent or likely to continue indefinitely.⁴¹

In modern society, it is inappropriate to define someone in terms of their medical diagnosis. A medical diagnosis alone does not provide adequate information regarding a person's functional abilities and limitations. Consider our client Emily. Emily is a thirty-eight-year-old woman who was first referred to LegalHealth for advice about her Medicaid eligibility. She was unable to attend an appointment at the medical clinic due to a scheduling conflict, so her first contact with a LegalHealth attorney was a telephone conversation. During that conversation, Emily struck the LegalHealth attorney as someone who is a good advocate for herself.

When the attorney met Emily face-to-face at a follow up appointment, the attorney discovered that Emily has Down Syndrome. Most people are familiar with some of the distinctive facial features common to people with Down Syndrome,⁴² facial features which often result in a label of "mentally retarded" for their wearers. It is true that Down Syndrome also affects cognitive development.⁴³ However, the severity of the cognitive delays experienced by people with Down Syndrome vary significantly from person to person and are usually characterized as "mild" to "moderate."⁴⁴

Emily lives independently, holds a job, takes public transportation unaccompanied, and pays her own bills every month from her own checking account. Emily's diagnosis does not, in any way, describe Emily's unique abilities and limitations, nor prove that she is unable to handle her own affairs, which she already does. Yet, if Emily's parents sought to be appointed as her guardians through Article 17A, New York courts would not be required to consider anything beyond her physicians' certification of her diagnosis.

40. *Id.* § 1750-a(1). The statute allows that the developmental disability may be attributable to cerebral palsy, epilepsy, neurological impairment, autism, traumatic head injury, dyslexia, or "any other condition found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons." *Id.*

41. *Id.* §§ 1750, 1750-a.

42. *See Facts about Down Syndrome*, CTRS. FOR DISEASE CONTROL & PREVENTION (Mar. 3, 2016), <http://www.cdc.gov/ncbddd/birthdefects/DownSyndrome.html> [<https://perma.cc/WF3J-KBGG>].

43. *Id.*

44. *Id.*

In contrast, Article 81 directs the court to assess the decision-making capacity and functional limitations of the alleged incapacitated person,⁴⁵ rather than focus on any underlying medical condition. To determine whether a person is incapacitated, the court must find by “clear and convincing evidence”⁴⁶ that she or he is both (1) unable to care for her personal needs and/or property, and (2) cannot adequately understand and appreciate the nature and consequences of such inability.⁴⁷ In making this determination, the court must give “primary consideration” to the person’s “functional level and functional limitations.”⁴⁸ Although the court may assess a person’s illness and mental disability,⁴⁹ the statute does not require supporting papers to contain medical information. Furthermore, the court’s assessment of mental illness or mental disability must focus on the way such medical condition affects the AIP’s behavior, cognition, and judgment.⁵⁰

To be clear, Article 17A does not allow the court to appoint a guardian after merely determining that a person is mentally retarded or developmentally disabled, but also requires the court to determine that the person is incapable of managing herself and/or her personal affairs by reason of her mental retardation or developmental disability.⁵¹ However, very little attention is given to a person’s actual abilities, behavior, and judgment. Rather, Article 17A, reflecting the attitudes of society at the time it was adopted, takes for granted that a person who is *diagnosed as* mentally retarded or developmentally disabled *must also be incapable of handling herself and/or her affairs*. As we have seen with Emily and others like her, many people with a diagnosis of mental retardation or developmental disability are *fully capable* of handling themselves and their affairs. Before determining that a person is in need of a guardian, Article 81 requires the court to consider the person as a whole and make a nuanced analysis, linking functional incapacity, inability to understand or appreciate their incapacity, and the likelihood that the person will suffer harm as a result.⁵² In contrast, Article 17A allows the court to make this

45. N.Y. MENTAL HYG. LAW § 81.02(c) (McKinney 2016).

46. *Id.* § 81.12.

47. *Id.* § 81.02(b).

48. *Id.* § 81.02(c).

49. *Id.*

50. *Id.*

51. N.Y. SURR. CT. PROC. ACT LAW § 1750-a (McKinney 2016).

52. N.Y. MENTAL HYG. LAW § 81.15(b) (McKinney 2016).

decision after two physicians have *checked a box* on forms provided by the court.⁵³

In practice, many judges recognize the insufficiency of Article 17A evidentiary requirements. These judges also routinely require those seeking guardianships to supply, in addition to the statements of two physicians, a comprehensive psychological or psychosocial evaluation. Such an evaluation typically includes a description of the person's living arrangements, the extent to which she can independently perform the activities of daily living, her ability to communicate, a description of any physical frailties or limitations, and her interests and how she enjoys spending her time. However, the statute itself requires nothing more than the two physicians' certifications, which may have been completed by a physician who has met the person only once and for the purpose of completing the form. It may be possible to diagnose someone as mentally retarded or developmentally disabled during one brief appointment, but it is not always possible to comprehensively assess her ability to manage herself and/or her own affairs. There is no guarantee that the physician completing the form has any knowledge of the ward's daily routines, degree of independence, or functional capabilities.

Emily has been diagnosed "mentally retarded," but she is far from incompetent. If Emily's family seeks Article 17A guardianship, it is possible that the court would never learn how well she independently manages her own affairs.⁵⁴ By focusing so much on the diagnosis of persons with intellectual disabilities, Article 17A fails to protect the ward at every step of the appointment process. From this flawed premise underlying Article 17A flows a cascade of potential civil rights and due process concerns.

53. N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-a (McKinney 2016) (stating the requirement of two physicians' certifications and the standardized form provided by the chief administrator of courts pursuant to Section 1752); *see also* AFFIDAVIT (CERTIFICATION) OF EXAMINING PHYSICIAN OR LICENSED PSYCHOLOGIST 1-4 (2016), <http://www.nycourts.gov/forms/surrogates/omni/gd17A.pdf> [<https://perma.cc/3XKG-NAKZ>].

54. However, as illustrated in *In re Chaim A.K.*, the court must serve as the gatekeeper in only allowing a 17A guardianship where the individual is mentally retarded and developmentally disabled as defined by statute. 26 Misc. 3d 837, 849-50 (N.Y. Sur. Ct. 2009). If the individual does not meet those criteria, an alternative route often must be taken. *See* Radigan & Hillman, *supra* note 7.

A. Article 17A Fails to Protect People with Intellectual Disabilities by Applying an Unduly Restrictive One-Size Fits All Approach to Guardianship

The only type of guardianship considered by Article 17A is plenary in scope and indefinite in duration. Article 17A allows the petitioner to seek guardianship over the person, their property, or both.⁵⁵ The statute also requires that the court consider and separately determine the person's ability to make health care decisions.⁵⁶ However, if the court determines that a person is able to make their own health care decisions, nothing precludes the court from appointing a guardian to make all other decisions.⁵⁷ In practice, LegalHealth has *never* seen a case in which a court appointed a guardian but left the ward's legal right to make his or her own health care decisions intact. Article 17A provides no other distinction or qualification to limit the guardian's power.

Article 17A's plenary model of guardianship can be attributed to its outdated diagnosis-driven approach. Based on a framework laid out by Article 17A, one might conclude that its drafters assumed that a person is incompetent based on their medical diagnosis, and further assumed that she must be incompetent in all domains.⁵⁸ In contrast, Article 81 recognizes that a person may be limited in some domains, but retain full functional and decision-making capacity in others.⁵⁹ Article 81's text reflects a more sophisticated understanding of intellectual disabilities, noting "that the needs of persons with incapacities are as diverse and complex as they are unique to the individual."⁶⁰ Article 81, therefore, mandates that guardianship should take a form that is "the least restrictive form of intervention which assists [the incapacitated person] in meeting their needs, but at the same time, permits them to exercise the independence and self-determination of which they are capable," and which is "tailored to the individual needs of the person, which takes into 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."⁶¹

55. N.Y. Surr. Ct. Proc. Act § 1750-a (McKinney 2016).

56. *Id.* § 1750.

57. *See id.*

58. *See* N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-a (McKinney 2016).

59. *See* N.Y. Mental Hyg. Law §§ 81.01, 81.29(a) (McKinney 2016).

60. *Id.* § 81.01.

61. *Id.*

David is a twenty-year-old man with “developmental disabilities.”⁶² His primary care physician describes David as having the intellectual capacity of a ten-year-old and referred his mother to LegalHealth. He suggested that his mother seek an Article 17A guardianship. With forms in hand already completed by his doctors, David’s mother sought plenary guardianship over David. It is important to note, however, that someone with the intellectual capabilities of a ten-year-old can reasonably be expected to make some decisions independently. Yet Article 17A does not require the court to determine which affairs David could competently handle himself. Furthermore, Article 17A does not consider David’s appreciation and understanding of his own limitations.

In fact, when the LegalHealth attorney met with David, she recognized that David may have had some learning disabilities that affected his education, but he was nevertheless competent to form an attorney-client relationship. She also recognized that he was competent to form valid, rational opinions about matters affecting his own life. David admitted difficulty navigating government bureaucracies, completing paperwork, as well as understanding and responding to requests from various agencies. He stated that he relies on his mother for assistance and that he trusts her to act in his best interest. Rather than pursue an Article 17A guardianship, LegalHealth assisted David to execute a power of attorney⁶³ and health care proxy,⁶⁴ appointing his mother as his agent.

Now, David’s mother is able to handle many of David’s affairs on his behalf, but she is doing so with his full consent. His personal liberty and autonomy remain intact. If David decides to appoint a different person to manage his affairs in the future, he can revoke the power of attorney. Most importantly, David is young and may still be able to learn the skills necessary to manage more of his own affairs in the future. Once Article 17A guardianship papers are issued, however, there is no further contact from the court; thus, dismantling

62. “Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime.” *Facts about Developmental Disabilities*, CTDS FOR DISEASE CONTROL & PREVENTION (Sept. 22, 2015), <http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html> [<https://perma.cc/XFQ3-GFPR>].

63. A power of attorney is “a written document . . . by which a principal with capacity designates an agent to act on his or her behalf.” N.Y. GEN. OBLIG. LAW § 5-1501(2)(j) (McKinney 2016).

64. A health care proxy is a legal document in which a principal with capacity may delegate the authority to make health care decisions to an agent in the event the principal later loses capacity. N.Y. PUB. HEALTH LAW § 2981 (McKinney 2016).

the guardianship would require David to initiate new proceedings on his own. Being locked into a plenary, open-ended guardianship would be unduly restrictive for David.

B. Article 17A Violates the Ward's Right to Due Process by Failing to Ensure Her Right to Participate in the Guardianship Proceeding

Article 17A fails to protect the respondent's right to participate in the guardianship process. Although the respondent has the right to request an attorney,⁶⁵ many respondents are not adequately informed about the nature of the proceeding and its potentially significant consequences. Needless to say, a lawyer is rarely requested. If the ward is a person so disabled that the court can determine she is in need of a guardian for life pursuant to Article 17A, then surely she should also be appointed a *guardian ad litem* (GAL) to protect her interests during the guardianship proceeding. Although some judges do appoint a GAL to represent the ward in an Article 17A proceeding, it is not required by statute and, in our experience, is seldom done.

Consequently, respondents with intellectual disabilities go without advocates in the courtroom. Consider the case of David discussed above.⁶⁶ Although David may possibly have the intellectual capabilities of a ten-year-old child, a ten-year-old child is certainly capable of having some valid and legitimate opinions concerning his living arrangements, social associations, medical treatment, and how his resources are spent. Indeed, children are always appointed a lawyer in Family Court proceedings when custody or guardianship arrangements are being decided.⁶⁷ The child's lawyer must regularly consult and advise the child in a manner consistent with the child's capacities throughout the course of the proceedings.⁶⁸ Lawyers are further instructed to ascertain the child's position and advocate

65. N.Y. Surr. Ct. Proc. Act Law 401 (McKinney 2016) (stating that competent adults can appear by their attorney), § 407(b) (stating that the court has discretion to appoint an attorney for indigent persons). However Sections 402(2) and 403(b) provide that the court may appoint a *guardian ad litem* in its discretion for a person "under disability." *Id.* §§ 402(2), 403(2).

66. See discussion *supra* Part II.A.

67. N.Y. Fam. Ct. Act § 249 (McKinney 2016).

68. See N.Y. State Supreme Court, Appellate Div., Fourth Dep't, Ethics for Attorneys for Children (2016), <https://www.nycourts.gov/courts/ad4/AFC/AFC-ethics.pdf> [<https://perma.cc/SZX4-9FCU>] (containing Section 7.2 of the Rules of the Chief Judge).

zealously according to the child's wishes, even when the lawyer believes the child's preferences are not in the child's best interests.⁶⁹

The concerns that motivate this requirement in Family Court also exist in adult guardianship proceedings. David and all other adults with intellectual disabilities should have someone to advise them and to help them articulate their preferences and desires in proceedings that impact their personal autonomy and decision-making authority. It is not right that Article 17A often allows guardianship papers to be granted without representation for the subject of the proceeding.

Article 81 also provides that the AIP has the right to court appointed counsel if requested.⁷⁰ In the event that the AIP does not request counsel, however, Article 81 provides a safeguard to ensure that the court does not only consider information submitted by a party with adverse interests to the AIP. Article 81 requires the appointment of a court evaluator at the commencement of every proceeding.⁷¹ A court evaluator does not represent the AIP. Rather, court evaluators are neutral agents of the court tasked with investigating the AIP's functional level and limitations and making a formal written recommendation to the court regarding whether intervention is needed, the least restrictive form of intervention, and the appropriateness of the proposed guardian.⁷² At a minimum, the court evaluator must meet, interview, and consult with the AIP, explain the proceeding and consequences in a language and manner that the AIP understands, inquire whether the AIP wants or needs an attorney, consult with any experts having specialized knowledge in the area of the alleged incapacity, interview the petitioner, and investigate any conflicts of interest that the petitioner may have in seeking guardianship.⁷³

A recent LegalHealth experience illustrates the perilous consequences of Article 17A's reliance on the good intentions of petitioners and the corresponding lack of protections for the respondents. John is a fifty-eight-year-old autistic and mentally retarded man, as defined by Article 17A. LegalHealth recently represented John's father and sister in an Article 17A proceeding. As required by the statute, both John's primary care physician and a licensed psychologist provided affidavits on the standard court-

69. *Id.*

70. N.Y. MENTAL HYG. LAW § 81.10 (McKinney 2016).

71. *Id.* § 81.09(a).

72. *Id.* § 81.09(c)(5).

73. *Id.* § 81.09(c).

mandated forms.⁷⁴ At the request of the court, a comprehensive psycho-social evaluation was completed and submitted to the court by Young Adult Institute, Inc. (YAI), a network of agencies offering people with intellectual and developmental disabilities a wide range of services.⁷⁵

John's physician and the psychologist both checked the boxes, stating the he is mentally retarded and developmentally disabled. YAI described John as an ambulatory, non-verbal male, who appeared well groomed and seasonally dressed. The psychologist wrote that he was cooperative during the interview and kept eye contact, though he was unable to respond to any questions posed to him. Though he is now non-verbal, the evaluation detailed that John had been able to say a few words in his youth and had attended public school where he was enrolled in special education classes through graduation. They concluded that John's receptive and expressive abilities are poor and that he requires a large amount of assistance with his activities of daily living, such as brushing his teeth, bathing, dressing, and undressing. The New York State Office of Children and Family Services performed the required background check on both John's father and sister.⁷⁶ John and his family appeared at a hearing in Surrogate's Court. John's father and sister were appointed his guardian and standby guardian respectively. Our office closed the file and wished John and his family luck.

Six months later, John's father and sister returned to our office, alarmed over a notice that John's homecare services were being terminated. We agreed to investigate their case for possible representation. As part of our investigation, we requested John's file from the homecare agency. The file contained numerous allegations of verbal abuse and maltreatment committed by the father and sister against many of John's home attendants. Even more disturbing was an allegation of physical abuse directed at John. We also learned that this was not the first time the family had to dispute loss of homecare services due to similar allegations.

John's Article 17A guardianship proceeding went very smoothly and was very routine. All requirements built into the statute, as well

74. See N.Y. Surr. Ct. Proc. Act Law § 1752 (McKinney 2016).

75. See YAI, [www.yai.org \[https://perma.cc/3TJM-GP7R\]](https://perma.cc/3TJM-GP7R).

76. See N.Y. Surr. Ct. Proc. Act § 1706(2) (McKinney 2016) (requiring the Department of Social Services to do a background check), § 1761 (stating that all provisions for proceedings for an "infant," as set forth in Article 17 of the SCPA, shall apply in proceedings for a "mentally retarded" or "developmentally disabled" person pursuant to Article 17A).

as the extra protections mandated by the court, were satisfied. Yet, there was nothing in this process that tipped off either LegalHealth or the court that the appointment of John's father and sister as guardians may not have been in John's best interest. Due process requires the appointment of an attorney or GAL in every guardianship proceeding. At a minimum, there should be a provision to ensure that the only evidence before the court is not submitted by an interested party with motivation to lie, obscure, or omit crucial information. Were this an Article 81 proceeding, or were Article 17A to provide for it, a conscientious court evaluator would have ideally spoken to John's home attendants and requested a copy of his file. A GAL or attorney for John would also have been expected to collect such information and assist John to articulate any preferences or concerns that he may have had.

Although John had a guardianship hearing, this is not required in Article 17A proceedings.⁷⁷ In contrast to Article 17A, a hearing must always be held in Article 81 proceedings.⁷⁸ With few exceptions, the presence of the AIP in Article 81 proceedings is required at the hearing "so as to permit the court to obtain its own impression of the person's capacity."⁷⁹

As attorneys for the petitioners, LegalHealth also faced an ethical dilemma upon learning of the alleged abuse of John post-appointment. Rule 1.6 of the New York State Rules of Professional Conduct states, in relevant part, that "(b) a lawyer may reveal or use confidential information to the extent that the lawyer reasonably believes necessary: (1) to prevent reasonably certain death or substantial bodily harm."⁸⁰ While we learned of various accusations of verbal hostility aimed at home health aides and one incident of alleged physical abuse of the ward, our clients insisted they were complete fabrications. We did not have any actual knowledge of abuse taking place. The alleged abuse listed in a complaint was, specifically, a slap across John's face when he refused to take his medications. Based upon the accusations, which we learned of second-hand in a homecare agency file, we had no reasonable basis

77. *Id.* § 1754(1) ("[T]he court may in its discretion dispense with a hearing for the appointment of a guardian and may in its discretion appoint a *guardian ad litem*, or the mental hygiene legal service . . . to recommend whether the appointment of a guardian . . . is in the best interest of the . . . disabled person.").

78. N.Y. MENTAL HYG. LAW § 81.11 (McKinney 2016).

79. *Id.* § 81.11(c).

80. N.Y. COMP. CODES R. & REGS. tit. 22, § 1200.0 (2016) (citing Rule 1.6).

upon which to conclude the ward was subject to a threat of reasonably certain death or substantial bodily harm.

As horrific as slapping a person with intellectual disabilities is, upending a guardianship based on second-hand accusations is a drastic move without further evidence. Moreover, it is not permitted by Rule 1.6(b). Rule 1.6 strictly prohibits the revelation of a client's confidential information.⁸¹ "The confidentiality duty applies not only to matters communicated in confidence by the client, which are protected by the attorney-client privilege, but also to all information gained during and relating to the representation, whatever its source."⁸² Revealing confidential information is permitted, though not required, under Section (b). Without more concrete evidence of abuse—and more precisely, a reasonably certain likelihood of *future* substantial bodily harm—rising to the level defined by Rule 1.6, we were not permitted, in this instance, to reveal the information.

We also made the very difficult decision not to represent John, via his guardians, in the homecare case. While we feel this was the appropriate decision in this case, it is important to clarify that the standard used when deciding to represent any person on a totally new matter is different than the standard used when deciding whether to report an existing client's alleged misconduct to authorities. Taking on a new case for an individual is, of course, never an obligation; and, due to a general lack of resources in civil legal aid organizations, representation has to be prioritized out of necessity. Considering these different standards, we deemed it inappropriate to represent the guardians in the home care matter and inappropriate to report the guardians to the court.

This dilemma is a perfect, yet unfortunate, illustration of the position in which lawyers can be put when navigating the lack of protections available in Article 17A. It is very possible that the allegations against our clients were untrue and the statute worked as intended. It is equally possible that due to the lack of procedural protections, an abusive guardian slipped through the cracks. At this point, the only party involved in John's guardianship proceeding, with knowledge of the allegations, is ethically prohibited from revealing the information. Under Article 17A, it has become apparent that to avoid situations like John's, lawyers must either refuse to represent

81. *See id.* (citing Rule 1.6).

82. *Id.* (citing Rule 1.6, Comment [3]).

clients in Article 17A proceedings or take extraordinary precautions.⁸³

C. Article 17A Endangers Persons with Intellectual Disabilities by Providing No Post-Appointment Protections

If not avoided in the first instance, John's situation could have potentially been corrected if Article 17A contained appropriate post-appointment procedural protections. After a guardian is appointed for an adult with intellectual disabilities in Article 17A proceedings, the court issues guardianship papers and has no further contact with either the ward or the guardian. We attribute this to the same diagnosis-driven approach that results in the severe lack of pre-appointment protections. The attitude of the legislature that enacted Article 17A seemed to be that mental retardation is permanent and hopeless, so any further monitoring by the court would be useless.⁸⁴ Even if this were correct, there is no rational basis to believe that a guardian, once appointed, will fulfill her duties competently and with good faith for the rest of time. Such lack of oversight is misguided.

In contrast, Article 81 offers post-appointment protections in two important ways. First, Article 81 seeks to ensure that all incapacitated people are appointed a guardian who is sufficiently capable. Pursuant to Section 81.39, upon appointment, all guardians are required to complete a court-approved training course that covers the legal responsibilities of the guardian, the rights of the incapacitated person, the benefits and resources available to incapacitated persons, and provides instructions on how to complete the initial and annual reports.⁸⁵

Second, Article 81 provides for continuous oversight by the court by requiring the guardian to file an initial report within ninety days of appointment, and an annual report for every year of service.⁸⁶ The initial report requires the guardian to provide an inventory of the property and financial resources of the incapacitated person, as well as the guardian's plan for management of such resources.⁸⁷ To the

83. See discussion *infra* Part IV.B.

84. The legislative history states that the purpose of Article 17A was to provide parents a lifetime guardianship because "the present law does not take into account the unique status of a retardate in that the fact and degree of retardations and the need for guidance and assistance are determinable from a very early age and remain so for life." Bailly & Nick-Torok, *supra* note 9, at 819 (quoting 1969 N.Y. LEGIS. ANN. 25, 325).

85. N.Y. MENTAL HYG. LAW § 81.39 (McKinney 2016).

86. *Id.* § 81.30.

87. *Id.*

extent the guardian has been granted powers over the person, the initial report must include a summary of all visits the guardian has paid to the incapacitated person, steps taken to provide for the person's personal needs, and a plan to provide for the future needs of the incapacitated person, including medical care, social services, and public benefits.⁸⁸ The guardian must file the initial report with the court and mail copies to the court evaluator, counsel for the incapacitated person, and the incapacitated person herself.⁸⁹

The guardian's annual report must include current contact information for both the guardian and incapacitated person, an account of how the guardian has managed the incapacitated person's property, and a statement regarding any change to the person's physical or mental condition over the past year.⁹⁰ The guardian is required to have the incapacitated person's functional abilities and limitations evaluated by an appropriate medical professional within three months prior to the filing of the annual report and the medical professional's written evaluation is a required component of the annual report. A list of all medical treatment provided to the incapacitated person must be included, as well as a plan for any medical treatment needed in the upcoming year.⁹¹ The guardian's annual report even requires information concerning the social condition of the incapacitated person, such as social services used and a description of the person's social skills and social needs.⁹²

The protections provided by Article 81 are not failsafe. Undoubtedly, some incapacitated persons fall through the cracks and have abusive or neglectful guardians. However, the existence of these protections alone elevates Article 81 far above Article 17A. In fact, at least one New York court has applied the *Mathews v. Eldridge* three-prong due process test⁹³ to determine that, as currently written, Article 17A is unconstitutional due to the lack of post-appointment periodic reporting and review for guardians of the person.⁹⁴ And, similar to our discussion above in Part II.A, another New York court found Article 17A unconstitutional due to its unduly restrictive, plenary nature.⁹⁵ We discuss both of these cases in the next section.

88. *Id.*

89. *Id.*

90. *Id.* § 81.31.

91. *Id.*

92. *Id.*

93. 424 U.S. 319 (1976).

94. *In re Mark C.H.*, 28 Misc. 3d 765, 776–87 (N.Y. Sur. Ct. 2010).

95. *See In re Dameris L.*, 38 Misc. 3d 570 (N.Y. Sur. Ct. 2012).

D. Recent Court Attempts to Salvage Article 17A

Many have argued that Article 17A is unconstitutional—under both the New York State and the federal constitutions—based on the lack of procedural protections afforded to individuals with intellectual disabilities discussed in Parts II.A-C. In response, some New York courts have read additional procedural protections into the statute. Some recent decisions, two of which are discussed below, are illustrative of the constitutional concerns and how the courts have endeavored to salvage Article 17A by reading in due process protections not specifically required by the statute.

1. *In re Mark C.H. and Annual Reporting Requirements After Appointment of a Guardian*

In 2010, the New York Surrogate's Court decided *In re Mark C.H.* and found that, in order to comply with constitutionally protected due process requirements, annual reporting must be read into Article 17A.⁹⁶

Mark was an adopted child diagnosed with autism at age seven.⁹⁷ He was institutionalized following the death of his adoptive mother from cancer.⁹⁸ At age fourteen, he entered a residential center for people with autism.⁹⁹ Mark's adoptive mother left behind a sizeable estate.¹⁰⁰ After her death, an Article 17A proceeding was initiated by a co-trustee of a three million dollar trust to which Mark was the beneficiary.¹⁰¹

The health care providers at Mark's autism facility described him "as suffering from 'profound' mental retardation and autism."¹⁰² According to the physician, Mark is "'nonverbal, has poor social skills,' 'engages in numerous repetitive and self-stimulating behavior' and 'exhibits aggressive behavior when placed in unfamiliar settings . . . includ[ing] spitting, throwing objects, and hitting his own head.'"¹⁰³ Based on the latter, the professionals recommended that Mark's appearance at the Article 17A hearing be dispensed with.¹⁰⁴

96. *See Mark C.H.*, 28 Misc. 3d 786–787.

97. *Id.* at 766.

98. *Id.*

99. *Id.*

100. *Id.*

101. *Id.* at 767.

102. *Id.* at 766.

103. *Id.* (alteration in original).

104. *Id.*

The court appointed a Mental Hygiene Legal Services attorney to represent Mark.¹⁰⁵ The co-trustee petitioner had never visited Mark prior to the initiation of the guardianship proceedings and never contacted authorities at the autism center.¹⁰⁶ Moreover, the three million dollars in the trust had not been spent on Mark at the time of the hearing.¹⁰⁷ Additionally, a GAL was appointed, and the petitioner was ordered to meet with Mark for the first time.¹⁰⁸

Using funds from the trust, the trustees acquired a certified care manager to assess Mark.¹⁰⁹ Despite his diagnosis of profound mental retardation and autism, the care manager observed Mark in “a classroom setting, noting that ‘though he is non-verbal, he appeared to respond appropriately to questions asked by classroom staff, using picture symbols and non-verbal gestures to communicate with others.’”¹¹⁰ The certified care manager was told by personnel at the autism center where Mark resided that Mark “‘enjoys swinging and climbing outdoors’ but, unfortunately, ‘there is no playground in the vicinity of his residence.’”¹¹¹

Mark received ongoing care management, access to more appropriate medications, and graduated from his educational program.¹¹² At the time of the proceedings, he was enrolled in vocational training and seeking community placement.¹¹³ The court found that “[a]lthough his basic needs were met, he lacked the resources to reach his best potential and to thrive.”¹¹⁴ The court further observed that “[t]he facts in this case dramatically demonstrate why a statute that gives a guardian control over the life of a person with mental retardation and/or developmental disabilities must include provision for periodic court review.”¹¹⁵

The court used the three-pronged test found in *Mathews v. Eldridge*¹¹⁶ to answer the question, “What process is due?”¹¹⁷ The

105. *Id.* at 767 n.3.

106. *Id.* at 767.

107. *Id.*

108. *Id.*

109. *Id.* at 768.

110. *Id.*

111. *Id.*

112. *Id.* at 769.

113. *Id.*

114. *Id.*

115. *Id.*

116. 424 U.S. 319 (1976) (addressing the Due Process Clause of the Fifth Amendment as it pertains to an individual’s right to a pre-termination hearing prior to losing Social Security disability benefits); *see also Mark C.H.*, 28 Misc. 3d at 776

first prong asks what private interest will be affected by the action.¹¹⁸ The second prong evaluates “the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any of additional or substitute procedural safeguards.”¹¹⁹ The third prong instructs the court to weigh the “[g]overnment’s interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirement would entail.”¹²⁰

The court easily answered the first prong, noting that “imposition of virtually complete power over the ward clearly and dramatically infringes on a ward’s liberty interests.”¹²¹ As to the second prong, the court concluded that “without periodic reporting and review, [Article 17A] could leave functioning, capacitated adults with guardians whose powers constitute a ‘massive curtailment of liberty.’”¹²² The court iterated that “[w]ith a periodic reporting and review requirement . . . the court can ascertain whether the deprivation of liberty resulting from guardianship is still justified by the ward’s disabilities, or whether she has progressed to a level where she can live and function on her own.”¹²³ Additionally, and similar to the LegalHealth example involving John and his family,¹²⁴ the court noted:

Much more likely, but equally serious, is the possibility that a guardian is no longer acting in the ward’s best interests. The guardian may have removed the ward from a program providing habilitation services for her own convenience but to the ward’s detriment. She may fail to attend to the ward’s physical health needs. She may have confined the ward to a single room, without outside stimulation, for years, causing the ward to “lose” the skills and capacities she learned while still in the educational system. She may fail to provide for the ward properly because she lacks

(addressing how analysis of an individual’s procedural due process rights under New York State statute falls under the Due Process Clause of the Fourteenth Amendment).

117. *Mark C.H.*, 28 Misc. 3d at 776. *But see In re Chaim A.K.*, 26 Misc. 3d 837 (N.Y. Sur. Ct. 2009) (refusing to read in additional protections and denying the Article 17A petition without prejudice to commencing an Article 81 guardianship proceeding).

118. *Mark C.H.*, 28 Misc. 3d at 776.

119. *Id.* (quoting *Mathews*).

120. *Id.*

121. *Id.*

122. *Id.* at 778 (internal citations omitted).

123. *Id.* at 777–78.

124. *See* discussion *supra* Part II.B.

knowledge of how to do so, often because of language limitations, or she may herself have become disabled, or partially disabled.¹²⁵

In its discussion of the third prong, the court noted that the policy of New York State is “the promotion and attainment of independence, inclusion, individuality and productivity for persons with mental retardation and developmental disabilities.”¹²⁶ The court explained that the government’s interest was “nothing less than ensuring that when, in the exercise of its *parens patriae* power, it places almost total control over a person with disabilities in the hands of another, that person is, at the very least, no worse off than she would have been had no guardianship been imposed.”¹²⁷ After its evaluation of the three-pronged *Mathews* test, the court held:

[I]t is clear that a court granting guardianship of the mentally retarded and developmentally disabled must require periodic reporting and review—or “monitoring”—by 17-A guardians of the person, even as it does, by statute, of 17-A guardians of the property. This monitoring requirement is inherent not only in the Fourteenth Amendment guarantee of due process of law, but also under the international human rights norms contained in the [Convention and Optional Protocol on the Rights of Persons with Disabilities] and the [International Covenant on Civil and Political Rights].¹²⁸

2. *In re Dameris L. and the Least Restrictive Alternative to Achieve the State’s Goal*

Guardianship should be a last resort. Before subjecting someone to such a “[d]raconian loss of liberty,”¹²⁹ as an Article 17A guardianship, it must be determined that there is not a less restrictive alternative available. In *In re Dameris L.*, the court found that Article 17A would violate the due process guarantees of both the U.S. Constitution and New York State Constitution unless it was “read to include the requirement that guardianship is the least restrictive alternative to achieve the state’s goal of protecting a person with intellectual disabilities from harm connected to those disabilities.”¹³⁰ In *Dameris L.*, a mother petitioned for guardianship over her twenty-nine-year-old daughter, Dameris, who was found to

125. *Mark C.H.*, 28 Misc. 3d at 778.

126. *Id.* at 780.

127. *Id.*

128. *Id.* at 786–87.

129. *In re Dameris L.*, 38 Misc. 3d 570, 576 (N.Y. Sur. Ct. 2012).

130. *Id.* at 579.

have “mild to moderate mental retardation, and to be ‘functioning at the mental age of a seven year old.’”¹³¹ She reportedly had “poor receptive and expressive skills—[and, while] ambulatory and able to care for most of her grooming needs, she [was] highly dependent for all other needs, including medical and financial matters.”¹³² Moreover, she was “sporadically[] attending a day adult habilitation program . . . where she was learning, and supervised in, cleaning tasks, particularly cleaning bathrooms.”¹³³

Dameris was also married.¹³⁴ When Dameris was pregnant, her mother petitioned for a guardianship under Article 17A.¹³⁵ At the hearing, Dameris’ husband appeared, initiating a “struggle over control of Dameris.”¹³⁶ The court concluded that “Dameris, very visibly pregnant, showed flat affect, spoke haltingly and in a limited way, and, on all of the evidence adduced at the hearing, appeared incapable of caring for herself and her soon to be born baby.”¹³⁷

Nobody in Dameris’ family spoke English.¹³⁸ They were also all people with disabilities, receiving Supplemental Security Income (SSI) and other public benefits.¹³⁹ The court appointed a GAL to assist Dameris.¹⁴⁰ The primary issue at the hearing was over responsibility for Dameris and her baby after she gave birth.¹⁴¹ The court found an attorney to assist as a *pro bono* mediator in the proceedings, which helped Dameris’ mother and husband agree on an arrangement in which they were appointed co-guardians.¹⁴²

Dameris and her husband then had a subsidy cut off resulting in the loss of their housing.¹⁴³ At the time, Dameris’ mother was out of the country and her husband petitioned to revoke Dameris’ mother’s co-guardianship.¹⁴⁴ The court temporarily relieved Dameris’ mother as guardian until her return to New York.¹⁴⁵ At the hearings after the

131. *Id.* at 571–72.

132. *Id.* at 572.

133. *Id.*

134. *Id.*

135. *Id.* at 571–72.

136. *Id.* at 572.

137. *Id.*

138. *Id.*

139. *Id.*

140. *Id.*

141. *Id.* at 572–73.

142. *Id.* at 573.

143. *Id.* at 573–74.

144. *Id.* at 574.

145. *Id.*

mother's return, Dameris appeared more confident and dealt appropriately with her children.¹⁴⁶ She had become friendly with her neighbors who were assisting her.¹⁴⁷ The couple now presented more as partners as opposed to guardian and ward.¹⁴⁸ As a result, the court terminated the Article 17A guardianship.¹⁴⁹

Due to Dameris' mother moving out of state and consenting to terminate the guardianship, the court lost jurisdiction over Dameris and the guardianship ended.¹⁵⁰ The court explained, however, that:

[E]ven if this were not the case, I would find that guardianship is no longer warranted because there is now a system of supported decision making in place that constitutes a less restrictive alternate to the Draconian loss of liberty entailed by a plenary 17-A guardianship. This use of supported decision making, rather than a guardian's substituted decision making, is also consistent with international human rights, most particularly article 12 of the United Nations Convention on the Rights of Persons with Disabilities.¹⁵¹

The Court ultimately held that:

In order to withstand constitutional challenge, including, particularly, challenge under our own State Constitution's due process guarantees, SCPA article 17-A must be read to include the requirement that guardianship is the least restrictive alternative to achieve the State's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, the court must consider the availability of "other resources," like those in Mental Hygiene Law § 81.03 (e), including a support network of family, friends and professionals before the drastic judicial intervention of guardianship can be imposed.¹⁵²

Due to its diagnosis-driven approach, Article 17A fails at every stage of the guardianship process to protect people with intellectual disabilities from a total loss of liberty and to allow them an opportunity to reach their full potential. Unfortunately, Article 17A was not enacted with these purposes in mind. As we discuss below,

146. *Id.*

147. *Id.* at 575.

148. *Id.*

149. *Id.* at 576.

150. *Id.*

151. *Id.* (emphasis omitted).

152. *Id.* at 578–79 (emphasis added); *see also In re John J.H.*, 27 Misc. 3d 705, 711 (N.Y. Sur. Ct. 2010) (holding that 17A is unduly restrictive and recommending that reform of the statute be undertaken in light of developments in the "care, treatment and understanding of [mentally retarded or developmentally disabled] individuals, as well as new legal theories and case law relating to the rights of such persons").

Article 17A also fails to live up to the purposes for which it was enacted.

III. ARTICLE 17A DOES NOT LIVE UP TO ITS ORIGINAL PURPOSE OF ELIMINATING THE COSTS AND COMPLICATIONS INVOLVED IN GUARDIANSHIP PROCEEDINGS AND IS NOT, IN PRACTICE, LESS ONEROUS THAN ARTICLE 81 GUARDIANSHIPS

At the time it was adopted, Article 17A was intended to be a less onerous process for parents of “retardates” than the costly and complex procedures of the committee and conservatorship laws in existence at the time.¹⁵³ Thus, Article 17A is an abbreviated proceeding in Surrogate’s Court that uses standardized forms to prove incompetence and, pursuant to the statute, does not even require a hearing.¹⁵⁴ Citing the expense and complexity of Article 81, some practitioners still argue that Article 17A is a valuable planning document for parents to maintain continuous care for their children with intellectual disabilities, and to hand pick a successor for when they are no longer able to care for their children themselves.¹⁵⁵

Article 17A, however, sacrifices procedural protections and the due process rights of adults with intellectual disabilities in the name of simplicity and convenience for their caretakers. In our experience, the supposed simplicity and convenience of Article 17A is grossly exaggerated. Without representation, even the abbreviated proceeding contemplated by Article 17A is too complicated and unattainable for many of our clients.

Although Article 17A is thought to be easier for *pro se* petitioners because the petition and supporting documents are all available as court provided standardized forms, the forms are still too complicated for most of our clients to complete independently. One form requires the proposed guardian to provide her address history, as well as the

153. Bailly & Nick-Torok, *supra* note 9, at 818 n.3 (“A statutory provision which will provide for lifetime guardianship of a retarded individual to eliminate the cost and complications caused by a separate proceeding in a separate court at age 21, eliminate the possibility of many retarded individuals being without necessary guidance after age 21, and to distinguish between guardianship for the retarded and committeehip for the mentally ill.”); *see also id.* at 819. (the legislature expressed that a purpose of Article 17A was to “provide for [a] lifetime guardianship” because “[t]he present law does not take into account the unique status of a retardate in that the fact and degree of retardation and the need for guidance and assistance are determinable at a very early age and remain so for life.”).

154. N.Y. Surr. Ct. Proc. Act Law § 1754 (McKinney 2016) (“The court may in its discretion dispense with a hearing for the appointment of a guardian.”).

155. Radigan & Hillman, *supra* note 7.

address history for any person eighteen-years-old or older who lives with her, for the past twenty-eight years.¹⁵⁶ This form is not formatted intuitively and does not provide clear directions on which addresses to include. It sometimes requires several submissions and rejections before the form is deemed sufficient and accepted by the clerk for filing. For example, our office has been advised by the Surrogate's Court clerk to "guess" when our clients cannot remember the street number or dates that they lived at a certain address.

In our experience, at least in New York City where we practice, the courts are aware that the statutory requirements of Article 17A do not adequately protect the interests of the person for whom guardianship is sought. In response, the courts have bolstered the filing requirements beyond what is required by statute. For example, in addition to two physicians' affidavits, the courts usually require a comprehensive psychosocial evaluation or psychological report. This is usually an eight to ten page evaluation describing the ward's living situation, biographical history, and functional level in greater detail than the physicians' affidavits. The courts also do not schedule a case for hearing if the physicians' affidavits were completed more than one year prior to the next available hearing date. Instead, the courts require that the petitioner complete the affidavits again.

The statutory focus on the diagnosis of wards produces other practical hurdles for our clients as well. The physicians' affidavits are often a burden for our clients to complete. The primary care physician affidavit is usually not difficult to obtain. But many of our clients do not have a regularly treating psychiatrist, neurologist, or someone else qualified to complete the second affidavit. In those instances, they need a referral to a specialist for the sole purpose of completing the second affidavit.

Many physicians also refuse to complete the affidavit on the (valid) basis that they have only met with the ward once and lack sufficient evidence to render an opinion on the ward's competency. If the physician completes the form, he or she may do a cursory job that the court may later reject for not containing sufficient detail. As a result, our clients pay for an additional appointment with a specialist for no real benefit.

We refer many of our clients whose loved one with intellectual disabilities does not have a regularly treating physician to non-profit

156. See N.Y. STATE OFFICE OF CHILDREN & FAMILY SERVS., REQUEST FOR INFORMATION GUARDIANSHIP FORM (2013), <https://www.nycourts.gov/forms/surrogates/omni/OCFS3909.pdf> [<https://perma.cc/A246-5KDK>].

organizations, such as YAI¹⁵⁷ or AHRC.¹⁵⁸ These non-profit organizations are able to complete the physicians' affidavits as well as provide comprehensive psychosocial evaluations.¹⁵⁹ However, the waiting list for an appointment may be six months or more. Often, by the time the second affidavit is complete, the first one is more than a year old and must be redone.

Another hurdle for many of our clients involves giving proper notice to all interested parties. If living, the statute requires that both parents and all adult siblings—and anyone else that may have had a close relationship with the ward—be served with Notice of Petition.¹⁶⁰ Many of our clients are single parents. Often, our clients' partners abandoned them when their children were young. As a result, our clients have had little, if any, contact with their partners for several years.

Finding a missing parent on whom to serve the Notice of Petition, not to mention finding all of the missing parent's children with other people (i.e., half-siblings of the ward) is a daunting and overwhelming task to most of our clients. Although the statute does not require it, the courts prefer a Waiver of Process Renunciation and Consent to Appointment of Guardian (“Waiver and Consent”) from parents,¹⁶¹ a form in which the parent not seeking guardianship may consent to the appointment of a guardian for the ward and waive all future service.¹⁶² If the parent's whereabouts are known, the court has insisted upon the Waiver and Consent and rejected proof of service of the Notice of Petition.

In our experience, petitioners are generally loving people with limited means and education doing their best to support and care for their loved ones with sometimes severe disabilities. When faced with gathering all of the information required for a guardianship proceeding, scheduling multiple medical appointments, and navigating the filing and service requirements, parents often become overwhelmed and give up. Despite our best efforts to assist clients with this process, a significant proportion of parents do not follow

157. *See* YAI, *supra* note 75.

158. AHRC NEW YORK CITY, <https://www.ahrcnyc.org> [<https://perma.cc/QM3H-7NHN>].

159. *Id.*; *see also* YAI, *supra* note 75.

160. N.Y. SURR. CT. PROC. ACT LAW § 1753 (McKinney 2016).

161. *See* WAIVER OF PROCESS RENUNCIATION AND CONSENT TO APPOINTMENT OF GUARDIAN 1–2 (2004), <https://www.nycourts.gov/courts/6jd/forms/SRForms/17A-Waiver.pdf> [<https://perma.cc/WQR9-G9YR>].

162. *Id.*

through, lose touch with us, and never complete the guardianship process.

Our point is not that notice should not be required for extended family members, nor that outdated medical reports should be sufficient for determining that a person is incapacitated. Rather, Article 17A is not the streamlined, *pro se*-friendly proceeding for the parents of adults with intellectual disabilities it was intended to be. The burdens and difficulties of completing an Article 17A proceeding are not significantly less than the requirements for an Article 81 proceeding. Thus, many of the protections and due process rights of the ward are sacrificed for no real gain in convenience or simplicity.

IV. RECOMMENDATIONS

A. Article 17A Should Be Repealed

The unconstitutional lack of due process protections and the diagnosis-driven approach of Article 17A are indefensible. For these reasons, Article 17A ought to be repealed and all guardianship proceedings in New York should be brought pursuant to Article 81. Article 81 solves many of the due process concerns that Article 17A presents by requiring narrowly crafted guardianships. Article 81 only grants a guardian those powers necessary to provide for the AIP demonstrated by clear and convincing evidence of incapacity.¹⁶³ Article 81's standard focuses on the functional level of the AIP, requiring the appointment of a court evaluator,¹⁶⁴ the filing of annual reports by the guardian,¹⁶⁵ and guardianship training.¹⁶⁶

The underlying cause of mental disability (i.e., the diagnosis) should not be the focus of a guardianship proceeding, nor should it determine what procedural protections a person is afforded. Given that Article 81 is a far superior piece of legislation, and more in line with contemporary standards of treatment of people with intellectual disabilities, Article 81 should be used for all guardianships in New York.

If repeal of Article 17A, however, is politically infeasible, the only other acceptable policy reform would be to complete the review of the statute mandated twenty-five years ago. Under such a review, the legislature would undertake a complete overhaul of Article 17A in

163. N.Y. MENTAL HYG. LAW §§ 81.01–81.02 (McKinney 2016).

164. *Id.* §§ 81.02, 81.09.

165. *Id.* § 81.31.

166. *Id.* § 81.39.

order to bring it line with the more evolved “care, treatment and understanding of [mentally retarded and/or developmentally disabled] individuals” of today.¹⁶⁷

On the other hand, it is difficult to see what the value of these reforms would be, as opposed to repeal. The major argument for keeping Article 17A—which we have already shown is highly suspect¹⁶⁸—is the ease, convenience, and affordability it may provide *pro se* parents or guardians. Even so, it is difficult to see how these supposed benefits could carry over to an Article 17A proceeding with the appropriate safeguards and procedural protections in place. It makes more sense to repeal Article 17A and enact the reforms necessary to make Article 81 more accessible and more affordable for guardians.¹⁶⁹

Of course, the repeal of Article 17A would necessitate some changes to Article 81. Article 81 should be more accessible to people of lesser means. That would mean lower fees, a reduction in paperwork, and greater access to counsel—which of course would require increased funding to legal services organizations and a push for more *pro bono* assistance from the legal community at large.

Still, it would be remiss of us not to mention at least some of the negative aspects of Article 81 guardianships as well as the direction in which a large portion of the international community and many leading advocates in the United States are headed in terms of protecting and nurturing the autonomy of individuals with intellectual disabilities.¹⁷⁰ These advocates argue for a move away from a

167. *In re* John J.H., 27 Misc. 3d 705, 711 (N.Y. Sur. Ct. 2010).

168. *See* discussion *supra* Part III.

169. The fees associated with an Article 81 guardianship in New York Supreme Court are an index number fee of \$210, *see* N.Y. C.P.L.R. 8018(a)(1), (3) (McKinney 2016), and a request for judicial intervention fee of \$95, *see* N.Y. C.P.L.R. 8020(a) (McKinney 2016); *see also* *Filing Fees*, N.Y. COURTS, (Sept. 22, 2015), <https://www.nycourts.gov/forms/filingfees.shtml> [<https://perma.cc/TK9Z-4ZXR>]. The post-appointment training for the guardian could be \$435. *See* NEW YORK CITY BAR, <http://www.nycbar.org/component/content/article/3-cle-regular/1422-skills> [<https://perma.cc/DW8S-V3D6>]. For a range of certified training programs and fees, *see* N.Y. STATE COURTS, SCHEDULE OF CERTIFIED TRAINING PROGRAMS FOR PART 36 FIDUCIARIES AND APPOINTEES, <https://www.nycourts.gov/ip/gfs/trainingprograms.pdf> [<https://perma.cc/ZD5A-ZENN>]. Due to the scarcity of *pro bono* legal services offering assistance with Article 81 guardianships, a petitioner would also have to pay a considerable attorney’s fee as well. Compare that with the \$20 filing fee in an Article 17A proceeding, N.Y. COURTS, FEE SCHEDULE 2, https://www.nycourts.gov/courts/1jd/surrogates/feeschedule_2.pdf [<https://perma.cc/BA4J-3U9W>].

170. *See generally* THE GUARDIANSHIP CLINIC, *supra* note 26; Glen, *supra* note 16; Salzman, *supra* note 35.

guardianship system to a system that would promote “supported decision-making.”¹⁷¹ In doing so, they look to international law and experience to make their case.¹⁷² The United Nations Convention on the Rights of Persons with Disabilities (CRPD), specifically Article 12, guarantees full legal capacity as a fundamental human right.¹⁷³ Judge Kristin Booth Glen describes Article 12 as containing three “paradigm-shifting assertions”:

- (1) [P]ersons with disabilities have the right to recognition everywhere as persons before the law [and]
- (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life [and that]
- (3) States Parties shall take appropriate measures to provide access by persons with disabilities to *the support they may require in exercising their legal capacity*.¹⁷⁴

More concisely, Article 12 redefines “persons with intellectual disabilities not merely as legal subjects with certain defined rights, but as legal actors with full capacity, equal to that of all other, non-disabled persons.”¹⁷⁵ Additionally, the responsibility for facilitating and supporting persons with intellectual disabilities in exercising their legal capacity is placed directly on the state.¹⁷⁶ This treaty has been signed by President Obama and, though not yet ratified by the Senate, was passed by the Senate Committee on Foreign Relations on July 26, 2012.¹⁷⁷ If ratified, the treaty would be binding, and the U.S. might have no choice but to change the law of guardianships to one of supported decision-making.¹⁷⁸

Moreover, some advocates, in particular Leslie Salzman,¹⁷⁹ have argued that Article 81 potentially violates the “integration mandate”

171. *See generally* THE GUARDIANSHIP CLINIC, *supra* note 26; Glen, *supra* note 16; Salzman, *supra* note 35.

172. *See generally* THE GUARDIANSHIP CLINIC, *supra* note 26; Glen, *supra* note 16; Salzman, *supra* note 35.

173. *See* Glen, *supra* note 16, at 123.

174. Glen, *supra* note 16, at 136 (alteration in original) (quoting Article 12).

175. *Id.* at 137–38.

176. *Id.*

177. *Id.* at 161.

178. Supported decision-making is currently recommended by the National Guardianship Summit. Glen, *supra* note 16, at 139.

179. Leslie Salzman is a Clinical Professor of Law at Benjamin N. Cardozo School of Law. She directs Cardozo’s Bet Tzedek Legal Services clinical program where she has been teaching since 1990. *Leslie Salzman*, YESHIVA UNIVERSITY, BENJAMIN N. CARDOZO SCHOOL OF LAW, <http://www.cardozo.yu.edu/directory/leslie-salzman> [<https://perma.cc/Z8YN-83P7>]. The clinic represents low-income individuals in

of the Americans with Disabilities Act (ADA).¹⁸⁰ The ADA “explicitly recogniz[es] that socially-created conditions and barriers, rather than disabled peoples’ individual ‘defects,’ are the cause of exclusion and nonparticipation.”¹⁸¹ Title II of the ADA provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”¹⁸² Pursuant to Title II, the Attorney General issued the “‘integration mandate,’ which requires that public entities ‘administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.’”¹⁸³ “Most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”¹⁸⁴ The important tie-in here is Leslie Salzman’s argument: supported decision-making is a less restrictive, more integrated alternative to guardianship.¹⁸⁵ The failure to provide the least restrictive alternative “presumptively violates the integration mandate.”¹⁸⁶

While it may be optimal to repeal both Article 17A and Article 81 by adopting instead a supported-decision making model, this Essay was not written to advocate for the repeal of Article 81. Without a drastic increase in resources to AIPs, supported decision-making is not realistic at this time. Until additional resources are made available, Article 81 remains a “model” guardianship statute in many ways. Article 81’s due process protections are not insignificant. The statute guarantees a hearing to avoid the deprivation of the AIP’s decision-making rights,¹⁸⁷ the appointment of a court evaluator,¹⁸⁸ and counsel, if requested.¹⁸⁹ “The statute mandates a least restrictive alternative approach so that persons under guardianship are deprived of no more of their decision-making rights than are necessary to

matters relating to public and private disability and health-related benefits and insurance, housing, and consumer transactions. *Id.* She is an expert in Elder law, amongst other things. *Id.*

180. *See* Salzman, *supra* note 35, at 160.

181. Glen, *supra* note 16, at 126.

182. 42 U.S.C. § 12132 (2014).

183. Salzman, *supra* note 35, at 186.

184. *Id.* at 186–87.

185. *Id.* at 217.

186. *Id.* at 219.

187. N.Y. MENTAL HYG. LAW § 81.11 (McKinney 2016).

188. *Id.* § 81.09.

189. *Id.* § 81.10.

protect them from harm.”¹⁹⁰ Additionally, “[d]etailed reporting requirements aim to ensure that guardians remain accountable to those under guardianship and to the courts.”¹⁹¹

It is of significant importance that the same arguments made against Article 81¹⁹² can also be made against Article 17A. There is arguably even a stronger case to be made that Article 17A violates both the CRPD and the integration mandate of the ADA. In the case of Article 17A, of course, there is a clearly less restrictive alternative already in place: Article 81.

The fact, however, that there is no realistic alternative to Article 81 guardianship at this point should not serve as an occasion for celebration. Rather, it should focus our attention on the potential loss of autonomy for these individuals and a call for more resources—so supported decision-making may one day be possible. As Judge Glen reminds us, “regardless of the procedural protection she is afforded, the respect given her past views, and the commitment to enhancing or reestablishing capacity, as to her *incapacity*, the person under guardianship is *not, or is no longer, a legal actor*.”¹⁹³

Another problem with Article 81 guardianships is the routine violation of the AIP’s medical privacy.¹⁹⁴ As discussed above, the enactment of Article 81 was meant to be a move away from the medical model of guardianship (as exemplified by Article 17A) and toward a more functional capacity framework and less restrictive alternative approach to guardianship.¹⁹⁵ In practice, some criticize Article 81 proceedings because “health care facilities that initiate guardianship proceedings routinely disclose medical information without the consent of the patient” or a court order.¹⁹⁶ In addition to running counter to the heart of Article 81 itself, these disclosures, it is argued, violate HIPAA and physician-patient privilege.¹⁹⁷

Nevertheless, Article 81 remains a less restrictive alternative to Article 17A guardianships and provides much greater procedural protections for AIPs both pre- and post-appointment. It is difficult to justify the continued existence of Article 17A. It is also notable that

190. THE GUARDIANSHIP CLINIC, *supra* note 26, at 2; *see also* N.Y. MENTAL HYG. LAW § 81.02(a)(2) (McKinney 2016).

191. THE GUARDIANSHIP CLINIC, *supra* note 26, at 2; *see also* N.Y. MENTAL HYG. LAW §§ 81.30–81.31 (McKinney 2016).

192. *See supra* notes 172–88 and accompanying text.

193. Glen, *supra* note 16, at 119 (alteration in original).

194. *See generally* Rosenberg, *supra* note 10.

195. *See supra* notes 26–34 and accompanying text.

196. Rosenberg, *supra* note 10, at 40.

197. *See id.*

“New York is one of only six states that have separate statutes for persons with intellectual disabilities and adults who have lost capacity.”¹⁹⁸ New York is already well behind the curve on this issue—about twenty-five years to be exact.

B. While We Wait for Repeal or Reform: Ethical and Practical Considerations

The seriousness and the urgency of our concerns with Article 17A require us, as legal service providers, to take immediate action while we wait for policy change. The following are a series of best practices that we recommend practitioners consider prior to agreeing to representation of a petitioner, during representation, and even after guardianship has been granted.

1. Considerations Prior to Representation

First, we believe that legal service providers have the right and duty to conduct their own independent investigation concerning the ward and the proposed guardians before agreeing to serve as counsel. This is especially important given that the only evidence before the court in an Article 17A proceeding are two forms completed by the ward’s treating physicians plus the word of the petitioner. Our experience with John taught us that this is not sufficient.¹⁹⁹ At minimum, the attorneys should meet with the ward to get a sense of her limitations first-hand and to inquire about the ward’s preference for guardianship. Although meeting the ward may seem like an obvious first step, many families of loved ones with disabilities do not bring them to appointments unless specifically asked. Many families may believe that the ward’s presence would be disruptive, or it may be particularly difficult for a non-ambulatory or bedbound ward to travel.

In addition to meeting the ward, the attorney should inquire about any previous investigations or referrals to protective service agencies. If possible, the attorney should question close relatives and caretakers of the ward and petitioner as part of a pre-retainer investigation. If other family members voice concerns or object to the appointment, the attorney must consider whether their claims are credible. If the attorney finds the claims credible and of such a nature that an appointment of this particular petitioner would not be in the best

198. Glen, *supra* note 16, at 119 n.125 (“The others are California, Connecticut, Idaho, Kentucky, and Michigan.”) (citations omitted).

199. *See* discussion *supra* Part II.B.

interest of the ward, the attorney should refuse further assistance to the petitioner. If at any time the attorney determines that continuing with the guardianship would not be in the best interest of the ward, the attorney may withdraw from representation.

Prior to representation in any guardianship proceeding, advocates should always consider alternatives to guardianship. It is important to remember that guardianship is a last resort and advocates should always seek the least restrictive alternative. If the advocate determines that the ward has the capacity to execute a power of attorney or health care proxy, guardianship proceedings would be inappropriate. The advocate should research all available options and resources available to help the ward function in society without the need for guardianship, such as representative payment, home care services, and supportive housing.

For instance, take Michael's story. His parents visited our legal clinic with the hope of obtaining a guardianship over their son. It was clear from the beginning that they were loving parents and only hoped to do what was best for Michael. Michael's doctors were also eager to assist his family. They provided generous medical affidavits that probably would have been sufficient to obtain an Article 17A guardianship. During the consultation process, Michael would often call our office and leave long rambling messages that the attorney could not decipher without the assistance of Michael's mother to translate. To be clear, Michael speaks English. After speaking with his mother, it became clear that Michael had legitimate concerns about the guardianship. The attorney reached out to Michael's doctor as well who, while obviously trying to preserve guardianship as an option for Michael, made it clear that Michael made all of his own doctor's appointments and was always on time.

At this point, the attorney determined that he must meet Michael and investigate alternative solutions. After meeting Michael in person, the attorney had no doubt that Michael understood most of what was happening. Michael also clearly expressed his hope to move out of his parent's home and into supportive housing. In person, the attorney was able to get Michael to slow his speech down, which turned out to be the problem in understanding Michael's voicemails, and have a meaningful conversation with him. Ultimately, LegalHealth helped Michael to execute a power of attorney and a health care proxy to save his family a lot of time and unnecessary effort with the guardianship process. Most importantly, Michael was able to retain his autonomy while allowing his parents to assist him with his finances, search for supportive housing, and medical care.

2. *Considerations During and After Representation*

Once an attorney has decided to represent a petitioner in a guardianship proceeding, there are a number of further considerations the attorney should take in order to better protect the individual with an intellectual disability for whom guardianship is sought. These include either representing the petitioner in an Article 81 proceeding or representing the petitioner in an Article 17A proceeding while asking the court to provide protections to the ward beyond those guaranteed in the statute.

a. *Practitioners May Commit to Only Assisting with Article 81 Guardianships*

We approve of courts' efforts in Article 17A proceedings to ascertain the functional level of the ward in more detail.²⁰⁰ But these efforts do not go far enough. There is still far too much focus on the diagnosis of the ward. The lack of a court evaluator and GAL in Article 17A proceedings means that no one is sufficiently investigating the ward's functional capacity, his relationships with his family, and his connections to the community. No third party is stepping in to look after the best interests the ward. Also, in most proceedings, the courts do not require post-appointment reports and protections for the ward, as would be required under Article 81.²⁰¹ Until more pre- and post-appointment protections are required by statute, a ward should not have to rely on the luck of drawing a judge willing to read protections into the statute. Even if the ward is so lucky, a judge can only go so far before she is effectively rewriting the statute.

If advocates determine that guardianship is the appropriate course, and that the proposed petitioner would be the best choice as guardian, the best practice solution may be to refuse to do Article 17A guardianships altogether. Instead, advocates should insist on filing only Article 81 guardianships. This would take a lot of work while we build a practice and familiarize ourselves with Article 81 proceedings. But, once we have an Article 81 practice up and running, it is difficult to see why this would be any more of a drain on our resources than Article 17A proceedings.

200. See discussion *supra* Part II.D.

201. See N.Y. MENTAL HYG. LAW § 81.31 (McKinney 2016).

b. Practitioners May Ask the Court to Read Protections Guaranteed under Article 81 Proceedings into Article 17A

If organizations serving low income clients do not have the resources to complete Article 81 guardianships, we believe that many of the protections available in Article 81 should be read into Article 17A—as courts have shown themselves willing to do.²⁰² Furthermore, we believe that legal practitioners have the ethical obligation to ask the courts to do so.

As in *Mark C.H.*, practitioners should ask the court to read in periodic reporting requirements to review the guardian and ward's status.²⁰³ Similarly, as in *Dameris L.*, practitioners should ask the court to require that a guardianship under Article 17A be “the *least restrictive alternative* to achieve the state's goal of protecting a person with intellectual disabilities from harm connected to those disabilities.”²⁰⁴ Practitioners should also ask the court to look beyond the medical certifications and assess the ward's functional level and limitations, as well as her availability of resources.²⁰⁵ This evaluation should lead to more limited guardianships, tailored to individual wards.

In re Yvette A. is another example of the ways in which a court can read Article 81 protections into Article 17A guardianships.²⁰⁶ In *Yvette A.*, however, the court read Article 17A differently. Unlike *Mark C.H.*,²⁰⁷ the court in *Yvette A.* did not specifically address the constitutionality of Article 17A, but instead found that its power to read Article 81 protections into the Article 17A proceedings was implicit in the statute itself.²⁰⁸ In *Yvette A.*, a father petitioned to be the guardian for his allegedly mentally retarded daughter, Yvette.²⁰⁹ Yvette was diagnosed as mentally retarded at two-and-a-half years old.²¹⁰ Her mother died when she was nearly three-years-old and her father cared for her for a year-and-a-half after the mother's death.²¹¹ Thereafter, Yvette was placed in a state school and then a social

202. See discussion *supra* Part II.D.

203. See *In re Mark C.H.*, 28 Misc. 3d 765 (N.Y. Sur. Ct. 2010); see also discussion *supra* Part II.D.1.

204. *In re Dameris L.*, 38 Misc. 3d 570, 579 (N.Y. Sur. Ct. 2012) (emphasis added).

205. *Id.*

206. 27 Misc. 3d 945 (N.Y. Sur. Ct. 2010).

207. See discussion *supra* Part II.D.1.

208. *Yvette A.*, 27 Misc. 3d at 945, 950.

209. *Id.* at 946.

210. *Id.*

211. *Id.*

services group home, where she remained at the time of the proceedings.²¹² From 1990 to 2005, Yvette's father had very little contact with her.²¹³

Yvette was "blind, [had] a history of seizures and anxiety, and exhibit[ed] aggressive and self-injurious behavior."²¹⁴ Yvette required assistance with her daily living activities, including feeding and hygiene.²¹⁵ "While she [could] make simple choices such as choosing certain food and drink, she [was] unable to attend to her finances, make complex decisions, medical or otherwise, or maintain her medical appointments."²¹⁶ Yvette required one-on-one attention at all times at least in part due to her blindness.²¹⁷ "Yvette [could] communicate by simple sounds such as asking for soda and requesting hugs when she meets someone."²¹⁸

Yvette's father included two certifications from medical doctors in his petition.²¹⁹ Both doctors "concluded that Yvette is severely and permanently mentally retarded and that she does not have the capacity to make health care decisions."²²⁰ The doctors also concluded that "Yvette's presence at a hearing should be dispensed with in view of her inability to understand the proceedings and the possibility that her attendance might cause her harm."²²¹

In *Yvette A.*, the court reasoned that "[a]lthough, Article 17A does not specifically provide for the tailoring of a guardian's powers or for reporting requirements similar to Article 81, the court's authority to impose terms and restrictions that best meet the needs of the ward is implicit in the provisions of § 1758 of the SCPA."²²² The court further concluded that under Surrogate's Court Procedure Act section 1755, it had the power to modify existing Article 17A orders appointing a guardian based on a change in circumstances and that the legislative history of Article 17A suggested that the court's power to modify existing orders was indeed broad.²²³ "By logical extension,

212. *Id.*

213. *Id.* at 948.

214. *Id.* at 947.

215. *Id.*

216. *Id.*

217. *Id.*

218. *Id.*

219. *Id.*

220. *Id.*

221. *Id.*

222. *Id.* at 950.

223. *See id.* at 951 n.23 (citing to the legislative history of the repealed 1969 version of the statute: "The bill will also enable a protective plan to be tailored to the

a court that has the power to modify a guardianship order once it has been issued to meet the needs of the ward surely also has the power to tailor the order to meet such needs at the outset.”²²⁴

Based on the medical certifications, the court found that Yvette was “mentally retarded” under Article 17A.²²⁵ Thus, the court found it was in Yvette’s best interests to appoint her father as guardian of the person under Article 17A.²²⁶ But, due to her father’s absence throughout most of Yvette’s life, the court limited the father’s rights and responsibilities vis-à-vis his daughter.²²⁷

The court ordered the father to file annual reports that included the current addresses for both him and his daughter, reports on Yvette’s current medical condition, and any changes in her care.²²⁸ Specifically, he was required to:

[I]dentify Yvette’s daily activities, including her frequency of attendance and participation at the day program, list the governmental or other financial benefits that are received by or for her, and identify any proposed plan that he has to change Yvette’s living arrangements, daily activities or care and the reason(s) for such proposed change(s).²²⁹

Finally, he was “also restrained from moving Yvette or changing her day program without further order of th[e] Court.”²³⁰

In addition to asking the court to evaluate the totality of the circumstances surrounding the ward (including functionality and availability of resources), to tailor the guardianship to the specific needs of the ward’s circumstances, and to require post-appointment annual reporting and review,²³¹ we also recommend that practitioners ask for the appointment of a GAL for the ward,²³² a court

individual needs of a retarded person by providing a broad flexibility in the types of guardianships that can be utilized”); *id.* (“The 1989 enactment specifically provides for modifications, i.e., tailoring of powers . . .”).

224. *Id.* at 950–51.

225. *Id.* at 951.

226. *Id.*

227. *Id.*

228. *Id.*

229. *Id.* at 951–52.

230. *Id.* at 952.

231. *See generally In re Dameris L.*, 38 Misc. 3d 570 (N.Y. Sur. Ct. 2012) (evaluating the wards’ functional capacities and availability of resources in order to tailor the guardianship to the wards’ specific needs); *In re Mark C.H.*, 28 Misc. 3d 765 (N.Y. Sur. Ct. 2010) (same); *Yvette A.*, 27 Misc. 3d 945 (providing post-appointment annual reporting and review).

232. *Dameris L.*, 38 Misc. 3d at 572 (appointing a GAL in an Article 17A proceeding); *Mark C.H.*, 28 Misc. 3d at 767 (same).

evaluator,²³³ counsel for ward,²³⁴ and insist on a hearing in which the ward's presence is required.²³⁵

3. *Ethical Considerations*

There are potentially some ethical concerns raised by asking the court to read in additional procedural protections for wards in guardianship proceedings. While our mission is to improve the life of patients with intellectual disabilities, our client is the petitioner and prospective guardian. Our client may feel that the additional obligations of post-appointment annual reviews, guardianship classes, and more in depth investigations performed by a court evaluator are adverse to her interests. We, of course, cannot ask the court to do something which our client does not want done. One way to avoid this conflict would be to make the parameters of our representation known up front and a condition of acceptance of representation. In this situation, we would engage the prospective client in a discussion about due process protections and their necessity. This would entail discussing our requirement that we personally meet with the ward him or herself in order to perform a capacity assessment and inquire as to the ward's preference for guardianship. Only upon a mutual understanding and agreement between the attorney and client could the representation proceed.

Even if we chose to only represent clients in Article 81 proceedings, we would still be obligated to inform our clients of all of their options under the law.²³⁶ Many might find the prospect of guardianship classes and annual reports and reviews as unnecessary obstacles and elect to seek new counsel, or proceed *pro se*. This is yet another reason that Article 17A should be repealed. No matter how noble the efforts of practitioners, the availability of an option that is

233. *Mark C.H.*, 28 Misc. 3d at 768 (appointing a "Certified Care Manager" for the ward who had many of the same responsibilities which theoretically would have been provided by a court evaluator in the Article 81 context). However, this Certified Care Manager was paid for using funds from the ward's trust. *Id.* How a court evaluator in an Article 17A proceeding would be funded is a question that would also need to be answered.

234. *Id.*

235. See N.Y. MENTAL HYG. LAW § 81.11 (McKinney 2016).

236. See N.Y. COMP. CODES R. & REGS. tit. 22, § 1200.0 (2016) (citing Rule 1.0(j)) (stating that a client must give informed consent to a proposed course of conduct, meaning "the lawyer has adequately explained to the person the material risks of the proposed course of conduct and reasonably available alternatives"); see also *id.* (citing Rule 1.4(b)) ("A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation.").

perceived as easier, cheaper, and involving fewer procedural hurdles will, understandably, continue to entice even the most well-intentioned of prospective guardians.

CONCLUSION

Article 17A was passed during a time when society had a limited perspective in regard to individuals with intellectual disabilities. While legislators were concerned with the ability of family members to continue to provide care for persons with intellectual disabilities, they completely overlooked their autonomy as individuals and their right to live as full a life as possible. As a result of our misplaced focus, we have been placing these individuals in permanent, plenary guardianships for decades, based almost entirely on diagnoses in two cursory physician affidavits. Article 17A does not provide individuals with intellectual disabilities with appropriate due process protections and safeguards—either prior to or following the appointment of a guardian.

Even after a series of guardianship reforms across the country and the enactment of Article 81 in New York—which does provide a variety of protections for individuals with intellectual disabilities—Article 17A remains an option. Additionally, we have neglected to reevaluate Article 17A despite the evidence that Article 17A guardianships often result in a loss of autonomy, abuse, and have the potential to deprive individuals of their constitutional due process rights.

It has been twenty-five years since we set out, and failed, to reform Article 17A. 2015 was also the twenty-fifth anniversary of the passage of the ADA, which Article 17A arguably violates. There is no better time than now to revisit Article 17A and either repeal the statute entirely or substantially reform it to provide appropriate protections for individuals with intellectual disabilities.