

REVISITING S.C.P.A 17-A: GUARDIANSHIP FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES*

*A Report of the Mental Health Law Committee and the
Disability Law Committee of the New York City Bar Association*†

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* This Report is dedicated to the memory and spirit of Karen Andreasian, former Chair of the Committee on Mental Health Law, who initiated the project of critiquing Art. 17-A, encouraged its completion, and who cared passionately about the rights to dignity and self-determination of people with intellectual and developmental disabilities.

† This is a report of the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association. This report was researched and written by Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah, and Naomi Weinstein on behalf of the New York City Bar Association. It has been reviewed and approved by the New York City Bar Association and is being published by the City University of New York Law Review in accordance with the Association’s protocols in the interest of bringing to publication an important contribution to the discussion on how the law should respond to people with intellectual disabilities.

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I. INTRODUCTION

More than four decades ago, in 1969, the New York State Legislature enacted Surrogate's Court Procedure Act, Article 17-A (17-A) authorizing a Surrogate to appoint a guardian over the person and/or the property of a person with mental retardation. At the time, various organizations and advocates for this population, primarily parents and parent organizations, voiced the need for an abbreviated proceeding for individuals with mental retardation when they reached the age of eighteen.¹ The underlying assumption was that the mentally retarded were perpetual children,² such that the legal powers all parents had over persons under eighteen should simply be extended indefinitely for the parents of the mentally retarded; 17-A was the outcome.³ In 1989, despite a substantial change in the understanding of disability, including intellectual and developmental disability, now based on a social, rather than a medical model, and without any significant discussion, S.C.P.A. Article 17-A was amended to include other "developmental disabilities."⁴

¹ At that time, the only vehicles available for substituted decision-making were the committee and conservator proceedings of Articles 77 and 78 of the Mental Hygiene Law ("M.H.L.").

² See generally, Janice Brockley, *Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History*, in *MENTAL RETARDATION IN AMERICA*, 130 (Steve Noll & James Trent, Jr. eds. 2004).

³ See Rose Mary Bailly & Charis B. Nick-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 *ALB. L. REV.* 807, 817-19 (2012).

⁴ 1989 N.Y. Sess. Laws 675 § 2 (McKinney).

In 1990, the legislature directed a study to re-evaluate Article 17-A in light of changes in the “care, treatment and understanding of these individuals,”⁵ as well as “new legal theories regarding the rights of such individuals.”⁶ Proposed amendments were to be submitted to the legislature by the close of 1991.⁷ Rather than altering 17-A, however, the New York State Law Revision Commission examined adult guardianship issues and proposed Mental Hygiene Law (“M.H.L.”) Article 81 (Art. 81), which was enacted in 1992 and which became effective in 1993.⁸ Apparently, a good deal of work was done on 17-A, and an extensive draft report with recommendations produced, but that draft never saw the light of day, and 17-A remains essentially unchanged today.⁹

The need for reconsideration, reform, or possibly even repeal is, however, greater than ever. There have been changes in the law, in other states and federally, as well as an evolution in constitutional principles and a burgeoning human rights movement. The population of persons covered by the now outdated term “mental retardation” and the preferred term developmental (or intellectual) disabilities¹⁰ has exploded, making issues relating to their

⁵ Nationally, the Developmental Disabilities Act, first enacted in 1963, was also the subject of updating based on these concerns. With the last significant amendments in 2000, changes in the “landscape” of developmental disability have been described as follows:

The [Developmental Disabilities] Act, in conjunction with activities of self-advocates, families, other advocacy groups, state and local governments, and other stakeholders, has changed the way people with [developmental disabilities] live. The social landscape in the United States has shifted from a place where people with [developmental disabilities] were unheard and neglected to a country where far fewer people are relegated to institutional care, children with [developmental disabilities] are in public schools, adults are living and in some cases working in the community, and a burgeoning self-advocacy movement is demanding that people with intellectual and developmental disabilities have power over their own lives.

Rising Expectations: The Developmental Disability Act Revisited, NAT’L COUNCIL ON DISABILITY, (Feb. 15, 2011), <http://www.ncd.gov/publications/2011/Feb142011>, archived at <http://perma.cc/T9FD-76L6>.

⁶ L. 1990, ch. 516, § 1.

⁷ *Id.* at § 4.

⁸ Bailly, Practice Commentary, McKinney’s Consol. Laws of N.Y., Book 34A Mental Hyg. § 81.01.

⁹ One major change was the addition of provisions allowing guardians to make end-of-life decisions for their wards. See N.Y. Surr. Ct. Proc. Act. § 1750-b and discussion in Bailly & Nick-Torok, *supra* note 3, at 820. The general provisions of 17-A remained the same.

¹⁰ See discussion *infra* at 12. The preferred term is “People with Intellectual and Developmental Disabilities” (“PWIDDS”), which will be utilized here, except where specific references to the existing statute are involved.

protection and rights an increasingly central question in legal and bio-ethical discourse. As in 1990, there have, as well, been significant social and cultural changes in the “care, treatment and understanding of such individuals.” Rethinking this clearly outdated statute is, thus, clearly both necessary and overdue.¹¹

This Report is intended to start the conversation about how, under what circumstances, or if at all, the state should provide substituted decision-making¹² for this vulnerable population. The Report begins with a brief description of relevant demographic trends that illustrate the extent, and growing importance of the issue. There is also a brief, but critical discussion about the changes in language that have occurred since the enactment of 17-A, including how those changes reflect and/or impact the ways in which society perceives PWIDDs. The Report then describes two very different lenses, due process and human rights, through which reconsideration of 17-A might proceed, seeking to locate each in the legal/historical contexts of the decades leading up to the initial call for reconsideration in 1990, and the enormous changes in disability laws, disability rights, and the growth of human rights that have occurred since the 1990s.

The shortcomings—or overkill—of existing 17-A are then examined through each of those lenses, noting also the legislature’s relatively recent efforts to provide substituted decision making outside of the guardianship context through its enactment of the Family Health Care Decisions Act (FHCDA).¹³ The Report neither proposes, nor attempts to propose, a revised statute, but without necessarily endorsing them, offers some suggestions for consideration and some available models under each of the lenses that have been previously identified.

¹¹ A recent report by a cabinet created by Governor Cuomo to further the mandate of *Olmstead v. L.C.*, 527 U.S. 581 (1999) called for modernization of 17-A in light of the *Olmstead* mandate. NEW YORK STATE, REPORT AND RECOMMENDATIONS OF THE OLNSTEAD CABINET: A COMPREHENSIVE PLAN FOR SERVING NEW YORKERS IN THE MOST INTEGRATED SETTING, 27-28 (Oct.2013), <http://www.governor.ny.gov/sites/governor.ny.gov/files/archive/assets/documents/olmstead-cabinet-report101013.pdf>, archived at <http://perma.cc/96YH-LAFV>.

¹² As discussed more fully, *infra*, 17-A and guardianship statutes generally involve the state giving power to an individual or institution to make decisions *for* a PWIDD, that is, *substituting* the guardian’s decision for that of the PWIDD and affording legal recognition only to the former. While the standard to be utilized by the guardian may differ, *see, e.g.*, Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491 (2014), it is clear that the decision belongs solely to the guardian.

¹³ N.Y. PUB. HEALTH LAW § 2994 *et seq.*

II. THE CHANGING LANDSCAPE OF PEOPLE WITH INTELLECTUAL DISABILITIES

A. *Demographics*

There are an estimated 4.7 million individuals in the United States with developmental disabilities.¹⁴ According to the American Association of Intellectual and Developmental Disabilities (“AAIDD”), “[d]evelopmental [d]isabilities is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood.”¹⁵ Developmental disabilities are a group of conditions that result from an impairment in physical, learning, language, or behavior.¹⁶ The conditions generally begin during the developmental period, before the age of twenty-two, and may impact day-to-day functioning, and usually last throughout a person’s lifetime.¹⁷

Intellectual disability encompasses the cognitive aspect of a developmental disability, generally affecting thought processes.¹⁸ The elements of intellectual disability include “(1) significant impairments in intellectual functioning, as measured by IQ testing; (2) deficits in real-world skills and abilities resulting from the disability (adaptive behavior deficits); and, in the case of developmental disability (3) onset of the disability before the individual became an adult.”¹⁹

Recent studies indicate a steady increase in the number of children diagnosed with a developmental disability in the United States. In a 2008 study spanning the course of twelve years, the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration surveyed children aged between three and seventeen years who had a current or prior diag-

¹⁴ See *Rising Expectations*, *supra* note 5.

¹⁵ *Frequently Asked Questions on Intellectual Disability*, AM. ASS’N ON INTELLECTUAL & DEVELOPMENTAL DISABILITY, <http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.VPxCklvfeal> (last visited Mar. 8, 2015), *archived at* <http://perma.cc/96QV-WWEN>.

¹⁶ *Facts About Developmental Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html> (last visited Mar. 8, 2015), *archived at* <http://perma.cc/R537-2XA3>.

¹⁷ *Id.*

¹⁸ *Frequently Asked Questions on Intellectual Disability*, *supra* note 15. Intellectual disability also refers to persons with psychosocial disability (mental illness) and progressive cognitive decline, such as Alzheimer’s disease, or dementia. Those persons are not, however, covered by 17-A.

¹⁹ Brief for the Am. Assoc. on Intellectual & Developmental Disabilities & the Arc of the U.S. et al. as Amici Curiae Supporting Pet’r, at 8, *Hall v. Florida*, 134 S. Ct. 1986 (2014) (No. 12-10882), *available at* [http://aaidd.org/docs/default-source/policy/freddie-lee-hall-v-state-of-florida .pdf?sfvrsn=0](http://aaidd.org/docs/default-source/policy/freddie-lee-hall-v-state-of-florida.pdf?sfvrsn=0).

nosis of attention deficit hyperactivity disorder; intellectual disability; cerebral palsy; autism; seizures; stuttering or stammering; moderate to profound hearing loss; blindness; learning disorders; and/or other developmental delays.²⁰ The data indicated that between 1997 and 2008, there was an alarming 17.1% increase of parent-reported developmental disabilities, with about one in six children in the United States diagnosed with a developmental disability.²¹ The study noted that “low-income and public health insurance were associated with a higher prevalence of many disabilities.”²²

Autism is the fastest growing developmental disability in the United States.²³ Based on the most recent statistics released by the CDC, the number of children diagnosed with an autism spectrum disorder²⁴ has increased dramatically. In the year 2010, one in fifty children eight years old were diagnosed with autism, compared to one in sixty-eight children of the same age in the year 2000,²⁵ a 30% increase from ten years ago.

The number of children with cerebral palsy, a developmental disability caused by damage to the brain “usually occurring during fetal development; before, during or shortly after birth; during infancy; or during early childhood,” is also staggering.²⁶ According to the CDC, one in every 323 (or 3.3 per 1,000) children in the United States has been identified with cerebral palsy, with almost

²⁰ *Key Findings: Trends in the Prevalence of Developmental Disabilities in Children 1997-2008*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html> (last updated Feb. 12, 2015).

²¹ *Id.*

²² Boyle et al., *Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008*, 127 *PEDIATRICS* 6, 1035-42 (2008), available at <http://pediatrics.aappublications.org/content/early/2011/05/19/peds.2010-2989.abstract> (abstract).

²³ *Facts and Statistics*, AUTISM SOCIETY, <http://autism-society.org/about-autism/facts-and-statistics/> (last visited Apr. 19, 2015), archived at <http://perma.cc/42DH-LYHF>.

²⁴ Autism Spectrum Disorder is defined as “a lifelong developmental disability . . . that include deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities.” *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010 Surveillance Summaries*, CTRS. FOR DISEASE CONTROL & PREVENTION (Apr. 19, 2015), <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm>, archived at <http://perma.cc/S7WH-NW57> (citing AM. PSYCHIATRIC ASS’N, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS* (5th ed. 2013)).

²⁵ *Autism Spectrum Disorder*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/autism/index.html> (last visited Apr. 19, 2015), archived at <http://perma.cc/CX8E-NA5F>.

²⁶ *Cerebral Palsy Fact Sheet*, UNITED CEREBRAL PALSY, available at <http://ucp.org/wp-content/uploads/2013/02/cp-fact-sheet.pdf> (last visited Apr. 19, 2015), archived at <http://perma.cc/SL6T-3BA5>.

7% having a co-occurring autism spectrum disorder.²⁷ Cerebral palsy affects body movement, posture, and muscle coordination.

Down Syndrome, formerly referred to as mental retardation,²⁸ occurs when an individual has a full or partial extra copy of chromosome twenty-one. One in every 691 babies in the United States is born with Down Syndrome. There are currently more than 400,000 people living with Down Syndrome in the United States, and they are living considerably longer—into their 60's and 70's—than when 17-A was passed (a life expectancy of less than twenty-five). This addition in life expectancy has, unfortunately, also led to increased risk of early onset Alzheimer's.²⁹

It is not just persons with Down Syndrome who are now expected to live longer. The total number of PWIDDS aged sixty and older is projected to nearly double from 641,860 in 2000 to 1.2 million in 2030.³⁰ All these demographics, but particularly those relating to aging, have significant consequences for 17-A, which was premised on the assumption that parents would almost certainly outlive their children with intellectual disabilities. That is no longer the case.³¹

B. *Changing Views and Resource*

History reflects that a diagnosis of a developmental and/or intellectual disability was once considered an insurmountable deficit to achieving independence and self-determination. As the National Institutes for Health has noted:

²⁷ It is important to note that the CDC's estimate comes from the Autism and Developmental Disabilities Monitoring (ADDM) Network, which tracks the number and characteristics of 8 year old children with autism spectrum disorder (ASD) and other developmental disabilities in diverse communities throughout the U.S. In 2008, there were 14 ADDM Network sites tracking ASD, and four of those sites also tracked CP. These four sites, which include areas in Alabama, Georgia, Missouri and Wisconsin.

²⁸ The leading advocacy organization for people with Down Syndrome notes that while "mental retardation" may still be clinically acceptable, the term "person with an intellectual disability" is preferable. *Preferred Language Guide*, NAT'L DOWN SYNDROME SOC'Y, <http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts> (last visited Apr. 19, 2015), archived at <http://perma.cc/7GQZ-79YU>.

²⁹ *Id.*

³⁰ Carolyn C. Tingling, *Adults With Intellectual and Developmental Disabilities: A Unique Population*, 6 TODAY'S GERIATRIC MED. 3, 22 (2013), <http://www.todaysgeriaticmedicine.com/archive/050613p22.shtml>, archived at <http://perma.cc/74UZ-57QB> (citing Tamar Heller, *People With Intellectual and Developmental Disabilities Growing Old: An Overview*, 23 IMPACT 1, 2 (2010), available at <https://ici.umn.edu/products/impact/231/231.pdf>, archived at <https://perma.cc/8HNR-EE7C>).

³¹ Anecdotally, many 17-A petitions are now brought by siblings or family friends when parents have died or become too frail to serve as guardians.

Historically, people with intellectual disabilities did not live as long as others and were at increased risk for health problems. Children often died because their condition could not be diagnosed. It was common for people with intellectual disabilities to be institutionalized, and treatments were either non-existent, ineffective, or harmful.³²

Through medical advances and policy initiatives designed to increase the independence, autonomy and self-determination of PWIDDS, intellectual and developmental disability is no longer a static diagnosis. Treatments and training techniques, for example, which focus on communication and behavior have proven effective in increasing the mental capacity of people with an intellectual disability.³³

Studies show that, if taught, self-determination, (e.g., decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, perceptions of efficacy, self-awareness, self-knowledge) can be learned in order to permit an individual with a disability to develop skills that promote independent decision-making.³⁴ Research has also shown that individuals with intellectual and developmental disabilities who maintain a self-determination status have more positive post-secondary outcomes, including employment, independent living and community inclusion.³⁵ And “students with disabilities given access to transition services focused on self-determination and independent living skills are more likely to live independently, be employed and exercise effective choice and decision-making,” removing the undue burden of guardianship.³⁶ Further, the advent of Assistive Technology Resources,

³² *Fact Sheet—Intellectual and Developmental Disabilities*, NAT’L INSTS. HEALTH (last updated Oct. 2010), <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100>, archived at <http://perma.cc/LV7R-D2YH>.

³³ *Id.*

³⁴ Susan B. Palmer & Michael L. Wehmeyer, *A Teacher’s Guide to Implementing the Self-Determined Learning Model of Instruction Early Elementary Version*, BEACH CTR. ON DISABILITY (2002), available at http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?%20Type=book&intResourceID=2599&JScript=1, archived at <http://perma.cc/EZT5-B7A3>; see also *Fact Sheet*, *supra* note 26.

³⁵ *Self-Determination and People with Intellectual and Developmental Disabilities: What Does the Research Tell Us?*, NAT’L GATEWAY TO SELF-DETERMINATION, <http://www.aucd.org/docs/SD-WhatDoWeKnow.pdf> (last visited Apr. 19, 2015), archived at <http://perma.cc/B92W-2HRJ>.

³⁶ Jonathan G. Martinis, *One Person, Many Choices: Using Special Education Transition Service to Increase Self-Direction and Decision-Making and Decrease Overbroad or Undue Guardianship*, THE JENNY HATCH JUSTICE PROJECT, 13, available at http://jennyhatchjusticeproject.org/docs/publications/jhjp_publications_draft_article_guardianship.pdf (last visited Apr. 19, 2015) (working paper), archived at <http://perma.cc/ZU3Y-ZWTV>.

which are devices and services (e.g. speech-recognition and word prediction programs, alternative keyboards and talking calculators) that advance learning and increase functionality, are being used to lessen or remove barriers faced by PWIDDS.³⁷

The diagnosis-driven regime of Article 17-A is out of step with the social, legal and medical advances that have evolved over the last forty years. Despite this social and cultural shift, Article 17-A has failed to recognize the ability of individuals with intellectual and developmental disabilities to live full, independent lives.

C. Language

The language utilized to name and define persons with a large variety of intellectual disabilities has changed—if not necessarily evolved—over centuries, with movement toward “respectful language” promoted by disability rights activists, only within the past two decades. Early English guardianship law divided PWIDDS into two classes: the “*idiot*,” who had never had mental capacity, and the “*lunatic*,” “a person who hath had understanding but hath lost the use of his reason.”³⁸ Our own laws followed a progression from “feeble-minded” to “mentally deficient,” and then in the 1960’s, to “mentally retarded”³⁹ (the latter now frozen in time in 17-A).

The stigmatizing, derogatory, and hurtful uses of “retarded” and “retards” are too well known to be repeated here.⁴⁰ Advocates for PWIDDS and self-advocates successfully lobbied states and, eventually the federal government, to abandon the term, and in October, 2010 President Obama signed “Rosa’s Law.”⁴¹ With its

³⁷ *How Does Rehabilitative & Assistive Technology Benefit People With Disabilities?*, NAT’L INST. OF CHILD HEALTH & HUMAN DEV., <http://www.nichd.nih.gov/health/topics/rehabtech/conditioninfo/pages/help.aspx> (last updated Nov. 30, 2012), *archived at* <http://perma.cc/F4LF-3ALX>.

³⁸ A. Frank Johns, *Ten Years After: Where is the Constitutional Crisis With Procedural Safeguards and Due Process in Guardianship Adjudication*, 7 *ELDER L.J.* 33, 48-49 (1999); AM. BAR. ASS’N, *THE MENTALLY DISABLED AND THE LAW* (Samuel J. Brakel & Ronald S. Rock, eds., 1971). This distinction was noted by the Supreme Court in *Heller v. Doe*, 509 U.S. 312, 326-27 (1993).

³⁹ See, e.g., ROBERT L. BURGDOFF, JR., *THE LEGAL RIGHTS OF HANDICAPPED PERSONS: CASES, MATERIALS AND TEXT*, 46-47 (1980).

⁴⁰ Sadly, however, they have returned to our attention in the current concerns and debates around bullying.

⁴¹ Rosa’s Law, Pub. L. No. 111-256, 124 Stat. 2643 (codified as amended in scattered sections of 20, 29, 42 U.S.C.). Rosa’s Law is named after a Maryland girl with Down Syndrome, whose elementary school recoded her education from stating she was “health impaired” to “mentally retarded.” Her family was successful in having the school change the terminology, and later successful in advocating for the change of terminology in Maryland’s Health and Education Code. See Susan Donaldson James, *Rosa’s Law to End Term “Mentally Retarded,”* ABC NEWS (Nov. 18, 2009), <http://>

passage, federal health, education and labor laws must no longer use the term “mental retardation,” rather substituting “intellectual disability.”⁴²

To some, dwelling on semantics might seem academic, and, of course, superficial changes without corresponding progress would be pointless. In fact, however, the movement to change terminology reflects a significant change in the evolving understanding of intellectual disability and what it means in, and to, the medical, advocacy and legal communities, as well as to families, support providers, and policy makers.

While “intellectual disability” is now the term of choice, it is also important to note the shift from the use of all these terms to modify the subject “person” or “child” (as in “mentally retarded child”) to a primary emphasis on the person, with the condition, intellectual disability, now seen as a characteristic of her/him, but not what defines her/him. Hence the move to a “*person with* (intellectual or other) disability,” underscoring her or his position as a legal *subject*.⁴³ The importance of language, the centrality of the person, and the harmful and stigmatizing effect of the term “mental retardation” are echoed in New York State’s “historic” decision in 2010 to change the name of the agency responsible for coordinating services for PWIDDs from the Office of Mental Retardation and Developmental Disabilities (OMRDD) to the Office for People With Developmental Disabilities (OPWDD).⁴⁴

III. EVOLVING MODELS OF DISABILITY AND THE TWO LENSES

As often noted in the literature, just as the language of intellectual disability has changed, so too, and perhaps partly because of that change, “models,” or general understandings of disability have also evolved. From the status model of 15th century England (the “idiot,” the “lunatic”) to a medical model of the late of the late 19th and early 20th centuries, in which disability was a condition to be treated and cured (and, for those who could not be cured, pitied), the civil rights movements of the 60’s and 70’s, embraced by an emerging disability rights movement, changed the model once

abcnews.go.com/Health/rosas-law-asks-senate-kill-slur-mentally-retarded/story?id=9109319.

⁴² Rosa’s Law, *supra* note 41.

⁴³ This change, growing from an equality model of human rights, as discussed in, e.g., Arlene S. Kanter, *What’s Disabilities Studies Got to Do With It or An Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 434 (2011).

⁴⁴ See *Agency Overview*, OFFICE FOR PEOPLE WITH DEV. DISABILITIES, www.opwdd.ny.gov/opwdd_about/overview_of_agency (last visited Feb. 8, 2015).

again, to a *social* model. As Syracuse Law Professor Arlene Kanter writes, that model “places the responsibility squarely on society (and not on the individual with a disability) to remove the physical and attitudinal barriers that ‘disable’ people with various impairments and prevent them from exercising their rights and fully integrating into society.”⁴⁵ Also referred to as the “socio-political” model, the “problem” of disability is understood as external to the PWIDD, that is, “in stereotypical attitudes and an environment that fails to meet their needs, rather than within [PWIDDs] themselves.”⁴⁶ This social model of disability was conclusively enshrined in U.S. law with the passage of the Americans With Disabilities Act (“the ADA”), whose twenty-fifth anniversary we celebrate this year.⁴⁷

A. *The Social Model and a Due Process Lens*

Rejection of the prior medical model of disability was implicitly reflected in the movement to reform adult guardianship laws that began in the late 1980’s; Article 81 of the Mental Hygiene Law (“Art. 81”), a product of that movement, specifically eschews a diagnosis-driven definition of incapacity, focusing instead on a functional analysis of the ways in which what is now denominated “the allegedly incapacitated person” (AIP) is unable to protect him/herself from harm with regard to specific domains. That is, it is no longer enough to allege—or prove—that an AIP “suffers from” a named disability like dementia or Alzheimer’s in order to appoint a guardian or substituted decision maker.⁴⁸

The move to a social, or socio-political model was very much a product of a variety of forces within and without the disability movement.⁴⁹ It was not, however, the end of reconceptualizing dis-

⁴⁵ Kanter, *supra* note 43, at 422.

⁴⁶ Nicholas A. Dorsey, *Mandatory Reassignment Under the ADA: The Circuit Split and Need for Socio-Political Understanding of Disability*, 94 CORNELL L. REV. 433, 446 (2009).

⁴⁷ Americans With Disabilities Act of 1990, 42 U.S.C. § 12101 *et seq.* As a leading commentator has noted:

The enactment of the [ADA] was viewed as a watershed in the disability community, not only because of the substantive rights it guaranteed . . . but also because it reflected a departure from the medical model and an adoption of the movement’s socio-political model of disability.

Laura L. Rovner, *Disability, Equality and Identity*, 55 ALA. L. REV. 1043, 1044 (2004) (citations omitted).

⁴⁸ See, e.g.,]Bailly, Practice Commentary, McKinney’s Consol. Laws of N.Y., Book 34A, N.Y. Mental Hyg. Law § 81.02.

⁴⁹ These included the rise of self-advocacy and the legacy of various civil rights movements. See, e.g., Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond*, 44 COLUMBIA HUM. RTS. L. REV. 93, 107-11, 123-31

ability and, by extension, disability rights. The rise of international human rights, the specific inclusion of disability in the discussion of human rights, and the imperative of equality, dignity and inclusion for all persons, regardless of disability, including intellectual disability, began in the 1990's⁵⁰ and reached its culmination with the entry into force of the United Nations Convention on the Rights of Persons With Disabilities (CRPD) in 2008.⁵¹

B. *The Human Rights Model and Lens*

The concept of human rights arose out of the horrors of World War II with the founding of the United Nations in 1945, and adoption of the Universal Declaration of Human Rights (“UDHR”) in 1948.⁵² The fundamental principles of human rights law, as enunciated by the UDHR, are “the equal and unalienable rights of all members of the human family” and “every person’s inherent dignity.”⁵³ Unlike the “negative rights” conferred by the U.S. Constitution (freedom from government interference with, e.g., speech, association, etc.) or by statutes such as the ADA, human rights exist solely by virtue of the fact that one is born human. As such, they are inalienable, indivisible, intra-dependent and inter-related; that is, each depends on the others, and none can be taken away by any law or any government.

Insofar as intellectual disability and guardianship are at issue, the critical human right is that of legal capacity, first recognized in Article 6 of the UHDR (“Everyone has a right to recognition, every-

(2012) (“*Changing Paradigms*”). For a fuller, and extremely rich account of the social movements and changes that fueled this first revolution in disability rights, see ALISON C. CAREY, *ON THE MARGINS OF CITIZENSHIP: INTELLECTUAL DISABILITY AND CIVIL RIGHTS IN TWENTIETH CENTURY AMERICA* (2009).

⁵⁰ See Arlene S. Kanter, *The Globalization of Disability Law*, 30 SYRACUSE J. INT’L L. & COM. 241 (2003).

⁵¹ The United Nations General Assembly resolution 61/106 for the Convention on the Rights of Persons With Disabilities (Dec. 13, 2006) entered into force with ratification by 20 Member States in 2008. *Entry into Force*, UNITED NATIONS ENABLE, <http://www.un.org/disabilities/default.asp?id=210> (last visited Apr. 20, 2015), *archived at* <http://perma.cc/K39L-NPKE>. As of September 2014, the CRPD has been ratified by 150 Member States including all members of the European Union and the E.U. itself. *Convention and Optional Protocol Signatures and Ratifications*, UNITED NATIONS ENABLE, <http://www.un.org/disabilities/countries.asp?id=166> (last visited Apr. 20, 2015), *archived at* <http://perma.cc/9WZV-2QE6>.

⁵² Universal Declaration of Human Rights, G.A. Res. 217 (III) A, U.N. Doc. A/RES/810 (Dec. 10, 1948). For a general discussion of this evolutionary process, see Robert S. Drinan, S.J., *The Mobilization of Shame: A World View of Human Rights*, 3-12 (2001).

⁵³ *Id.*

where, as a person before the law”)⁵⁴ and further explicated in Article 12 of the CRPD,⁵⁵ which additionally provides that

- (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.⁵⁶

Debate that preceded adoption of the CRPD clarified that legal capacity involves not only all persons’ capacity to have, or bear rights, but also to have the exercise of those rights legally recognized.⁵⁷ On its face, the CRPD would appear to prohibit substituted decision making of any kind. In its First General Comment, the body charged with interpreting and enforcing the CRPD, the Committee on the Rights of Persons With Disabilities, has clearly stated that guardianship as it currently exists is in violation of the Convention while recognizing, as well, that Article 12 and the right to legal capacity also necessarily includes freedom from abuse and exploitation.⁵⁸

Rethinking 17-A may thus be grounded in the due process framework prevalent when the legislature first called for re-examination, a framework reflected in the multiple procedural protection included in the coterminous enactment of Art. 81. Alternatively, it may take into account the “paradigm shift” in understanding the rights of PWIDDs through a human right lens that has arisen since then with the globalization of disability rights and

⁵⁴ *Id.* at 207.

⁵⁵ It is important to note that the CRPD does not create any *new* human rights; legal capacity is enshrined in the UDHR, which the U.S. has ratified. The CRPD merely expounds the specific obligations of member states for implementation of that right. *See, e.g.,* Kristin Booth Glen, *The Perils of Guardianship and the Promise of Supported Decision-Making*, 48 CLEARINGHOUSE REVIEW 17 (2014) (“*Perils of Guardianships*”).

⁵⁶ CRPD, *supra* note 51, Art. 12. The CRPD Preamble also states this essential principle that States parties:

Recogniz[e] the importance for persons with disabilities of their individual autonomy and independence including the freedom to make their own choices . . .”

Id. at Preamble.

⁵⁷ *See, e.g.,* Anita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future*, 34 SYRACUSE J. INT’L. L. & COM. 429 (2007).

⁵⁸ Committee on the Rights of Persons with Disabilities, *Eleventh Session General Comment*, CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, at No. 1 ¶¶21-23 (April 11, 2014), available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement> (last visited Apr. 20, 2015), archived at <http://perma.cc/J732-Q586>.

the enactment of the CRPD.⁵⁹ First, however, the obvious shortcomings of the existing statute, and the case law that it has engendered, must be examined.

C. Utilizing Art. 81 in a Due Process Critique of 17-A

What follows is a description of the obvious and uncontroverted deficiencies of 17-A; that description utilizes the more nuanced approach of Article 81 to highlight those deficiencies. It is not, however, intended to endorse the provisions of Article 81 as an alternative for at least two reasons.

First, the population of persons employing 17-A, or, in the future, seeking some statutory power over or protection for PWIDDs, is quite different from petitioners under Article 81.⁶⁰ The 17-A procedure is, admittedly, far simpler, and can be managed relatively easily by *pro se* petitioners. Clerks in most Surrogate's Courts have been trained to, and do assist *pro se* petitioners, including a significant group for whom English is not a first language. Many 17-A petitioners are also poor, so the cost of a court evaluator, mandated by Article 81, becomes a serious issue. A statute that is exemplary on paper, but unusable by those for whom it is designed, cannot be a desirable goal for any rethinking of 17-A.

Second, a statute exemplary on paper, as Art. 81 arguably is under the due process lens, may look very different as it is applied in practice. That is certainly the case as to many of the provisions of Article 81 that are routinely ignored, including the availability of less restrictive alternatives, the preference for tailored guardianship, and the requirement of detailed periodic reporting and review. It would be cynical in the extreme to change 17-A to look more like Art. 81, without an honest assessment of whether such change would actually protect the rights of PWIDDs, rather than simply making society feel better about the process.⁶¹

⁵⁹ *Changing Paradigms*, *supra* note 49.

⁶⁰ A recent article by an investigative journalist suggests that Art. 81 may be utilized for reasons other than the protection or care of an "incapacitated person," noting the use of guardianship by nursing homes as a bill collection technique. Nina Bernstein, *To Collect Debts, Seizing Control Over Patients*, N.Y. TIMES, January 26, 2015, at A1.

⁶¹ For example, any proposal to increase the protection of rights for persons for whom guardianship is sought by requiring the assignment of counsel is, at best, disingenuous without a commitment to the additional financial and personnel resources that would be required.

IV. THE CURRENT LAW OF GUARDIANSHIP FOR PWIDDs

17-A was intended to provide a simple, speedy method to permit parents of mentally retarded children⁶² to retain sole legal decision making power when those children reached their majority, and it more than accomplished that goal, albeit at great cost to the rights of those young adults.⁶³ The main features of 17-A are that:

- It is entirely diagnosis driven, relying on a finding, by certain enumerated health care professionals, of mental retardation (and, after 1989, certain enumerated developmental disabilities);
- In most instances there is no hearing, the Surrogate makes a determination based solely on the papers submitted by the petitioner, and never sees or hears from the person for whom guardianship is sought;
- The guardianship is plenary; that is, the person under guardianship loses to right to make any and all decisions.
- The appointment of a guardian has no time limit and continues indefinitely;
- There is no requirement that a guardian of the person ever report on her “ward’s”⁶⁴ situation, and there is no review of the necessity for continuation of guardianship by the court.

As this cursory description of the statute demonstrates, it is entirely out of date with regard to procedural protections that are now both statutorily and constitutionally required.⁶⁵

⁶² Despite the earlier discussion of the importance of respectful language, because the statute, and the legislative history, utilize the terms “mental retardation” and “mentally retarded,” those terms are employed here as well.

⁶³ For the intent of the statute, *see, e.g.*, Bailly & Nick-Torok, *supra* note 3, at 817-819 (“[T]he legislature was mindful of the desire of parents to ‘provide for 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 retardation and the need for guidance and assistance are determinable at a very early age and remain so for life.’ (footnote omitted)).

⁶⁴ For the same reason that language has evolved with regard to the disabilities that persons may possess, and to an emphasis on the person rather than her/his disability, *see* Bailly & Nick-Torok, *supra* note 3, advocates argue against the term “ward” as entirely defining a person for whom guardianship may have been ordered. Thus, the use of the terms “person to whom guardianship is sought” or “person under guardianship”. There is currently a legislative proposal in Texas to change that state’s statute precisely in this way. Guardianship Reform and Supported Decision Making Group, *Changing the Term Ward to Person Under Guardianship, A Policy Paper in Bill Form* (on file with committees).

⁶⁵ The apparent constitutional infirmities of 17-A have been noted by commentators. *See, e.g.*, Bailly & Nick-Torok, *supra* note 3; *Changing Paradigms, supra* note 49, at 119-21; Jeffrey A. Cohen, Thomas A. Dickerson & Joanne Matthews Forbes, *A Legal Review of Autism, A Syndrome Rapidly Gaining Attention Within Our Society*, 77 ALB. L. REV. 381 (2013) (“[P]rior to judicial interpretation, [17-A] lacked most, if not all the due

A. *Least Restrictive Means*

Central to the substantive, as opposed to procedural due process required for the deprivation of liberty caused by the imposition of guardianship, and resonating throughout the discussion of 17-A which follows, is the concept of least restrictive means. That is, as one court has explained:

Beginning with *O'Connor v. Donaldson*, 422 U.S. 563, 95 S.Ct. 2486, 45 L.Ed.2d 396 [1975], substantive due process has been understood to include a requirement that when the state interferes with an individual's liberty on the basis of its police power, it must employ the least restrictive means available to achieve its objective of protecting the individual and the community. New York courts have embraced the principle of least restrictive alternatives (see, e.g., *Kesselbrenner v. Anonymous*, 33 N.Y.2d 161, 165, 350 N.Y.S.2d 889, 305 N.E.2d 903 [1973]) ("To subject a person to a greater deprivation of his personal liberty than necessary to achieve the purpose for which he is being confined is, it is clear, violative of due process"); *Manhattan Psychiatric Center v. Anonymous*, 285 A.D.2d 189, 197-98, 728 N.Y.S.2d 37 (1st Dept. 2001).⁶⁶

When passing non-criminal statutes that curtail liberty, the legislature has taken account of the constitutional imperative of least restrictive means.⁶⁷ And, of course, that is precisely the rationale behind Art. 81, where the Law Revision Commission described the goal of the statute as "requiring a disposition that is the least restrictive form of intervention."⁶⁸

Taking Article 81 as a due process-based model of what the legislature has understood as necessary before the deprivation of liberty (and, in the case of guardianship of the property, of that

process protection of Art. 81.") (citing *In re Mark C.H.*, 28 Misc.3d 765 (Sur. Ct. N.Y. Cnty. 2010)) (note that the two lead authors are Associate Justices of the Appellate Division, Second Department). It has also been noted in judicial decisions. See, e.g., *In re Dameris L.*, 38 Misc.3d 570 (Sur. Ct. N.Y. Cnty. 2012); *In re Chaim A.K.*, 26 Misc.3d 837 (Sur. Ct. N.Y. County 2009); *In re Mark C.H.*, 28 Misc.3d 765 (2010).

⁶⁶ *Matter of Dameris L.*, 38 Misc.3d at 526; see also *In re Andrea B.*, 94 Misc.2d 919, 925 (Fam. Ct., N.Y. Cnty. 1978) ("[S]ubstantive due process requires adherence to the principle of least restrictive alternative . . .").

⁶⁷ See, e.g., MENTAL HYG. LAW §§ 9.60(h)(4), (i)(2) (codifying "Kendra's Law," which deals with assisted outpatient treatment).

⁶⁸ Law Revision Commission Comments, 34 A. McKinney's Consol. Laws of N.Y. § 81.03. The statutory language incorporates the least restrictive means imperative in slightly different language, "The legislature recognized that the legal remedy of guardianship should be the *last resort* for addressing a person's need because it deprives the person of so much power and control over his or her life." MENTAL HYG. § 81.01 (emphasis added).

right as well), the specific deficiencies of 17-A in this respect are apparent.

B. Basis for Appointing a Guardian

Following the general reform trend of the late 1980's, Article 81 eschews a diagnosis-driven determination of "incapacity," requiring instead a functional determination.⁶⁹ The New York Court of Appeals has embraced the functional approach: "Recognizing that the presence of a particular [medical or psychiatric] condition does not necessarily preclude a person from functioning effectively."⁷⁰

Utilizing this functional approach, and proceeding from the presumption that all adults possess full capacity, guardianship can only be imposed when:

- 1) the person is likely to suffer harm; *and*
- 2) the person is unable to provide for personal needs and/or property management; *and*
- 3) the person cannot adequately understand and appreciate the nature and consequences of such inability, MHL 81.02(s) (b) (1)-(2).⁷¹

By contrast to the tri-partite requirement of likely harm, inability to provide, and inability to understand and appreciate, 17-A provides:

When it shall appear to the satisfaction of the court that a person is a developmentally disabled person, the court is authorized to appoint a guardian of the person or property, or both, if the appointment of such guardian or guardians is in the best interest of the developmentally disabled person.⁷²

That is, amazingly for 2014, a person with a developmental disability, no matter how high functioning, and in the absence of any likelihood of danger or harm, may have all decision-making permanently removed *solely* on the subjective determination of a surrogate that the appointment of a guardian is in the person's "best interest." No citation is necessary to demonstrate that such a standard falls far short of any notion of constitutional liberty and/or property rights and substantive due process.

⁶⁹ "In reading its determination the Court shall give primary consideration to the functional level and functional limitations of the person." MENTAL HYG. § 81.02(c).

⁷⁰ Law Revision Commission Notes to N.Y. Mental Hyg. Law §81.02 (McKinney 2012) (citing *In re Grinker* (Rose), 77 N.Y.2d 703 (1991), and *Rivers v. Katz*, 67 N.Y.2d 485 (1986), *reargument den.*, 68 N.Y.2d 808 (1986)).

⁷¹ This is the classic definition of cognitive incapacity that informs most existing guardianship laws, often shortened to "understand and appreciate."

⁷² N.Y. Surr. Ct. Proc. Act. § 1750-(1).

C. *The Requirement of a Hearing*

Given the liberty and/or property interests at stake, Art. 81 requires a hearing in all cases.⁷³ By contrast, under 17-A, if the petition for guardianship is brought by the parents, or by another person with the consent of the parents, the court may, in its discretion, dispense with the hearing. Anecdotally, most 17-A guardians are appointed without a hearing, and thus without the court, which is charged with determining “best interest,” ever seeing the person for whom guardianship is sought. While both statutes theoretically provide for a jury trial,⁷⁴ anecdotally, and for obvious reasons, such trials are seldom demanded in Art. 81 guardianships, and are essentially non-existent for guardianships under 17-A.

D. *Presence at the Hearing*

Art. 81 provides that the person for whom guardianship is sought must presumptively be present at the hearing, even if that requires the judge to travel to a place, outside the courthouse, where the person resides, “so as to permit the court to obtain its own impression of the person’s capacity.”⁷⁵ Exceptions are limited to situations in which the person is outside the state or, by clear evidence, the person “is completely unable to participate” or “no meaningful participation will result from the person’s present”⁷⁶

By contrast, presence may be dispensed with under 17-A where, upon medical evidence, presence “is likely to result in physical harm” or the person is “medically incapable” of attendance, or,

⁷³ “A determination that the appointment of a guardian is necessary for a person alleged to be incapacitated shall be made only after a hearing.” MENTAL HYG. § 81.11(a). As the Third Department has held, the failure to hold a hearing makes it impossible for an appellate court to determine whether the powers granted to either the guardian of the person or guardian of the property are the least restrictive form of intervention or, for that matter, whether there is clear and convincing evidence of incapacity. *See, e.g., In re Ruth T.T.*, 267 A.D.2d 553, 554 (3d Dep’t 1999); *In re Lula XX*, 224 A.D.2d 742 (3d Dep’t), *appeal dismissed*, 88 N.Y.2d 842 (1996); *In re Maher v. Maher*, 207 A.D.2d 133 (2d Dep’t 1994), *appeal denied*, 86 N.Y.2d 703 (1995).

⁷⁴ MENTAL HYG. § 81.11(f); N.Y. Surr. Ct. Proc. Act. §1754. Both also provide that unless a jury trial is demanded, it is deemed waived.

⁷⁵ MENTAL HYG. § 81.11(2).

⁷⁶ *Id.* §§ 81.11(c)(1)-(2). The Law Revision Commentary to MENTAL HYG. § 81.11 stresses the importance of “having present at the hearing the person whose rights may be affected by the proceeding,” and notes that “seeing the person” also allows the court to draw a carefully crafted and nuanced order which takes into account the person’s dignity, autonomy and abilities, because the judge has had opportunity to learn more about the person as an individual rather than a case description in a report.”

under an indeterminate standard, big enough to drive a truck through, there are “such other circumstances which the court finds would not be in the best interests of the mentally retarded or developmentally disabled person.”⁷⁷ And, of course, the person is not present at a hearing in the vast majority of cases, because no hearing is held.

E. Burden of Proof

In accordance with the importance of liberty issues implicated, Art. 81 requires proof of clear and convincing evidence of each of the three criteria—likely harm, inability to provide, and inability to understand and appreciate—described above.⁷⁸ There is no indication of the burden of proof in Art. 12, so, as a civil proceeding, the burden is presumptively preponderance of the evidence.⁷⁹

F. Right to Counsel

While Art. 81 grants the AIP “the right to choose and engage legal counsel of the person’s choice,”⁸⁰ it also requires appointment of counsel in a number of circumstances, including when the AIP requests counsel, wishes to contest the proceeding, does not consent to major medical or dental treatment, or to transfer to a nursing home. As a matter of case law, where the AIP is indigent, and important constitutionally protected interests are at stake, the state, or its appropriate subdivision, is required to pay for assigned counsel.⁸¹

There are no such provisions in, or case law, about 17-A except that where the person for whom guardianship is sought resides in a facility, as defined by MHL 47.01(a). Mental Health Legal Services (“MHLS”) in the appellate division department must be

⁷⁷ Surr. Ct. Proc. Act. §1754(3). Where there is a hearing, but the presence of the person for whom guardianship is sought has been dispensed with, the court *may* (but is not required to) appoint a guardian *ad litem*. Surr. Ct. Proc. Act. § 1754(4). There is no provision for payment of anyone so appointed.

⁷⁸ MHL § 81.12(a).

⁷⁹ See *In re* Chaim A.K., 26 Misc.3d 837, 847 n.28 (Surr. Ct. N.Y. Cnty. 2009) (citing *In re* Jaime S., 9 Misc.3d 460 (Fam. Ct. Monroe Cnty. 2005); *In re* Jonathan Alan Mueller, 25 Misc.3d 165, 166 (Surr. Ct., Dutchess Cnty. 2009) (stating that it is unlikely that Art. 81’s requirement of clear and convincing evidence applies. “[T]he decision to appoint a guardian of the person or property, or both, under N.Y. Surr. Ct. Proc. Act. § Art. 17-A is based upon a less stringent standard of proof, namely, the best interests of the mentally or developmentally disabled person.”).

⁸⁰ MENTAL HYG. § 81.10(a).

⁸¹ See *In re* St. Lukes-Roosevelt Hospital Ctr. (Marie H.), 226 A.D.2d 106 (1st Dep’t 1996), *aff’d*, 89 N.Y.2d 889 (1996).

served with the petition.⁸²As a matter of practice, MHLS generally appears when a hearing is held, or files a report when a hearing is dispensed with.

G. *Right to Cross Examine*

Art. 81 specifically provides a person opposing guardianship with the hallowed right to cross examine.⁸³ Not only is there no comparable provision in 17-A, but the use of form affidavits for the medical “proof” necessary to impose guardianship means that the critical element of the need for 17-A guardianship—the medical diagnosis of mental retardation or developmental disability⁸⁴—is routinely met by pure, and purely inadmissible, hearsay. The healthcare professionals need only check a box, on a form, that the person “suffers from” mental retardation or developmental disability; a box that such disability began prior to the persons reaching twenty one; a box that by virtue of her or his disability, the person is unable to manage her or his affairs; and a box that such disability is likely to continue indefinitely.

H. *Medical Privacy and the Doctor-Patient Privilege*

There is another major issue related to the use of affidavits in 17-A proceedings, and the records, however incomplete, that are frequently appended to them. Such submissions clearly violate the privacy rights,⁸⁵ and the physician/patient privilege,⁸⁶ of the person for whom guardianship is sought as well as her/his statutory

⁸² Surr. Ct. Proc. Act §1753(2)(b).

⁸³ MENTAL HYG. § 81.11(b)(3). The Supreme Court has continuously emphasized the centrality of this right to due process. *See, e.g., Crawford v. Washington*, 541 U.S. 36 (2004) (reviewing the history of the confrontation clause and concluding its purpose was directed at keeping *ex parte* examinations out of the record); *Morrissey v. Brewer*, 408 U.S. 471, 489 (1972) (holding that one of the minimum requirements of due process includes the right to confront and cross-examine adverse witnesses).

⁸⁴ Two health care professionals, one of whom must be an M.D., must certify that the person for whom guardianship is sought suffers from either mental retardation, or developmental disability, that the condition is likely to continue indefinitely, and that s/he cannot manage her personal affairs and/or property. *See* N.Y. Surr. Ct. Procedure Act Law §1750-a (McKinney 2005), Affidavit (Certification) of Examining Physician or Licensed Psychologist (GMD-2a), and Affirmation (Certification) of Examining Physician (GMD-2B) as included in the Petition for Appointment of Guardian, *available at* www.nycourts.gov/forms/surrogates/omni/gd17A.pdf, *archived at* <http://perma.cc/HEX2-MKFU>.

⁸⁵ *See* Joseph Rosenberg, *Routine Violations of Medical Privacy in Article 81 Guardianship Cases: So What or Now What?*, N.Y. ST. BAR ASS’N J., Jan. 2013, at 34.

⁸⁶ The physician/patient privilege is codified in C.P.L.R. § 4504. Additionally, MHL Section 33.13(c) provides that records maintained by a mental health facility may be disclosed only with a patient’s consent or by court order.

rights under the Health Insurance Portability and Accountability Act (“HIPAA”).⁸⁷ HIPAA requires health care providers to maintain the confidentiality of information about a patient unless the patient gives consent or a court orders the production of such information; neither of these circumstances routinely—if ever—occur in 17-A proceedings.

One Surrogate’s Court has recognized this issue in a contested proceeding where the person for whom guardianship was sought made an equal protection claim. Relying on an appellate decision that disallowed testimony by a former physician in an Art. 81 proceeding without the consent of the AIP as violative of CPLR 4504,⁸⁸ the Surrogate held that there was no rational basis for treating the subjects of Art. 81 and 17-A proceedings differently. The court went on to hold that when the subject of a guardianship proceeding does not waive the privilege, or affirmatively put his or her medical condition into controversy, testimony about her/his medical treatment is inadmissible.⁸⁹ The same, presumably, would be true for medical records.

I. Findings

In order to appoint a guardian of the person and/or property under Art. 81, the court must make specific findings on the record.⁹⁰ Even where the AIP agrees to appointment, the court must find (in addition to the agreement) the person’s functional limitations; necessity for a guardian to deal with those limitations; the specific powers granted to the guardian; and the duration of the appointment.⁹¹

Where there is no consent, additional findings are required, demonstrating that petitioner has met its burden, by clear and convincing evidence, that the AIP lacks understanding and appreciation of the nature and consequences of her or his functional limitations; the likelihood of harm resulting from the lack of understanding and appreciation; not only the specific powers granted to the guardian, but that they are the least restrictive form of intervention necessary;⁹² and whether the A.I.P.,⁹³ now denominated

⁸⁷ 45 C.F.R. §§160.103, 164.508, 164.512(e) (2006).

⁸⁸ *In re Rosa B.S.*, 1 A.D.3d 355 (2d Dep’t 2003).

⁸⁹ *In re Derek*, 12 Misc.3d 1132 (Surr. Ct. Broome Cnty. 2006).

⁹⁰ MENTAL HYG. § 81.15.

⁹¹ *Id.* §§ 81.15(a) (2-5).

⁹² *Id.* §§ 81.15(b) (2-3), (5).

⁹³ Like the term “ward,” the language employed by Art. 81 after the imposition of guardianship, “Incapacitated Person,” or “I.P.” unfortunately and inappropriately en-

the I.P.⁹⁴ should receive copies of the initial and annual report. Where a guardian of the property is appointed, the court must also make findings as to the type and amount of property involved and “any additional findings that are required under Section 81.21.”⁹⁵

The purpose of record findings in Art. 81 as in other proceedings where the legislature has also required findings⁹⁶ is to ensure that the court has fully complied with the statutory requirement of proof, as well as to provide a record for appeal. There is no requirement for findings after a hearing under 17-A and, of course, where there is no hearing, there can be no record findings.

J. Eligibility and Qualification of Guardian

Article 81 provides detailed considerations for who should be appointed a guardian, including consideration of the AIP’s preferences and/or nomination.⁹⁷ The court is required to consider, *inter alia*, the social relationship between the proposed guardian and the AIP, and between the proposed guardian and “other persons concerned with the welfare of the incapacitated person;”⁹⁸ the care and services being provided to the incapacitated person;⁹⁹ the unique requirements of the incapacitated person;¹⁰⁰ and whether there are any conflicts of interest between the proposed guardian and the incapacitated person.¹⁰¹

tirely defines the person by virtue of her/his disability; while I.P. is used here in its statutory context, “person under guardianship” is the preferred term.

⁹⁴ Given that a person for whom a guardian is appointed under Art. 81 has the right to move to terminate the guardianship, MENTAL HYG. §§ 81.36(a) and (b), it is difficult to understand—or to justify—why she or he should not be entitled to copies of the report that allegedly contain information as to why the guardianship should continue.

⁹⁵ MENTAL HYG. § 81.15(c)(1).

⁹⁶ See, e.g., N.Y. DOM. REL. LAW § 236(B)(5)(g) (stating that in equitable distribution of marital property, court must consider fourteen enumerated factors and, in its decision “shall set forth the factors” consider that were not waived by counsel).

⁹⁷ MENTAL HYG. § 81.19.

⁹⁸ MHL 81.19(d)(2).

⁹⁹ MHL 81.19(d)(3).

¹⁰⁰ MHL 81.19(d)(7).

¹⁰¹ MHL 81.19(d)(8). Unfortunately, the reality of ensuring appropriate qualifications for guardians under Art. 81 has fallen far short of what is necessary to protect those who are placed under their power and control. A 2010 study by the federal Government Accountability Office found that in New York, among other states, persons who applied for certification as guardians using false identification with the name of a deceased person, or with a bad credit record, were routinely certified. U.S. Govt. Accountability Office, GAO-1046, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors* (2010), available at <http://www.gao.gov/products/GAO-10-1046> (last visited Apr. 20, 2015), archived at <http://perma.cc/3P7R-3DGY>. The practice in appointing 17-A guardians appears more thorough in some respects, as

Presumably because 17-A was enacted to allow parents to continue exercising control over children with mental retardation who attained their majority, and because it was presumed that parents were the “natural” caretakers who inevitably had their children’s best interests at heart, there are no provisions whatever in 17-A as to considerations to be taken into account by the court if a guardian is to be appointed.¹⁰²

K. Powers of the Guardian: Plenary or Limited

One of the most significant differences between the protection of Art. 81 and 17-A, and perhaps the most glaring constitutional failure of the latter, is that, upon the diagnosis and “best interest” finding, the Surrogate’s only choice, without regard to “least restrictive alternative,”¹⁰³ is imposition of a plenary guardian, and thus removal of *all* decision making power from the person on whom guardianship is imposed.

As the legislative findings clearly state,¹⁰⁴ Art. 81 demonstrates

both prospective guardians and standby guardians must be fingerprinted, with their prints sent to the statewide criminal registry for review.

¹⁰² One court has read into the statute a preference for relatives, and in particular, for a parent, finding a “presumption that ‘parents prevail in a contest with a non-parent’ that can be overcome only where the non-parent establishes ‘extraordinary, circumstances.’” *In re Timothy R.R.*, 42 Misc.3d 775 (Sur. Ct. Essex Cnty. 2013) (relying on, *e.g.*, *Bennett v. Jeffreys*, 40 N.Y.2d 543 (1976), and citing an unreported case, *In re Boni P.G.*, 13 Misc.3d 1235[A] (N.Y. Sur. Ct. 2006)).

¹⁰³ One court, considering 17-A, has noted that “least restrictive means” is a constitutional imperative, as well as a statutory requirement under Art. 81. *In re Dameris L.*, 38 Misc.3d at 526.

¹⁰⁴ “Legislative findings and purpose. 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.” MENTAL HYG. § 81.01.

a strong, if not overwhelming preference against plenary guardianship, in favor of guardianship that is closely tailored to meet the specific functional impairments that might result in harm to the I.P. The statute specifically provides that if the court has found the AIP incapacitated *and* that appointment of guardian is necessary: “The order of the court shall be designed to accomplish the least restrictive form of intervention by appointing a guardian with powers limited to those which the court has found necessary to assist the incapacitated person in providing for personal needs and/or property management.”¹⁰⁵

Subsequent sections detail in illustrative, but not exhaustive examples, the powers which may be conferred on guardians of the person and the property.¹⁰⁶ Art. 81 also provides for protective, or single purpose transactions (“one shots”) as an even less restrictive means than appointing a full guardian.¹⁰⁷ And, reiterating the least restrictive means mandate, Art. 81 imposes an obligation on every guardian to “[a]fford the incapacitated person the greatest amount of independence and self determination with respect to [personal needs and/or property management]—in light of—that person’s wishes, preferences and desires”¹⁰⁸ By contrast, 17-A simply provides that “[i]f the court is satisfied that the best interests of the mentally retarded or developmentally disabled person will be promoted by the appointment of a guardian of the person, or the property, or both, *it shall make a decree naming such person or persons as guardians.*”¹⁰⁹ That is, there is not only no preference for a lim-

¹⁰⁵ *Id.* § 81.16(c)(2).

¹⁰⁶ *Id.* § 81.21-22.

¹⁰⁷ *Id.* § 81.16. As the Law Revision commentary notes with respect to 81.16, “[t]he list of alternatives available to the court emphasizes the statute’s underlying goal of promoting the least restrictive alternative. The most significant part of this section is the provision governing protective arrangements and single transactions, a provision based on section 5-40 of the Uniform Probate Code. With this section, Article 81 fills a gap in New York’s law identified by the Court of Appeals in *In re Grinker* (Rose), namely, that where a person may require assistance but does not require the equivalent of either a conservator or a committee, or even where the equivalent of either a conservator or a committee, or even where the equivalent of a conservator is appropriate, appointment of the equivalent of “a conservator with its consequent affront to the integrity and independence of the individual . . . ought to be among the last alternatives.” 77 N.Y.2d at 712. Proposed Article 81 allows the court to fashion remedies which may include protective arrangements or single transactions which assure security, service or care to meet the foreseeable needs of the incapacitated person but do not deprive the person of independence and autonomy.” Law Revision Commission Comments, McKinney’s Cons. Laws of N.Y., Book 34A, Mental Hygiene Law § 81.16.

¹⁰⁸ MENTAL HYG. §§ 81.20(6)(1), (7) (“Duties of Guardian”).

¹⁰⁹ N.Y. Surr. Ct. Proc. Act. § 1754(5) (emphasis added).

ited or tailored guardian, there is no provision for anything *but* a plenary guardian.¹¹⁰

There is one very limited exception to the plenary guardianship imposed under 17-A. The statute provides for a “limited guardian of the property” when the person for whom guardianship is sought is 18 or over and “wholly or substantially self-supporting by means of his or her wages or earnings from employment.” Under these circumstances, the court may appoint a guardian for all property of the person other than that received from wages or earnings. In addition, despite the imposition of a property guardian with the specified restriction, the person who is otherwise denied the right to contract by virtue of the guardianship “shall have the power to contract or legally bind himself or herself for such sum of money not exceeding one month’s wages or earnings . . . or three hundred dollars, whichever is greater, or as otherwise authorized by the court.”¹¹¹

While it is difficult to understand why a PWID who is working and supporting him or herself needs a guardian at all, calling the entire enterprise into question, this is the sole instance of “tailoring” permitted by 17-A.

Relying on this “*inclusio unius est exclusio alterius*,” one Surrogate has held that 17-A does not permit tailoring such that guardians of the property may make gifts from that property,¹¹² while another Surrogate in New York County has read into 17-A authority to tailor a guardianship where necessitated by best interests.¹¹³ This difference in approaches, without clarification from a higher court, has led to confusion among practitioners,¹¹⁴ but, more sig-

¹¹⁰ Because 17-A is such a “blunt instrument,” as well as because of its constitutional infirmities, one court has held that it must be strictly construed, such that where proof indicated that the person for whom guardianship was sought had a primary diagnosis of mental illness, rather than mental retardation or developmental disability, only the more flexible, limited Art. 81 could be employed. *In re Chaim A.K.*, 26 Misc.3d 837 (Sur. Ct. N.Y. Cnty. 2009).

¹¹¹ N.Y. Surr. Ct. Proc. Act. § 1756.

¹¹² See *In re John J.H.*, 27 Misc.3d 705 (Surr. Ct. N.Y. Cnty. 2010). The court also relied in the general proposition that “when enacting a statute the Legislature is presumed to act with deliberation and with knowledge of the existing statutes on the same subject.” *In re Jonathan E.E.*, 86 A.D.3d 696, 698 (3d Dep’t 2011) (citing McKinney’s Consol. Laws of N.Y., Book 1 Statute §222 at 384). Upon a finding that the relief requested was not available in a 17-A proceeding, the petitioner parents withdrew their petition in favor of commencing a new proceeding under Art. 81, under which such relief is specifically authorized.

¹¹³ *In re Yvette A.*, 27 Misc.3d 945 (Surr. Ct., N.Y.Cnty. 2010); see also *In re Joyce SS.*, 30 Misc.3d 765 (Surr. Ct. Bronx Cnty. 2010) (holding that Surrogate had the power to invoke the doctrine of substituted judgment in authorizing gifting by a guardian).

¹¹⁴ Bailly & Nick-Torok, *supra* note 3, at 834.

nificantly, spotlights the shortcomings of a statute that makes no provision for the limitation of powers that is constitutionally required, or the tailoring necessary to delineate the powers of a guardian if one is appointed.

It is also important to note that as a consequence of the requirement of “tailoring,” Art. 81 specifically provides that a person for whom a guardian is appointed “retains all powers and rights except those powers and rights which the guardian is granted.”¹¹⁵ Such rights include constitutionally protected rights such as voting and marriage. The wholesale grant of plenary power to a 17-A guardian would appear to deprive the person under guardianship of *all* rights, though there is surprisingly little case law explication.¹¹⁶

There is also a strong caveat here. Although Art. 81 uses all the right words, and includes all the appropriate provisions to ensure the constitutional imperative of least restrictive intervention, the reality on the ground is far different. There are no available statistics on the number of guardianships sought or awarded,¹¹⁷ much less on whether plenary or limited,¹¹⁸ but anecdotally, the vast majority of adult guardianships imposed are plenary; a 2007 national survey found that in 90% of cases, persons found to be incapacitated were deprived of all of their liberty and property rights.¹¹⁹ That is to say, while Art. 81 is useful as a comparison in demonstrating the shortcomings of 17-A, it is hardly a guarantee that the rights of “incapacitated persons” are actually being protected.

L. Reporting and Review

Art. 81 includes detailed reporting requirements¹²⁰ for guardi-

¹¹⁵ MHL 81.29(a).

¹¹⁶ One court has placed limitations on a 17-A guardian’s power where reproductive rights are involved, refusing to permit sterilization upon the guardian’s consent. *In re DD*, 90 Misc.2d 236 (Tompkins County Ct. 2002).

¹¹⁷ Bernstein, *supra* note 60, ¶ 5.

¹¹⁸ This is a national problem: see Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A “Best Guess” National Estimate and the Momentum for Reform*, in *Future Trends in State Courts* 107, 109 (2011).

¹¹⁹ Pamela B. Teaster, *et al.*, *Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?*, National Study of Public Guardianship, Phase II Report, 96 (2007).

¹²⁰ For guardians of the person, the report must include information on the person under guardianship’s residence, including whether the current residence is best suited to the person’s needs; physical condition, including a health care provider’s report made within three months, also detailing the current functional level of the incapacitated person; any major changes in physical or mental condition, or in medications; an account of medical treatment over the preceding year and a plan for medi-

ans of both the person and the property, including an initial report, to be filed within ninety days of issuance of a commission to the guardian;¹²¹ and, thereafter, annual reports, MHL 81.31, which are reviewed by court examiners, appointed and supervised by the Appellate Division for the Department in which the appointing court is located.¹²² The purpose of the report is primarily to ensure the well being of the person under guardianship and, where appropriate, the good stewardship of her/his property,¹²³ but, significantly, the report also must include any “facts indicating the need to terminate the appointment of the guardian” or for any change in powers. That is, Art. 81 recognizes that conditions may change, and/or functional capacity increase (or decrease), thus altering the least restrictive intervention and requiring a “new look” by the court.¹²⁴

By contrast, although 17-A requires a yearly filing on finances

cal, dental and mental health treatment for the coming year; and “information concerning the social condition of the incapacitated person including: the social and personal services currently utilized . . . , the social skills . . . and the social needs of the incapacitated person.” MHL § 81.36(6) (iv). For guardians of the property, “the information required by [the Surrogate’s Court Procedure Act] . . . for an annual accounting of a general guardian of an infant’s property.” MHL § 81.31(7). The initial report also requires a complete inventory of the person’s property over which the guardian has control and the guardian’s plan for that property’s management and control. MHL § 81.30(b).

¹²¹ MHL 81.30(b).

¹²² MHL 81.32(b).

¹²³ Two leading commentators have summarized the reasons for periodic reporting and review, also called “monitoring” as follows:

First, historically courts have had a *parens patriae* duty to protect those unable to care for themselves. *Parens patriae* is the fundamental basis for guardianship and the primary justification for curtailing civil rights. The court appoints the guardian to carry out this duty and the guardian is a fiduciary bound to the highest standards. ‘In reality,’ observed one judge, ‘the court is the guardian; an individual who is given that title is merely an agent or arm of that tribunal in carrying out its sacred responsibility.’ Second, unlike with decedents’ estates, the incapacitated person is a living being whose needs may change over time. This argues for a more active court role in oversight. Third, monitoring can be good for the guardian by offering guidance and support in the undertaking of a daunting role. Fourth, monitoring can be good for the court by providing a means of tracking guardianship cases and gauging the effect of court orders. Finally, monitoring can boost the court’s image and inspire public confidence.

Sally Balch Hurme and Erica Wood, *Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role*, 31 *Stetson L.Rev.* 867, 871-872 (citations omitted) (2002).

¹²⁴ The importance of periodic reporting and review was noted in the “Wingspread Recommendations” that led to guardianship reform in the late 1980’s and early 1990’s the Uniform Guardianship Procedure and Protection Act (UGPPA) and in the National Probate Court Standards, *In re Chaim A.K.*, 26 *Misc.3d* 837, n.18 and 19.

by a guardian of the property,¹²⁵ once a guardian of the person is appointed s/he is *never, ever* again required to provide any information about the well-being—or not—of the person under guardianship, or whether there is any continuing reason *for* a guardian.¹²⁶ The former raises serious concerns that abuse and/or neglect may be occurring, unknown to the court which has vested total power in the guardian. Surely substantive due process requires that when the state intervenes to deprive someone of her/his liberty in the guise of protection, that person should not be worse off because of the intervention. This is what monitoring is intended to prevent; its absence is a grave and almost certainly a constitutional failure.

The latter is equally serious, continuing a massive deprivation of liberty when a person is capable of living—and thriving—with a less restrictive form of intervention, or no intervention at all. Without periodic review there is no way for the court to know whether the guardianship should be modified (assuming that such tailoring were available under the statute) or terminated (see discussion *infra*). In addition to the likely constitutional violation,¹²⁷ the failure to review, caused by absence of any periodic reporting, may well also violate the “least restrictive setting” requirement of the American With Disabilities Act (ADA).¹²⁸

M. *Modification, Termination, & Restoration of Rights*

However defined, a person’s “capacity” is seldom static; people gain or lose functional capacity, or their circumstances change such that greater or lesser functional capacity is required to permit

¹²⁵ Unlike the Art. 81 reports, which are reviewed by paid outside court examiners, the clerks in Surrogate’s Court are expected to perform this service for reports by guardians of the property, including following up when reports are not timely filed. The extent to which this occurs, and the care and/or expertise available is nowhere assessed or reported.

¹²⁶ The absence of any reporting requirement was undoubtedly premised on the view that it was parents who would be guardians, and that parent always have the best interests of their children at heart. Unfortunately, as the tragedies of child abuse demonstrate, this is not always the case. But, equally important—and now mistaken—was the view forty years ago that mental retardation and, subsequently, developmental disabilities were permanent, unchanging conditions, with little or no likelihood of improvement, much less “cure.”

¹²⁷ One court has held that, in the absence of periodic reporting and review, 17-A is unconstitutional; the Surrogate administratively imposed the requirement of yearly reporting on all guardians of the person in that court. *In Re Mark C.H.*, 28 Misc.3d 765 (2010).

¹²⁸ See *Olmstead v. L.C.*, 527 U.S. 581. For a thorough and provocative discussion of the ADA in the context of PWIDDS and guardianship, see Leslie Saltzman, *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).

them to live without substantial risk of harm. For persons who are under Art. 81 guardianship because of a stroke or a traumatic brain injury, symptoms can be alleviated through medical treatment; functional abilities lost to disease or accident can be regained (by the same token, of course, function and/or cognitive abilities may progressively decline, as they do with Alzheimer's Disease). When such changes occur, the imperative of least restrictive intervention mandates concomitant changes in the powers granted to a guardian, or, in some cases, termination of the guardianship and the full restoration of all rights.

Article 81 recognizes this shifting continuum of functional capacity/incapacity and specifically provides for modification of a guardian's powers—whether an increase¹²⁹ or decrease—or termination¹³⁰ “where the incapacitated person has become able [or unable] to exercise some or all of the powers necessary to provide for personal needs or property management which the guardian is authorized [or not authorized] to exercise.”¹³¹ There is broad standing to initiate a proceeding for modification or termination.¹³² A hearing is presumptively required,¹³³ and a jury trial is available on demand by the incapacitated person or her/his counsel.¹³⁴ Where the relief sought is termination, the burden of proof is on the *party opposing such relief*—that is, it must be proven, by clear and convincing evidence, that the grounds for guardianship continue to exist.¹³⁵ These provisions embody and instrumentalize the principle

¹²⁹ If the statute were strictly adhered to, for example, a person with early or moderate Alzheimers might have a property guardian to manage investments, but still retain a bank account and the power to engage in ordinary, day-to-day financial transactions. If and when her cognitive abilities significantly declined, the guardian might seek—and obtain—more extensive powers. In actual practice, partly out of concern for the expense and disruption of repeated proceedings, courts tend not to tailor, or limit powers, but rather to grant plenary guardianships, even when unjustified under the statute, to avoid having petitioners return to court at a later date when expanded powers might be required.

¹³⁰ MENTAL HYG. LAW § 81.36

¹³¹ MENTAL HYG. LAW §§ 81.36(a)(1)-(2).

¹³² “The application . . . may be made by the guardian, the incapacitated person, or any person entitled to commence a proceeding under this article.” MENTAL HYG. LAW § 81.36(b). There is a wide range of persons “entitled to commence proceedings.” While *Id.* § 81.06(a)(1)-(6) does not explicitly include a close friend, domestic partner, or other relative who is not a “presumptive distributee” under the Surrogate's Court Procedure Act, it includes “a person otherwise concerned with the welfare of the person alleged to be incapacitated” which could presumably include any or all of the above.

¹³³ MENTAL HYG. LAW § 81.36(c).

¹³⁴ *Id.*

¹³⁵ *Id.* § 81.36(d). By the same token, where the petitioner seeks to increase the powers of the guardian, the same evidentiary burden falls on her/him. *Id.*

of least restrictive intervention.

Like those persons for whom guardianship is commonly sought under Art. 81, PWIDDS also fall on a spectrum of capacity requiring greater or lesser intervention or assistance,¹³⁶ and, like the subjects of Art. 81 guardianships, their conditions and life circumstances may change.¹³⁷ For example, no longer is a diagnosis of autism (or a condition on the autism spectrum) an indication of a permanent, unchanging disability. Persons with autism may, with various interventions, significantly improve their functioning¹³⁸ or even “recover” or be “cured,”¹³⁹ and there is promising new research on interventions for persons with Down Syndrome.¹⁴⁰

Under 17-A, guardianship presumptively continues for the entire life the person under guardianship.¹⁴¹ The statute provides for modification “to protect the mentally retarded or developmentally disabled person’s financial situation and/or his or her personal interests.”¹⁴² Such modification, which does not require a hearing,¹⁴³ is generally employed to replace one family member guardian with another,¹⁴⁴ or where a person for whom a guardian of the person has been appointed comes into money, requiring the additional powers of a guardian of the property.

While there is explicit statutory provision for termination,¹⁴⁵

¹³⁶ For example, mental retardation is determined by IQ scores, themselves subject to “challenge, as illness, motor or sensory impairments, language barriers, or cultural differences may hamper a child’s test performance.” The Merck Manual of Diagnosis and Therapy, Mental Retardation, 18th ed. 2006.

¹³⁷ A change in life circumstances, as in the development of a system of supported decision-making (see discussion *infra*) may alter or negate the need for a guardian. See, e.g., *In re Dameris L.*, 38 Misc.3d 570 (Sur. Ct. N.Y. Cnty. 2012); A recent article in the American Journal of Intellectual and Developmental Disabilities reports research that young adults with Down Syndrome have significantly higher “adaptive” skills than their low I.Q. scores might suggest. James Edgin & Fabian Fernandez, *The Truth About Down Syndrome*, N.Y. TIMES, Aug. 28, 2014, http://www.nytimes.com/2014/08/29/opinion/the-truth-about-down-syndrome.html?_r=0.

¹³⁸ Advances in treatment of autism may result in substantial and potentially legally significant increases in functional capacity. See, e.g., Susan Kabot et al., *Advances in the Diagnosis and Treatment of Autism Spectrum Disorders*, 34(1) PROF. PSYCHOL.: RES. & PRAC. 26 (2003).

¹³⁹ See, e.g., Ruth Padawer, *After Autism: The Recovered*, N.Y. TIMES MAG., Aug. 3, 2014, at 20.

¹⁴⁰ See Edgin & Fernandez, *supra* note 137.

¹⁴¹ N.Y. Surr. Ct. Proc. Act. § 1759 (“[G]uardianship shall not terminate at the age of majority or marriage of [the] mentally retarded or developmentally disabled person but shall continue during the life of such person, or until terminated by court.”).

¹⁴² *Id.* § 1755.

¹⁴³ See *In re Lemmer*, 179 A.D.2d 926 (3d Dep’t 1992).

¹⁴⁴ See, e.g., *In re Garrett YY*, 258 A.D.2d 702 (3d Dep’t 1999).

¹⁴⁵ A person eighteen years or older for whom such a guardian has been previously appointed or anyone, including the guardian, on behalf of a

there is no indication as to the burden of proof, or, indeed, even what must be proved for the guardianship to be “dissolved.” Anecdotally, applications for termination of guardianship brought by a person under guardianship are extremely rare.¹⁴⁶

N. Brief Detour: OPWDD Regulations and The Health Care Decisions Act

One reason that parents or others might be motivated to seek guardianship for a PWIDD is the fear that, in the absence of a guardian, no one would be empowered to make major medical decisions, including end of life decisions, for the person. This concern may be slightly, if not entirely alleviated by two legal regimes that permit surrogate decision-making for a PWIDD with respect to major medical decisions, including end of life decisions.

With respect to major medical decisions that do NOT involve the withholding or withdrawal of life sustaining medical treatment, individuals who are receiving services under the auspices of New York State Office for People with Developmental Disabilities (“OPWDD”), fall within the OPWDD regulation contained in title 14, section 633.11 of the Compilation of Codes, Rules & Regulations of the State of New York. Section 633.11 sets forth the procedures for obtaining informed consent for “professional medical treatment.”¹⁴⁷ If a guardian has not been appointed, the following individuals may provide consent for a minor:

- (2) an actively involved spouse;¹⁴⁸
- (3) a parent;

mentally retarded or developmentally disabled person for whom a guardian has been appointed may petition the court which made such appointment or the court in his or her county of residence to have the guardian discharged and a successor appointed, or to have the guardian of the property designated as a limited guardian of the property, or to have the guardianship order modified, dissolved or otherwise amended. Upon such a petition, the court shall conduct a hearing pursuant to section seventeen hundred fifty-four of this article.

N.Y. Surr. Ct. Proc. Act. § 1759(2). The reference to N.Y. Surr. Ct. Proc. Act. § 1754 suggests that the determination might be made without a hearing, though no case law has been found one way or the other.

¹⁴⁶ *In re* Mark C.H., 28 Misc.3d 765, n.28 (2010).

¹⁴⁷ The term “professional medical treatment” is defined as follows: “A medical, dental, surgical or diagnostic intervention or procedure in which a general anesthetic is used or which involves a significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having a significant recovery period, or any professional diagnosis or treatment to which informed consent is required by law.” 14 N.Y. COMP. CODES R. & REGS. § 633.99(da) (2015).

¹⁴⁸ “Actively involved” is defined as: “Significant and ongoing involvement in a person’s life so as to have sufficient knowledge of the person’s needs.” *Id.* § 633.99(ax).

- (4) an actively involved adult sibling;
- (5) an actively involved adult family member;¹⁴⁹
- (6) a local commissioner of social services with custody over the person pursuant to the social services law or family court act (if applicable); or
- (7) a surrogate decision-making committee (SDMC) or a court.¹⁵⁰

If the person is eighteen or older, but lacks capacity to understand appropriate disclosures regarding proposed professional medical treatment, and no guardian or health care agent has been appointed, informed consent shall be obtained from one of the surrogates listed, in the order stated:

- (2) an actively involved spouse;
- (3) an actively involved parent;
- (4) an actively involved adult child;
- (5) an actively involved adult sibling;
- (6) an actively involved adult family member;
- (7) the Consumer Advisory Board for the Willowbrook Class (only for class members it fully represents); or
- (8) a surrogate decision-making committee (SDMC) or a court.¹⁵¹

There is no standard for decision-making by the identified surrogate set out in the OPWDD regulation, nor is there any duty imposed on the surrogate to consult with the person on whose behalf the surrogate is providing informed consent.

End-of-life decision-making, also known as the withholding or removal of life-sustaining treatment, is governed by the provisions of the Health Care Decisions Act for Persons with Mental Retardation (the "HCDA-MR").¹⁵² The HCDA-MR affords both court-appointed guardians,¹⁵³ as well as "qualified family members" who do not need to be court-appointed guardians, the authority to consent to medical treatment, including but not limited to the withholding or withdrawing of life-sustaining treatment.¹⁵⁴ The HCDA-MR pro-

¹⁴⁹ Family member is defined as "Any party related by blood, marriage, or legal adoption." *Id.* § 633.99(bf).

¹⁵⁰ *Id.* § 633.11(a)(1)(iii)(a).

¹⁵¹ *Id.* § 633.11(a)(1)(iii)(b).

¹⁵² See N.Y. Surr. Ct. Proc. Act § 1750-b (McKinney's Supp. 2007), 2002 N.Y. Laws. 500, S4622-B, A8466-D, signed on September 17, 2002.

¹⁵³ The New York Court of Appeals has held that the HCDA-MR applies not only to guardians appointed after its effective date (Mar. 17, 2003), but to all guardians regardless of when appointed. See *In re. M.B.*, 6 N.Y.3d 437 (2006).

¹⁵⁴ Surr. Ct. Proc. Act § 1750-b(1)(a).

vides for surrogate decision-making on the withholding or withdrawal of medical treatment for persons with developmental disabilities which either include mental retardation or result in similar impairment of intellectual functioning or adaptive behavior.¹⁵⁵ If there is no guardian, a surrogate decision maker will be appointed from a list of priorities:

- (1) Article 17-A guardian
- (2) an actively involved spouse
- (3) an actively involved parent
- (4) an actively involved adult child
- (5) an actively involved adult sibling
- (6) an actively involved adult family member
- (7) The Consumer Advisory Board for the Willowbrook Class (only for class members it fully represents): or
- (8) a surrogate decision-making (SDMC) or a court.¹⁵⁶

The surrogate is empowered to make any and all decisions to withhold or withdraw life-sustaining treatment.¹⁵⁷ The surrogate is required to base all advocacy and health care decision-making solely and exclusively on the best interests of the person with mental retardation or developmental disabilities and,¹⁵⁸ “when reasonably known or ascertainable with reasonable diligence,” on the wishes of the person with mental retardation or developmental disabilities, including moral and religious beliefs.¹⁵⁹

The statute specifically provides that if the PWIDD objects to the surrogate’s decision to withhold or withdraw life-sustaining treatment, the surrogate’s decision will be suspended pending judicial review, except if the suspension would be likely to result in the death of the person with mental retardation or developmental disa-

¹⁵⁵ N.Y. Surr. Ct. Proc. Act § 1750(1).

¹⁵⁶ Surr. Ct. Proc. Act § 1750-b(1)(a); 14 N.Y. COMP. CODES R. & REGS. §§ 633.10(a)(7)(iv), 633.11(a)(1)(b).

¹⁵⁷ N.Y. Surr. Ct. Proc. Act § 1750-b.

¹⁵⁸ An assessment of the best interests of the person with mental retardation or developmental disabilities shall include consideration of five factors: (1) the dignity and uniqueness of every person; (2) the preservation, improvement or restoration of the health of the person; (3) the relief of the suffering of the person by means of palliative care (care to reduce the person’s suffering) and pain management; (4) the unique nature of artificially provided nutrition or hydration, and the effect it may have on the person; and (5) the entire medical condition of the person. In addition, a surrogate’s health care decisions may not be influenced by a presumption that the person with mental retardation or developmental disabilities is not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to other persons, nor by financial considerations of the surrogate. *Id.* § 1750-b(2)(b).

¹⁵⁹ *Id.* § 1750-b(2)(a).

bilities.¹⁶⁰ OPWDD regulations and the HCDA-MR thus provide family members some power, in limited circumstances, to make healthcare decisions for a PWIDD without the necessity of a proceeding under 17-A.

V. RETHINKING 17-A THROUGH TWO DIFFERENT LENSES

A. *The Civil Rights/Procedural Due Process/Civil Liberties Lens*

Had the legislature's 1990 direction been followed to completion, any reconsideration of 17-A would have involved an analysis roughly similar to that which informed guardianship reform at the time. In the same way in which procedural guarantees were incorporated into the Adult Guardianship Statute, Art. 81, a reformed 17-A would be expected to include those guarantees, including the right to a hearing; to presence at that hearing; to call witnesses and cross examine; to an enhanced burden of proof, namely clear and convincing evidence; to specific findings on the record; to the privacy of medical records and the Fifth Amendment right against self-incrimination; to periodic reporting and review; and to an avenue for modification and/or termination in which the burden of proof was squarely on the opponent of such relief. In addition, the constitutional and potentially statutory¹⁶¹ imperative of least restrictive intervention which so permeates Art. 81 would necessarily imbue the requirements *for* guardianship, the obligation to explore and exhaust less restrictive alternatives, and a non-waivable preference for limited or tailored guardianship. All of these were aspects of the "first round" of guardianship reform.¹⁶²

Since that "first round," however, the movement for reform has continued,¹⁶³ and there are several widely acknowledged subse-

¹⁶⁰ *Id.* § 1750-b(5).

¹⁶¹ See discussion of the potential impact of the ADA on guardianship law, Saltzman, *supra* note 128.

¹⁶² As illustrated by, *e.g.*, the Uniform Guardianship Protective Proceedings Act (UGPPA), Prefatory Note (1998). These include the Standards of Practice of the National Guardianship Association adopted in 2007, available at www.guardianship.org/documents/standards_of_practice.pdf (last visited Sept. 15, 2014), archived at <http://perma.cc/QQ4R-GQMX> and the Yokohama Declaration of the First World Congress on Guardianship, available at http://www.international-guardianship.com/pdf/IGNY-okohama_Declaration_2010.pdf (last visited Sept. 15, 2014). The Commission on National Probate Standards has promulgated standards for courts, Nat'l Probate Court Standards (Comm'n on Nat'l Probate Court Standards & Advisory Comm. on Interstate Guardianships 1993) (revised 1999) (upcoming review in process).

¹⁶³ A useful summary of state actions to reform existing guardianship laws in a variety of areas, from pre-adjudication issues, mediation in contested guardianships, qualification of guardians, to post-appointment monitoring, is found in COMM'N ON LAW & AGING, AM. BAR ASSOC., STATE ADULT GUARDIANSHIP LEGISLATION: DIRECTIONS OF

quent sources that ought to be considered in any rethinking of 17-A. Foremost among these are the recommendations of the Third National Guardianship Summit, which grew out of an invitation-only conference of national guardianship experts held in Salt Lake City in 2011.¹⁶⁴ The Uniform Law Commissioners have begun a process to reconsider the UGPPA in light of those recommendations.¹⁶⁵

Among the Summit Recommendations that go farther than the UGPPA and most “reform” guardianship statutes, including Art. 81, are recommendations that:

- In healthcare decision-making, the guardian should maximize the participation of the person (55.1) and encourage and support the individual in understanding the facts and *directing a decision*. (55.2).¹⁶⁶
- In residential decision-making, the guardian should utilize a person-centered plan that seeks to fulfill the person’s goals, needs and preferences, and emphasizes her/his strengths, skills and abilities to the fullest extent in order to favor the least restrictive setting. (56.4).

More recently, a conference held at Cardozo Law School brought together attorneys, advocates, court personnel, judges, and service providers “to foster dialogue and develop consensus about the next wave of guardianship reform in the state.”¹⁶⁷ Rec-

REFORM 2013, available at http://www.americanbar.org/publications/bifocal/vol_35/issue_2_dec2013/2013_guardianship.html (last visited Apr. 15, 2015), archived at <http://perma.cc/XK9M-JAZU>. Similar compilations exist for every year since 2004.

¹⁶⁴ The recommendations are published in a symposium issue of the Utah Law Review, Julia R. Nack, Carolyn L. Dessin, & Judge Thomas Swift, *Creating & Sustaining Interdisciplinary Guardianship Committees*, 2012 UTAH L. REV. 1157 (2012), and are also available at http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_gship_sumt_stmnt_1111v2.authcheckdam.pdf (last visited May 9, 2015).

¹⁶⁵ See David English, Chair, Am. Bar Assoc. on Law and Aging, Presentation at the Third World Congress on Adult Guardianship (Apr. 14, 2014), available at <http://www.guardianship.org/IRL/Resources/Handouts/Beyond%20Substituted%20Judgment%20Presentation.pdf> (last visited Apr. 15, 2015), archived at <http://perma.cc/HCP2-PD3R>.

¹⁶⁶ This recommendation has been seen as moving traditional guardianship law toward supported decision-making, insofar as it differs significantly from formulations like “taking the person’s wishes and desires into consideration.” *Changing Paradigms*, *supra* note 49, at 139, n.207.

¹⁶⁷ THE GUARDIANSHIP CLINIC, BENJAMIN N. CARDOZO SCHOOL OF LAW, GUARDIANSHIP IN NEW YORK: DEVELOPING AN AGENDA FOR CHANGE, REPORT OF THE CARDOZO SCHOOL OF LAW CONFERENCE 4 (2012), available at <http://www.cardozo.yu.edu/sites/default/files/GuardianshipReport.pdf>, archived at <http://perma.cc/UXL6-3WEM>. Although the conference focused on Art. 81, the Report notes that “some of the recommendations bear on Article 17-A guardianships as well.” *Id.*

ommendation 4 was to “Promote Alternatives to Guardianship and Create a Guardianship Diversion Program.” The group assigned to this issue noted, “Guardianship is a last resort. Yet, there was widespread recognition that guardians are sometimes appointed when less restrictive alternatives would address unmet needs.”¹⁶⁸

Other relevant recommendations included “Screen All Potential Guardians Up-Front” (Recommendation 10); “Evaluate Guardianships Regularly to Determine if They Should Be Terminated” (Recommendation 7); and, creating a segue to the other lens through which 17-A might be re-thought, “Explore Replacing Guardianship with Supported Decision-Making Models” (Recommendation 5).¹⁶⁹

B. Other State Statutes On Guardianship for PWIDDs

There is one additional area that might be profitably explored in a traditional, due process-based reconsideration of 17-A, that of the few other states that have statutes dealing separately with guardianship for this population (California, Connecticut, Idaho and Michigan).¹⁷⁰ Those statutes all require specific attention to the individual’s functional limitations rather than her or his diagnosis, seek to authorize only the most limited form of guardianship sufficient to address otherwise current needs,¹⁷¹ and obligate the guardian to seek support to develop and maximize the individual’s functioning.¹⁷²

¹⁶⁸ *Id.* at 7.

¹⁶⁹ Interestingly, the group that developed this recommendation also proposed “developing a lawsuit to challenge the validity of Article 17-A guardianships, which have been widely recognized as not comporting with all the due process and rights-based principle incorporated in Article 81.”

¹⁷⁰ CAL. PROB. CODE §§ 1801, 1821-23, 1828.5, 1830, 1850.5, 1860.5, 1872, 1890-91, 1952 (West 2014); CONN. GEN. STAT. §§ 45a-669 to -684 (2015); IDAHO CODE ANN. §§ 15-5-301 to -318 (West 2014); KY. REV. STAT. ANN. §§ 387.500-.800 (2014); MICH. COMP. LAWS ANN. §§330.1600 -1644 (West 2014) (guardianship for the developmentally disabled).

¹⁷¹ For example, the California statute permits the appointing court to allow the person for whom limited conservatorship (guardianship) is sought, to “enter into transactions . . . as may be appropriate in the circumstances of the particular conservatee.” CAL. PROB. CODE § 1873 (West 2014). The Law Revision Comments on this section explain: “The court might, for example, permit the conservatee to enter into specific types of transactions or transactions not exceeding specified amounts (such as contracts not in excess of \$500).” *Id.*

¹⁷² For example, closely adhering to the constitutional requirement of least restrictive means, the California statute (which uses the term “conservator” rather than guardian) provides:

A limited conservator of the person or of the estate, or both, may be appointed for a developmentally disabled adult. A limited conservatorship may be utilized only as necessary to promote and protect the well

The California statutory scheme is particularly strong in its provisions for independent fact gathering, both for the initial determination as to whether a conservator or guardian should be appointed¹⁷³ and, in contradistinction to Art. 81,¹⁷⁴ whether there is a basis for continuing the conservatorship. The appointing court is mandated to review the “appropriateness of the conservatorship and whether the conservator is acting in the best interests of the conservatee regarding the conservatee’s placement; quality of care, including physical and mental treatment; and finances” six months after the initial appointment, one year later, “and annually thereafter.”¹⁷⁵ The court is, therefore, actively engaged not only in ensuring the conservatee’s well being, but in determining whether changes have occurred such that a conservatorship is no longer the

being of the individual, shall be designed to encourage the development of maximum self-reliance and independence of the individual, and shall be ordered only to the extent necessitated by the individual’s proven mental and adaptive limitations. The conservatee of the limited conservator shall not be presumed to be incompetent and shall retain all legal and civil rights except those which by court order have been designated as legal disabilities and have been specifically granted to the Institutions Code, that developmentally disabled citizens of this state receive services resulting in more independent, productive, and normal lives is the underlying mandate of this division in its application to adults alleged to be developmentally disabled.

Id. § 1801. Similarly, Michigan provides:

(1) Guardianship for individuals with developmental disability shall be utilized only as is necessary to promote and protect the well-being of the individual, including protection from neglect, exploitation, and abuse; shall take into account the individual’s abilities; shall be designed to encourage the development of maximum self-reliance and independence in the individual; and shall be ordered only to the extent necessitated by the individual’s actual mental and adaptive limitations.

(2) If the court determines that some form of guardianship is necessary, partial guardianship is the preferred form of guardianship for an individual with a developmental disability.

MICH. COMP. LAWS ANN. § 330.1602 (West 2014).

¹⁷³ When a petition for limited conservatorship is filed, the person for whom the conservatorship is sought is, if s/he consents, to be examined by a regional center in accordance with Cal. Prob. Code § 1827.5; if the conservatee withholds the consent to be assessed by the regional center, the court shall determine the reason for such withholding. *Id.* § 1828.5(a)(5).

¹⁷⁴ While under Art. 81’s reporting requirements, the guardian is supposed to advise whether the guardianship should continue, the court, through the court examiner, has only the guardian’s word, which may or may not accurately describe the situation.

¹⁷⁵ CAL. PROB. CODE §§ 1850(a)(1)-(2). The court may set any subsequent review at two years, but if it does so, in the interim, a court examiner must make an investigation including an unannounced visit to the conservatee, and file a report as to whether, *inter alia*, “the conservatorship still appears to be warranted.” *Id.* § 1850(a)(2).

least restrictive alternative, and that it should be terminated or modified.

Significantly, the independent court investigator is required to inform the conservatee of her or his right to petition for termination of the conservatorship and to determine whether she or he wishes to do so.¹⁷⁶ The investigator is also required to issue a report, prior to the court's review, as to "whether the present condition of the conservatee is such that the terms of the [appointing] order should be modified or the order revoked."¹⁷⁷

Michigan takes a somewhat different approach to ensuring that continuation of a guardianship remains the least restrictive means. In addition to a requirement that the appointing court verbally inform the PWID of his or her "right . . . to request at a later date his or her guardian's dismissal or a modification of the guardianship order," the person for whom a guardian has been appointed is also entitled to "a written statement . . . indicating his or her rights pursuant to [the section on termination and modification] and specifying the procedures to be followed in petitioning the court."¹⁷⁸

The burden to initiate termination however, is not, however, left solely to the person under guardianship or those acting on her or his behalf. By statute, all guardianships of PWIDDS are limited to five years;¹⁷⁹ if the guardianship is to continue, a new petition for guardianship has to be filed, and a hearing held, with all the attendant due process protections, including the imposition of a burden of proof by clear and convincing evidence¹⁸⁰ on the proponent of the guardianship.¹⁸¹ And, it should be noted, when guardianship—or renewal of guardianship—is sought, Michigan offers another protection to the PWID, the right to assigned counsel paid for by the state.¹⁸² Despite all the protections contained the Michigan statute, one of its authors, Dohn Hoyle, Executive Director of The Association for Retarded Children (ARC) Michigan, notes the inconsistency of its application, and is, instead, strongly advocating

¹⁷⁶ CAL. PROB. CODE § 1851(a).

¹⁷⁷ *Id.* For a more extensive description and discussion of the California statute, see Melinda Hunsaker, *Limited Conservatorships: A Delicate Balance*, 50 ORANGE CNTY. LAWYER 26 (2008).

¹⁷⁸ MICH. COMP. LAWS § 330.1634.

¹⁷⁹ *Id.* § 330.1626(2).

¹⁸⁰ Like California, and Art. 81, Michigan imposes this enhanced burden of proof. MICH. COMP. LAWS §330.1618(4).

¹⁸¹ MICH. COMP. L. SERV. §330.1626(3).

¹⁸² *Id.* § 330.1615.

for a human rights based supportive decision-making regime.¹⁸³

The guardianship/conservatorship statutes of other states that deal specifically with PWIDDs should thus be instructive and valuable in any rethinking of 17-A, especially insofar as they provide, in muscular fashion, either through mandatory periodic review or time-limited guardianship, that the twin imperatives of least restrictive means and the protection and well being of the person under guardianship are being met.

C. *The Human Rights Lens*

Passage of the CRDP, and its ratification by more than 120 nations, has spurred a movement away from traditional guardianship and substituted decision-making, to a new model of autonomy and self-determination, based on supported decision-making.¹⁸⁴ The movement has, necessarily, involved two separate projects: one to collect existing models of supported decision-making and to plan and create pilot projects around the world; and, second, to develop and propose new legislation consistent with Article 12 and premised in the human right of legal capacity.¹⁸⁵ These efforts are useful in understanding supported decision-making and in imagining how it might be incorporated in New York law grounded in a human rights model.¹⁸⁶

¹⁸³ DOHN HOYLE, *THE ARC MICHIGAN, RETHINKING GUARDIANSHIP*, n.d., <http://www.arcmi.org/pdf/Rethinking%20Guardianship%20MAF%20-%20Michigan.pdf> (last visited Apr. 15, 2015), archived at <http://perma.cc/BRC6-VLHC>; See also personal communication with Dohn Hoyle, on file with author.

¹⁸⁴ As Professor Arlene Kanter has written: "Instead of paternalistic guardianship laws, which substitute a guardian decision for the decision of the individual, the CRPD's supported decision-making model recognizes first, that all people have the right to make decisions and choices about their own lives." Arlene Kanter, *The United Nations Convention on the Rights of Persons With Disabilities and Its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U.L. REV. 527, 563 (2009); see also, Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8 (Winter 2012).

¹⁸⁵ For an example of a planning process to bring a State Party's laws into compliance with Article 12, see Elizabeth Kumandia, The Kenya National Commission on Human Rights and the Open Society Initiative for Eastern Africa, *How to Implement Article 12 of the Convention on the Rights of Persons With Disabilities Regarding Legal Capacity in Kenya: A Briefing Paper* (June 2013), available at <http://www.knchr.org/portals/o/group/rightsreports/briefing%20on%20legal%20capacity-disability%20rights.pdf>.

¹⁸⁶ The two leading theorists of Canadian law reform on legal capacity, Michael Bach and Lana Kerzner, have suggested three main kinds of supports that could or should be provided for decision-making consistent with Art. 12: supports to assist in formulating one's purpose; supports to explore the range of choices and make a decision; supports to engage in the decision-making process with other parties to make agreements where one's decision requires this; and supports to act on the decision

It is important, however, first to understand the concept of supported decision-making, and the various models it may take. Quite simply, it begins with an understanding that no one makes decisions, especially important decisions like where to live, whether to have a particular medical treatment, or who to marry, entirely alone, or in a vacuum. Ordinary citizens seek information from others, consult, and solicit opinions. PWIDDS similarly utilize support in making choices and decisions, but because of their disabilities, may require different kinds, and a greater degree of support—to have information made available to them in a way they understand, to consider and weigh consequences, and, for PWIDDS with communicative disabilities, to make their wishes known.¹⁸⁷

As the Committee on the Rights of Persons With Disabilities notes in the first General Comment:

Support is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self advocacy support, or assistance with communication).

The Comment also notes that:

For many persons with disabilities, the ability to plan in advance is an important form of support . . . A choice of various forms of advance planning mechanisms can be provided . . . but all options should be non-discriminating. Support should be provided to an individual where desired to complete an advanced planning document.¹⁸⁸

Support systems also can, and quite frequently do, grow quite

one has made, and to meet one's obligations, under any agreement made for that purpose. Michael Bach & Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Oct. 2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>, archived at <http://perma.cc/M53F-U8RL>.

¹⁸⁷ The First General Comment notes that “[s]upport can . . . constitute the development and recognition of diverse, non-conventional means of communication, especially for those who use non-verbal forms of communication to express their will and preference.” No.1 at ¶17. General Comment, *supra* note 58. For a discussion of a variety of forms of supported decision-making and a call for more research in the area, see Nina A. Kohn, Jeremy A. Blumental, & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN. ST. L. REV. 1111, 1121-25 (2013).

¹⁸⁸ The significance of the “non-discriminating” and “support” language with respect to advanced planning requires moving away from traditional requirements of “mental capacity” necessary for, e.g., creating a valid power of attorney or healthcare directive, using, if necessary, supports to make an individual’s “will and preference” known. This, together with a “trusting relationship,” is the basis for representation

informally, in ways that may eliminate¹⁸⁹ or limit the need for guardianship.¹⁹⁰ The now well-publicized story of Jenny Hatch demonstrates how a young Virginia woman with Down Syndrome lived safely and successfully in the community with a support network of friends, co-workers and service providers for twenty-seven years. An accident that caused her mother and stepfather to bring a guardianship proceeding resulted in the denial of her right to choose where and with whom to live, her job, and contact with her friends and supporters. Fortunately, her plight came to the attention of Quality Trust, an advocacy organization in D.C. which, in a six-day trial, with expert witnesses, persuaded a Virginia judge to remove her parents, and appoint as guardian, for one year only, two of her supporters, to work with her on supported decision-making.¹⁹¹ Happily, Jenny's guardianship was entirely terminated in August, 2014.¹⁹² As a result of the publicity around Jenny's story, Quality Trust has created the Jenny Hatch Justice Project, which collects and disseminates information about supported decision-making.

One model of supported decision-making, pioneered in British Columbia Canada, involves "representation agreements" by which a PWIDD names one or more persons to assist her or him in making particular kinds of decisions.¹⁹³ The support persons do not make decisions *for* the PWIDD, and if there is disagreement, the PWIDD's choice prevails. The PWIDD may also cancel the agreement at will. For this model to work, however, that is to afford

agreements under British Columbia law. Representation Agreement Act, R.S.B.C. Ch. 405 (1996).

¹⁸⁹ *In re Dameris L.*, 38 Misc.3d 570 (Sur. Ct. N.Y. Cnty. 2012), the court terminated a 17-a guardianship on a finding that a support network had grown up around the person under guardianship such that she was able—with their support—to make her own decisions, and so no longer required a guardian.

¹⁹⁰ *See, e.g.*, the story of a Texas woman with Down Syndrome whose support network convinced a judge to replace her state agency guardian with her supporter/foster care provider, in anticipation of terminating the guardianship completely. Robin Thorner, *Challenging Guardianship and Pressing for Supported Decision-Making for Individuals With Disabilities*, SARGENT SHRIVER NAT'L CTR. ON POVERTY LAW (Jan. 7, 2014), <http://stage.povertylaw.org/content/challenging-guardianship-and-pressing-supported-decision-making-individuals-disabilities>.

¹⁹¹ Materials and press about Jenny's story are available at <http://www.jennyhatchjusticeproject.org/trial>, archived at <http://perma.cc/93GJ-2GB4>.

¹⁹² Don Dahler, *Woman with Down Syndrome Becomes Icon for Disabled*, CBSNEWS.COM (Nov. 30, 2013), <http://www.cbsnews.com/news/woman-with-down-syndrome-becomes-icon-for-disabled/>.

¹⁹³ Different people, or groups of people might be chosen for different kinds of decisions, like financial, residential, healthcare, etc. R.S.B.C. 1996 Chapter 405, Part 2.

the PSWIDD her or his right to have her or his decisions acted upon, third parties, like financial institutions, healthcare providers, landlords, etc. have to be willing—or required—to recognize those decisions; this is where legislation is necessary to facilitate and enforce supported decision-making.

While all of this may seem Utopian, there are at least partial models in existence in Canada and several European countries.¹⁹⁴ Thoughtfully planned pilot projects have been successful in Bulgaria¹⁹⁵ and Australia.¹⁹⁶ Similarly, there is proposed legislation,¹⁹⁷ a set of principles for legislation,¹⁹⁸ and actually enacted legisla-

¹⁹⁴ See, e.g., *Changing Paradigms*, *supra* note 49, at 140-52 for a discussion of Sweden, Germany, and several provinces in Canada (British Columbia, Manitoba, Yukon, and Alberta).

¹⁹⁵ For materials on this project, which was funded by the Open Society Foundation, see Bulgarian Ctr. For Not-For-Profit Law, <http://www.bcnl.org/en/nav/40-analyses.html>, archived at <http://perma.cc/JN7T-JTAE>. It is particularly inspiring as it involved a number of PWIDDs who had long been institutionalized in Bulgaria's horrendous "hospitals" and who, with the aid of support, are now living and functioning successfully in the community.

¹⁹⁶ Margaret Walker, *Evaluation of the Supported Decision-Making Project*, Office of the Public Advocate (South Australia) (Muirgen Nominees Pty. Ltd., 2012), available at http://www.opa.sa.gov.au/files/batch1376447055_final_supported_decision_making_evaluation.pdf.

¹⁹⁷ A multi-year effort in Canada has produced a detailed legislation proposal, for the Law Commission of Ontario, Bach & Kerzner, *supra* note 186; see *Policy Document Submitted to Justice Aims to Aid People with Intellectual Disabilities*, NFLD. ASS'N OF CMTY. LIVING, <http://www.nlacl.ca/news/article/getting-power-make-decisions-policy-document-submi>. See Shih-Ning Then, *Evaluation and Innovation in Guardianship Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 133 (2013), for an extensive discussion of proposals for legislative reform in Australia.

¹⁹⁸ E.g., Ctr. of Disability Law and Policy, *Essential Principles: Irish Legal Capacity Law*, NAT'L UNIV. OF IRELAND GALWAY (Apr. 2012), available at http://www.nuigalway.ie/cdlp/documents/principles_web.pdf (the National University of Ireland Galway Center of Disability Law and Policy created a "Principles and Key Issues for Capacity Legislation" after a year of extensive consultation with stakeholders). Its principles and key issues include:

The law must protect people's rights to make decisions about all aspects of their lives . . . [for example] healthcare, finances, relationships and where and with whom to live.

People who need support to make decisions have a right to be provided with that support by the state, e.g. advocate supports should be recognized and assist the person in understanding options and expressing their "will and preference."

Reasonable accommodation should be made to help the person understand the decision. Different ways of providing information must be explored (including sign language, alternative communication, flexibility with regard to time and location for delivering information . . . , etc.).

There should be a range of advocacy supports including state-appointed advocates with statutory powers, as well as other forms of individual advocacy (e.g., citizen advocacy, peer advocacy, self-advocacy support).

Decisions made by someone else is [are] a last resort when all supports

tion¹⁹⁹ that incorporates supported decision-making to a greater or lesser degree.

Work on supported decision-making, legal capacity and guardianship is not only international, it is very much alive and thriving in the U.S.²⁰⁰ and in New York.²⁰¹ In 2012, the A.B.A. Commissions on Disability Rights (CDR) and on Law and Aging (COLA) sponsored an invitational, interdisciplinary Roundtable, *Beyond Guardianship: Supported Decision-Making by Persons with Intellectual Disabilities*, funded in part by the New York Community Trust.²⁰² The Roundtable noted the need for a central body to collect information and best practices on supported decision-making, and to do policy advocacy and strategy around legislative reform.²⁰³

In May 2014, the U.S. Administration for Community Living (ACL)²⁰⁴ announced a five-year grant to create a Supported Deci-

have been considered (facilitated decision-making). It should only apply for specific decisions and for the length of time necessary for that purpose.

See, e.g., Czech Republic Enacts Legal Capacity Law Reform

¹⁹⁹ See Eilionoir Flynn and Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction or Fantasy*, 32 BERKELY J. INT'L L. 134, 144-146 (2014) (discussing legislation adopted or proposed in countries including Canada, India, and Ireland); *see also Legal Capacity in Europe: A call to Action to Governments and to the EU*, MENTAL DISABILITY ADVOCACY CTR. (2013), available at http://mdac.info/sites/mdac.info/files/legal_capacity_in_europe.pdf, for a discussion of the legislation in Czechoslovak Republic that has abolished plenary guardianship and introduced alternatives to guardianship such as supported decision-making.

²⁰⁰ See CTR. FOR PUB. REPRESENTATION, <http://www.centerforpublicrep.org/litigation-and-major-cases/supported-decision-making> (last visited Mar. 6, 2015), for information about the first planned pilot project on supported decision-making that is currently underway in Northampton, Mass., as a joint venture between the Center for Public Representation and Nonotuck Resource Associates. *See, e.g., Czech Republic Enacts Legal Capacity Law Reform* (Feb. 12, 2012), available at www.mdac.org/en/news/czech-republic-enacts-legal-capacity-law-reform, archived at <http://perma.cc/V8S4-QTGM> (“[N]ew law introduced support [for] decision-making as an alternative to the guardianship system.”).

²⁰¹ New York State’s new P&A, Disability Rights New York, is proposing a pilot project on supported decision-making as well as a project on restoration of rights (utilizing supported decision-making) for persons currently under 17-A guardianships (on file with author). Disability Rights New York, the Protection and Advocacy organization for New York State, with the Developmental Disability Planning Council, will be funding a three-to-five year pilot program on supported decision-making.

²⁰² *See Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities: A Short Summary from the 2012 National Roundtable*, AM. BAR ASS’N, http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf, archived at <http://perma.cc/XV2L-Y6SY> (last visited Apr. 15, 2015).

²⁰³ *Id.*

²⁰⁴ ACL is a newly created body within the U.S. Department of Health and Human Services that incorporates the Administration on Intellectual and Development Disabilities (AIDD) and the Administration on Aging (AOA).

sion Making Technical Assistance and Resource Center. According to ACL, “[s]upported decision making is a process that provides individuals, including older adults and people with I/DD assistance to understand the situations and choices they face, so they can make decisions for themselves. The process is an alternative to and an evolution from guardianship.”²⁰⁵ Specifically citing and embracing the CRPD and Article 12, ACL continues:

By declaring “legal capacity” for all people, the CRPD separates a person’s cognitive and communicative abilities from this basic right. In other words, all people, regardless of their disability or cognitive abilities have the right to make decisions and have those decisions implemented. These concepts have helped inform and frame the conversation around developing the supported decision-making process.²⁰⁶

The purpose of the Center on Supported Decision Making is to:

[D]ocument and disseminate successful decision-making practices; conduct research to fill data and information gaps; develop training materials and provide technical assistance to ACL networks on SDM issues, including youth transition; develop a strategy that measures and demonstrates the impact of supported decision-making on the lives of people with I/DD and older Americans; design and commence implementation of a small grants demonstration program that awards funding to four to seven community organizations . . .; and develop a clearinghouse of existing materials and resources, academic work and practices, success stories, and newly-developed research and training materials, to be made available to the general public.²⁰⁷

In August 2014, the grant was awarded to a consortium headed by Quality Trust, the entity responsible for Jenny Hatch case,²⁰⁸ and including the Autistic Self Advocacy Network (ASAN).²⁰⁹ Now up and running, the Center has become a major resource for information about supported decision-making and an

²⁰⁵ Dep’t of Health & Human Serv. Admin. for Cmty. Living., *Supported Decision Making*, HHS-2014-ACL-AIDD-DM-0084, 6 (2014), available at <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168> (last visited Apr. 15, 2015), archived at <http://perma.cc/4AQV-A2XF>.

²⁰⁶ *Id.* at 7.

²⁰⁷ *Id.* at 1.

²⁰⁸ See *infra* p. 59.

²⁰⁹ Admin. for Cmty. Living, *Preserving the Right to Self-Determination: Supported Decision-Making*, ACL BLOC (Jan. 29, 2015), http://www.acl.gov/NewsRoom/blog/2015/2015_01_28.aspx, archived at <http://perma.cc/VM22-A8X3>.

instigator of legislative reform from a human rights perspective.²¹⁰

There are a variety of other U.S.-based resources for re-consideration of 17-A in light of the CRPD, including materials developed by Michigan ARC,²¹¹ a well planned restoration of rights project incorporating supported decision-making, now in its second year in Florida,²¹² and efforts toward legislative reform including those in Texas and Virginia.²¹³ And, as a superb starting point, ASAN has drafted model legislation, dealing with one area of decision-making and avoiding the need for guardianship.²¹⁴

VI. FINAL THOUGHTS

The Committee notes an “intermediate” approach that will be proposed in the Uniform Law Commissioners’ forthcoming reconsideration of the UGGPA.²¹⁵ Drawing in part on the New York Surrogate’s Court decision in *In re Dameris L.*,²¹⁶ the existing UGPPA would be amended to specifically include supported decision-making as an alternative that must be attempted before guardianship may be considered or imposed.

²¹⁰ See the impressive collection of materials at www.supporteddecisionmaking.org/research_library.

²¹¹ HOYLE, *supra* note 183.

²¹² *Restoration of Capacity Study and Work Group Report*, FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, (Feb. 28, 2014), available at http://www.guardianship.org/IRL/Resources/Handouts/Charting%20a%20New%20Course_Restoration%20Report.pdf. This project is sponsored by H.H.S., AIDD and the Florida Development Disabilities Council, Inc., with significant input from the Florida judiciary.

²¹³ Guardianship Reform and Supported Decision Making Group Relating to a Supported Decision-Making Agreement: A Policy Paper in Bill Format (2014) (on file with committees). See Peter Blanck & Jonathan G. Martinis, “*The Right to Make Choices*”: *The National Resource Center for Supported Decision-Making*, 3 Inclusion 24-33 (2015), available at http://bbi.syr.edu/publications/2015/SDM_Overview.pdf, archived at <http://perma.cc/4NS3-M9PF>.

²¹⁴ *Model Legislation: An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults With Disabilities*, AUTISTIC SELF ADVOCACY NETWORK (2014), <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>.

²¹⁵ *Perils of Guardianships*, *supra* note 55. See English, *supra* note 165.

²¹⁶ *In re Dameris L.*, 38 Misc.3d 570, 580 (Sur. Ct. N.Y. Cnty. 2012), the Court wrote:

The internationally recognized right of legal capacity through supported decision making can and should inform our understanding and application of the constitutional imperative of least restrictive alternative. That is, to avoid a finding of unconstitutionality, N.Y. Surr. Ct. Proc. Act. § 17-A must be read to require that supported decision making must be explored and exhausted before guardianship can be imposed or, to put it another way, where a person with an intellectual disability has the ‘other resource’ of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian.

While not endorsing any particular approach or proposing specific provisions in a rethinking of 17-A, the Committee embraces one imperative of the CRPD,²¹⁷ the ACL proposal and new National Center on Supported Decision-Making, and the decades long disability rights movement—that the conversation must prominently include PWIDDS. While lawyers, judges, providers, parents and siblings, and academics all have important contributions to make, the Committee urges meaningful inclusion of PWIDDS in accordance with the slogan they brought to the U.N. working group on the CRDP, and which has informed the work of self-advocates for decades,²¹⁸ “Nothing about us without us.” And, as the discussion of language demonstrates, any reform effort must pay serious attention to the necessity of “person-centered” terminology that respects and enhances dignity.

It should also be noted that guardianship, or any legally sanctioned form of substituted decision-making, is never entirely beneficial. It is, therefore, important to consider the “downsides” of guardianship for a PWIDDS. As one commentator has noted:

This loss of decision-making rights deprives individuals with disabilities of numerous opportunities to participate in daily community life. For example, individuals under guardianship may not be able to bank, shop, apply for jobs, or seek routine health care without the participation and consent of the guardian. This lack of autonomy can cause individuals under guardianship to withdraw from community life and become disengaged from management of their own affairs. Thus, disengaged, they also lose opportunities to practice previously acquired decision-making skills or build new ones.²¹⁹

Whatever lens is employed, there must be concern for, and provision to protect decision-making, whether for or by (with supports) PWIDDS, against abuse²²⁰ and/or exploitation.²²¹ Although the motivating principle of 17-A is the protection of vulnerable persons, the existing statutory scheme is entirely devoid of any mecha-

²¹⁷ CRPD, *supra* note 51, at §4(3). The CRPD requires that PWID’s be actively engaged and included in its implementation.

²¹⁸ For a general history of disability rights activism incorporating this principle, see JAMES I. CHARLTON, NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT (2000).

²¹⁹ Samantha Alexandra Crane, *Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self-Determination Among People With Disabilities*, INTERNAT’L J. OF LAW & AGING ___ (2014) (forthcoming) (citing Kohn, *supra* note 188, at 1119 n.27).

²²⁰ Potential abuse could be physical, sexual, or emotional.

²²¹ Exploitation primarily, but not exclusively, applies to guardians (or supporters) over financial matters.

nisms to provide oversight or to ensure against abuse.²²²

Article 81 relies on court supervision, through an extensive reporting and review system—on paper—that may or may not be working, especially in a period of shrinking court budgets and competition for resources.²²³ But that system, even at its best, has serious issues in terms of any real certainty about the protection of those whose rights have been taken away and conferred on third parties, giving them the power to act in ways that should be beneficial, but may also be detrimental, to the needs of persons under guardianship.

First, obviously, the system relies entirely on what guardians report, with no provision for independent verification. Second, the use of paid court examiners, whose compensation depends on the size of the estate of the person under guardianship being reviewed, raises serious equity issues. There is no necessary correlation between the needs or vulnerability to abuse of a person with substantial financial resources and a frail elderly person on SSI living in the community—or a nursing home—yet the funds available for review vary tremendously.²²⁴ Finally, court examiners are chosen almost entirely for their ability to review reports of property guardians, and are not screened for (nor do most possess) any expertise in the issues relevant to evaluating guardians of the person, like rehabilitation services, appropriate medication, community services that enhance inclusion and participation, government benefits availability, etc.

These defects of Art. 81's monitoring system were pointed out in a Report of this Association more than two decades ago,²²⁵ but since that time virtually nothing has changed. That is, any hopes that grafting the "protective provisions" of Art. 81 onto a replace-

²²² As previously noted, there is absolutely no requirement that a 17-A guardian of the person ever report to the court—or anyone else—once the appointment is made. And, without reporting, there can be no oversight.

²²³ The statute was described as "revenue neutral" in order to secure its passage, and has never provided any additional resources for court supervision. Although the primary responsibility for review falls on external court examiners, it is the court's responsibility both to supervise them and then to review and act on their reports.

²²⁴ The incapacitated person ("IP") shall pay for the examination of initial and annual reports if her/his estate amounts to \$5,000 or more; or otherwise, the expenses is paid out of court funds. MENTAL HYG. LAW § 81.32(f). When the court appoints a counsel and/or referee for the purpose of protecting the IP's interest and assessing the immediate and final reports, the court has discretion to determine the compensation for the counsel and referee. *Id.* § 81.33(e).

²²⁵ The Comm. on the Legal Problems of the Aging, *Guardianship Monitoring in the Supreme Court*, 49 REC. ASS'N B. CITY N.Y 604 (1994).

ment for 17-A would provide meaningful protection against abuse, neglect or exploitation are naïve at best, and dishonest at worst.

The human rights lens explicitly calls for protection against abuse and exploitation; drawing directly on provisions of the CRPD. Article 12 requires:

States Parties all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measure relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.²²⁶

Article 16 provides, with more explicit obligations, for "Freedom From Exploitation, Violence and Abuse."²²⁷ Legislative proposals to replace substituted decision-making²²⁸ with supported decision-making and existing models incorporate provisions for protection, generally focusing on the use of "monitors"²²⁹ but many questions

²²⁶ U.N. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, Article 12, § 4, U.N. Doc. A/RES/61/106 (Dec. 13, 2006), available at <http://www.un.org/esa/socdev/enable/documents/tccconve.pdf>.

²²⁷ *Id.* Article 16, §§ 2, 3, 5, naming three types of measures which States Parties are required to undertake to ensure assistance and support for persons with disabilities, their families and caregivers, including information and education on how to avoid, recognize and report instances of exploitation, violence and abuse, to ensure effective monitoring by independent authorities, and to put in place effective legislation and policies to ensure that instances of exploitation, violence and abuse are identified, investigated and, where appropriate, prosecuted.

²²⁸ As two leading proponents of supported decision-making have written:

The key difference between safeguards for support model and those which have existed in substitute decision-making regimes is that safeguards for support are based on the core principle of respect for the individual's will and preferences, no matter what level of decision-making ability she holds. For example, in a support model there must be an adjudication mechanism for challenging support people if they fail to respect the will and preference of the individual. In contrast, adjudication in most current substituted decision-making regimes focuses on "protecting" the individual and discovering what is in her "best interest," with little importance placed on her will and preference.

Flynn and Arstein-Kerslake, *supra* note 199, at 152.

²²⁹ *Statutory Framework for the Right to Legal Capacity and Supported Decision-Making*, THE CANADIAN ASS'N FOR CMTY. LIVING (Draft 2012), cited in *The Roundtable Briefing*, AM. BAR ASS'N, 20 (Oct. 18, 2012), http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/Roundtable_brief_10182012.authcheck

remain. Among them:

To what extent, and how, will there be qualifications, standards and screening for those serving in either a supportive or substituted decision-making role, including identifying and avoiding existing and/or potential conflicts of interest?

In addition to, or in lieu of a required reporting system, should there be a system of routine or targeted checks to ensure against abuse by guardians or persons serving as supporters? What entity would conduct such checks and how? Who would pay for it?

How can PWIDDs have meaningful access to the court system to challenge abusive practices or to end unnecessary restrictions on their autonomy?

VII. CONCLUSION

SCPA 17-A, as it currently exists, discriminates against persons with intellectual and developmental disabilities, denies procedural and substantive due process to those for whom guardianship is sought, and over whom guardianship is imposed, fails to honor or promote autonomy, self-determination and dignity, and fails to protect persons under guardianship from abuse, neglect and exploitation. The compelling need to address these issues, first raised almost a quarter of a century ago, should be delayed no longer.

dam.pdf. It provides perhaps the most well-considered approach to protection from abuse in its concept of designated “monitors.” It states:

Given that some people are at higher risk of neglect and abuse because of the nature of their disability, isolation, or other factors, some provision should be in place to enable ‘monitors’ of supported decision-making and representative decision-making arrangements to be appointed. An appointment should be made only on request by an adult, supporter, representative or where there are reasonable grounds to indicate that this safeguard is required to ensure the decision-making process with and around the adult maintains integrity A monitor would be independent and act to ensure supporters and representatives are fulfilling their statutory obligations.

