ALTERNATIVES TO GUARDIANSHIPS FOR THE LGBT CLIENT:

Advocating for People with Intellectual and Developmental Disabilities without Judicial Intervention

sage SM
Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders

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A CLE hosted by SAGE
305 Seventh Ave., 15th Fl.
September 10, 2014
8:00 - 10:30 A.M.

Title:

Alternatives to Guardianships for the LGBT Client: Advocating for People with Intellectual and Developmental Disabilities without Judicial Intervention.

Description:

For years, the bar and the bench have seen guardianship proceedings as the sole way to allow personal needs and financial decision-making on behalf of individuals with disabilities, often overlooking non-judicial means. The quick resort to guardianship has often had a negative impact on LGBT individuals. This session proposes non-judicial alternatives, including resources available under existing law to allow individuals to exercise the capacity they currently possess to make their own decisions, with the assistance of existing family, friends, and community support structures. This program will involve looking at various case studies of common clients and discuss available planning options attorneys may propose. It will also address the cutting-edge global paradigm shift in the way courts and legislatures look at the rights of the intellectually disabled. Finally, the panel will review the ethical considerations surrounding clients with intellectual and developmental disabilities, and discuss ways to avoid having your effective advocacy called into question at a later date.

Speakers:

- Natalie Chin, Esq., Associate Professor of Clinical Law and Director, Advocates for Individuals with Developmental Disabilities Clinic, Brooklyn Law School, former Staff Attorney at Lambda Legal Defense and Education Fund.
- Hon. Kristin Booth Glen, Surrogate, New York County Surrogate's Court 2006-2012 (ret.), and University Professor and Dean Emirita, CUNY Law School.
- Thomas Sciacca, Esq., Principal, Law Offices of Thomas Sciacca, PLLC.

Who should attend:

Members of the Trusts & Estates, Elder Law, and Disability bars. Members of the Personal Injury and Special Education bars. Any attorney who has a person in their life that has an intellectual or developmental disability. Anyone who is concerned about their own ability to make their own decisions as they age. You!

CLE:

This program is approved for 1.5 credits (1.0 in areas of professional practice and 0.5 in ethics)

Cost:

Gratis. CLE generously provided by the LGBT Bar Association of Greater New York (LeGaL), and complimentary breakfast is provided by Services and Advocacy for GLBT Elders (SAGE).

Location:

SAGE, 305 Seventh Avenue (28th Street) – 15th Floor. Come see SAGE's national headquarters, their official NYC innovative senior center, and learn about everything SAGE is and everything SAGE does.

TIMED OUTLINE FOR PROGRAM

8am – 8:30am	Registration and breakfast provided on-site **(non-CLE)**
8:30am – 8:35am	Welcome from Jerry Chasen, Director of Legacy Planning at SAGE **(non-CLE)**
8:40am-8:45am	Introduction of panel and overview of presentation (Sciacca) **(5 minutes)**
8:45am – 8:55am	Guardianship overview. Difference between different types of guardianship proceedings? What are the underlying human rights and Constitutional issues? What unique issues does the LGBT community face when dealing with a guardianship proceeding? (Chin) **(10 minutes)**
8:55am – 9:05am	Current alternatives and effective advocacy. Discussion of the Family Healthcare Decisions Act and the limited supportive decision making it allows. Asking for limited guardianship powers from a Court, and the current statutory barriers to same (Glen) **(10 minutes)**
9:05am – 9:30am	Paradigm shift. Trends in the law, concerns raised by the bar and the bench. The United Nations Convention on the Rights of Persons with Disabilities. Re-training your legal brain to identify how a person with intellectual disabilities can use their existing capacity to advocate for themselves, with the help of counsel and/or the Court. Reconsidering dispositional alternatives available to Courts when presented with a guardianship proceeding. (Glen) **(25 minutes)**
9:40am-9:55am	Rules of ethics concerning representing clients with limited capacity, including intellectual and developmental disabilities. Overview of existing ethical rule and shortcomings thereof. Discussion of client loyalty and conflicts when a person with intellectual or developmental disabilities meets with an attorney, often escorted by someone else, who may be paying for the legal services. (Chin) **(15 minutes)**
9:55am-10:10am	Presentation of scenarios. Using the three scenarios provided in the materials, the panel will discuss alternatives to guardianships in each of them, as well as judicial alternatives for cases that are already pending in Court. Discussion will focus heavily upon effective advocacy practitioners can use in their everyday practice while operating within the rules of ethics. Panel will also discuss how attorneys can help a client with intellectual or developmental disabilities execute a Power of Attorney, Health Care Proxy, and a Living Will while minimizing the risk of a Court calling the integrity of the legal services or the documents into question at a later date. (Sciacca to introduce and present scenarios, with input and commentary from Chin and Glen) **(15 minutes)**
10:10am – 10:15am	Questions and answers (panel) **(5 minutes)**
10:15am-10:30am	Closing from Jerry Chasen, and tours of the SAGE's innovative Senior Center **(non-CLE)**

SPEAKER BIOGRAPHIES

NATALIE CHIN, ESQ. has recently joined the faculty at Brooklyn Law School as an Associate Professor of Clinical Law and Director, Advocates for Individuals with Developmental Disabilities Clinic. Prior to joining the faculty at Brooklyn Law School, Ms. Chin served as a Clinical Teaching Fellow in the Guardianship Clinic at Benjamin N. Cardozo School of Law from 2012-2014. From 2008-2012, Ms. Chin served as a Staff Attorney at Lambda Legal Defense and Education Fund, where she conducted impact litigation, education and policy reform to achieve equal rights for LGBT people and individuals living with HIV, with an emphasis on LGBT and HIV aging issues. She has also worked at MFY Legal Services and the New York City Law Department. She is a graduate of George Washington University (JD) and Boston University (BA).

HON. KRISTIN BOOTH GLEN (ret.) was elected Surrogate of New York County in 2005 and served until the end of 2012, when she was mandatorily retired. She had previously been a Judge of the NYC Civil Court (1980-1985), a Justice of the Supreme Court, New York County (1986-1992), and an Associate Justice of the Appellate Term, First Department (1992-1995). She left the bench in 1995 to become the Dean of the City of New York (CUNY) School of Law for a ten year term. As Surrogate, where she had jurisdiction over guardianship of people with mental retardation and developmental disabilities under SCPA 17-a, and as a Supreme Court Justice where she was instrumental in writing MHL Article 81, as well as training judges, lawyers, and social workers in its implementation, she has developed an expertise in all forms of guardianship, and has written and lectured widely on the topic. As Surrogate, she wrote several groundbreaking decisions on guardianship including *Matter of Demaris L.*, 38 Misc. 3d 570 (2012), *Matter of Mark C.H.*, 28 Misc. 3d 765 (2010), and *Matter of Chaim A.K.*, 26 Misc. 3d 837 (2010), as well as on the fiduciary responsibility of Trustees to the disabled beneficiaries of Supplemental Needs Trusts and/or support trusts, including *Matter of JP Morgan Chase Bank NA (Marie H.)*, 38 Misc. 3d 363 (2012). Judge Glen is currently involved in international human rights work as it relates to persons with intellectual disabilities and older persons with progressive cognitive decline, and has written and lectured widely on the right of legal capacity as set forth in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities. Her institutional affiliations in this area include membership on the Board of the ABA Center for Human Rights, Global Action of Acing, the New York City Bar Mental Health Committee, and the Brookdale Center on Aging of Hunter College. She is a past member and past Chair of the NYSBA Public Interest Law Committee, and has been active in numerous other bar and professional organizations. She is a graduate of Stanford University and Columbia Law School and has received many honors, including the NYSBA Ruth Schapiro Award for Service to Women, the Columbia Law School Lawrence Wien Social Justice Award, the Society of Hispanic Judges Frank Torres Diversity Award, and the National Association of Public Interest Lawyers Dean of the Year Award.

THOMAS SCIACCA, ESQ. is the Principal of Law Offices of Thomas Sciacca, PLLC, where, since 2007 he has focused his practice on Trusts & Estates, Estate Administration, Surrogate's Court Litigation, and Guardianship. In addition, Mr. Sciacca is an Adjunct Assistant Professor at New York University's School of Continuing and Professional Studies, an appointment he has held since January 2006. In 2013, Mr. Sciacca received two distinguished awards – recognition as a Rising Star by SuperLawyers and as Empire State Counsel by the New York State Bar Association in recognition of his *pro bono* efforts. Mr. Sciacca is a frequent speaker on various topics related to his various areas of practice. Mr. Sciacca is a graduate of New York University School of Law (LLM – taxation), Pace University School of Law (JD), and the University at Albany, State University of New York (BA). He is licensed to practice law in New York, New Jersey, Florida, and the United States Tax Court.

Introduction to Guardianship

Background on Article 81 Guardianship[1]

New York's primary system of adult guardianship is codified as Article 81 of the Mental Hygiene Law. The cornerstone of Article 81 is the concept of appointing a guardian whose powers are tailored specifically to the particular needs of a person with respect to personal care, property management, or both. This section of the statute sets forth the concept of a specifically tailored appointment based on a functional assessment of the person and sets the tone for the remaining provisions.

The appointment of a guardian must be found to be necessary because the person is unable to meet the needs for personal care, property management, or both. In deciding whether the appointment of a guardian is necessary, the court must consider all the evidence including the information and independent observations provided by the court evaluator (an independent attorney, social worker or other professional appointed by the court to investigate the guardianship petition) as to the person's condition, affairs and situation, and the sufficiency and reliability of available resources such as visiting nurses, homemakers, home health aides, adult day care, powers of attorney, health care proxies, trusts and representative and protective payees.

The court should regard guardianship as a last resort and should assess the advantages and disadvantages of alternatives to guardianship, deciding on guardianship only when it clearly benefits the person who is the subject of the proceeding and when the alternatives are not sufficient and reliable to meet the needs of the person.

The person must either agree to the appointment or be found by the court to be incapacitated. There are two components to a determination of incapacity: 1) the person cannot adequately understand and appreciate the nature and consequences of the person's particular inabilities; and 2) the person is likely to suffer harm because of these limitations and the inability to appreciate the consequences of the limitations. The court is required to give primary consideration to the functional level and functional limitations of the person.

The words "primary consideration" are used to reinforce the underlying intent of the statute that the court is not to assign undue weight to any medical diagnosis but rather should consider such diagnosis in light of information about the behavior and functional limitation of the person.

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[1] This Section is from BROOKDALE CENTER FOR HEALTHY AGING & LONGEVITY OF HUNTER COLLEGE SADIN INSTITUTE ON LAW, PUBLIC POLICY & AGING AND THE NEW YORK STATE LAW REVISION COMMISSION, *Guide to Adult Guardianship, Article 81 of the New York State Mental Hygiene Law, Appointment of a Guardian for Personal Needs and/or Property Management* 8 (2005), *available at* http://ocfs.ny.gov/ohrd/materials/151670.pdf.

Finally, Article 81 emphasizes that even if all the elements of incapacity are present, a guardian should be appointed only as a last resort and should not be imposed if available resources or other alternatives will adequately protect the person. If the court determines that the appointment of a guardian is necessary, the guardian should be granted only those powers that are necessary to provide for the person's needs in a manner consistent with the principle of employing the least restrictive alternative, i.e., the appointment of a guardian is appropriate to the individual and affords the person the greatest amount of self-determination and independence in light of his or her understanding and appreciation of his or her functional limitations.

EXCERPTS FROM N.Y. S.C.P.A. Article 17-A

McKinney's Consolidated Laws of New York Annotated Currentness
Surrogate's Court Procedure Act (Refs & Annos)
Chapter 59-A. Of the Consolidated Laws (Refs & Annos)
Article 17-A. Guardians of Mentally Retarded and Developmentally Disabled Persons (Refs & Annos)

§ 1750. Guardianship of mentally retarded persons

When it shall appear to the satisfaction of the court that a person is a mentally retarded person, the court is authorized to appoint a guardian of the person or of the property or of both if such appointment of a guardian or guardians is in the best interest of the mentally retarded person. Such appointment shall be made pursuant to the provisions of this article, provided however that the provisions of section seventeen hundred fifty-a of this article shall not apply to the appointment of a guardian or guardians of a mentally retarded person.

1. For the purposes of this article, a mentally retarded person is a person who has been certified by one licensed physician and one licensed psychologist, or by two licensed physicians at least one of whom is familiar with or has professional knowledge in the care and treatment of persons with mental retardation, having qualifications to make such certification, as being incapable to manage him or herself and/or his or her affairs by reason of mental retardation and that such condition is permanent in nature or likely to continue indefinitely.

2. Every such certification pursuant to subdivision one of this section, made on or after the effective date of this subdivision, shall include a specific determination by such physician and psychologist, or by such physicians, as to whether the mentally retarded person has the capacity to make health care decisions, as defined by subdivision three of section twenty-nine hundred eighty of the public health law, for himself or herself. A determination that the mentally retarded person has the capacity to make health care decisions shall not preclude the appointment of a guardian pursuant to this section to make other decisions on behalf of the mentally retarded person. The absence of this determination in the case of guardians appointed prior to the effective date of this subdivision shall not preclude such guardians from making health care decisions.

§ 1750-a. Guardianship of developmentally disabled persons

1. 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 of the property or of both if such appointment of a guardian or guardians is in the best interest of the developmentally disabled person. Such appointments shall be made pursuant to the provisions of this article, provided however that the provisions of section seventeen hundred fifty of this article shall not apply to the appointment of a guardian or guardians of a developmentally disabled person. For the purposes of this article, a developmentally disabled person is a person who has been certified by one licensed physician and one licensed psychologist, or by two licensed physicians at least one of whom is familiar with or has professional knowledge in the care and treatment of persons with developmental disabilities, having qualifications to make such certification, as having an impaired ability to understand and appreciate the nature and consequences of decisions which result in such person being incapable of managing himself or herself and/or his or her affairs by reason of developmental disability and that such condition is permanent in nature or likely to continue indefinitely, and whose disability:

(a) is attributable to cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury;

(b) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons; or

(c) is attributable to dyslexia resulting from a disability described in subdivision one or two of this section or from mental retardation; and

(d) originates before such person attains age twenty-two, provided, however, that no such age of origination shall apply for the purposes of this article to a person with traumatic head injury.

2. Notwithstanding any provision of law to the contrary, for the purposes of subdivision two of section seventeen hundred fifty and section seventeen hundred fifty-b of this article, "a person with mental retardation and his or her guardian" shall also mean a person and his or her guardian appointed pursuant to this section; provided that such person has been certified by the physicians and/or psychologists, specified in subdivision one of this section, as (i) having mental retardation, or (ii) having a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes mental retardation, or (B) results in a similar impairment of

general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability.

➡§ 1754. Hearing and trial

1. Upon a petition for the appointment of a guardian of a mentally retarded or developmentally disabled person eighteen years of age or older, the court shall conduct a hearing at which such person shall have the right to jury trial. The right to a jury trial shall be deemed waived by failure to make a demand therefor. The court may in its discretion dispense with a hearing for the appointment of a guardian, and may in its discretion appoint a guardian ad litem, or the mental hygiene legal service if such person is a resident of a mental hygiene facility as defined in subdivision (a) of section 47.01 of the mental hygiene law, to recommend whether the appointment of a guardian as proposed in the application is in the best interest of the mentally retarded or developmentally disabled person, provided however, that such application has been made by:

(a) both parents or the survivor; or

(b) one parent and the consent of the other parent; or

(c) any interested party and the consent of each parent.

2. When it shall appear to the satisfaction of the court that a parent or parents not joining in or consenting to the application have abandoned the mentally retarded or developmentally disabled person or are not otherwise required to receive notice, the court may dispense with such parent's consent in determining the need to conduct a hearing for a person under the age of eighteen. However, if the consent of both parents or the surviving parent is dispensed with by the court, a hearing shall be held on the application.

3. If a hearing is conducted, the mentally retarded or developmentally disabled person shall be present unless it shall appear to the satisfaction of the court on the certification of the certifying physician that the mentally retarded or developmentally disabled person is medically incapable of being present to the extent that attendance is likely to result in physical harm to such mentally retarded or developmentally disabled person, or under such other circumstances which the court finds would not be in the best interest of the mentally retarded or developmentally disa-

bled person.

4. If either a hearing is dispensed with pursuant to subdivisions one and two of this section or the mentally retarded or developmentally disabled person is not present at the hearing pursuant to subdivision three of this section, the court may appoint a guardian ad litem if no mental hygiene legal service attorney is authorized to act on behalf of the mentally retarded or developmentally disabled person. The guardian ad litem or mental hygiene legal service attorney, if appointed, shall personally interview the mentally retarded or developmentally disabled person and shall submit a written report to the court.

5. If, upon conclusion of such hearing or jury trial or if none be held upon the application, 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 property, or both, it shall make a decree naming such person or persons to serve as such guardians.

➞§ 1756. Limited guardian of the property

When it shall appear to the satisfaction of the court that such mentally retarded or developmentally disabled person for whom an application for guardianship is made is eighteen years of age or older and is wholly or substantially self-supporting by means of his or her wages or earnings from employment, the court is authorized and empowered to appoint a limited guardian of the property of such mentally retarded or developmentally disabled person who shall receive, manage, disburse and account for only such property of said mentally retarded or developmentally disabled person as shall be received from other than the wages or earnings of said person.

The mentally retarded or developmentally disabled person for whom a limited guardian of the property has been appointed shall have the right to receive and expend any and all wages or other earnings of his or her employment and 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 from such employment or three hundred dollars, whichever is greater, or as otherwise authorized by the court.

➞§ 1759. Duration of guardianship

1. Such guardianship shall not terminate at the age of majority or marriage of such mentally retarded or developmentally disabled person but shall continue during the life of such person, or until terminated by the court.

2. A person eighteen years or older for whom such a guardian has been previously appointed or anyone, including the guardian, on behalf of a 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 for review, the court shall conduct a hearing pursuant to section seventeen hundred fifty-four of this article.

3. Upon marriage of such mentally retarded or developmentally disabled person for whom such a guardian has been appointed, the court shall, upon request of the mentally retarded or developmentally disabled person, spouse, or any other person acting on behalf of the mentally retarded or developmentally disabled person, review the need, if any, to modify, dissolve or otherwise amend the guardianship order including, but not limited to, the appointment of the spouse as standby guardian. The court, in its discretion, may conduct such review pursuant to section seventeen hundred fifty-four of this article.

38 Misc.3d 570
Surrogate's Court, New York County, New York.

In the Matter of the GUARDIANSHIP OF DAMERIS L., Pursuant to SCPA Article 17–A.

Dec. 31, 2012.

Synopsis
Background: In guardianship proceeding over person with mental retardation, co-guardian, who was ward's husband, petitioned to revoke the letters of guardianship issued to himself and ward's mother as co-guardians.

Holdings: The Surrogate's Court, New York County, Kristin Booth Glen, J., held that:

[1] court no longer had jurisdiction over ward;

[2] even if court had jurisdiction over ward, appointment of guardianship was no longer warranted; and

[3] substantive due process requirement of adherence to principal of least restrictive alternative applied to guardianships sought for mentally retarded persons.

Petition granted.

West Headnotes (3)

[1] **Mental Health**
Particular courts

In guardianship proceeding over person with mental retardation, court no longer had jurisdiction over ward, after ward's family became fully settled in Pennsylvania, as opposed to the temporary move the court previously authorized.

[2] **Mental Health**
Mental incompetency or incapacity in general

Even if court had jurisdiction over ward, after her move out-of-state, appointment of guardianship for person with mental retardation was no longer warranted, since there was a system of supported decision making in place that constituted a less restrictive alternate to loss of liberty entailed by guardianship; ward had become friendly with neighbors who were assisting her in various ways, husband's family member was constant presence in household explaining and helping ward make decisions, ward was enrolled in literacy class, ward had assistance from social worker, ward's mother and husband had resolved most of their difficulties, and ward's relationship with husband was more of a partnership than as guardian and ward. U.S.C.A. Const.Amend. 14; McKinney's SCPA § 1750.

[3] **Constitutional Law**
Guardianship
Mental Health
Mental incompetency or incapacity in general

Substantive due process requirement of adherence to the principal of the least restrictive alternative applied to guardianships sought for mentally retarded persons to achieve the state's goal of protecting a person with intellectual disabilities from harm connected to those disabilities; thus, proof that a person with an intellectual disability needs a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends and mental health professionals. U.S.C.A. Const.Amend. 14; McKinney's SCPA § 1750.

West Codenotes

Validity Called into Doubt
McKinney's SCPA § 1750

Attorneys and Law Firms

****849** Parties appeared pro se.

Opinion

KRISTIN BOOTH GLEN, J.

***571** This case presents the opportunity to reconcile an outmoded,[1] CONSTITUTIONALLy suspect[2] STATUTE, scpa 17–a, WITH THE requirements of substantive due process and the internationally recognized human rights of persons with intellectual disabilities.

History
On March 9, 2009, Cruz Maria S. filed a petition[3] for guardianship of her then 29–year–old daughter, Dameris L. The certifications[4] accompanying the petition showed Dameris to have mild to moderate mental retardation, and to be "functioning at the ***572** mental age of a seven year old." She is ****850** reported to "have poor receptive and expressive skills—[and, while] ambulatory and able to care for most of her grooming needs, she is highly dependent for all other needs, including medical and financial matters." At the time Dameris was, sporadically, attending a day adult habilitation program run by AHRC where she was learning to, and supervised in, cleaning tasks, particularly cleaning bathrooms.

On March 29, 2009, Dameris married Alberto R. at the Office of the Clerk in Kings County. Alberto had problems of his own, including a history of drug and substance abuse, mental illness and criminal charges.

In mid-May, 2009, Cruz came to the court and requested expedited consideration of her petition because, she explained, Dameris was pregnant and due to give birth imminently. A hearing was immediately scheduled for May 20 and, on that date, Alberto appeared and informed the court of his recent marriage to Dameris. It was clear that this was now a struggle over control of Dameris between Cruz, who entirely disapproved of, and distrusted Alberto, and Alberto, who had the same negative feelings about Cruz. Dameris, very visibly pregnant, showed flat affect, spoke haltingly and in a limited way, and, on all of the evidence adduced at the hearing, appeared incapable of caring for herself and her soon to be born baby.

None of the parties spoke English; both households, Cruz's and Alberto's,[5] were supported entirely by government benefits including S.S.I. In order to obtain more information about the living situations and care taking capacities of the contesting parties,[6] the court hastily appointed a Guardian ad Litem, Raul Garcia, Esq.[7]

After an extremely helpful report from Garcia, the parties returned to court, with the primary issue that of responsibility ***573** for Dameris and the baby after she gave birth.[8] The court again benefitted from pro bono services, this time from an expert mediator, Edward Bonsignore, Esq. On June 4, 2009, after a full day of mediation, the parties reached an agreement that provided for Dameris to reside with Alberto, but gave Cruz a substantial role after the baby's birth, and continued contact and visitation at her home. The parties also agreed that, with the court's approval, Alberto and Cruz would act as co-guardians for Dameris.

The case was adjourned, with the Guardianship Clerk and a court attorney charged with following developments and monitoring the mediation agreement. On June 10, 2009, the baby, Damaris Cruz R., was born at Brooklyn Hospital, and Dameris and Alberto returned with her to Cruz's apartment. Eventually, with some intermediate stops,[9] and with home care ****851** assistance from AHRC, they settled in transitional homeless housing (subsidized by Housing Stability Plus) where, with full-time homemaker services, Dameris, Alberto and the baby were doing well. They returned to court on March 19, 2010, and again on October 5, 2010, when the court formally appointed Cruz and Alberto as co-guardians with Dameris's consent.[10]

Despite some intermittent problems, things were going relatively well for the R. family until, as a result of the budget crisis, the subsidy program was cancelled, and Dameris and Alberto faced eviction.[11] Cruz was visiting family in the Dominican Republic, as was her custom, and neither Alberto nor the court were able to reach her. Alberto had located rental housing in ***574** Pottstown, Pennsylvania, near a cousin, and needed permission to move Dameris and the baby there.

On January 17, 2012, Alberto petitioned to revoke Cruz's letters as co-guardian, returnable February 9, 2012. Cruz, who was served by substituted service, did not appear. At a special calendar, Alberto presented a proposed lease for a home in Pottsville, and applications for benefits and services he had filed with Service Access & Management (SAM), a case management and crisis intervention service funded by Schuylkill County.

The court was able to reach the director of SAM by phone, and to fax certain records on file here that were necessary to process the applications. With this assurance, and in the absence of any viable housing alternative in New York, the court temporarily suspended Cruz's letters and granted permission for temporary relocation to Pennsylvania. Alberto and Dameris were directed to return to court on December 4, 2012, by which time it was expected that Cruz would have returned to New York.

On December 4, 2012, all parties appeared, together with the now almost three-year-old Damaris (nicknamed "Chi Chi") and Alberto's 9–year–old daughter Bianca.[12] SAM was working on obtaining services, but the family was basically functioning on its own, and doing well, utilizing support from Alberto's cousin, and especially his wife, Margarita, who had previously worked for a different social services agency in Schuylkill County.

Dameris appeared much more confident and dealt appropriately and lovingly with both Chi Chi and Bianca. She revealed that she was, again, pregnant, although she and Alberto also informed the court that she planned to undergo a tubal ligation immediately after the baby was born. Questioned by the court, it was clear that ****852** Dameris understood what she had consented to, and why; she explained that she had made her decision after consultation with Alberto, the health care professionals, and Margarita, who had fully explained the procedure to her. Concerned about the availability of homemaking and child care services that Dameris would surely need when the new baby was born, the court continued the hearing to December 12, in order to obtain more information.

***575** On December 12, Cruz, Alberto, Dameris, Chi Chi and Bianca[13] appeared. Because of conflicting appointments on December 11, 2012, Alberto and Dameris had missed a meeting with their social worker, Amy Hessron, so the necessary services were not yet in place. After a call from the court, the appointment with Ms. Hessron was rescheduled for December 18. Alberto and Cruz were directed to return to the court on December 19 for the continued hearing. The now visibly pregnant Dameris was excused. There was, however, opportunity to take testimony about Dameris's current situation, which proved both enlightening and most encouraging.

[Family and friend support] - Dameris had become friendly with nearby neighbors, who were assisting her in various ways, and whom she and Alberto had asked to serve as the new baby's godparents. Alberto's cousin's wife, Margarita, was a constant presence in the household, explaining and translating for Dameris, and helping her make everyday decisions, as well as more significant decisions such as the tubal ligation. With Ms. Hessron's assistance, Dameris was enrolled in a literacy class; Hessron had also become part of Dameris's support network. Cruz and Alberto had resolved most of their difficulties, and the advice and assistance Cruz offered Dameris in frequent phone calls was now welcomed and incorporated. Alberto had shown remarkable resiliency and perseverance settling his family and dealing with a number of health issues for his mother and his two daughters. His relationship to Dameris, while always loving, had clearly evolved, and they now presented as far more of a partnership than as a guardian and his ward.

Between the 12th and the continued hearing on the 19th, the court attorney assigned to the case spoke with Dameris's pre-natal health care provider and with Ms. Hessron.

On the 19th, Cruz and Alberto appeared, accompanied by the prospective godfather, Raul Eusebio, who described his family's relationship with Alberto and Dameris, and the assistance they were—and intended to continue—providing. The court attorney testified to her conversation with Ms. Hessron, who was working diligently to get Dameris the waiver necessary for post-natal home care services, and who had also reiterated the family's ***576** progress despite considerable obstacles.[14] The court attorney confirmed that Dameris had executed an informal consent to the post-birth sterilization, and that the doctor who took the consent was satisfied that it was both knowing and voluntary.[15] Cruz testified that she would be going to Pennsylvania to help after the baby's birth, and that she was now satisfied with, and had no ****853** concerns about, the relationship between Dameris and Alberto.

Finally, Alberto spoke about what he had accomplished with Dameris over the past eight months in their new home—the progress she had made, what a good job she

was doing now with two children, and how together they had found and utilized a support system that was helping them succeed despite all the difficulties they faced. He spoke movingly of his respect for Dameris, and how he understood his role, not as deciding for her, but in assisting her in making her own decisions. At the conclusion of the hearing, for the reasons discussed below, the court terminated the 17–A guardianship of the person of Dameris L. (now R.).

Discussion

[1] [2] The family is now fully settled in Pennsylvania, as opposed to the temporary move the court previously authorized. As such, with Cruz suspended, and giving consent to termination of the guardianship, the court no longer has jurisdiction over Dameris. But, even if this were not the case, I would find that guardianship is no longer warranted because there is now a system of supported decision making in place that constitutes a less restrictive alternate to the Draconian loss of liberty entailed by a plenary 17–A guardianship. This use of *supported* decision making, rather than a guardian's *substituted* decision making, is also consistent with international human rights, most particularly Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).[16]

577** ***A. Least Restrictive Alternative

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[17] 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 [lst Dept.2001].

The legislature, as well, has incorporated least restrictive alternative in liberty curtailing statutes including those dealing with "assisted outpatient treatment" (AOT) (*e.g.* Mental Hygiene Law 9.60[h][4];[i][2] ["Kendra's Law"]),[18] and ****854** adult guardianship (Mental Hygiene Law 81.01) ("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"); (*see* Rose Mary Bailly, Practice Commentaries, 34 A McKinney's Consol. Laws of N.Y. Mental Hygiene § 81.01)("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").

***578** Thus, under Article 81, in determining the conditions under which a guardian may be appointed, the court is specifically directed to consider "the sufficiency and reliability of available resources, as defined in subdivision (c) of Section 81.03 of this article,[19] to provide for personal needs or property management without the appointment of a guardian." The Law Revision Commission Comments note

> "This definition promotes the goal of the statute of requiring a disposition that is the least restrictive form of intervention. It is incumbent upon the ... court to consider voluntary alternatives to judicial intervention under [Article 81] ... The list is not meant to be restrictive but rather to set the wheels of investigation in motion for considering what possibly could be done to assist this person without appointing a guardian." 34A McKinney's Consol. Laws of N.Y. § 81.03.

[3] To the extent that New York courts have recognized least restrictive alternative as a constitutional imperative (*see e.g. Kesselbrenner v. Anonymous,* 33 N.Y.2d 161, 350 N.Y.S.2d 889, 305 N.E.2d 903; *Matter of Andrea B.,* 94 Misc.2d 919, 925, 405 N.Y.S.2d 977 [Fam. Ct., New York County 1978]) ("substantive due process requires adherence to the principle of least restrictive alternative"), it must, of necessity, apply to guardianships sought pursuant to 17–A, as well as under the more recent and explicit Mental Hygiene Law Article 81. Thus, proof that a person with an intellectual disability *needs* a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends and mental health professionals.

In order to withstand constitutional challenge,[20] including, particularly, challenge under our own state Constitution's due ***579** process guarantees, SCPA 17–A must be read to

include the requirement that guardianship is the least restrictive alternative to achieve the state's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, the court must consider the availability of "other resources," like those in MHL 81.03(c), including a ****855** support network of family, friends and professionals before the drastic judicial intervention of guardianship can be imposed.

B. International Human Rights

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." As the deliberations that accompanied drafting and passage of the CRPD demonstrated, legal capacity is not only the capacity to *have* rights, but also the capacity to *act on,* or *exercise* those rights[21] which, the Preamble to the CRPD[22] makes clear, includes the right to make one's own decisions. Recognizing that persons with disabilities may require support to exercise their legal capacity, Art. 12(3) requires States Parties to provide access to those supports (*see e.g.* Robert D. Dinnerstein, *Human Rights and the Protection of Persons with Disabilities: 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. Br. 8 [2012]) (Dinnerstein).

The body created by CRPD to review and comment on compliance by States Parties to the Convention has repeatedly found that guardianship laws that impose substituted decision making on persons with mental and intellectual disabilities violate Art. 12, and thus the human rights of persons subjected to guardianship.[23]

While the CRPD does not directly affect New York's guardianship laws, international adoption of a guarantee of legal capacity ***580** for all persons, a guarantee that includes and embraces supported decision making, is entitled to "persuasive weight" in interpreting our own laws and constitutional protections (*see e.g.Lawrence v. Texas,* 539 U.S. 558, 576, 123 S.Ct. 2472, 156 L.Ed.2d 508 [2003]; Johanna Kalb, *Human Rights Treaties in State Courts: The International Prospects of State Constitutionalism After Medellin,* 115 Penn. St. L. Rev. 1051, 1059–1060 [2011]).

As Dinnerstein notes,

> "The paradigm shift reflected in the move from substituted to supported decision making aims to retain the individual as the primary decision maker but recognizes that an individual's autonomy can be expressed in multiple ways, and that autonomy itself need not be inconsistent with having individuals in one's life to provide support, guidance and assistance to a greater or lesser degree, so long as it is at the individual's choosing."

(Dinnerstein, at 10).

The instant case provides a perfect example of the kind of family and community support that enables a person with an intellectual disability to make, act on, and have her decisions legally recognized as, for example, by acceptance of her "informed consent" to a tubal ligation. Because ****856** Dameris has such assistance, she is now able to engage in supported decision making, rather than having substituted decision making, in the form of guardianship, imposed upon her by the court.

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, SCPA 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.

Based on all the evidence in this case, Dameris has demonstrated that she is able to exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network which has come together for her since she first appeared in this court. Terminating the letters of guardianship previously granted to Cruz and Alberto recognizes them, instead, as persons assisting and supporting her autonomy, not ***581** superseding it. Terminating the guardianship recognizes and affirms

Dameris's constitutional rights and human rights and allows a reading and application of SCPA 17–A that is consistent with both.

This decision constitutes the order of the Court.

Parallel Citations

38 Misc.3d 570, 956 N.Y.S.2d 848, 2012 N.Y. Slip Op. 22386

Footnotes

1 In 1990, when the legislature was working on reform of the existing adult guardianship laws, then called conservators and committees, it directed the Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) (now the New York State Office for People With Developmental Disabilities or OPWDD) to undertake a study of SCPA 17–A in light of national guardianship reform efforts and the "momentous changes [that] have occurred in the care, treatment and understanding of these individuals [with intellectual disabilities]" (1990 N.Y. Laws 3208). Nothing ever came of that study.

2 *See e.g. Matter of Mark C.H.,* 28 Misc.3d 765, 906 N.Y.S.2d 419 (Sur. Ct., N.Y. County 2010) (holding statute unconstitutional in the absence of periodic reporting and review, and reading a requirement of same into the law); *Matter of Chaim A.K.,* 26 Misc.3d 837, 885 N.Y.S.2d 582 (Sur. Ct., New York County 2009) (criticizing procedural shortcomings of statute as potentially unconstitutional). And see, Rose Mary Bailly and Charis B. Nick–Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York,* 75 Alb. L. Rev. 807, 840 (2011/2012) ("Because SCPA 17–A and MHL 81 had their beginnings at different times, 1969 and 1992 respectively, and with different motivations and approaches to guardianship, they are now tripping over one another. Courts are debating the constitutionality of 17–A in light of different treatment of individuals under the respective statutes ...").

3 The petition was sworn to in May, 2008, so presumably Cruz began the process prior to Dameris's involvement with Alberto (see below).

4 SCPA 1750–a(1) requires certifications by two health care professionals, whose credentials are spelled out in the statute. In fact, in almost all 17–A proceedings those certifications—that the subject of the proceeding "suffers from" "mental retardation" or "developmental disability," that such condition began before the age of 21, that the condition is likely to be permanent, are made by checking boxes on a form "Affidavit (Certification) of Examining Physician or Licensed Psychologist." Generally there is little or no other information from which the affiant drew her/his conclusions. The statute permits a hearing to be dispensed with if the petition is brought by a parent or parents, or if the parent [s], consents (SCPA 1754[1]). Even where, as in New York County, hearings are held in all cases, use of the form affidavits completely eliminates any possibility of cross-examination.

5 At the time Alberto was living with his mother, also on S.S.I.

6 Alberto opposed Cruz's petition, but did not actually file a cross-petition until much later. Dameris was, however, apparently living with him, in Brooklyn, and part of Cruz's "plan" of guardianship was to bring her home to Cruz's apartment in Washington Heights.

7 Garcia, who is Spanish speaking, served without fee and provided extraordinary assistance to the court in a very compressed period of time. He, and the firm for which he worked, O'Dwyer and Bernstine, deserve the gratitude of the court.

8 There was significant concern that the baby might be taken from the hospital by Child Welfare Services (CWS), and Lynn Paltrow, Director of National Advocates for Pregnant Women (NAPW) attended the first two hearings as a potential resource.

9 For a time they lived with Alberto's mother, and when that became untenable, they were temporarily placed in a homeless family shelter, before obtaining a subsidized two bedroom apartment under EARP (Emergency Assistance Rehousing Program). The unavailability of affordable housing in New York City has been a continuing issue for this family which has led, on two separate occasions, to proposals to leave the city and state.

10 At the October hearing, Dameris was considerably more engaged, perhaps as a result of the success she was experiencing as a mother. She was also much more verbal, agreed that she needed help in making decisions, and stated that she was willing to have Alberto and her mother as her co-guardians. It is this court's experience that guardianship on consent is not only autonomy-

enhancing, it also generally results in greater co-operation between the guardian(s) and the ward.

11 The rent was $1,070/month, and, without the city subsidy, exceeded the total benefits received by both Alberto and Dameris from S.S.I.

12 Bianca is the child of a relationship prior to Alberto's marriage to Dameris, and initially lived with her mother, but when custody was removed she was placed with her grandmother, Alberto's mother. Subsequently the grandmother, her husband and Bianca also moved to Pottsville, but with the grandmother's worsening health and her husband's death, Alberto took custody of Bianca, and she came to live with him, Dameris, and Chi Chi.

13 Bianca, a bright and charming child, explained that she was not missing a "real" school day, but rather a pageant, and proudly described how well she was doing in school.

14 Primary among these is the paucity of Spanish speakers in Schuylkill County, including health care providers, educators and service providers. Alberto is the primary translator, but Dameris is now learning English in her literacy class.

15 Interestingly, the health care provider, Comprehensive Women's Health Services, did not require Alberto's consent, as guardian, to the procedure, but rather took and accepted the consent given by Dameris.

16 Convention on the Rights of Persons with Disabilities, Gen. A. Res. 61/106, U.N. Doc. A/RES/6/106 (Dec. 13, 2006), available at http:// www.un.org/disabilities/convention/conventionfull.shtml. (Last visited Dec. 27, 2012)

17 Most of the early least restrictive alternative cases involved some form of involuntary confinement, but the more general principle applies equally to lesser deprivations of liberty, including guardianship. See discussion of MHL Art. 81, below.

18 *See Manhattan Psychiatric Center v. Anonymous,* 285 A.D.2d at 197, 728 N.Y.S.2d 37 (noting the "underlying concern of the legislature in enacting Kendra's Law, i.e. to place as few restrictions as possible on persons who, though suffering from mental illness, are capable of living in the community with the help of family, friends and mental health professionals" [L. 1999, Ch. 408 § 2]). *See, e.g.* Kendra's Law: The Process for Obtaining Assisted Outpatient Treatment, OMH Q, Dec. 1999 at 416 (Kendra's Law requires that AOT be the least restrictive alternative); Illise L. Watnik, *Comment; A Constitutional Analysis of Kendra's Law: New York's Solution for Treatment of the Chronically Mentally Ill,* 147 U. Pa. L. Rev. 1181, 1199–1204 (discussing due process imperatives incorporated in the statute).

19 81.03 (c) defines "available resources" as meaning "resources such as, but not limited to, visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers, powers of attorney, health care proxies, trusts, representative and protective payees, and residential care facilities."

20 There is also a potential equal protection challenge if the least restrictive alternative provisions of MHL 81 are not read into SCPA 17–A (*see Matter of Guardianship of B,* 190 Misc.2d 581, 738 N.Y.S.2d 528 [County. Ct., Tompkins County 2002]) ("The equal protection provisions of the Federal and State Constitutions ... require that mentally retarded persons in a similar situation be treated the same whether they have a guardian appointed under Article 17–A or Article 81", citing *City of Cleburne v. Cleburne Living Center,* 473 U.S. 432, 105 S.Ct. 3249, 87 L.Ed.2d 313 [1985]).

21 See discussion of the debates and ultimate adoption of the more expansive definition of legal capacity in Amrita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future,* 34 Syracuse J. Int'l L. & Com. 429, 442 (2007).

22 CRPD Preamble, Par. (n) (recognizing "the importance for people with disabilities of their individual autonomy and independence, including the freedom to make their own choices").

23 *See e.g.* Dinnerstein, at 11–12; Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond,* 44 Colum. Hum. Rts. L. Rev. 91 (2012) (collecting decisions on Tunisia, Spain and Peru).

956 N.Y.S.2d 848, 2012 N.Y. Slip Op. 22386

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38 Misc.3d 363, 956 N.Y.S.2d
856, 2012 N.Y. Slip Op. 22387

In the Matter of the Accounting of JP Morgan Chase Bank, N.A., et al., as Cotrustees of the Mark C.H. Discretionary Trust of 1995, Created by Marie H., Grantor

Surrogate's Court, New York County
December 31, 2012

CITE TITLE AS: Matter of JP Morgan Chase Bank, N.A. (Marie H.)

HEADNOTE

Trusts
Breach of Fiduciary Duty
Failure to Provide for Needs of Disabled Beneficiary

The cotrustees of a multimillion dollar trust left by decedent for the care of her severely disabled, vulnerable, institutionalized son, who was wholly dependent on Medicaid, breached their fiduciary obligations by failing to visit the beneficiary, inquire after his needs or apply any of the trust income towards improving his condition. Accordingly, they were subject to the remedies available for such breach, which include denial or reduction of commissions, pending the completion of an accounting. The plain language of the trust elucidated decedent's intent in creating it and reflected both the importance of the beneficiary's quality of life to decedent and the minimum knowledge that decedent expected her trustees, a major banking institution and an individual personally involved with the decedent, to have about the beneficiary and his situation. Moreover, the individual trustee, as the drafter of the trust and decedent's will, was aware of the beneficiary's incapacity for years before serving as trustee. By leaving the beneficiary to languish for several years with inadequate care, despite the fact that the trust had abundant assets, the trustees failed to exhibit a reasonable degree of diligence toward the beneficiary. It was not sufficient for the trustees merely to prudently invest the trust corpus and safeguard its assets. Rather, they were affirmatively charged with applying trust assets to the beneficiary's benefit and given the discretionary power to apply additional income to his service providers.

RESEARCH REFERENCES

Am Jur 2d, Trusts §§ 316, 318, 331, 333, 344, 345, 360, 363, 549, 550, 554, 644.

Carmody-Wait 2d, Duties, Powers, and Liabilities of Fiduciaries §§ 157:20, 157:21, 157:186.

NY Jur 2d, Trusts §§ 247, 345, 362, 367, 466, 476, 477, 481.

ANNOTATION REFERENCE

See ALR Index under Fiduciaries and Personal Representatives; Trusts and Trustees.

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Query: fiduciary & trustee /s fail! /s diligence & discretion!

*364 APPEARANCES OF COUNSEL

Roy H. Carlin for H.J.P., individual trustee. *Davidson, Dawson & Clark* for Chase Manhattan Bank, trustee.

OPINION OF THE COURT

Kristin Booth Glen, S.

This case raises important questions about the obligations of fiduciaries, including institutional trustees, to beneficiaries, with disabilities, of trusts that seek to provide for the welfare of those beneficiaries. A review of the history of this trust and related proceedings places the issue in sharp perspective.

This history reveals a severely disabled, vulnerable, institutionalized young man, wholly dependent on Medicaid, unvisited and virtually abandoned, despite a multimillion dollar trust left for his care by his deceased mother. It reveals two cotrustees, one who was personally involved with the deceased and who holds himself out as an expert in planning for children with intellectual disabilities, and one which is a major banking institution, neither visiting or inquiring after the beneficiary's needs nor spending a single penny on him.

The history turns brighter after a serendipitous SCPA article 17-A proceeding, where the cotrustees were called to task, educated about available services, and hired a certified care manager to attend to the beneficiary's needs. That intervention, now after almost four years, has dramatically improved the beneficiary's quality of life and his functional capacity to enjoy what is now a near "normal" existence in the community.

This history, and the legal consequences that flow from it, discussed below, should provide a clarion call for all fiduciaries of trusts whose beneficiaries are known to have disabilities to fulfill their "unwavering duty of complete loyalty to the beneficiary" (106 NY Jur 2d, Trusts § 247) or be subject to the remedies available for breach of their fiduciary obligation.

History

Will and Trusts

Marie H. died on March 20, 2005 at the age of 85, survived by two adopted children, Charles A.H., and Mark C.H., then 16 years old. Prior to her death, upon learning of her terminal cancer, Marie searched for an appropriate residential setting for Mark, and ultimately ****2** placed him in the Anderson School in ***365** Straatsburg, New York.[1] Mark's disabilities are described more fully below.

In her will, Marie left her entire estate to the Marie H. Revocable Trust of 1995, created by trust agreement dated March 23, 1995 (the Revocable Trust).[2] The Revocable Trust provided that, upon Marie's death, after dividing her tangible property between her two children, the balance was to be divided into two equal shares, one for Mark's trust, and one for Charles's trust. The will, also dated March 23, 1995, named her sister Betty as executor and guardian of the person and property of her minor children. Marie's attorney, H.J.P., was named the successor executor.

The will was admitted to probate on July 5, 2005. Because Betty predeceased Marie, letters testamentary issued to H.J.P.[3] The federal estate tax return (the 706) indicated a gross estate of approximately $12 million, of which $2,575,000 was the date of death valuation of Marie's co-op apartment, and $8,973,653.79 was the date of death value of her stocks and bonds. Other miscellaneous property was valued at $471,439,77. According to the 706, the only assets that were transferred to the Revocable Trust during Marie's lifetime were two Citibank accounts totaling $1,390.41.

The 706 estimated the executor's commission at $133,000 and attorney fees at $300,000,[4] with other administration expenses[5] shown as $462,717.45. Federal estate taxes were shown as $3,479,561.55.[6] ****3**

***366** On the same day that she executed her will and the Revocable Trust, March 23, 1995, Marie entered into two irrevocable trust agreements, one for Charles and one for Mark, the Mark C.H. Discretionary Trust of 1995 (the Mark Trust), with herself and Betty as trustees. H.J.P. was named successor trustee if either of the two named trustees should cease to serve, and, upon Marie's death, the Chase Manhattan Bank, N.A. (Chase) was designated as additional trustee "to serve with the other Trustees in office." The Mark Trust was funded with an initial contribution of $18.

It is clear that the Mark Trust is for the benefit of a person with disabilities.[7] Article 2.1 provides for distributions of income and principal to Mark for his "care, comfort, support and maintenance," in the trustees' discretion, and further provides:

> "(ii) In the event such net income shall in any year be insufficient to provide for the support, maintenance, care and comfort of the beneficiary or for necessary medical expenses as determined by the Trustees, in their sole and absolute discretion, the said trustees shall expend out of the principal of said fund such sums as they deem necessary for any such purposes. Before expending any amounts from the net income and/or principal of this trust, the Trustees may wish to consider the availability of any benefits from government or private assistance programs for which the Grantor [sic] may be eligible and that where appropriate and to the extent possible, the Trustees may endeavor to maximize the collection of such benefits and to facilitate the distribution of such benefits for the benefit of the beneficiary."

In article 2.1, section (iii) continues, authorizing the trustees "to pay or apply . . . to any facility [the beneficiary] may be ***367** residing in and/or to any organization where he may be a client or a participant in any program (s) sponsored by

them, as the Trustees shall determine, for the general uses of such **4 facility and/or organization." [8]

Article 2.1, § (v) gives the trustees the right to terminate the trust "as if the beneficiary were deceased" if the existence of the trust causes the beneficiary to be excluded from government benefits.

The Account

After probate of Marie's will, in the SCPA article 17-A proceeding, described below, this court, sua sponte, ordered H.J.P. and Chase to account as trustees of the Mark Trust, [9] noting, "questions having arisen as to whether the funds intended by Marie H. to benefit Mark . . . had been duly applied by [sic] for such purposes by her chosen fiduciaries." The court appointed a guardian ad litem (GAL) for Mark in this accounting proceeding (SCPA 403 [2]).

On December 7, 2010, the trustees filed an amended accounting covering the period of March 23, 1995 through March 31, 2010. Schedule A of that accounting showed the total amount of principal received as $1,420,343.28. In objections filed by the GAL, he noted his belief that, with a net estate of approximately $10 million, the Mark Trust should have been funded with $5 million. After meeting with Chase's attorney, he concluded, based on her statements to him, that estate taxes of $3,479,561.55 accounted for the diminution of the amount with which the Trust was funded. This, of course, was clearly not the case, as the estate tax would have been paid before distribution of the residuary estate, first to the Revocable Trust, and from there, in equal shares to the Mark Trust and the trust for Charles. If, in fact, all the estate taxes were somehow allocated to Mark's share, a major error would have occurred.

Schedule G, "the Statement of Principal Assets on Hand," as of March 31, 2010, showed a market value of $2,733,094.49. The substantial increase over the amount shown as principal received in 2005 is, however, not due to investment strategies but rather, according to a subsequent communication from Chase, the result of underreporting the initial principal received *368 with many securities incorrectly listed at a $0 inventory value on schedule A. [10]

Schedule C shows commissions paid to the trustees in amounts of $17,622.53 to H.J.P. [11] **5 and $34,914.61 to Chase. [12] Significantly, schedule G-1 shows income on hand of $248,881.36, while schedule E-1, distribution of income, shows $0. The statement of administration expenses chargeable to income, schedule C-2, totals $29,493.49, of which the largest items are the commissions paid to the trustees. Of the total administrative expenses and taxes shown on schedule C, New York State income taxes (after substantial refunds) constituted $7,158.54; federal income taxes (after substantial refund) were $6,367.70; commissions were, as already noted, to Chase ($34,914.61) and H.J.P. ($17,622.53); H.J.P.'s firm's legal fees were $11,500; the fees of the guardian ad litem were $7,375; and the fees of Staver Eldercare Services (the care manager hired for Mark as a result of the article 17-A proceeding) were only $3,525.

The almost negligible amount paid to Staver, beginning in February 2009, is the *only* money paid out for the benefit of Mark, the disabled beneficiary, in five years. That is 1.4% of the income on hand at the end of the accounting period and 3.6% of all expenses. On an almost $3 million trust, the money spent on the beneficiary, over a five-year period—and only because of the court's intervention—was approximately 0.1%.

The Article 17-A Proceeding

In October 2006, H.J.P. brought a proceeding pursuant to article 17-A to be appointed as guardian of the person [13] of Mark. In support of his petition, he submitted affirmations from two *369 health care providers. One, Robert C. Williams, Ph.D., described Mark as "[p]rofound[ly] mentally retarded, suffering from autism," as well as "non-verbal and engag[ing] in numerous repetitive and self stimulating behaviors." Dr. Lynn Liptay provided a diagnosis of autism and mental retardation, noting that Mark was "nonverbal and requires constant supervision and assistance with all ADL's," [14] and, as well, that he "engaged in frequent aggressive behaviors including spitting, throwing objects and hitting his own head."

Because Mark was living in an institution, he was represented by Mental Hygiene Legal Services (MHLS) (Mental Hygiene Law § 81.07 [g] [1] [vii]). The report of the principal attorney for MHLS in the Second Department, who visited him there, notes that, according to the Anderson School records, Mark "has the receptive communication skills of someone less than two years old and the expressive skills of a three

month old." The attorney described her visit to Anderson and her observation of Mark: "[E]ffective communication was not possible, [Mark's] only responses were facial grimaces and attempts to return to his classroom chair. He remained nonverbal, did not make eye contact, and appeared to be responding to internal stimuli." **6

At the initial hearing, on September 18, 2007,[15] where Mark's presence was excused,[16] H.J.P. revealed that, although he was applying for guardianship as a result of a promise to Mark's mother on her death bed, he had not seen Mark since Mark was six years old, when Marie brought him and Charles to H.J.P.'s law office. H.J.P. had never visited Anderson to ascertain Mark's condition nor, more critically, his needs,[17] nor had he inquired of the staff about any unmet needs. Also revealing the existence of *370 Mark's trust[18] and his position as cotrustee, H.J.P. admitted that he had not expended a single dollar on Mark's behalf in almost three years.

I adjourned the hearing to permit the other cotrustee to appear. Subsequently, a representative of Chase came to court with H.J.P. in response to my instruction; Chase's "excuse" for inaction was its lack of institutional capacity to ascertain or meet the needs of this severely disabled, institutionalized young man. If the bank lacked such expertise, I noted, they should obtain the services of someone who could assess Mark's situation and ascertain his needs. After some initial missteps, H.J.P. and Chase retained the services of a certified care manager with extensive experience with people with intellectual disabilities, Robin Staver, M.S., Ed., CMC.

First contacting, and then visiting Anderson, she learned of a list of items the professionals there believed would enhance Mark's quality of life and assist his learning and development. Over the past four years she has, as a representative of the trustees, been actively involved in Mark's life and care, attending meetings, in person or by phone, planning meetings, arranging medical and other consultations, purchasing equipment, including assistive communication devices, recreational materials, clothing, etc., and providing for Mark's first forays into the community. What follows is a brief snapshot of the extraordinary—and heartwarming—progress Mark has made since the funds his mother left for his care have been well and thoughtfully used **7 for that purpose.[19] The detail included, what anthropologists call a "thick description," is important in *371 understanding how apparently trivial expenditures and interventions can have a huge impact on the progress and quality of life of a person with intellectual disabilities.

December 2008

This was Staver's first meeting with Mark and the staff at Anderson. She noted that

> "Mark enjoys swinging and climbing outdoors. However, there is no playground in the vicinity of his residence. [In response to communications about Mark's needs, initiated by the court,] in August a proposal for a play structure with swings and Adirondack chairs was sent to H.J.P. To date, no plans for the structure are in place."

The residence manager poignantly told Staver that "as far as she knew, Mark has not had any visitors in the five years she has worked with him nor has he had a vacation. She stated that most of the students leave the school over Christmas vacation, and Mark remains on campus with staff."

Staver reported on Mark's pharmacological regime at the same time that she recommended an independent neurology consult with a non-Medicaid neurologist and a speech evaluation "to determine appropriate augmentative communication devices and purchase those devices." Significantly for the issues presented here, Staver reported that "Mark currently takes Keppra 500 mg. which is covered by Medicaid. However, this medication causes adverse reactions including physical aggression, agitation, frustration and vocalizations. Keppra SR, which is an extended release medication, causes fewer side effects, but is not covered by Medicaid."[20]

Staver also recommended the purchase of a personal computer and computer programs for Mark's room, an electric synthesizer and/or electric keyboard, gift certificates for restaurants and clothing stores, the playground system and outdoor chairs previously requested, a one-week vacation to Disney World with two staff members on duty 24 hours a day, and a recliner chair with **8 massage capabilities.[21]

*372 July 2009

Mark "graduated" from the special ed program in June, [22] and was being prepared to enter a vocational program and to move to an IRA (individualized residential alternative) residence in the community. He still required assistance with some ADL's (tooth brushing, applying deodorant) but was able to dress himself independently, eat with regular utensils and drink from a cup. He demonstrated "a limited sense of safety and require[d] supervision when out in the community." He had no skills in the areas of money, time-telling or calendar recognition. While he was still engaging in aggressive behavior, he was also enjoying some community activities including playing ball and watching videos. As previously reported, "Mark loves to climb on the playground and go on the swings. He smiles and will reciprocate gestures such as high fives or handshakes." Staver also reported that Mark was now using the PECS (picture exchange communication system) for communication with others, and had made "significant progress," although the speech pathologist recommended that an augmentative communication device be purchased to further enhance Mark's communication skills.

April 2010

Mark continued to reside on the Anderson campus, awaiting completion of a new IRA site targeted for December 2010. In January 2010, he transitioned from Anderson's education program to adult day habilitation services. Mark, still entirely nonverbal, continued to use the PECS, but his inability to communicate effectively with others made it "difficult for him to self-regulate when transitioning from one activity to another . . . [causing him to become] agitated and exhibi[t] aggressive behavior."

Because of frequent signs of aggression, the residence manager "requested contact information for Mark's brother. Staff would like him to visit Mark. After Mark's mother died, he no longer had any contact with his brother. [The residence manager] believes that it would be beneficial for Mark emotionally to see his brother again." Finally, Staver reported that she had now been able to purchase gift certificates for a computer and headphones, clothing for Mark, grocery items, and meals in local restaurants. Recommended ****9** items included two air purifiers, ***373** [23] a portable DVD player, a radio with wireless headphones, a recliner chair, and more gift certificates for restaurants in the community.

August 2010

Mark was just about to move to his new housing; because he "does not adapt well to change," he was exhibiting more outbursts of aggression, including lunging and throwing items while in the van that takes him to and from his day program. The behavior specialist instituted a protocol for use of a safety harness in the van, but also

> "stated that Mark would benefit from use of enjoyable sensory items in the van. These items will assist in calming Mark and hopefully turn the van ride into a positive experience. [The behavior specialist] will consult with . . . the Occupational Therapist regarding items to be purchased for Mark . . . [and] forward all requests to [Staver]."

Staver reported that since her last report, she had purchased a touch screen computer, a computer table, Boardmaker Plus! software, clothing and certificates for dining out in the community, and was planning to purchase additional needed items once Mark moved to his new residence.

November 15, 2010

Staver reports purchasing an iPad, and gift cards to Best Buy for accessories and apps, a trampoline, a recumbent bike, augmentative communication devices, educational puzzles and, as requested, "sensory items."

March 2011

Mark transitioned well to the Plutarch Residence. He "continues to exercise daily, enjoys taking long walks, brushes his teeth independently, helps with the laundry, and participates in afternoon meetings." He was progressing toward having "40 van rides without lunging out of his seat" so that the safety harness could be discontinued. In addition, "Mark continues to show significant improvement during community integration. He enjoys meals, bowling, haircuts and shopping." Staver reports that she purchased for Mark's new residence a laptop computer, a 32-inch television, a mattress and box spring, headboard and footboard, a rocker/reclining chair with heat and ***374** massage, a recumbent bicycle, a trampoline and rubber mats for safety.

Under consideration for purchase were playground equipment for use at Mark's residence, a trampoline to be used at Mark's day program, Wii and XBox, a hammock, an iPad, and a Mayer-Johnson Tech/Talk augmentative

communication system that aids users to communicate using direct selection.

August 26, 2011

Mark was reported to have continuously improved in the tasks and activities of daily life in his new residence, "participat[ing] in household tasks including putting laundry in the washing machine and transferring clean clothes to the dryer; reviewing his daily schedule, ****10** removing his plate from the table after meals, scraping the plate, rinsing it off and putting it in the dishwasher."

The importance of exercise was noted,[24] with Mark "playing basketball, walking, sprinting and running, as well as using an exercise ball, recumbent bike, Wii exercises and a trampoline at home." He no longer required the safety harness in the van and, in the classroom, "accepts changes in his routine, shortens break time himself, interacts more with staff and is able to sit and complete tasks." The speech language pathologist noted that Mark's use of the recently purchased XBox allowed him to "pair an enjoyable game with work tasks and aid in peer interactions."

Staff requested purchase of a number of items including an iPad with apps for music, communication, labeling and categorization; a Proloquo2Go for augmentative and alternative communication; wireless headphones for music [for self-soothing] at his day program; Boardmaker software for communication pictures and symbols; and sensory items including a compression vest, hand held massager, and neck/shoulder weighted compression.

November 2011

Staver wrote to H.J.P.: "Staff reports that Mark has benefited from recent purchases [of the items noted in the August 26, 2011 report] on his behalf" and, as well, "I am working to coordinate a visit with Mark's brother. Staff thinks this would be beneficial to Mark."

***375** July 2012

Mark was now ensconced in his IRA, where he had his own room, and where he was making substantial progress in communicating. He was able to lose the weight he gained over the winter through portion control and exercise, including his trampoline and recumbent bike. He showed "significant progress in the classroom" and "mastered most tasks including attending speech and occupational therapy sessions without staff accompaniment." He participated in preparation for the Special Olympics 50-meter run, though ultimately he was unable to start.[25]

The staff had begun planning a vacation for Mark, beginning with an introduction "to an amusement park and/or water park to see how he reacts and how accepting he is to new activities." Options for the vacation include Disney World, as previously suggested by Staver, ****11** Autism on the Seas, a cruise for autistic individuals and their families/residential staff, and autism-friendly Broadway shows.

Also reported: "The case manager is working with Mark's brother, Charles, to facilitate a visit to Mark."

September 24, 2012

Despite some new physical problems, the most recent communication was positive on many fronts. Mark is reported as "using pleasant table manners" and using PECS, and is able to make his own choices for meals and snacks. He clears the table after meals, rinses and puts dishes in the dishwasher, and independently takes his laundry from his room to the laundry room where he places it in the washer without prompts. He "showers independently" though with a staff member nearby due to his seizure disorder. He "has become less prompt-dependent at home" and "will independently leave the living room to go upstairs to his room or to the bathroom and return to the living room alone." As an example of his increasing life skills, Mark is reported to enjoy walking on the rail trail, after which "Mark likes purchasing a drink, and especially likes receiving change from his payment."

Demonstrating the beneficial results of purchases made for him, his "gross motor skills have improved. He enjoys bouncing ***376** on the trampoline, using it as a sensory activity . . . He likes having meals in restaurants and enjoys dressing up prior to going out for dinner."

His communication skills are also improving, in part because of the devices that have been purchased for him and that are being incorporated into his regimes. According to the report, "Mark uses sign language to communicate the words 'cracker' and 'apple.' He uses the Super Talker 8 for dinner and chooses the foods he likes. Mark will start using programs on his iPad at home." And, as an apparently small, but

enormously encouraging, advance, Staver reports that, as she was leaving Mark's classroom, he waived "bye" and, although previously entirely nonverbal, said, for the very first time, "buh"!

Finally, as a truly happy ending, Staver reports that she

> "facilitated a visit and accompanied Mark's older brother Charles to see Mark at his residence on September 22, 2012 . . . [Charles] stated that he was amazed at the progress Mark made in the last 8 years. He also said he felt reassured by the staff's caring, sensitivity and commitment to their clients. He said he knows Mark thrives because of the environment he's in and looks forward to bringing his family to meet Mark in the near future."

Discussion

As this history demonstrates, once the trustees were required to make themselves knowledgeable about Mark's condition and his needs, and the availability of services that would ****12** enable them to provide for those needs, they began, and continue to use funds from his trust for the purposes his deceased mother anticipated and so deeply desired.

The history brings into sharp focus the obligations of trustees, both individual and institutional, to the beneficiaries of trusts they administer when they know,[26] or should know,[27] that those beneficiaries have disabilities, and have medical, educational or quality of life needs that can and should be met from trust income.

***377** It is fundamental that a fiduciary takes on obligations beyond those imposed by ordinary relationships or transactions; in the oft-quoted works of Judge Cardozo, her responsibility is "something stricter than the [mere] morals of the market place . . . but the punctilio of an honor the most sensitive" (*Meinhard v Salmon*, 249 NY 458, 464 [1928]). This is no less the case for trustees, who have "an unwavering duty of complete loyalty to the beneficiary of the trust to the exclusion of the interests of all other parties" (106 NY Jur 2d, Trusts § 247).

The Mark Trust empowers the trustees with "absolute discretion," gives them latitude to withhold or pay out income, and, in the event of an income shortfall, to invade the principal, for the "care, comfort, support and maintenance" of Mark and his descendants. However, the words "absolute discretion" do not insulate the trustees, even trustees of lifetime trusts, as here, from liability.

Article 6.1 purports to absolve the trustees from a duty to account (except for a final account). That violates public policy and cannot be enforced (*Matter of Malasky*, 290 AD2d 631 [3d Dept 2002]) where, as here, the beneficiary is a person under a disability, and no one is protecting the beneficiary's interests (*Matter of Shore*, 19 Misc 3d 663 [Sur Ct, NY County 2008]). In an accounting, the court can assess the trustees' failure to take reasonable interest in and action on behalf of Mark.

The trustees left Mark to languish for several years with inadequate care, despite the fact that the Mark Trust had abundant assets. In so doing, the trustees failed to exhibit a reasonable degree of diligence toward Mark. Courts will intervene not only when the trustee behaves recklessly, but also when the trustee fails to exercise judgment altogether ("even where a trustee has discretion whether or not to make any payments to a particular beneficiary, the court will interpose if the trustee, arbitrarily or without knowledge of or inquiry into relevant circumstances, fails to exercise the discretion") (Restatement [Third] of Trusts § 50, Comment *b*). That is, sadly, precisely what occurred here.

The plain language of the Mark Trust elucidates Marie's intent in its creation. Article 2.1, § (iii) authorizes the trustees to pay any income not applied for Mark's benefit ****13** "to any facility he may be residing in and/or to any organization where he may be a client or a participant in any program(s)." This provision reflects both the importance of Mark's quality of life to Marie and the minimum knowledge that Marie expected her trustees ***378** to have about Mark and his situation. In order to exercise their discretionary power of expenditure, at the very least they are required to take steps necessary to keep themselves fully informed of Mark's residential situation and ancillary services. It is not sufficient for the trustees to simply safeguard the Mark Trust's assets; instead, the trustees have a duty to Mark to inquire into his condition and to apply trust income to improving it. The trustees abused their discretion by failing to exercise it. H.J.P.'s complicity is exacerbated by the fact that as drafter of the Mark Trust, as well as the drafter of Marie's will, he was aware of Mark's incapacity for years before serving as trustee.

Although New York case law concerning inactive fiduciaries is sparse, the Appellate Division has clearly ruled that executors may not deny a needy beneficiary payment from an estate under circumstances far less compelling than those presented herein. In *Matter of Van Zandt* (231 App Div 381 [4th Dept 1931]), the decedent bequeathed his real property to his sons subject to a life estate in the same property to his wife. As in the Mark Trust, the decedent gave his executors discretion over spending, authorizing but not requiring them to invade the trust corpus if the income supplied by the widow's life estate was insufficient for her "care, support and maintenance" (*id*. at 383). As in the Mark Trust, decedent's will gave the executors wide latitude "to expend . . . so much of the corpus of his estate as, in their opinion, might be necessary" (*id*. at 382). The executors subsequently refused to pay the widow's health care expenses.

Despite the discretion that the words "in their opinion" afforded to the executors, the *Van Zandt* Court held that the will required the executors to expend estate assets on the beneficiary's behalf. The Court looked to the plain language of the will to determine the testator's intent:

> "The language of [the] will . . . indicates a design on his part to devote his estate to the support of his wife. It is evident that he regarded her as the first object of his bounty. He makes it clear that, if the income from his property is insufficient for her care, support and maintenance, the corpus is available for that purpose" (*id*. at 383).

In addition, the Court qualified the executor's discretion, noting that it was not an "arbitrary" power that the executors could refuse to apply altogether:

> "The executors . . . cannot shut their eyes to Mrs. VanZandt's needs, and neglect to act, or refuse to ***379** approve proper and necessary payments which come early within contemplation of the bequest. The testator's intent to devote his entire estate, if need be, to the support of his wife must not be lost sight of" (*id*. at 384).

Rather, the Court suggested that trustees had an affirmative duty to exercise their spending power on expenses that fell within the parameters set forth in the will: "Where a trustee has been given freedom to act according to his own judgment in matters pertaining to another, and he fails, in the opinion of the court, to exercise such discretion in a proper manner, he may be compelled to do that which the trust fairly requires him to do" (*id*.). By not spending, the executors obstructed the testator's intent.

As in *Van Zandt*, it was not sufficient for the trustees merely to prudently invest the trust corpus and to safeguard its assets. The trustees here were affirmatively charged with applying trust assets to Mark's benefit and given the discretionary power to apply additional income to Mark's service providers. Both case law and basic principles of trust administration and fiduciary obligation require the trustees to take appropriate steps to keep abreast of Mark's condition, needs, and quality of life, and to utilize trust assets for his actual benefit.

While the accounting in this trust is not yet complete,[28] their failure to fulfill their fiduciary obligations should result in denial or reduction of their commissions for the period of their inaction.

Next Steps

The current accounting leaves many questions unanswered, particularly since an accurate statement of the opening principal received depends on the administration under both Marie's will and the somewhat inexplicable[29] Revocable Trust. Without expressing a view, or making any negative assumption, whether or not the estate and Revocable Trust were appropriately ***380** administered affects the amount of assets the Mark Trust should rightfully have received.

There is no question that this court has the power to order such accountings sua sponte (SCPA 2205). The power, and, indeed the obligation to do so is especially important where, as here, the only interested person, the sole beneficiary, is under a disability, and there is no one but the court to protect his interests.

Accordingly, H.J.P. is ordered to account as executor of the will of Marie H., and he and Chase are ordered to account as cotrustees of the Marie H. Revocable Trust of 1995 within 90 days of the order to be entered following this decision. Further, the cotrustees of the Mark Trust are ordered to file and serve a supplemented and revised accounting herein

for proceedings through December 31, 2012, reflecting the proper values of the assets with which the trust was funded, by that same deadline.

FOOTNOTES

Footnotes

1 Charles is Mark's biological brother, and is one year older. He had no contact with Mark from the time Mark was placed at the Anderson School.

2 Marie was named trustee, with section 9 (c) of the Revocable Trust providing that, upon her incapacity, her sister Betty and H.J.P. should become successor trustees. Section 9 (b) provides that, upon Marie's death, the Chase Manhattan Bank, N.A. should become a successor trustee with Betty and H.J.P., or the survivor of them.

3 According to the guardian ad litem's report, H.J.P. reported that he specializes in estate planning and trusts and estates, and has long been involved in issues around people with intellectual disabilities, having served, inter alia, as co-chairperson of the New York State Association for Retarded Children Trust and on the Board of the Association for the Help of Retarded Children (AHRC). He has lectured on planning for families who have children with intellectual disabilities, and, in fact, met Marie H. after one such lecture.

4 According to a letter from H.J.P., his fees are "charged on a flat fee basis," and not on time spent. Accountant fees were estimated at $10,000.

5 These expenses related primarily to the sale of Marie's co-op apartment.

6 According to an affidavit in response to the report of the guardian ad litem in this accounting, discussed below, a federal audit increased the estate tax due by $38,496.44, plus interest of $5,584.65, while there was a refund of New York State taxes of $16,048.87. The affidavit continues, "the attorney fees for the estate were increased by $100,000"; expenses are shown on the 706 totaling $917,217.45.

7 Much later, H.J.P. argued that the trust should not disqualify Mark from Medicaid eligibility as it was, and was intended to be an "*Escher* Trust." A precursor to the statutory supplemental needs trust (EPTL 7-1.12 [eff July 26, 1993]) was established in New York law by *Matter of Escher* (94 Misc 2d 952 [Sur Ct, Bronx County 1978], *affd on op below* 75 AD2d 531 [1st Dept 1980], *affd* 52 NY2d 1006 [1981]). There, the trustee with absolute discretion as to principal distributions could not be directed to transfer the trust corpus to the government entity providing for the life beneficiary's care (*id.*).

8 Notably, these provisions do not appear in the trust for Mark's brother, Charles, established on the same day.

9 It was the court's intention, at the same time, to order an accounting in the estate of Marie H., but, inexplicably, that order was never signed.

10 It is difficult, if not impossible, to ascertain the amount with which the Mark Trust was funded, and thus also to compare that amount to the closing balance for purposes of evaluating the trustees' prudence as a manager of trust funds. A rough calculation of the net value of Marie's estate based on the 706 suggests that the Mark Trust would have received approximately $2.5 million. In a phone communication, the attorneys for Chase have agreed to file corrected schedules, but as reflected in the conclusion herein below, the trustees will be ordered to do so.

11 According to H.J.P., the commissions to him were computed in accordance with SCPA 2309.

12 Pursuant to article 5.7 of the Mark Trust, a corporate trustee is authorized to receive commissions in accordance with its published rates of compensation in effect when such compensation is payable (*see* SCPA 2312).

13 The original petition sought appointment both as guardian of the person and of the property, but in communications with the Guardianship Clerk, H.J.P. made clear that he was not, at that time, applying for the latter.

14 ADL's are activities of daily living and include bathing, feeding oneself, toileting, dressing, etc. Mark was, according to Anderson's records, unable to perform any of these activities.

15 The proceeding was delayed for almost a year as a result of H.J.P.'s health-related issues.

16 The health care professionals at Anderson wrote that Mark's aggressive and self-harming behavior would be seriously exacerbated by the changes accompanying a trip from the institution in Straatsburg to the court in Manhattan.

17 According to the guardian ad litem, the director of corporate compliance at Anderson, Linda Geraci,

> "stated that she is concerned that [H.J.P.] has not inquired into Mark's needs nor has he purchased anything for him—[despite the fact] that Mark's residence manager has recommended purchasing the following for Mark's benefit : an acoustic synthesizer and other musical equipment, furniture, clothing, adult swings, slides, climbing equipment, a stereo system and a computer with game software."

18 Because Mark was placed in Anderson before his mother died, Anderson was not aware of the trust, and H.J.P. never informed them of its existence. This raised substantial concerns about Mark's Medicaid eligibility, which were ultimately favorably resolved.

19 The information comes primarily from the quarterly reports prepared for formal team meetings at Anderson which Staver attends, in person or by phone, and which she has supplied to the court, as well as her invoices and communications with H.J.P. and Chase. In accordance with the appointing order, H.J.P. now files extensive yearly reports which include the notes of the quarterly meetings and some additional, usually medical, information (*see Matter of Mark C.H.*, 28 Misc 3d 765, 783 [Sur Ct, NY County 2010] [requiring annual reports in the form described by Mental Hygiene Law § 81.31]).

20 That is, had funds been made available for Mark's "medical needs" from the Mark Trust, he could have avoided the serious aggression and exacerbating effects of the only medication covered by Medicaid.

21 Staff utilized massage and soft touching to deal with Mark's agitation, and the chair was intended to give him the ability to "self soothe."

22 This is automatic, upon a special ed student's reaching the age of 21, and does not necessarily suggest any particular level of scholastic achievement. It is, however, the transition from one set of government funded benefits to a different and separate system.

23 Mark suffers from numerous allergies causing red and itchy eyes, and the air purifier was recommended by staff both for use in his residence and at the day habilitation program.

24 Because Mark's medications have weight gain as a side effect, exercise is critical to maintain him at a healthy weight and BMI.

25 According to the residence manager, there was a long wait between trials, and Mark removed his sneakers, behavior he engages in when frustrated. As a result, he was disqualified from the race, but staff "looks forward to Mark's participation next year and is hopeful there will be environmental accommodations for the participants."

26 Through his 10 years of work with her, and the planning he did, H.J.P. unquestionably knew of Mark's severe disability, and the circumstances which had caused Marie to institutionalize him. Further, H.J.P. holds himself out as an expert in the legal needs of children with disabilities, and, in fact, first met Marie after giving a lecture on the subject at AHRC.

27 Presumably Chase had conversations with its cotrustee H.J.P. But the language of the Mark Trust itself, quoted, supra, was more than enough to put them on notice that this was, as H.J.P. characterized it, an *Escher* trust for a person with disabilities (*see* n 7 *supra*).

28 Many questions are left open by the accounting as it now stands, and they cannot be fully resolved without accountings in Marie's estate and the Revocable Trust, ordered below. The guardian ad litem may also wish to amend his objections to more clearly include commissions paid out in light of the abrogation of fiduciary duty.

29 It is difficult to understand the use of this Revocable Trust, created on the same day as the execution of Marie's will and as the Mark and Charles trusts, and like the latter, only nominally funded, as a planning device. Marie's estate could, as easily and without any negative tax consequences, simply have poured directly into the Mark and Charles trusts. Without an accounting, it is impossible to know if commissions, appropriate or otherwise, were taken, or what expenses, if any, were charged to the Revocable Trust.

The Concept of Legal Capacity

Legal capacity is a concept we all take for granted. At its most basic, it is "the recognized 'power' to enter into transactions, contracts, and legally regulated relationships with others."[1] Guardianship deprives individuals of their legal capacity in particular ways, depending on the powers granted to the guardian.

Excerpt of UN Convention on the Rights of Persons with Disabilities
Article 12 - Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

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.

4. States Parties shall ensure that 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 measures 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.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

[1] Kristin Booth Glen, *The Challenge: The CRPD and the Right to Legal Capacity*, 42 Int'l Law News No. 2, available at http://www.americanbar.org/publications/international_law_news/2013/spring.html.

ARTICLE: The Perils of Guardianship and the Promise of Supported Decision Making

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LexisNexis Summary

… Even with a clear statutory preference for limited guardianships, most petitioners request, and most courts grant, plenary guardianships; a 2007 study found that, in about 90 percent of guardianship proceedings, allegedly incapacitated persons were deprived of all of their liberty and property rights. … Those stories are critical in persuading parents that they need not seek guardianship and in persuading judges that they should not impose it. … Actions to Take Now Shortly after the Convention on the Rights of Persons with Disabilities took effect, a leading international organization for the rights of persons with intellectual disabilities cautioned that a system of supported decision making ″will take time to develop and would run the risk of becoming dysfunctional, if all existing measures of traditional guardianship were declared illegal at the same time, without the conditions in place that make supported decision-making effective for a particular individual.″ … Buoyed by the victory and the interest aroused by Jenny's story, Quality Trust has established the Jenny Hatch Project to challenge ″over-reliance on guardianship and share resources and knowledge gained from her case and promote alternatives to guardianship for people with disabilities.″ … While much effort went into legislating procedural protections where guardianship is sought, restoration of rights--or termination of guardianship--is surprisingly undertheorized and, at least with regard to reported decisions, underlitigated. … The best restoration provisions are found in the Uniform Guardianship Protection and Procedures Act, which requires guardians to encourage the person under guardianship to work toward regaining capacity and which gives the person seeking restoration the same rights and protections found in the establishment of the guardianship.

Highlight

Through guardianship the state removes the decision-making authority of an allegedly incapacitated person. But Article 12 of the Convention on the Rights of Persons with Disabilities holds that legal capacity should be enjoyed by everyone regardless of disability. To that end, advocates are working to move from the substituted decision making of guardianship to a new system of supported decision making.

Text

[*17] Why, with all the problems that public interest lawyers confront, should we care about guardianship? What may seem like an arcane, specialized issue, affecting only older people with progressive cognitive decline, is, in fact, one of the most extensive deprivations of liberty in the justice system. Guardianship laws apply not only to older persons but also to those persons born with intellectual disabilities, to traumatic-brain-injury victims, such as returning veterans, and to persons with psychosocial (mental health) disabilities. [1] Guardianship is a real imposition. As Rep. Claude Pepper noted almost 30 years ago, ″The typical ward has fewer rights than the typical convicted felon…

[1] Most states have a single guardianship statute that covers all of these groups. Five states have separate, additional statutes for persons with intellectual disabilities generally defined as beginning at birth or before the age of 21 (CAL. PROB. CODE § 1850.5; CONN. GEN. STAT. §§ 45a-669-45a-684; IDAHO CODE ANN. § 15-5-301; KY. REV. STAT. ANN. §§ 387.500-387.800; MICH. COMP. LAWS §§ 700.5401-700.5433; N.Y. SURR. CT. PROC. ACT §§ 1750-1761).

[Guardianship] is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty." [2]

Like so much else about how guardianship actually works, we have no hard information about how many individuals are currently under guardianship in the United States. The best estimate is 1.5 million, but the actual number may be as high as 3 million. [3] Compare this figure with the total number of people imprisoned in the United States--currently estimated at 2,228,424. [4] For most of those incarcerated, there will, at some point, be a return to liberty. For the vast majority of persons under guardianship, there will not.

So, what is guardianship, how did we get here, and what are the prospects of moving beyond a system that results in massive deprivation of liberty but that is only minimally accountable? And how does the paradigm shift from guardianship's substituted decision making to the supported decision making in Article 12 of the Convention on the Rights of Persons with Disabilities lead to dignity, equality, and inclusion for people with a wide variety of intellectual disabilities?

The Current Regime and How We Got Here

Guardianship, or something like it, has been around since Roman times, and guardianship laws have existed in this country since the 18th century. [5] Premised on the *parens patriae* power of the state, guardianship is understood as necessary to protect persons whose lack of cognitive intellectual capacity places them in danger and who are unable to understand the consequences of that impaired (or lack of) mental capacity. Guardianship has undergone a transformation from a status model (a person was a "lunatic" or an "idiot" under English law) to a medical model, based on diagnoses as indeterminate (and now discredited) as "organic brain syndrome," to most recently a more functional inquiry. The issue now is what, specifically, an impaired person is incapable of doing, such that a guardian must be given the legal power to make decisions for that person, over that domain?

A reform effort that began in the mid-1980s led to significant procedural protections for the subjects (now often called "allegedly incapacitated persons") of guardianship proceedings, including notice, hearing, the right to cross-examination, the right to counsel (including, in some instances and in some states, a publicly paid lawyer), and a higher burden of proof. Many states have court-appointed or court-annexed evaluators to investigate the allegedly incapacitated person's circumstances and make recommendations. In addition to these apparent protections in the hearing process, most states allow (and express an explicit preference for) limited or "tailored" guardianships. On paper, at least, these limited guardianships **[*18]** are a far cry from the plenary guardianships that transferred absolute power over an allegedly incapacitated person's life to a guardian and frequently terminated the person's civil rights, including voting, marriage, and the right to contract. These reform statutes generally require periodic reporting by guardians and review by the appointing court--ranging from paper review to personal visits or hearings on the need for continued guardianship.

Despite these major reforms and the enormous efforts of so many advocates that brought them about, the guardianship system all too frequently, as a Utah Judicial Council found, "terminate[s] this fundamental and basic right (to make decisions for oneself) with all the procedural rigor of processing a traffic ticket." [6] Even with a clear statutory preference for limited guardianships, most petitioners request, and most courts grant, plenary guardianships; a 2007 study

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[2] CHAIRMAN OF THE SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE OF THE HOUSE SELECT COMMITTEE ON AGING, 100TH CONGRESS, ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE 4 (Comm. Print 1988).

[3] Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*, IN NATIONAL CENTER FOR STATE COURTS, FUTURE TRENDS IN STATE COURTS 2011, at 107, 109 (2011).

[4] International Centre for Prison Studies, United States of America ([2012]).

[5] For a comprehensive description of the history of guardianship, guardianship reform, and the effect of Article 12 of the Convention on the Rights of Persons with Disabilities, see my *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUMBIA HUMAN RIGHTS LAW REVIEW 93 (2012).

[6] Utah Judicial Council's ad hoc Committee on Probate Law and Procedure (Feb. 2009), quoted in Uekert & Van Duizend, *supra* note 3, at 107.

found that, in about 90 percent of guardianship proceedings, allegedly incapacitated persons were deprived of all of their liberty and property rights. [7] Cuts in court budgets, competing demands for services, and a variety of other factors mean that, in many jurisdictions, postappointment monitoring is minimal, especially as to personal rather than financial reporting. Having given a guardian total and complete power over an incapacitated person, the court may have no way of ever knowing whether that power is being used to foster the allegedly incapacitated person's well-being or to exploit or abuse the person.

To be sure, there are fine guardians who work to maximize the autonomy of their wards; there are excellent lawyers, often legal aid lawyers, who insist on the procedural protections of reform guardianship statutes, avoid guardianship for their clients, and sometimes even terminate guardianships previously imposed. [8] Volunteer monitoring project workers review reports and visit persons under guardianship and thereby ensure that, at the very least, those in whose lives the state has so dramatically intervened are no worse off than they were before guardians were appointed. [9]

Despite all this good work, the guardianship system has not fulfilled the hopes of reformers for a regime that adequately protects liberty interests and satisfies the requirements of both procedural and substantive due process. But even more important, in 2014, the guardianship system fundamentally violates the emerging--in the United States, at least--*human* right of legal capacity.

Legal Capacity and Supported Decision Making: A New Paradigm

The Convention on the Rights of Persons with Disabilities is described elsewhere in this May-June 2014 issue of CLEARINGHOUSE REVIEW. [10] Among the convention's many provisions in support of the rights of persons with disabilities is Article 12, which says that the right of legal capacity shall be enjoyed equally by all persons, without regard to disability. [11] Legal capacity means the right to make one's own decisions *and* the right to have them legally recognized. [12] This means choosing where and with whom to live and how to spend one's money, make health care decisions, and enter into contracts such as leases. Legal capacity recognizes that many persons with intellectual **[*19]** lectual disabilities need support to make decisions and to communicate them to others, but it insists that all persons have the human right to make those decisions and that the state has an obligation to give whatever supports are necessary. Thus guardianship, which imposes *substituted* decision making through the imposition of state power, must, as a matter of human rights, give way to *supported* decision making, with all that may entail.

The guarantee of legal capacity is hugely radical; it disengages familiar notions of cognition and functional assessment of *mental* capacity from the right to *legal* capacity. Given ever-decreasing public resources for the poor, the vulnerable, and the marginalized, supported decision making may seem unbelievably utopian. And yet, around the

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[7] 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).

[8] For an excellent example of this work, see Robin Thorner, *Challenging Guardianship and Pressing for Supported Decision-Making for Individuals with Disabilities*, SARGENT SHRIVER NATIONAL CENTER ON POVERTY LAW ADVOCACY STORIES (Jan. 7, 2014).

[9] For information on volunteer monitoring projects and a manual for creating such a project, see American Bar Association Commission on Law and Aging, Court Volunteer Guardianship Monitoring Handbooks (n.d.); Ellen M. Klem, American Bar Association, Volunteer Guardianship Monitoring Programs: A Win-Win Solution (2007).

[10] See David T. Hutt, *The Disability Rights Treaty and Advocacy Strategies Using International Human Rights*, 48 CLEARINGHOUSE REVIEW 4 (May-June 2014).

[11] Article 12 states: ″(1) [P]ersons with disabilities have the right to recognition everywhere as persons before the law. (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. (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.″ (Convention on the Rights of Persons with Disabilities art. 12, Dec. 13, 2007, 2515 U.N.T.S. 3).

[12] The United Nations high commissioner for human rights has expansively defined legal capacity to include ″the 'capacity to act,' intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status or relationship with another individual and more in general, to create, modify or extinguish legal relationships″ (Office of the United Nations High Commissioner for Human Rights, Legal Capacity 20 (n.d.)).

world, less wealthy countries are moving to develop supported decision-making projects and to alter or abolish their existing guardianship laws. [13]

Supported Decision Making and How to Get There

Each person is different. Some may communicate in nontraditional ways and need someone who knows them well to interpret their wishes for others. Some need support in understanding choices and consequences. Some may wish to make certain decisions--such as where to live or with whom to have relationships--on their own but welcome support in making financial decisions. The relationship between the individual and the individual's supporters--for there may be many--is critical, but for the full exercise of legal capacity, supporters must be afforded legal recognition by third parties such as health care professionals and financial institutions. So long as critical third parties, including the educational system and benefits offices, refuse to honor the choices of individuals with intellectual disabilities, guardianship is the default position and the sole means by which those individuals can interact with the world. Implementation of Article 12's guarantees thus ultimately requires legislation that recognizes and legitimates supported decision making. Efforts to write and enact such legislation are ongoing in many countries that have ratified the Convention on the Rights of Persons with Disabilities. [14]

Equally if not more important are efforts designed to create, measure, and evaluate supported decision making on the ground to demonstrate that persons, even those with severe disabilities, can make decisions with appropriate supports. [15] Showing supported decision making in the real world is critical to persuading the skeptical (judges, policymakers, benefits providers, legislators, lawyers) as well as the families (of persons with intellectual disabilities) whose understandable desire to protect their loved ones has heretofore had a single legally sanctioned form: guardianship.

Although the United States has one small pilot project, other countries have had, or **[*20]** are conducting, far more robust projects. [16] The evidence from these projects and the individual stories of dignity and empowerment they produce powerfully demonstrate the efficacy and workability of supported decision making. Also powerful are the innumerable stories, as yet uncollected, of families, friends, and communities that have created networks of support to permit persons with intellectual disabilities to live good, pleasurable, dignified, and productive lives, without the necessity of state intervention that deprives them of liberty and their fundamental human rights. [17] Those stories are critical in persuading parents that they need not seek guardianship and in persuading judges that they should not impose it. The stories and data from more formalized supported decision-making initiatives are essential for the legislative change necessary to enshrine the right to legal capacity, without regard to disability, in our legal system.

Actions to Take Now

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[13] See, e.g., Bulgarian Center for Not-for-Profit Law, Bulgarian Center for Not-for-Profit Law Launches an Online Training Program for Supported Decision-Making (Dec. 17, 2013); Mental Disability Advocacy Center, Europe (2011); Doris Rajan, Institute for Research and Development on Inclusion and Society, IRIS' International Work on Legal Capacity--Zambia (Dec. 21, 2013).

[14] While the United States has signed but not ratified the Convention on the Rights of Persons with Disabilities, Canada has been in the forefront of this work, with a comprehensive effort, involving multiple stakeholders, over a period of years. Canadian proposals, and a representative set of principles from a similar effort in Ireland, may be found among the online resources of the American Bar Association Commission on Disability Rights (American Bar Association, Article 12 (n.d.)).

[15] See Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship*, 117 PENNSYLVANIA STATE LAW REVIEW 1111 (2013) (calling for more examples and research).

[16] The U.S. project is a collaboration between the Center for Public Representation and Nonotuck Resource Associates in Northampton, Massachusetts (see Center for Public Representation, Supported Decision-Making (n.d.)). The Soros Foundation has supported significant pilot projects in Bulgaria, Zambia, and Colombia (see, e.g., Bulgarian Center for Not-for-Profit Law, *supra* note 13. South Australia has completed a trial of a ″stepped model of supported and substituted decision making,″ which involved a ″non-statutory supported decision-making agreement″ (South Australia Office of the Public Advocate, Supported Decision Making (n.d.)).

[17] Many providers in the United States are working to implement supported decision making on a more informal basis; a number of manuals and publications detail their efforts (see, e.g., JOAN KAKASCIK ET AL., WHERE HUMAN RIGHTS BEGIN: HUMAN RIGHTS AND GUARDIANSHIP FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES--IN PLAIN LANGUAGE (2013); Dohn Hoyle, The Arc Michigan, Rethinking Guardianship (n.d.)).

Shortly after the Convention on the Rights of Persons with Disabilities took effect, a leading international organization for the rights of persons with intellectual disabilities cautioned that a system of supported decision making ″will take time to develop and would run the risk of becoming dysfunctional, if all existing measures of traditional guardianship [were] declared illegal at the same time, without the conditions in place that make supported decision-making effective for a particular individual.″ [18]

Advocates and providers need to develop replicable models of supported decision making on the ground to pave the way for more comprehensive legislative reform, in accordance with Article 12. Meanwhile, however, several other strategies can move that project forward and protect and enforce the existing rights of persons with intellectual disabilities.

First, litigation can push courts to incorporate supported decision making into existing statutory schemes, as an alternative, where feasible, for persons facing guardianship. One excellent and nationally publicized example of this approach is the case of Jenny Hatch, a courageous young woman with Down syndrome. Hatch led an independent and productive life for all of her young adulthood until her parents sought guardianship and placed her in a restrictive group home. Jenny was fortunate to be vigorously represented by Quality Trust, a Washington, D.C., advocacy organization, with the assistance of Prof. Robert Dinerstein and the American University Law School Disability Rights Clinic. After a year of litigation and a six-day trial, with expert witnesses and moving testimony by Jenny herself, the court granted a one-year temporary guardianship to the friends with whom she had been living; the court directed them to use supported decision making to help Jenny learn how to handle her affairs independently. Jenny's case is believed to be the first time that a court has ordered supported decision making. [19]

Buoyed by the victory and the interest aroused by Jenny's story, Quality Trust has established the Jenny Hatch Project to challenge ″over-reliance on guardianship [and] share resources and knowledge gained from her case and promote alternatives to guardianship for people with disabilities.″ [20]

A second promising path to advancing supported decision making within the current system is by a more expansive focus on the ″least restrictive alternatives″ requirement of many existing guardianship statutes. Describing that requirement as a constitutional imperative, one court held that supported decision making must be explored and attempted before the drastic remedy of guardianship may be ordered. [21] The decision not only relied on a statutory and constitutional analysis but also specifically referenced Article 12 and the human right of legal capacity. [22]

Third, in an analogous vein, Prof. Leslie Saltzman makes an insightful and provocative argument that guardianship violates the Americans with Disabilities Act (ADA) because it isolates people with intellectual disabilities, thus removing them from participation in the larger world **[*21]** and inhibiting the growth of which they are capable. [23] Drawing on the inclusion mandate of *Olmstead v. L.C.*, Saltzman's ADA analysis can reinforce arguments that

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[18] Inclusion Europe, Key Elements of a System for Supported Decision-Making (2008).

[19] Michelle Diament, *Center to Promote Alternatives to Guardianship*, DISABILITY SCOOP, Oct. 25, 2013.

[20] *Id.* The results of a symposium that the Jenny Hatch Project held in October 2013 make an excellent introduction to alternatives to guardianship and a blueprint for practical action (Supported Decision-Making: An Agenda for Action (Feb. 2014)).

[21] In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. N.Y. Cnty. 2012). That case involved termination of guardianship for a woman with intellectual disabilities on a finding that there was now a support network in place that enabled her to make her own decisions. (Disclosure: this was my decision on my last day as surrogate, before my mandatory retirement.)

[22] ″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 … 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… Terminating the guardianship recognizes and affirms Dameris's constitutional rights and human rights and allows a reading and application of [the New York statute] that is consistent with both″ (id. at 856).

[23] Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 UNIVERSITY OF COLORADO LAW REVIEW 157 (2010).

meaningful attempts at supported decision making must be made before the more restrictive, more isolating alternative of guardianship is permissible. [24]

Advocates can explore a fourth, more systemic possibility to influence legislation. The Uniform Law Commissioners recently formed a committee to consider changes in the Uniform Guardianship Protection and Procedures Act in response to recommendations of the Third National Guardianship Summit. [25] This review process is an opportunity for advocacy to include supported decision making as a least-restrictive alternative that must be explored before guardianship can be imposed.

Finally, but of enormous practical importance, is the issue of restoration. At a 2012 national roundtable, ″Supported Decision-Making: Beyond Guardianship,″ convened by two American Bar Association Commissions with the support of the Agency for Intellectual and Developmental Disabilities, self-advocates argued passionately for legal strategies and litigation to free individuals currently under guardianship. [26]

While much effort went into legislating procedural protections where guardianship is sought, restoration of rights--or termination of guardianship--is surprisingly undertheorized and, at least with regard to reported decisions, underlitigated. In a comprehensive survey undertaken in response to the 2012 roundtable, the American Bar Association Commission on Law and Aging published a report and 50-state survey of the laws relating to restoration. [27] The report found that

> the statutory legal procedure for restoration is often unclear and ambiguous. The procedural process, as well and [sic] the duties of the court and of the guardian, vary significantly by state, court, and judge. Due to the inconsistency among state statutes, variations in practice, and lack of hard data on restoration proceedings, it is unclear whether current guardianship law adequately protects an individual's right to restoration. [28]

The best restoration provisions are found in the Uniform Guardianship Protection and Procedures Act, which requires guardians to encourage the person under guardianship to work toward regaining capacity and which gives the person seeking restoration the same rights and protections found in the establishment of the guardianship. [29]

A key issue is the burden of proof. Logic (and perhaps constitutional imperative) would seem to dictate that the party opposing restoration should be required **[*22]** to prove that the need for guardianship continues. But among the states the standard varies widely and is ″often unclear.″ [30] The best existing procedures are incorporated in the Uniform Guardianship Protection and Procedures Act and require the petitioner or person under guardianship to

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[24] See Olmstead v. L.C., 527 U.S. 581 (1999).

[25] See *Third National Guardianship Summit Standards and Recommendations*, 2012 UTAH LAW REVIEW 1191 (2012). While the recommendations generally adhere to a substituted decision-making model, they specifically reference supported decision making with regard to health care and housing decisions.

[26] The two convening committees were the American Bar Association Commission on Disability Rights and the American Bar Association Commission on Law and Aging (see American Bar Association, *supra* note 14). Interestingly those same two commissions, then with different names, convened the now eponymous Wingspread Conference that began the first round of guardianship reform in the 1980s (see my *Changing Paradigms, supra* note 5, at 109).

[27] [Jenica Cassidy], State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship ([2013]); Restoration in Adult Guardianships (Statutes) (June 2013).

[28] [Cassidy], *supra* note 27, at 1.

[29] National Conference of Commissioners on Uniform State Laws, Uniform Guardianship and Protective Proceedings Act (1997). Eighteen states that have adopted the Uniform Guardianship and Protective Proceedings Act specifically so provide, as do several other nonadopting states ([Cassidy], *supra* note 27, at 2 n.7).

[30] [Cassidy], *supra* note 27, at 3. The standards range from Maine and Minnesota, which have adopted the Act's standard, to the clear and convincing evidence required by case law in New Jersey. Thirty-three states have no statutory evidentiary standard (*id.* at 3-4).

make out a prima facie case for termination, after which the burden shifts to the proponent of guardianship to establish the need for its continuation by clear and convincing evidence. [31]

A number of states have procedural bars to petitions for restoration. These hurdles include constraints placed on the guardian, minimum time periods before a petition for termination may be filed, and restrictions on who may file a petition. [32] The American Bar Association's report notes the many unknowns, such as the number of petitions to terminate a guardianship that are actually filed and the number of petitions granted. The report underscores the ″compelling need for additional research and data collection to determine which state practices [if any] adequately protect the individual's right to restoration.″ [33]

As providers and advocates develop and facilitate supporters for decision making by persons with intellectual disabilities, the opportunities for, and the necessity to seek restoration for, those many persons for whom guardianship is no longer the least restrictive alternative can only grow. Their stories, too, will be an integral part of any successful effort for legislative change. Commitment to ending the deprivation of liberty imposed by guardianship is critical to moving the human right of legal capacity forward and to bringing our legal system close to the challenge and inspiration of the Convention on the Rights of Persons with Disabilities. It is a commitment for individuals, despite their disabilities, to be able, with or without support, to make the decisions that allow them to be actors in their own lives.

Clearinghouse Review: Journal of Poverty Law and Policy

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[31] National Conference of Commissioners on Uniform State Laws, Uniform Guardianship and Protective Proceedings Act (1998) §§ 318(c), 431(d) (1997) (National Conference of Commissioners on Uniform State Laws drafted Act and approved and recommended it for enactment in all states).

[32] [Cassidy], *supra* note 27.

[33] *Id*. at 9.

Excerpt from New York Model Rules of Professional Conduct Rule 1.0
Terminology and Comments

(j) "Informed consent" denotes the agreement by a person to a proposed course of conduct after the lawyer has communicated information adequate for the person to make an informed decision, and after the lawyer has adequately explained to the person the material risks of the proposed course of conduct and reasonably available alternatives.

Comment

Informed Consent

[6] Many of the Rules of Professional Conduct require the lawyer to obtain the informed consent of a client or other person (*e.g.*, a former client or, under certain circumstances, a prospective client) before accepting or continuing representation or pursuing a course of conduct. *E.g.*, Rules 1.2(c), 1.6(a) and 1.7(b). The communication necessary to obtain such consent will vary according to the Rule involved and the circumstances giving rise to the need to obtain informed consent. The lawyer must make reasonable efforts to ensure that the client or other person possesses information reasonably adequate to make an informed decision. Ordinarily, this will require communication that includes a disclosure of the facts and circumstances giving rise to the situation, any explanation reasonably necessary to inform the client or other person of the material advantages and disadvantages of the proposed course of conduct, and a discussion of the client's or other person's options and alternatives. In some circumstances it may be appropriate for a lawyer to advise a client or other person to seek the advice of other counsel. A lawyer need not inform a client or other person of facts or implications already known to the client or other person; nevertheless, a lawyer who does not personally inform the client or other person assumes the risk that the client or other person is inadequately informed and the consent is invalid. In determining whether the information and explanation provided are reasonably adequate, relevant factors include whether the client or other person is experienced in legal matters generally and in making decisions of the type involved, and whether the client or other person is independently represented by other counsel in giving the consent. Normally, such persons need less information and explanation than others, and generally a client or other person who is independently represented by other counsel in giving the consent should be assumed to have given informed consent. Other considerations may apply in representing impaired clients. *See* Rule 1.14.

[7] Obtaining informed consent will usually require an affirmative response by the client or other person. In general, a lawyer may not assume consent from a client's or other person's silence. Consent may be inferred, however, from the conduct of a client or other person who has reasonably adequate information about the matter. A number of Rules require that a person's consent be confirmed in writing. *E.g.*, Rules 1.7(b) and 1.9(a). For definitions of "writing" and "confirmed in writing" *see* paragraphs (x) and (e), respectively. Other Rules require that a client's consent be obtained in a writing signed by the client. *E.g.*, Rules 1.8(a) and (g). For the meaning of "signed," *see* paragraph (x).

RULE 1.14:
CLIENT WITH DIMINISHED CAPACITY

(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a conventional relationship with the client.

(b) When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian.

(c) Information relating to the representation of a client with diminished capacity is protected by Rule 1.6. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized under Rule 1.6(a) to reveal information about the client, but only to the extent reasonably necessary to protect the client's interests.

Comment

[1] The responsibilities of a lawyer may vary according to the intelligence, experience, mental condition or age of a client, the obligation of a public officer, or the nature of a particular proceeding. The conventional client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. Any condition that renders a client incapable of communicating or making a considered judgment on the client's own behalf casts additional responsibilities upon the lawyer. When the client is a minor or suffers from a diminished mental capacity, maintaining the conventional client-lawyer relationship may not be possible in all respects. In particular, a severely incapacitated person may have no power to make legally binding decisions. Nevertheless, a client with diminished capacity often has the ability to understand, deliberate upon and reach conclusions about matters affecting the client's own well-being.

[2] The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client attentively and with respect.

[3] The client may wish to have family members or other persons participate in discussions with the lawyer. The lawyer should consider whether the presence of such persons will affect the attorney-client privilege. Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must look to the client, and not family members, to make decisions on the client's behalf.

[4] If a legal representative has already been appointed for the client, the lawyer should ordinarily look to the representative for decisions on behalf of the client. In matters involving a minor, with or without a disability, the question whether the lawyer should

look to the parents as natural guardians may depend on the type of proceeding or matter in which the lawyer is representing the minor. If the lawyer represents the guardian as distinct from the ward and reasonably believes that the guardian is acting adversely to the ward's interest, the lawyer may have an obligation to prevent or rectify the guardian's misconduct. *See* Rule 1.2(d).

Taking Protective Action

[5] If a lawyer reasonably believes that a client is at risk of substantial physical, financial or other harm unless action is taken, and that a conventional client-lawyer relationship cannot be maintained as provided in paragraph (a) because the client lacks sufficient capacity to communicate or to make adequately considered decisions in connection with the representation, then paragraph (b) permits the lawyer to take reasonably necessary protective measures. Such measures could include: consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decision-making tools such as durable powers of attorney, or consulting with support groups, professional services, adult-protective agencies or other individuals or entities that have the ability to protect the client. In taking any protective action, the lawyer should be guided by such factors as the wishes and values of the client to the extent known, the client's best interest, and the goals of minimizing intrusion into the client's decision-making autonomy and maximizing respect for the client's family and social connections.

[6] In determining the extent of the client's diminished capacity, the lawyer should consider and balance such factors as: (i) the client's ability to articulate reasoning leading to a decision, (ii) variability of state of mind and ability to appreciate consequences of a decision; the substantive fairness of a decision, and (iii) the consistency of a decision with the known long-term commitments and values of the client. In appropriate circumstances, the lawyer may seek guidance from an appropriate diagnostician.

[7] If a legal representative has not been appointed, the lawyer should consider whether appointment of a guardian ad litem, conservator or guardian is necessary to protect the client's interests. Thus, if a client with diminished capacity has substantial property that should be sold for the client's benefit, effective completion of the transaction may require appointment of a legal representative. In addition, rules of procedure in litigation sometimes provide that a minor or a person with diminished capacity must be represented by a guardian or next friend if they do not have a general guardian. In many circumstances, however, appointment of a legal representative may be unnecessarily expensive or traumatic for the client. Seeking a guardian or conservator without the client's consent (including doing so over the client's objection) is appropriate only in the limited circumstances where a client's diminished capacity is such that the lawyer reasonably believes that no other practical method of protecting the client's interests is readily available. The lawyer should always consider less restrictive protective actions before seeking the appointment of a guardian or conservator. The lawyer should act as petitioner in such a proceeding only when no other person is available to do so.

[7A] Prior to withdrawing from the representation of a client whose capacity is in question, the lawyer should consider taking reasonable protective action. *See* Rule 1.16(e).

Disclosure of the Client's Condition

[8] Disclosure of the client's diminished capacity could adversely affect the client's interests. For example, raising the question of diminished capacity could, in some circumstances, lead to proceedings for involuntary commitment. Information relating to the representation is protected by Rule 1.6. Therefore, unless authorized to do so, the lawyer may not disclose such information. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized to make the necessary disclosures, even when the client directs the lawyer to the contrary. Nevertheless, given the risks of disclosure, paragraph (c) limits what the lawyer may disclose in consulting with other individuals or entities or in seeking the appointment of a legal representative. At the very least, the lawyer should determine whether it is likely that the person or entity consulted will act adversely to the client's interests before discussing matters related to the client.

Guardianship in New York:

Developing an Agenda for Change

Report of the Cardozo School of Law Conference

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Guardianship in New York: Developing an Agenda for Change

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Contents

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Introduction

It has been twenty years since the Legislature passed a comprehensive set of reforms to modernize the primary means of obtaining adult guardianship in New York. Those reforms, which became Article 81 of the Mental Hygiene Law, were in keeping with a national movement at the time to increase protections for persons facing or living under guardianship.[1]

Article 81 was – and remains – a model guardianship statute in many ways. Its due process protections are significant; the statute calls for no one to be deprived of their decision-making rights without a hearing, investigation by a court evaluator, and counsel, if requested.[2] The statute mandates a least restrictive alternative approach so that persons under guardianship are deprived of no more of their decision-making rights than are necessary to protect them from harm.[3] Detailed reporting requirements aim to ensure that guardians remain accountable to those under guardianship and to the courts. [4] In these ways, Article 81 differs significantly from New York's other form of guardianship, Article 17-A of Surrogate Court Procedures Act, which is limited to individuals with intellectual and developmental disabilities.[5]

Notwithstanding these important reforms, noteworthy challenges remain two decades later. Practitioners report long delays in what is supposed to be an expedited proceeding.[6] Family members and friends encounter substantial problems commencing a guardianship case when unrepresented and navigating reporting and other requirements when they serve as lay guardians of their loved ones. A dearth of resources and services places guardianship out of reach for families who cannot afford counsel and do not qualify for the limited non-profit guardianship services that are available.[7] And, in some cases, guardianship is a blunt instrument, imposed too readily and with excessive powers, when a less restrictive alternative would suffice.

A dearth of resources and services places guardianship out of reach for families who cannot afford counsel and do not qualify for the limited non-profit guardianship services that are available.

More dramatically, periodic scandals have exposed big shortcomings in the system for overseeing and monitoring guardians. In 2004, the Queens District Attorney impaneled a grand jury to investigate how an attorney was able to steal more than $2 million over a five-year period from fourteen different persons for whom he served as guardian. Much of the blame, according to the grand jury, was attributable to inadequate scrutiny by court examiners – the court-appointed monitors who are mandated to review annual reports filed by guardians and are responsible for verifying the information in the reports.[8]

A 2010 Government Accountability Office ("GAO") report identified additional examples of guardianship exploitation in New York, including a case in which the guardian misappropriated at least $327,000 to herself, family and friends from an 82-year-old retired judge – all while presiding over the decrease of his estate from several million dollars to almost nothing.[9] The same GAO investigation found that screening processes for guardians in New York need tightening.[10]

New York is certainly not alone in these problems.[11] Inadequate monitoring of guardianships appears to be the norm in many states.[12] Throughout the country, there is insufficient data about guardianship filings and caseloads. This lack of data extends to the most basic of facts; for example, it is not known how many people are under guardianship across the country.[13] Training, particularly of family and friends who serve as guardians, is lacking nationwide.[14]

As the problems in guardianship practice persist, evolving civil and human rights norms have called into question whether guardianship itself is a violation of the rights of persons with disabilities.[15] The Convention on the Rights of Persons with Disabilities[16] ("CRPD"), adopted in 2006 during the sixty-first session of the United Nations General Assembly, recognizes the right of all individuals to exercise legal capacity and to receive support to exercise that capacity if, and to the extent that, assistance is needed.[17] The United States is one of the 154 signatories to the CRPD.[18] Although the United States has not ratified the CRPD, more than 100 countries have done so.[19] The CRPD's dictates therefore represent "the overwhelming weight of international opinion."[20] Article 12 of the CRPD provides that any measures that limit an individual's exercise of legal capacity must "respect the rights, will and preferences of the individual, must be free of conflict of interest and undue influence, must be proportional and tailored to the person's circumstances, must apply for the shortest time possible and must be subject to regular review by a competent, independent and impartial authority or judicial body."[21] The Committee on the Rights of Persons with Disabilities, the authoritative body interpreting the CRPD, has urged States Parties, under the framework of compliance with Article 12, "to replace regimes of substituted decision-making with supported decision-making, which respects the person's autonomy, will and preferences."[22]

As the guardianship landscape changes, state and national efforts at reform continue. In October 2011, the National Guardianship Network convened the Third National Guardianship Summit, which produced a set of national guardian standards and related recommendations for action by courts, legislatures and other entities.[23] The standards emphasize person-centered planning, preserving the dignity and self-determination of the person under guardianship, and maintaining communication with the court regarding changes in personal needs and financial status. Organizers aim to have local affiliates promote the standards and advocate for their incorporation into state court or administrative rules.[24] In New York, the Guardian Assistance Network program began offering online training for new guardians, thereby expanding the

training available to lay guardians significantly. And in the face of severe budget cuts, New York courts have preserved guardianship compliance units to monitor guardian reporting and have expanded training for court examiners.

Aims of the Conference

Against this backdrop, Cardozo Law School hosted a conference on November 15, 2011 to coincide with the launch of its new Guardianship Clinic. "Guardianship in New York: Developing an Agenda for Change" was a day-long convening of attorneys, advocates, court personnel, judges, and service providers, designed to foster dialogue and develop consensus about the next wave of guardianship reform in the state. The conference focused primarily on Article 81 but some of the recommendations bear on Article 17-A guardianships as well. The day began with a morning plenary that offered a variety of perspectives on guardianship, including an overview of national developments, discussion of alternatives to guardianship, and descriptions of public guardianship and similar programs.

After the plenary, participants broke into four working groups: 1) Streamlining Without Steamrolling; 2) Monitoring Issues; 3) Problems of Poor People in the Guardianship System; and 4) Alternatives to Guardianship. Each group was charged with discussing the problems in their particular area, envisioning ideal solutions, and then developing workable recommendations for reform. There was not a formal approval process for the working group proposals; rather, each group arrived at a consensus or majority view on core recommendations and identified some issues about which there was disagreement. The recommendations were presented initially as part of a final plenary during the conference. Afterwards, reporters for each group wrote summaries of the proceedings and circulated them to the participants for comment and revision.

The core findings and recommendations from the conference are summarized below. It was noteworthy that while the working groups' agendas were disparate, in many cases they arrived at the same reform recommendations. Some of the suggested reforms require amendments to Article 81 and/or contemplate major changes in the guardianship system. But many recommendations are operational tweaks that could be fairly quickly accomplished with great benefit to parties and the courts alike.

The summary below captures what the conference organizers have identified as the key recommendations. It was not possible to repeat every recommendation of all the working groups and still produce a summary. The working group reports, all attached in their entirety as appendices, describe the various problems and suggested solutions at greater length and contain additional detailed recommendations.

Recommendations

General

1) **Establish a statewide task force on guardianship in New York.**

If anything is clear from the history of guardianship, it is that ongoing scrutiny is needed to ensure the system functions as intended and evolves to meet changing needs. Many of the recommendations that emerged from the working groups have been suggested repeatedly by various experts but have never been implemented. Without a standing body to identify key policy and practice issues and to coordinate reform implementation, change is not likely to occur.

New York should follow the recommendation of the Third National Guardianship Summit and establish a Working Interdisciplinary Network of Guardianship Stakeholders—or "WINGS" group—to facilitate cooperative efforts to advance best practices in guardianship.[25] This WINGS group would be an ongoing state-wide guardianship task force that would be charged with identifying key policy and practice issues and making and implementing recommendations for reform. Such a group would be composed of multiple stakeholders, including the courts, advocates, persons with disabilities, the private bar, persons with disabilities, lay guardians, and the service-provider community.

To date, planning for such statewide stakeholder entities has begun, is anticipated, or is ongoing at least in Missouri, Ohio and Delaware. New York can join these states at the forefront of the national guardianship reform movement by establishing its own WINGS group.

2) **Create Simplified, Standardized, Statewide Forms and Make Them Accessible Through the Web and Other Means.**

The Monitoring, Streamlining, and Problems of Poor Persons groups all recommended that guardianship-related forms be standardized, simplified, and made accessible to the public. These recommendations echo calls from nearly every group to study guardianship in New York in the last two decades.[26] The lack of standardized and simplified forms, combined with the lack of

The lack of standardized and simplified forms, combined with the lack of assistance filling out existing forms, makes it next to impossible for unrepresented individuals to bring a guardianship proceeding.

assistance filling out existing forms, makes it next to impossible for unrepresented individuals to bring a guardianship proceeding. Moreover, the lack of standardization makes it very difficult to train lay guardians in their reporting obligations once appointed. The variety of forms among counties also poses challenges for practitioners.

The Streamlining group recommended the development of standardized, statewide orders to show cause, petitions, and judgments[27]. These forms should be downloadable and should provide the standard language required.[28] Procedural guidance, broken down by county as appropriate, should also be available on the courts' websites. In addition, the Problems of Poor Persons group recommended that the Offices of the Self-Represented be responsible for providing forms and assistance to individuals seeking guardianship and individuals without counsel.

The Monitoring and Streamlining groups also recommended that standardized, statewide official forms be created for all initial, annual and final reports and be made available online. Both groups urged the courts to expand the e-filing system to accept initial and annual reports electronically.[29] Currently, forms vary from county to county and the requirements or standards for adequately completing these forms varies from judge to judge and from Court Examiner to Court Examiner. This makes it extremely difficult to train lay guardians.

3) **Implement Data-Gathering Systems.**

As a result of the courts' antiquated data management system, it is practically impossible to collect meaningful and comprehensive data about the guardianship system. While the system allows for calculation of the number of guardianship cases filed, it does not aggregate the number of active cases, or cases where the person under guardianship is still alive. The Monitoring group recommended implementing a data-gathering system to track the number of active cases, guardians' specific powers, whether the person under guardianship lives in the community or in an institutionalized setting, the amount of fees dispensed, and the names of the individuals appointed as court examiners and guardians. The group recognized that this information was available in individual court files but highlighted the need for a data management system that could aggregate this information and make it accessible.

Accurate, aggregate data could also guide important policy decisions. For example, the Monitoring group suggested it would be of particular benefit to know how much money was spent throughout the state on court examiners. This same amount, the group speculated, might be able to fund a non-profit agency to conduct monitoring.

4) **Promote Alternatives to Guardianship and Create a Guardianship Diversion Program.**

Guardianship is a last resort. Yet, there was widespread recognition that guardians are sometimes appointed when less restrictive alternatives would address unmet needs. The Streamlining Group recommended that a guardian of the property should normally not be appointed when assets are nominal and income can be managed through the representative payee or legal custodian process. The Alternatives group suggested studying why people do not choose available alternatives to guardianship (including power of attorney, representative payee and financial management systems, health care proxies, etc.) and ascertaining best practices for alternatives that support self-determination. The group also suggested gathering success stories about those who have used alternatives to guardianship and developing publications that describe the alternatives in ways that are easy to understand. In addition, the group recommended that advocates work with the court system to develop a guardianship diversion program to implement less restrictive alternatives to guardianship.

5) **Explore Replacing Guardianship with Supported Decision-Making Models.**

The Alternatives group recommended exploring the potential for law reform to comply with the CPRD by replacing substituted decision-making regimes with support that ensures respect for the person's autonomy, will, and preferences. The group also recommended determining whether funding might be available for a supported decision-making pilot program, which could explore the use of alternative supports in lieu of guardianship. In addition, as part of the effort to move away from guardianship toward decision-making support, the group recommended 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 principles incorporated in Article 81.[30]

Monitoring and Guardian Accountability

6) **Improve Court Examiner Training on Personal Needs Monitoring and Ensure Persons Under Guardianship Are Living in the Least Restrictive Setting.**

Both the Monitoring and Problems of Poor Persons groups recommended that the courts improve their monitoring of the personal needs of those under guardianship. The Monitoring group noted that court examiners (individuals appointed by the court to review annual reports submitted by guardians) tend to focus almost exclusively on

the finances of the individual under guardianship without scrutinizing to the same degree their personal needs or general well-being. Court examiners should receive more training on personal needs monitoring and annual reports should include more specific questions on residential status, medical treatment and social activities. The Monitoring group also called for more rigorous enforcement of the rules requiring that copies of initial and annual reports be provided to Mental Hygiene Legal Service ("MHLS") when it represented the Alleged Incapacitated Person in the guardianship proceeding;[31] this way, the attorneys most familiar with the individual's needs can spot any problems.

Court examiners tend to focus almost exclusively on the finances of the individual under guardianship without scrutinizing to the same degree their personal needs or general well-being.

In addition, both groups called for court examiners to do more to ensure that the person under guardianship is being maintained in the least restrictive setting, as required by the statute.[32] One means of clarifying this would be to adopt statewide guardian standards stating that the least restrictive setting is a priority that trumps the conservation of money in the person under guardianship's estate.[33] The "least restrictive setting" standard is of particular importance to Article 81 guardianships, the Monitoring group noted, because persons under Article 81 guardianships are generally not connected to another protection or advocacy agency. As an additional measure, the Problems of Poor Persons group suggested developing more services to determine if those in nursing homes or otherwise institutionalized can resume living in the community and to assist in moving those who are able to back to community settings.

7) **Evaluate Guardianships Regularly to Determine if they Should Be Terminated.**

The Problems of Poor Persons group recommended that guardianships regularly be evaluated to determine if they should continue or, ultimately, terminate and recommended that more free legal services be made available for persons who wish to terminate their guardianships. While guardians are required to state in annual reports any facts indicating the need to terminate the guardianship or alter the guardian's powers, there is little proactive effort by the courts to determine if a guardianship should end.[34]

8) **Develop a Pilot, Interdisciplinary, Volunteer Monitoring Program.**

There was consensus among the Monitoring and Problems of Poor Persons groups that personal visits to persons under guardianship are needed to ensure effective monitoring. Under the current system, guardians are supposed to visit the person under guardianship four times a year and report on their visits to court examiners. But neither the court examiner nor anyone from the court necessarily checks with the person under guardianship themselves to see how they are doing. In addition to reporting, personal visits by someone from the court ought to be made and routine status conferences held to determine the conditions and needs of the person under guardianship. Participants gave examples of situations where just a single intervention, such as a short personal visit, could have stopped significant abuse of a guardianship arrangement.[35] A pilot volunteer monitoring program should be created to do personal visits with individuals under guardianship.[36] Such a program exists now in Suffolk County and in a number of jurisdictions outside New York.[37] Should the pilot prove successful, a longer-term goal would be the establishment of a not-for-profit organization dedicated to interdisciplinary monitoring of guardianships. Such an organization would help train and supervise students from disciplines such as social work, law and accounting, retirees, and other volunteers.

Participants gave examples of situations where just a single intervention, such as a short personal visit, could have stopped significant abuse of a guardianship arrangement.

9) **Reduce Backlogs for the Review of Reports and Develop a "Tickler System" to Remind Guardians of Overdue Reports.**

A significant amount of time can pass before anyone reviews a guardian's report, let alone responds to problems, in certain counties. The Problems of Poor Persons group noted that the process is akin to a lottery: in some cases the court catches when reports are overdue while, in others, it might go unnoticed. Along with the Monitoring group, it recommended the development of a "tickler system"—a program that would automatically send letters to guardians reminding them of their reporting requirements and providing due dates.[38] An automated system would not only provide guardians with extra reminders, but it would also save the court the time, effort, and money spent on following up on missing reports.

10) **Screen All Potential Guardians Up-Front.**

The Monitoring group recommended that courts conduct routine background checks of proposed guardians with the aim of identifying individuals with a criminal history or a

history of unethical conduct that should be disqualifying. Such screening should include a review of a person's criminal background, bar complaints, and Family Court orders of protection for domestic violence. Furthermore, it should be determined prior to the hearing, whether the proposed guardian can be bonded. The Streamlining group recommended that counsel be alerted on the courts' website and/or through official forms of the need to determine whether a proposed guardian can be bonded, has committed a felony, or has declared bankruptcy.

Improving Access for Low-Income and Unrepresented Individuals

11) **Create a Standardized Complaint Procedure.**

It is currently unclear how a concerned person or a person under guardianship should register a complaint about a guardian's conduct. There is no central place where such complaints can be directed. The process currently requires the complainant to track down the particular judge with authority over the guardianship—a burdensome process for non-lawyers—and contact chambers. Every judge, in turn, handles complaints differently.

It is currently unclear how a concerned person or a person under guardianship should register a complaint about a guardian's conduct.

The groups recommended two responses to this problem. First, the Problems of Poor Persons group recommended that letters to the court from unrepresented individuals not be discarded or disregarded as ex parte communications, but should be furnished by the court to all parties and reviewed to determine if the letter should be treated as a motion for relief. Second, the Monitoring group recommends the creation of a Guardianship Ombudsman office – similar to the Long Term Care Ombudsman Program—that would be responsible for fielding complaints about the guardianship process.

12) **Simplify Reporting Requirements for Lay Guardianships with Minimal Assets.**

The Streamlining group suggested two changes that would help simplify the requirements where the guardianship has limited funds. First, the group recommended that clerks not conduct a review of the court examiner's report concerning property where resources are below a specified floor and when there has been no significant principal received during the accounting period. This streamlining measure may be in tension with the concern for personal needs monitoring expressed

by the Monitoring group. The group made room for exceptions, in which case review of such accountings should be limited to the staff of the appointing judge and the Court Examiner. Second, the group posited that annual accountings for low-asset/income cases should consist only of copies of bank statements and canceled checks together with a brief summary statement. The Streamlining Group also suggested that when appropriate, in low asset/income cases, guardians should be given an approved budget and not be required to give a line item accounting of expenditures within that budget.

The Problems of Poor Persons group suggested simplifying the reporting requirements for low-asset/income estates, in particular where the sole asset is Social Security, Supplemental Security Income ("SSI") benefits. The group envisages a far less detailed accounting form potentially modeled on the short reporting form used by the Social Security Administration for representative payees.

13) **Improve Language Access in All Guardianship Matters and Especially for Lay Guardians.**

Both the Monitoring and Problems of Poor Persons groups flagged the lack of translation services and forms in languages other than English as a serious concern. Currently, all correspondence (including, for example, report forms and supplemental testimony questions sent by court examiners) in guardianships is conducted only in English. The Monitoring group noted that family members who serve as guardians often times have limited English proficiency and, as result, have great difficulty filling out reports and adequately corresponding with court examiners. This results in court examiners, and ultimately the court itself, not being able to properly monitor the financial condition and/or personal well-being of the person under guardianship.

The groups recommend that (1) the courts provide translation services for interactions that guardians have with their court examiners, and that (2) the courts develop pro se "plain English" forms and instructions for guardians, as well as instructions in other languages.[39]

14) **Expand Guardian Training and Mechanisms for Guardian Assistance.**

Three of the four workgroups recommended more guardian training and assistance post-appointment. While guardians are required to attend training after appointment, there is little continuing training or assistance thereafter. These shortcomings cause problems. Monitoring is more difficult when guardians do not file proper and timely reports. It is especially a problem for low-income, lay guardians.

The Monitoring group called on the courts to provide *pro se* guardian clerks who would be available to walk lay guardians through the various processes and explain requirements. For those guardians requiring the most assistance, this would be a quick and easy way for them to obtain the help that they need. The Problems of Poor Persons group recommended enlarging and replicating the Kings County-based Guardianship Assistance Network, which provides assistance and services to family members or friends appointed as Article 81 guardians.

Lastly, the Streamlining group recommended the creation of a procedure whereby lay guardians can get assistance in qualifying. The group posited that such a responsibility might fall on petitioner's counsel or on a pre se clerk. Additionally, the Streamlining group recommended creating a hotline that lay guardians could access for assistance after being appointed, at which volunteers or court personnel could refer guardians to online resources or otherwise point them in the right direction.

15) **Evaluate the Impact of Fee Caps for Guardians and Exempt Court Examiners from the Caps.**

Current court rules provide that if an individual has been awarded more than $75,000 in compensation from court appointments during any calendar year, that person may not receive compensated fiduciary appointments during the next calendar year.[40] In addition, no one may receive more than one appointment within a calendar year for which the compensation anticipated to be awarded in a calendar year exceeds $15,000.

It is widely recognized that the goal of these "caps"—to root out corruption and patronage in court appointments—is salutary. However, concerns have been expressed about unintended consequences such as preventing economies of scale necessary to build a successful practice as a professional guardian or court examiner.

Accordingly, the Problems of Poor Persons group recommended studying whether the cap on appointments adversely affects the ability of private law firms to take on low-income guardianship cases and, if so, re-evaluating the cap. Likewise, the Streamlining group recommended that Court Examiners' fees should not be subject to these caps, and that the court examiner fee structure as a whole be re-examined and revised.

16) **Expand public guardianship-type services and free legal services.**

Unlike other states, New York does not have a Public Guardian program to serve as guardian for those with limited income. This creates enormous problems when no one is available to serve as guardian. In New York City, when a guardianship is

commenced by Adult Protective Services, non-profit agencies may serve as community guardians. Nassau County has a community guardianship program as well for cases commenced by the Department of Social Services. However, when cases are not brought by Adult Protective Services, there is no such service in place and judges struggle to find guardians to serve, especially when the person under guardianship has no significant resources. In other parts of the state, there are no significant community guardianship programs. The Vera Institute of Justice fills this gap somewhat in New York City by serving as a pilot public guardian-type project. Projects such as Vera should receive increased funding to permit them to be expanded and replicated throughout the state, as an alternative to a public guardian program.

Projects such as Vera should receive increased funding to permit them to be expanded and replicated throughout the state, as an alternative to a public guardian program.

In addition, more free legal services are needed at every step in the process: legal services to avoid guardianship, to commence guardianship proceedings, to help guardians with guardianship related filing requirements and the legal problems of their wards, to terminate guardianships that are no longer necessary. Dedicated funding for legal services programs for this purpose (from public and philanthropic sources) would be appropriate, as well as encouragement of pro bono initiatives, including provision of CLE credits for volunteer attorneys. However, even in the absence of additional funding, legal services programs should be encouraged to provide guardianship-related legal services; currently almost no such offices do so.

Eliminating Unnecessary Procedural Bottlenecks

17) **Combine the Order and Judgment Appointing a Guardian with the Commission.**

The Streamlining group recommended having a single document contain the Order and Judgment and the Commission, thereby consolidating what are now two independent steps that can produce delay in the process.

18) **Notify Guardians When Court Examiners Change and Ensure Examiners Turn Over their Files to Their Successors.**

The Streamlining group recommended that guardians be notified when court examiners are removed and steps be taken to ensure that the exiting examiner hands over his or her file to their successor.

19) **Reduce Unnecessary In-Court Appearances.**

Routine status conferences, such as initial conferences to determine whether the guardian has obtained his or her commission or those to verify whether all qualifying documents have been filed, should be held by conference call unless the court determines it is not appropriate. A status conference to address financial reporting issues may be waived if the court examiner confirms to the court that the guardian has carried out his duties.

20) **Simplify the Final Accounting Process Upon the Death of A Person Under Guardianship.**

The Streamlining group suggested a number of measures to expedite what can now be a drawn out process to settle a final accounting and discharge the guardian upon the death of a person under guardianship. First, the use of Mental Hygiene Law § 81.34—which permits the court to issue a decree discharging the guardian upon the filing of a petition—should be encouraged; there should be streamlined or no review where accountings are submitted on that basis. Guardians should be permitted to file final accountings that consist of copies of all approved annual accountings, an accounting for any period for which an annual account has not been approved, plus a summary statement. The final accounting should supersede and make unnecessary review of unapproved annual accountings by the court examiner.

Appendix A

Streamlining without Steamrolling Working Group Report

FACILITATORS:

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Laura Negrón – Director, The Guardianship Project, Vera Institute of Justice
Ira Salzman – Partner, Goldfarb, Abrandt, Salzman & Kutzin LLP

On November 15, 2011 the Cardozo Law School hosted an all-day conference on the subject "Guardianship in New York, Developing an Agenda for Change." This report is a summary of the discussions and recommendations emanating from a workshop that was held as part of that conference concerning streamlining the guardianship process.

THE PARTICIPANTS:

In addition to the facilitators, there were 20 attendees at the workshop, as shown below. Attendees agreed that in order for any recommendation to be adopted, 75 percent of the participants would have to voice agreement. Therefore, the fact that a recommendation was adopted by the group is not a statement with regard to the views of any particular attendee. In addition, a small number of participants were not present for the entire workshop.

Office of Court Administration and Court Personnel (11)

Debra Gandler, Principal Law Clerk, Supreme Court, Kings County
Hon. Sylvia Hinds-Radix, Justice, Supreme Court, Kings County
Michele Gartner, Special Counsel, Office of Court Administration, Fiduciary & Surrogate Matters
Jung M. Lee, Assistant Law Clerk, Supreme Court, Bronx County
Laura Messiana, Court Attorney Referee, Richmond County
Joseph Musolino, Case Management Coordinator, Supreme Court, Kings County
Margherita Racanelli, Senior Law Clerk, Supreme Court Kings County
Jerry Rodriguez, Associate Clerk, Supreme Court Bronx County
Lorraine Ross, Court Attorney, Supreme Court, Bronx County
Hon. Sharon Townsend, Justice, Supreme Court, Eighth Judicial District
Hon. Laura Visitación-Lewis, Justice, Supreme Court New York County

Practitioners (6)

Robert Abrams, of counsel to Abrams, Fensterman, Fensterman, Eisman, Greenberg, Formato & Eininger, LLP; Editor of treatise on guardianship practice in New York
Louise Albenda, Attorney
Alan Ferster, Director of Community Affairs, New York City Department of Social Services, Division of Adult Protective Services
Fern Finkel,Attorney
Joe Rosenberg, Director, Elder Law Clinic, CUNY School of Law
Frances Febres (intern), Elder Law Clinic, CUNY School of Law

Guardian Services (3)

Patricia Kaufman, Director, Selfhelp Community Services, Inc, Community Guardian Program
Maxine Lynn, Director, Community Guardian Program, New York Foundation for Senior Citizens Guardian Services, Inc.
Ruth Rosado, Program Director Guardianship Program for Nazi Victims, Selfhelp Community Services Inc.

RECOMMENDATIONS

The following recommendations were agreed upon by at least 75% of those who attended the workshop.

Web Site Issues

1. Statewide forms should be adopted and be made available at one web site in a form that is downloadable to a word processor.

2. Procedures should be adopted to make people aware of the web site, including but not limited to rubber stamps placed on all orders to show cause and judgments appointing guardians that alert participants to the web site.

3. Procedural guidance, broken down by county as appropriate, should be available on the web site.

4. Procedures on paper should be available for pro se litigants who do not have web access.

The Application Process

1. There should be state-wide official forms for the order to show cause, petition and judgment. These forms should be available online in a format that is downloadable to a word processor. The goal of these forms should be to advise counsel of the standard language that is required, while at the same time, providing flexibility based on the facts of each case. The forms could provide checklists with regard to powers, but should not be an excuse to eliminate the process by which powers are tailored to the needs of each incapacitated person. When the need to file a petition is emergent, subject to any statutory requirements, there should be sufficient flexibility to skip certain information on the condition that it be provided as soon as it becomes available but in no case later than by the return date.

2. Counsel should be alerted, on the web site and/or in official forms, of the need to determine prior to any hearing whether the proposed guardian can be bonded, has committed a felony, or has declared bankruptcy. In addition, all proposed guardians need to be made aware of the duties of a guardian. Counsel should be alerted to the possibility of using restricted accounts or other options, such as but not limited to the appointment of a co-guardian, when a proposed guardian cannot be bonded for all of the assets of the incapacitated person.

3. Normally, a guardian of the property should not be appointed when assets are nominal and income can be managed through the representative payee or legal custodian process. Nominal assets can be transferred to a representative payee or legal custodian account by court order without the need for the appointment of a guardian.

4. Reducing the time between the court's decision to appoint a guardian and the guardian's authority to act could be achieved by consolidating the steps involving the submission of the bond and executed Oath and Designation with the signing of the Order and Judgment, such that a single document could include the Order and Judgment and Commission. This option should be further explored and implemented.

Serving as Guardian

1. There should be a mechanism whereby lay guardians are assisted in qualifying. This responsibility should in the first instance, fall to the petitioner's counsel,

or where appropriate, a pro se clerk. Ministerial assistance, such as referral to online resources, could be provided by court personnel.

2. Routine status conferences, such as initial conferences to determine whether the guardian has obtained commission or to verify whether all qualifying documents have been filed, should be held by conference call unless the court determines that a conference call is not appropriate. A status conference to address financial reporting issues may be waived if the court examiner confirms to the court that the guardian has carried out his duties.

3. There should be a formal procedure to obtain relief or guidance with regard to expenditures requiring court approval. A procedure similar to the one utilized in Queens County should be considered. (*See* Short Form Application/Order on page 23.)

Technology Issues Concerning Initial Reports, Annual Accounts, Intermediate Accounts and Final Accounts

1. In Minnesota, all accountings are filed online. The online system checks math and flags possible errors. The use of a similar system in New York should be explored. If an electronic filing system is established, it should accommodate the uploading of statements.

2. Absent an online system, statewide official forms, made available online in a form that can be downloaded to a word processor, should be mandated for all initial reports, annual accountings, intermediate accountings and final accountings.

Annual Accountings

1. Manhattan is currently conducting a pilot effort whereby all annual accountings are intermediate accountings, and a similar procedure is followed in Kings County. If successful, this approach should be implemented statewide.

2. Annual accountings for which the opening and closing balance is under $25,000.00 should not be reviewed by guardianship clerks unless there has been significant principal received during the accounting period. In such cases, review should be limited to the court examiner and the staff of the guardianship judge.

3. For guardianships in low-asset/income cases, annual accountings should consist of copies of all bank statements and canceled checks plus a brief summary statement. Specific asset and income levels should be defined.

4. The rules with regard to the interpretation of S.C.P.A. § 2307 and § 2309 should be standardized.

5. Financial institutions should be required to send electronic copies of all statements to the court examiners, with the understanding that the court examiners would not be required to actually review them until they review the annual accounts.

6. Where court examiners are removed or have resigned, the guardians whose cases are assigned to them should be timely notified by the court. In addition, there should be specific requirements that resigning or removed court examiners turn over their files to their successors. A compliance conference should be scheduled to make sure that this turnover has taken place.

7. When appropriate, in low asset/income cases, guardians should be given an approved budget and not be required to give a line item accounting of expenditures as long as they stay within the budget. Specific asset and income levels should be defined.

8. The fees of court examiners should not be subject to the Part No. 36 caps. The fee structure of court examiners should be revisited.

Final Accountings

1. The use of Mental Hygiene Law § 81.34 should be encouraged and there should be no review or streamlined review where accountings are submitted on that basis.

2. In appropriate cases, the order appointing guardian should have different definitions of interested parties when an incapacitated person is alive and when an incapacitated person is deceased. This would make it clear who needs to consent when an application to settle a final accounting under Mental Hygiene Law § 81.34 is made.

3. Guardians should be permitted to file final accountings that consist of copies of all approved annual accountings, an accounting for any period for which an annual account has not been approved, plus a summary statement.

4. Review of unapproved annual accountings by the court examiner should cease upon the filing of the final accounting.

Education

More comprehensive education and training of guardians should be ensured. This would promote greater efficiency and reduced delays.

ADDENDUM

There were a number of issues that were discussed at the workshop but about which no consensus could be reached. In addition, there were a number of issues that the facilitators planned to submit to the workshop for discussion, but were prevented from doing so because of time constraints. The facilitators believe that some or all of these issues are nevertheless worthy of at least continued discussion if not active consideration. They are therefore listed below.

1. While there was total agreement that there is sometimes an unacceptably long delay between the conclusion of a hearing at which a decision is made to appoint a guardian and the issuance of an order that allows the guardian to qualify and act, there was no consensus as to how to eliminate this "choke point." Court personnel expressed a preference for ordering the transcript and crafting the order and judgment in accordance with the findings on the record despite the delay it causes while practitioners generally felt that this step should be dispensed with.

2. There was some discussion of issues about how to filter out guardianship cases that should not be brought in the first place without adding another step that makes the process even more cumbersome. There was little agreement as to how to deal with this problem, the obstacle being the court clerks cannot give legal advice and should not be deciding legal issues. It was proposed that cases filed by nursing homes and hospitals to facilitate collection efforts with no benefit to AIP should be diverted and dealt with separately. It was proposed that cases brought to obtain health care decision-making authority should be reviewed in light of the Family Health Care Decision Making Act and, in appropriate cases, be diverted and dealt with separately. However, the mechanics of implementing proposals such as these was a major concern to all in that no one wanted to add a step that would cause further delay in all cases.

3. It was suggested by some that it would be helpful to bifurcate some contested proceedings and/or utilize the services of a mediator in these cases. If a case was bifurcated, the court could hold an evidentiary hearing on the issue of whether the AIP needed a guardian and then use the service of a mediator to attempt to forge a consent as to who should be appointed as guardian. Those concerned about this process felt that it might make the process more cumbersome, more time-consuming, and more expensive. One participant thought that bifurcation should be used to isolate the issues that are not germane to the determination of whether the AIP is functionally impaired and in need of a guardian. This might include issues such as applications to void real estate transactions and/or gifts made by the AIP. Others thought that issues with regard to voiding transactions often involve the same underlying facts which necessitate the appointment of a guardian. It was pointed out that at least with regard to some ancillary issues, if they remain in the guardianship proceeding for determination, third parties who may be affected by the determination would have to be made parties to the proceeding. This might actually prolong cases rather than speed them up. There was some agreement that it would be possible to separate the determination of the need for a guardian from the determination of who should serve in that capacity, but the questions of what mediation would look like, whether it be done by the court or outside mediator and how it would be paid for were not resolved.

4. It was suggested by some that the testimony prepared by the court examiners should be eliminated. One idea was to have testimonies replaced with a brief statement and make a summary sheet stating the total assets, total income, total expenditures, where the AIP lives and the age of the AIP. It was thought that the annual accounts of the guardian are given under oath and that the

testimony represents unnecessary duplication of work. This issue was never fully discussed by the workshop participants.

5. It was suggested by some that the Mental Hygiene Law be amended to permit final accountings to be settled in the same way as estates are settled in the Surrogate Court. This would include the use of receipts and releases. It was suggested by some that if this statutory amendment was proposed it should specifically limit the use of receipts and releases to guardians who are family members and/or guardians who are not Part 36 appointees.

6. It was suggested by some that there needs to be a structured operational review of the guardianship process. Vera Institute of Justice is now undertaking a preliminary review of 175 Kings County cases. It is examining the time period between petition and signed order, the fee payments on accounting and the time between the date of the death of the incapacitated person and the date of discharge of the guardian. This could be useful as a model for other guardians to document their experiences or for further study/grant funding and may help provide a stronger, evidence-based approach in making the fee lag and other service delay and resource drain issues clear. This issue was not fully presented to the workshop participants because of time constraints.

Exhibit to Streamlining Report, Queens County Form for Expenditures Requiring Court Approval (Serving as Guardian, Point 3)

SUPREME COURT: STATE OF NEW YORK
COUNTY OF QUEENS

SHORT FORM APPLICATION/ORDER
FORM 101

In The Matter of

Index No._____

[Name of IP]

An Incapacitated Person.

To The Justice Presiding

1. Guardian respectfully requests permission to expend the sum of $_____
For the following:

_____

_____

The current amount of the estate is $_____

2. The Guardian believes that the aforesaid expenditure is for the direct benefit of the incapacitated person.

3. I have annexed supporting expense estimates and other necessary information.

Date_____ _____
Signature of Guardian/Fiduciary

_____
Notary Public

----------To Be Submitted to Court Examiner For Consideration----------

I respectfully recommend_____ I do not Recommend_____
Comments_____

_____

_____

Date_____ _____
Signature of Court Examiner

----------TO BE SUBMITTED TO ASSIGNED JUDGE FOR DECISION----------

UPON READING AND FILING THE FOREGOING EXPENDITURE IS

APPROVED_____ NOT APPROVED_____

DATE_____ _____, J.S.C.

Appendix B

Monitoring Working Group Report

PARTICIPANTS

Facilitators: Jean Callahan, Executive Director, Brookdale Center for Healthy Aging & Longevity of Hunter College
Erica Wood, Assistant Director, American Bar Association Commission on Law & Aging

Reporter: Rebekah Diller, Clinical Assistant Professor of Law and Director, Guardianship Clinic, Benjamin N. Cardozo School of Law

Participants: Meg Bailey, Mental Hygiene Legal Service ("MHLS"), Orange County
Jamie Butchin, MHLS, Nassau County
Hon. Kristin Booth Glen, Surrogate, New York County
Hon. Paula L. Feroleto, Administrative Judge, Eighth Judicial District
Debra Gandler, Guardianship Compliance Part - Kings County Supreme Court
Kathy Greenberg, Esq.
Degna Levister, Supervising Attorney, CUNY School of Law Elder Law Clinic
Alex Mondesir, Guardianship Compliance Part – Kings County Supreme Court
Emily Rees, Student Attorney ,CUNY School of Law Elder Law Clinic

DISCUSSION

This Working Group examined ways in which the monitoring of existing guardianships could be improved.[41] The group began by defining "monitoring" as everything that happens in the guardianship process after a guardian is appointed. The discussion was then divided into three parts. First, the group discussed problems and gaps in New York's current system for monitoring guardians. Second, the group engaged in a visioning exercise, in which we developed a "wish list" of how guardianship monitoring would take place in ideal circumstances. Third, we transformed this wish list into concrete, achievable recommendations for reform. This report follows the same three-part structure.

A. Monitoring Problems

The group discussed a wide range of monitoring problems known to occur after the appointment of a guardian. They largely fell into one of the following four categories: 1) problems with the court examiner system; 2) the lack of a standardized complaint

procedure when guardians perform unsatisfactorily; 3) obstacles encountered by lay guardians attempting to comply with reporting requirements; and 4) lag times and inadequate data management systems in the courts.

1) **Problems with the Court Examiner System**

New York law requires that guardians submit an initial report within 90 days of appointment and annual reports thereafter. The courts rely on "court examiners" – usually private attorneys appointed by the courts[42] -- to examine those reports and determine the condition, care, and finances of the person under guardianship as well as the manner in which the guardian has carried out her duties and exercised her powers.[43] Court examiners are generally compensated for their work out of the individual's estate, when the estate has sufficient funds.

Participants pointed to a number of problems with the court examiner system. First, while the court examiner is statutorily required to "determine the condition and care" of the person under guardianship,[44] many in the group believed that court examiners tended to focus almost exclusively on examining finances and not personal needs or well-being. For example, one participant noted that she had never heard of a court examiner demanding a conference with a guardian to inquire about a personal needs issue.

This tendency, some thought, reflected the fact that court examiners tend to be drawn primarily from the ranks of attorneys and not from other professions, such as social work, that are more accustomed to assessing personal needs. In addition, participants noted, examiners do not receive special training in personal needs assessments.

Relatedly, while Article 81 generally incorporates the "least restrictive alternative" concept, participants observed that there is often no meaningful analysis by the court examiner of whether the person under guardianship is being maintained in the least restrictive setting. In the initial, 90-day report, guardians with personal needs powers must set forth a plan for providing for those needs. In annual reports thereafter, guardians of personal needs must include "a statement of whether the current residential setting is best suited to the current needs" of the person under guardianship.[45]

However, participants observed that court examiners were not in the practice of scrutinizing these aspects of the reports closely to determine if the person

under guardianship was living in the least restrictive setting. Participants believed that there should be a clearer standard requiring such scrutiny. It was also suggested that the standard for examining reports should be clarified to emphasize that living in the least restrictive setting is a priority that trumps the conservation of money in the individual's estate.[46] The lack of clarity on this point, combined with the obstacles people in the community face when seeking home care, creates a perverse incentive structure that pushes persons under guardianship toward nursing homes and institutionalized care.

One participant noted that this "least restrictive alternative" watchdog function was especially important for those under Article 81 guardianships because they are generally not connected to any other agency charged with looking after their welfare, as exists for developmentally disabled individuals under Article 17-A guardianships.[47]

Participants from Mental Hygiene Legal Service who represent Alleged Incapacitated Persons during the guardianship proceeding also noted that they do not generally receive copies of the initial and annual reports filed by guardians though service on them is required under the statute[48] and they may be uniquely situated to spot problems in the personal needs area.

2) **Lack of standardized complaint procedure**

Participants also noted that despite the various safeguards built in to Article 81, it was unclear how a concerned person or individual under guardianship could register a complaint about a guardian's conduct. Lodging a complaint requires figuring out who the judge is with authority over the guardianship, a cumbersome task for a non-lawyer. There is no centralized place or one individual to whom complaints about guardianship can currently be directed.

In addition, once the correct judge is identified, the procedure for registering a complaint is likely to vary significantly from court to court and chambers to chambers. Some judges may ask that a letter be submitted; others may handle it differently. Several participants noted that even if someone writes to the court or registers a complaint in some other fashion, there is no guarantee that the court will follow up on such a complaint or investigate the allegations further.

3) **Obstacles for lay guardians**

The group also discussed the many problems encountered by lay guardians – usually family members or loved ones of the person under guardianship -- who have trouble navigating the reporting requirements. A common complaint heard from lay guardians is that court examiners require lengthy "testimony" in addition to reports submitted. The testimony – additional questions to be answered in writing under oath – is often onerous, confusing, and unnecessary for lay guardians, participants said.

The lack of standardized reporting forms was also seen as a significant problem. Forms vary from county to county and requirements for filling out those forms vary from judge to judge and court examiner to court examiner. In addition, there is no standardized form for the additional testimony court examiners may require. This lack of standardization makes it very difficult to train lay guardians.

Beyond the initial court-mandated training for lay guardians, there is little assistance for lay guardians in meeting their compliance obligations after they are appointed. The courts do not send letters to remind them of their deadlines to submit annual reports. Lay guardians often have trouble filling out the financial parts of the annual reports. For example, it is sometimes the case that a court evaluator, when performing his or her investigation prior to the appointment of a guardian, might identify the possible existence of certain bank accounts but not establish their existence for a fact. As a result, when a guardian files the initial report 90 days after appointment, there is not a definitively established list of accounts against which the court examiner can compare the guardian's report. Lay guardians in particular have trouble resolving this appearance of a discrepancy.

Language access was also identified as a significant barrier for lay guardians. Family members who serve as guardians may have limited English proficiency (LEP) and, as a result, may have difficulty filling out the report forms, which currently exist only in English. In addition, the supplemental testimony questions sent by court examiners are also only sent in English, making it difficult for family members to comply.

4) **Lag times and inadequate data management systems**

Participants noted a more fundamental problem of long lag time and backlogs for reviewing all reports. For example, Kings County currently has 24 examiners for a total of 1,500 guardianship cases filed (though it is unknown how many of these cases remain open). In many parts of the state, long stretches of time can go by before anyone takes a look at reports submitted, much less responds to any problems noted. In addition, the current data management system used by the courts does not generate "ticklers" to remind guardians of their obligation to submit reports.

Antiquated data management systems in the courts also mean that it is impossible to obtain basic data about the guardianship system. Current court data systems can determine how many guardianship cases have been filed (via the specialized index number for guardianships). However, the information systems do not reflect how many of those filed cases are still active or in how many of the cases the person under guardianship is still alive. In addition, there is a lack of transparency about fees expended in guardianships. It may be possible to determine how fees were dispensed within one guardianship case; however, there is no data on the total amounts of fees expended for court evaluators and court examiners. The lack of aggregate data makes it difficult to make basic policy decisions in an informed way.

B. **Wish List: Ideal Solutions to the Monitoring Problems**

The group then brainstormed about ideal solutions to these problems. First, participants said they would want better data about the guardianship system, including the total number of existing adult guardianships, how many of those are guardianships of the person or of the property or of both, the primary reason for the guardianship, the time it took from filing to commission, the time it took to examine and settle a report, and the aggregate number of appointments for individual guardians and court examiners. Of particular use would be to know how much money is spent statewide on court examiners. Depending on the answer, it is possible that the aggregate amount could be used to create a more efficient and vigorous monitoring system.

Second, the group discussed using the aggregate amount of fees currently spent on court examiners to fund a not-for-profit organization whose mission would be to engage in interdisciplinary monitoring of guardianships. This monitoring organization could train and supervise students from disciplines such as social work, law and accounting,

retirees and other volunteers to monitor guardians. Monitoring would be done in teams consisting of students or volunteers with backgrounds in different disciplines.

Key to this approach would be personal visits by the monitoring team to the person under guardianship to assess his or her condition and needs. One participant who represented a young person who had been financially exploited by his guardian noted that if just one person from the courts had talked to the boy and his family about the choices his guardian was making, the abuse could have been stopped and/or prevented.[49]

Under the existing system, participants also recommended the following changes to ensure that monitoring is vigorous, as due process requires[50]:

- substantial training of court examiners on personal needs issues;
- having the court evaluator who has made an extensive factual investigation at the appointment stage serve as the court examiner;
- the creation and imposition of standards for guardians[51]; and
- an ombudsperson to field complaints about the guardianship system, like the existing Long Term Care Ombudsman Program (or LTCOP) in New York that investigates long-term care complaints.

The group also recommended the following changes to help lay guardians comply with their reporting obligations:

- ensuring the availability of adequate translation services for lay guardians when are asked to submit testimony[52];
- standardizing guardian report forms and the monitoring process statewide;
- the creation of *pro se* guardian clerks who could walk lay guardians through the process;
- the creation of do-it-yourself ("DIY") computer kiosks that lay guardians could use to enter information and generate reports.

C. Recommendations for Reform

The group then refined and expanded upon these ideas to develop a list of achievable reform recommendations. Those recommendations were grouped into five categories:

1) **Standardize the monitoring process and improve the courts' data management capacity.** Better information systems and standardization were seen as key to the following needed improvements:

- **Standardize the forms used in the guardian reporting process.** There should be one set of forms for initial, annual and final reports used statewide.
- **Place the forms online, preferably in an interactive program that permits guardians to enter information, generate a report, and then e-file that report.** For example, Minnesota has recently instituted an online program to generate and file annual accountings.[53]
- **Implement a data-gathering system that could generate reports on the total number of existing adult guardianships, whether the guardianships are of the person, the property or both, the primary reason for the guardianship, the time it took from filing of the petition to issuance of the commission, the time it took to examine and settle a guardian's report, whether the persons under guardianship live in the community or institutionalized settings, the amounts of fees dispensed, and the aggregate number of appointments for individual guardians and court examiners.** This information exists in individual court files but there is no data management system to aggregate the information.
- **Develop a "tickler system" to send letters to remind guardians that reports are due.** Currently, Article 81 guardians receive no such reminder notice; rather, they only hear from the court after they have missed a deadline. An automated system to send reminder notices could save the courts time and effort later to track down missing reports. The Surrogate's Court in New York County currently sends such reminders to Article 17-A guardians.

2) **Improve personal needs monitoring.**

- **Under the existing system, train court examiners to assess more rigorously guardians' reporting on personal needs.** Appointing the court evaluator in a case as the court examiner after the guardianship commences may also be helpful because the court evaluator has visited the individual and done an extensive factual investigation of his or her needs.

- **Make clear that personal needs should be prioritized over cost savings in guardian decision-making.** This principle should be incorporated into court examiner and guardian training.
- **As an alternative to the existing court examiner system, develop a pilot, interdisciplinary monitoring program in which team members from various disciplines visit persons under guardianship and review guardian reports.** Such a program could leverage participation from local social work, accounting and law schools and recruit retirees and other volunteers to participate. This pilot would benefit from the American Bar Association's Commission on Law and Aging recently published Volunteer Guardianship Monitoring Handbooks that provide a template for development of volunteer monitoring programs.[54]
- **Ensure that attorneys who have represented an alleged incapacitated person receive subsequent guardian reports.** The statute currently requires guardians to send Mental Hygiene Legal Service with copies of annual reports when MHLS served as court evaluator or counsel for the alleged incapacitated person.[55] However, MHLS attorneys report that they rarely receive such reports.

3) **Conduct better screening of guardians up-front.** The courts should conduct background checks up front of proposed guardians to identify and permit judges to screen out those with a criminal history or history of unethical conduct. Such screening should include a criminal background check, review of bar complaints, and a check of Family Court orders of protection for domestic violence. To conduct these checks, proposed guardians should be required to provide their Social Security numbers and dates of birth; the courts need mechanisms to protect the privacy of this information.

4) **Improve language access for lay guardians.** The courts should provide annual report forms in multiple languages so that lay guardians with limited English proficiency are better able to comply with their reporting obligations. In addition, the courts should ensure that translation services are available when lay guardians must respond to testimony or other requests from their court examiners.

5) **Create an ombudsperson's office and standardized complaint procedure.** There should be one central office that a concerned individual could call to register a complaint or concern about a guardian. In addition, there should be

an accessible and standardized process in place in the courts to make a complaint.

Appendix C

Problems of Poor Persons in the Guardianship Process Working Group Report

FACILITATORS:

Janet Lessem, M.S.W.
Toby Golick, J.D.

PARTICIPANTS:

The participants comprised a mixed group of advocates (including lawyers and law students in law school elder law clinical programs), and court personnel, including judges:

Steve Atchison, Selfhelp Community Services Inc.
Hon. Betsy Barros, Justice, Dedicated Guardianship Part, Kings County Supreme Court
Georgeann Caporal, Mental Hygiene Legal Services
Helen Ferraro-Zaffram
Professor Gretchen Flint, Clinical Professor, Pace Law School
Jesse Freeman, CUNY Law Student, Elder Law Clinic
Carrie Goldberg, Supervising Attorney, Vera Institute of Justice Guardianship Project
Professor Toby Golick, Clinical Professor, Cardozo Law School
Aaron Hauptman, Court Attorney, Hon. Hagler, Special Integrated Guardianship Part
Janet Lessem, Director, Guardian Assistance Network
Deirdre Lok, The Weinberg Center for Elder Abuse Prevention at the Hebrew Home
Diane Lutwak, Supervising Attorney, Legal Aid Society Office for the Elderly
Renee Murdock, CUNY Law Student, Elder Law Clinic
Michael D. Neville, Mental Hygiene Legal Services
Marita Robinson, CUNY Law Student, Elder Law Clinic
Professor Edward Tetelman, former New Jersey Public Guardian, Adjunct Professor Rutgers University School of Social Work
Felice Wechsler, Mental Hygiene Legal Services, 1st Department

DISCUSSION:

There is widespread recognition that the problems resulting from incapacity are not limited to persons of financial means. But much of the guardianship system is focused on protection of

finances of an incapacitated person, with the expectation that funds exist to meet the costs of managing a guardianship. When the incapacitated person has inadequate resources, though, these assumptions collapse, and the problems of incapacity, along with the burdens of poverty, create huge challenges. Our discussion group identified some of these challenges, and made a number of recommendations, some easily implemented, and some possible but requiring legislative or regulatory changes.

Avoiding Guardianship: All agreed that guardianship, with its attendant loss of autonomy, is a last resort. We discussed some of the ways that guardianship could be avoided, with a particular focus on low-income individuals. Some recommendations were in the category of providing more outreach and education to individuals in low income groups about planning for the possibility of incapacity, to increase the use of planning documents like powers of attorneys where appropriate. The need for increased available of social services that would include voluntary financial management was noted. Other recommendations focused on the potential role some of the agencies that have contact with poor persons could play in identifying "at risk" individuals earlier in the process. The New York City Housing Authority (NYCHA) was particularly mentioned, since over 630,000 people live in NYCHA housing, but too frequently that agency's first, rather than last, step in dealing with a problem tenant is an eviction proceeding. Finally, participants discussed the problems of agencies, such as Medicaid or Mitchell-Lama housing, refusing to deal with family members, making it necessary to get a guardianship merely to accomplish a non-controversial task such as recertifying for housing.

Some participants mentioned the fact that although Article 81 contemplates limited and short-term guardianships, guardianship orders tend to give full powers to the guardian for convenience, to avoid the need for coming back to court repeatedly to expand powers. It was also mentioned that guardianships, once established, tend to continue, without much consideration of whether they are still needed. These issues are not unique to low-income populations, however.

Simplification: While simplification of procedures has virtues across the board, the complexity of guardianship procedures causes particular problems for poor people who may not have access to legal counsel, and who may also be poorly educated or not fluent in English. A number of recommendations dealt with making the procedures more accessible and easier for unrepresented individuals to use, by providing clear instructions and forms using plain language.

Gaps in service: There was considerable discussion of the areas where limited (or non-existent) funding has created great difficulties in the system. Lack of funding for

free legal services creates huge barriers for individuals attempting to navigate the guardianship system: services are seldom available for individuals seeking legal help to commence a proceeding, to deal with reporting requirements, or to seek changes in the guardianship. Reduced funding and availability of legal services also creates burdens for family guardians seeking help with legal issues their wards may have with Medicaid, Medicare, Social Security and SSI benefits, housing and other matters.

Most critically, problems arise when there are no funds to pay a guardian. By law, the Community Guardian program is available only for cases commenced by Adult Protective Services (APS). APS in New York City does not seek guardianship on behalf of individuals in nursing homes (on the ground that they are not "at risk") so there is a category of persons who could potentially reside in the community with community guardian services, but who cannot access these services. Other individuals in the community similarly have no access to community guardian services because APS has determined not to commence a guardianship proceeding. Community Guardian programs do not exist in much of the state. Judges in guardianship cases where no one is available to serve as guardian are put in the unfair position of having to entreat individuals to serve, leading to a perception that favors are being traded, which looks bad to outside observers.

Monitoring: The annual reporting required of guardians is frequently difficult for lay guardians, who do not understand how to prepare and complete the required documents. No reminders are sent prior to the time forms are due; some courts in some cases seem to catch cases where reports are not sent, but in other cases, the lack of annual reports goes unnoticed. At the same time, although a "medical report" or some similar information may be requested by the court evaluator, the monitoring system is not set up to assure the physical well-being of the ward, and nothing in the monitoring system would be likely to catch the fact that a ward is being inappropriately cared for, or even not cared for at all.

RECOMMENDATIONS

The following recommendations had the full support of the group. It is recognized that some of the suggestions here are already being implemented in some courtrooms and agencies, but are included because the implementation is not widespread.

1. Legal services and bar groups should increase outreach efforts to encourage individuals to consider executing durable powers of attorney, as well as providing counseling on the risks and correct use of these planning documents. Legal services programs in particular should be encouraged to provide this information to individuals who come to their offices for services on other matters.

2. Simplified instructions should be created for powers of attorney to explain the use and risk of these forms.

3. Educational materials should be created for the use of organizations dealing with populations of poor persons (including the police) to help identify "at risk" individuals and make referrals for other services or protective interventions when needed. There should be special outreach to programs such as the New York City Housing Authority and other large housing programs to encourage consideration of such steps prior to commencing eviction proceedings.

4. Programs that provide voluntary financial management, such as APS and AARP financial management services, should be expanded.

    1. Administrative or legislative changes, as appropriate, should be implemented so that friends or family members of an incapacitated individual can engage in certain transactions with government agencies and housing programs on behalf of the incapacitated individual without the necessity of formal guardianships. These changes can be modeled on the "representative payee" program of Social Security, which permits such actions, and provides safeguards such as notice to the affected individual.

    2. More use should be made of limited guardianships, notwithstanding the convenience of giving broad powers in the initial guardianship order.

    3. Guardianships should be regularly evaluated to determine if they continue to be needed or can be terminated.

Simplification

1. Develop pro se "plain English" forms and instructions for non-lawyers, as well as instructions in other languages.

2. Offices of the Self-Represented in the state courts should be willing to provide forms and assistance to individuals without counsel in guardianship cases, and should be asked to collaborate with advocates and guardianship clerks in preparing usable forms and templates for unrepresented individuals.

3. Courts should create automatic scheduling for compliance hearings, have templates of orders and similar forms in the format the court wishes, and avoid unnecessary

"settling orders on notice" and similar steps that are confusing to unrepresented individuals.

4. Letters to the court from unrepresented individuals involved in a guardianship should not be discarded or disregarded as ex parte communications, but should be furnished by the court to all parties and reviewed to determine if the letter should be treated as a motion for relief.

5. Financial reports for small estates should be simplified, and in cases where the only asset is Social Security, Supplemental Security Income or SSI benefit, detailed accounting should be not required; a form modeled on the short reporting form used by the Social Security Administration for representative payees should be sufficient.

Monitoring

1. Instead of detailed financial reporting, the annual reports should include more questions about the well-being of the ward, including residential status, medical treatment, and social activities.

2. There is a need to actually visit persons under guardianships and to report on their findings. A pilot program to train and use volunteers for their purpose should be undertaken.

3. APS should not automatically stop services and oversight once a guardian is appointed, but should continue to monitor at least until it is clear that the guardianship is underway and the guardian has qualified and commenced services.

Filling gaps in services

1. The Community Guardian program should not be limited to cases brought by Adult Protective Services, but should be an option for the court in cases where there is no other appropriate guardian.

2. Projects such as the VERA Institute of Justice Guardianship Project should receive increased funding to permit them to be expanded and replicated throughout the state, as an alternative to a public guardian program.

3. More free legal services are needed at every step in the process: legal services to avoid guardianship, to commence guardianship proceedings, to help guardians with guardianship related filing requirements and the legal problems of their wards, to

terminate guardianships that are no longer necessary. Dedicated funding for legal services programs for this purpose (from public and philanthropic sources) would be appropriate, as well as encouragement of pro bono initiatives, including provision of CLE credits for volunteer attorneys. However, even in the absence of additional funding, legal services programs should be encouraged to provide guardianship-related legal services. Simplified procedures and forms, discussed elsewhere in these "Recommendations" would facilitate the provision of services by legal services programs.

4. The "Guardianship Assistance Network" providing services to family guardians should be enlarged and replicated throughout the state.

5. "On-line" resources should be developed, where forms and instructions are available to individuals with sufficient computer literacy to make use of them. However, this should not be the exclusive way to obtain forms and instructions.

6. We should develop services and outreach to individuals in nursing homes to determine if they could resume living in the community. This may require coordination of housing (since housing is often lost following institutionalization), home care and financial management services, either in the context of a formal guardianship, or using alternatives to guardianships.

7. Coordinate with programs that recruit and train volunteers to Increase the use of volunteers, including creating a volunteer guardian program, and a program of "volunteer mentors" for lay guardians, who could assist in various tasks.

8. Encourage agencies and programs (for example, Medicaid, the Social Security Administration, NYCHA, the Department of Finance SCRIE/DRIE program) that serve poor people to designate high level liaisons to expedite solving problems encountered by the courts handling guardianships.

9. Related to the above recommendation, provide social work services for use by the courts handling guardianships.

10. Better training for Guardians ad Litem with regard to their role in assisting litigant and accessing community resources.

11. Evaluating whether the "cap" on guardianship appointments is adversely affecting the availability of law firms to take low-income guardianships, and, if so, reconsidering the cap.

Appendix D

Alternatives to Guardianship Working Group Report

A. Participants

Co-Facilitators:	Donna Dougherty (Jewish Association for Services for the Aged) Leslie Salzman (Cardozo Bet Tzedek Legal Services)
Reporter:	Kevin Cremin (MFY Legal Services, Inc.)
Participants:	Cathy Anagnostopoulos (Mental Hygiene Legal Services) Lisa Caligiuri Boranian (Mental Hygiene Legal Services) Ann Brownhill-Gubernick (Fordham University-Graduate School of Social Service) Amanda Caccavo (Henry Viscardi School) Gregg Cohen (Law Office of Gregg Cohen) Gene Flagello (Mental Hygiene Legal Services) Lisa Herman (Mental Hygiene Legal Services) Cecille Hershkovitz (Jewish Association for Services for the Aged) John Holt (Vera Institute for Justice) Arlene Kanter (Syracuse University Center on Disability Studies, Law, and Human Policy) Grace Machuca (Supreme Court – Civil) Beatrice Maloney (Beth Israel Medical Center) Tina Minkowitz (Center for the Human Rights of Users and Survivors of Psychiatry) Ken Onaitis (Carter Burden Center for Aging) Kiana Douglas Osei (Vera Institute for Justice) Raquel Romanick (Brookdale Center for Healthy Aging & Longevity - Hunter College) Marcie Serber (Attorney, Private Practice) Doen Zheng (Elder Law Clinic)

B. Background

In New York, two laws directly govern guardianship proceedings. Guardianships are generally determined under Article 81 of the Mental Hygiene Law ("MHL"). Guardianships for people who are "mentally retarded" or "developmentally disabled" are determined under Article 17-A of the Surrogate's Court Procedure Act ("SCPA").

Under Article 81 of the MHL, a court should not appoint a guardian unless an individual is at risk of harm due to an inability to meet personal and/or financial management needs, considering the "sufficiency and reliability of available resources as defined in 81.03(e)." Although the list of "available resources," is not exclusive, the list of alternatives is quite limited and contemplates fairly traditional (and generally non-client centered) resources, i.e., "visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers, powers of attorney, health care proxies, trusts, representative and protective payees, and residential care facilities."[56]

Article 81 requires that the guardianship petition set forth "the available resources, if any, that have been considered by the petitioner and the petitioner's opinion as to their sufficiency and reliability."[57] The court evaluator reports to the court on whether there are "sufficient and reliable" "available resources" to meet the individual's personal and property management needs without the appointment of a guardian.[58] When appointing a guardian, the court must make a formal finding that the appointment is necessary to prevent harm and must set forth the duration of appointment.[59] The court is required to discharge the guardian or modify the guardian's powers if the "incapacitated person" dies or experiences an increase or a decrease in needs.[60]

The SCPA governs guardianship proceedings for people who are "mentally retarded" or "developmentally disabled."[61] For purposes of the SCPA, a person is "mentally retarded" if medical professionals certify that the person as "as being incapable to manage him or herself and/or his or her affairs by reason of mental retardation and that such condition is permanent in nature or likely to continue indefinitely."[62] A person is "developmentally disabled" if medical professionals certify that the person has "an impaired ability to understand and appreciate the nature and consequences of decisions which result in such person being incapable of managing himself or herself and/or his or her affairs by reason of developmental disability and that such condition is permanent in nature or likely to continue indefinitely . . . ."[63] For people with "developmental disabilities," the disability has to be attributable to: "cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury"; "any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons"; or dyslexia.[64]

Article 17-A was passed "primarily to provide a means for parents of mentally retarded children to continue exercising decision making power after those children reached age twenty-one."[65] A petition for Article 17-A guardianship can be brought by a parent, an interested adult, or a "corporation authorized to serve as a guardian."[66]

A court is authorized to appoint a guardian for a person who is "mentally retarded" or "developmentally disabled" if the appointment is in the person's "best interest."[67] Although Article 17-A gives the alleged incapacitated person "the right to jury trial," that right is waived unless the person demands a jury trial.[68] The court also has the discretion to dispense with a hearing if the petition has been filed by: "(a) both parents or the survivor; or (b) one parent and the consent of the other parent; or (c) any interested party and the consent of each parent."[69] Article 17-A does not require that the alleged incapacitated person be represented by counsel or present at the hearing.[70] By default, the scope of an Article 17-A guardianship is plenary.[71]

Other laws are potentially relevant to guardianship proceedings and systems. For example, the Americans with Disabilities Act is relevant to guardianship because it requires governments to provide services in the most integrated setting appropriate to the person who has a disability. Title II of the ADA protects the rights of individuals with disabilities to participate in the services, programs, and activities of public entities.[72] A "public entity" is a state or local government or "any department, agency, special purpose district, or other instrumentality of a State or States or local government."[73] The ADA requires public entities to make "reasonable modifications to rules, policies, or practices" for qualified individuals with disabilities.[74]

The Attorney General has the responsibility to promulgate regulations for Title II.[75] The Title II regulations flesh out the ADA's prohibitions against discrimination by public entities.[76] These regulations elaborate on the ADA's focus on the right to full and equal participation in civil society.[77] One Title II regulation requires that: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[78] The preamble to the Title II regulations explains that the "most integrated setting" for an individual is "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."[79]

Guardianship programs have been criticized as potentially violating the ADA's integration mandate.[80] Leslie Salzman has made a compelling case that substituted decision making systems "violate the [ADA]'s mandate to provide services in the most integrated and least restrictive manner."[81] Although people who have guardians might "reside in the community and are not physically segregated by the walls of an institution, guardianship creates a legal construct that parallels the isolation of institutional confinement."[82] Like institutionalization, guardianship entails the loss of civic participation—"when the state appoints a guardian and restricts an individual from making his or her own decisions, the individual loses crucial opportunities for interacting with others."[83] There is evidence that guardianship often leads to institutionalization.[84] Salzman emphasizes that less segregated options than guardianship are used by other countries and that the United Nations Convention on the Rights of Persons with Disabilities dictates supported—as opposed to substitute—decision making.[85]

As Salzman points out, the Convention on the Rights of Persons with Disabilities[86] (CRPD) is also potentially relevant to guardianship. The CRPD was adopted on the 13th of December, 2006, during the sixty-first session of the United Nations General Assembly.[87] Pursuant to Article 42, the CRPD and its Optional Protocol was opened for signature as of March 30, 2007.[88] The United States is one of the 153 signatories to the CRPD.[89] Although the United States has not ratified the CRPD, over 100 countries have.[90] The CRPD's dictates therefore represent "the overwhelming weight of international opinion."[91]

The purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[92] "Discrimination" is broadly defined to include "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."[93]
The CRPD prohibits "torture or [] cruel, inhuman or degrading treatment or punishment."[94] State parties are required to "take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities [] from being subjected to torture or cruel, inhuman or degrading treatment or punishment."[95] The CRPD also repeatedly focuses on the right that people with disabilities have to liberty and to participate and be included in the community.[96]

Article 12 of the CRPD recognizes the right of all individuals to exercise legal capacity and to receive support to exercise that capacity if, and to the extent that, assistance is needed. Article 12 also provides that any measures that limit an individual's exercise of legal capacity must "respect the rights, will and preferences of the individual, must be free of conflict of interest and undue influence, must be proportional and tailored to the person's circumstances, must apply for the shortest time possible and must be subject to regular review by a competent, independent and impartial authority or judicial body."[97]

The Committee on the Rights of Persons with Disabilities, the authoritative body interpreting the CRPD, has urged States Parties, under the framework of compliance with Article 12, "to replace regimes of substituted decision-making with supported decision-making, which respects the person's autonomy, will and preferences."[98]

C. Discussion

In New York, Article 81 of the MHL provides that guardianship should not be utilized when an individual does not need assistance with personal needs or property management because there are other "available resources." Nevertheless, courts continue to appoint guardians for

individuals who have adequate informal supports, for individuals who could manage their property and personal needs if existing resources were made available to them, and for those who could exercise their capacity to make decisions and express their desires with appropriate decision-making support.[99] With the goal of ensuring that individuals are not divested of their decision-making rights through guardianship except in very rare circumstances, this workgroup discussed:

1) Resources and supports that have been successfully utilized to enable individuals to exercise their own capacity and avoid or defeat guardianship petitions;

2) How best to ensure that individuals and courts give meaningful consideration to all potential resources and supports; and

3) Whether there is a need to reform the guardianship system.

Discussion Point 1: Existing Alternatives to Guardianship

There are many existing potential alternatives to guardianship. New York appellate courts have reversed orders appointing guardians where the individual had a validly executed advanced planning instrument or surrogate decision-making document, such as a power of attorney, living will or health care proxy, and there was no showing that the appointed agent was unreliable or acting improperly.[100] However, trial court decisions have not uniformly found such arrangements to be adequate alternatives to guardianship, and in a range of legal contexts, advocates have been told by courts to seek guardianships in cases where the court has been unwilling to recognize a valid power of attorney or health care proxy.

This workgroup began by discussing the existing alternatives to guardianship,[101] including:

- Informal Financial Management/ Representative Payment
- Power of Attorney
- Health Care Proxy/Psychiatric Advanced Directive/Living Will/Family Health Care Decisions Act, etc.
- Case Management
- Assertive Community Treatment
- Peer Support
- Home Care Services/Consumer directed home care/Home and Community Based Services (under waiver and under a state plan option 1915(i) (no requirement for budget neutrality but stricter financial eligibility criteria)(funds

psychosocial rehab, home health/personal care/nursing, habilitation and case management)

- Supportive Housing[102]
- Supported Housing[103]
- Self-Directed Care: Newer option that provides facilitation and funding to allow individuals to develop and fund a life/recovery plan that sets goals for health/mental health, social and family relationships, civic participation, education and employment and utilizes friends, family, and paid and unpaid peer supports to assist individual with development and achievement of goals.[104]
- Money Follows the Person Demonstration (requires minimal 6 mo. institutional stay and provides only one year of services)
- Positive Behavioral Interventions and Supports (PBIS) as part of Nursing Home Transition and Diversion Waiver

While many potential alternatives to guardianship exist, the workgroup noted that many people are not choosing those alternatives that are currently in place. People are sometimes resistant to taking advance action and utilize alternatives to guardianship such as powers of attorney. Part of the problem could be a lack of knowledge about the available alternatives, but part of the problem could also be that the available alternatives are not desirable. The workgroup agreed that additional study was necessary to determine why people often do not choose the currently available alternatives to guardianship. Some members of the workgroup raised concerns about the impact that some of the available alternatives have on autonomy and the need to speak to individuals who have been personally involved in some of the existing alternatives to determine the strengths and weaknesses of the available alternatives.

Discussion Point 2: Ensuring that People with Disabilities, Attorneys, and Judges are Aware of and Utilize the Alternatives to Guardianship

Workgroup participants shared examples of people with disabilities who had successfully utilized available resources or supports to avoid guardianship. Financial management, for example, was cited as an example of a service that can address a concern that can sometimes lead to guardianship proceedings, while allowing the person retain autonomy. Restrictions can be placed on the amount of money a person is allowed to spend while allowing them the freedom to decide how they will spend that money. Unfortunately, cuts to social service programs are jeopardizing community supports that are less restrictive than guardianship. The workgroup agreed that it is essential to protect access to and strengthen the community resources that people with disabilities use to avoid guardianship.

While there are such success stories, workgroup participants agreed that they were not as prevalent as they could be for at least two reasons. First, judges, court evaluators, attorneys, people with disabilities, and family members of people with disabilities are not always aware of the less restrictive alternatives to guardianship. Second, it is often difficult for people with disabilities to access vital community resources and supports without sacrificing their autonomy.

In addition to promoting the civil and human rights of people with disabilities, many of these community services are also cost-effective. Workgroup participants agreed that people with disabilities should not be forced to choose between autonomy and access to services.

Discussion Point 3: Reforming the Guardianship System

In addition to discussing alternatives to guardianship that currently exists in New York, the workgroup also discussed whether there was a need to reform the guardianship system. Some members of the workgroup believed that the guardianship system could be improved with reforms. Other members were less optimistic that meaningful reform could be achieved within the current guardianship paradigm, which divests individuals of legal capacity rather than providing them with any necessary support to exercise that capacity.[105] The workgroup was particularly critical of Article 17-A of the SPCA, because it lacks the procedural safeguards that are present in Article 81 of the MHL. We discussed the theory that substitute decision-making programs like New York's guardianship system might violate the Americans with Disabilities Act.

The workgroup also discussed New York's supported housing program. We noted that supported housing is now generally accepted as a more integrated and cost-effective alternative to psychiatric institutions. The workgroup discussed whether a pilot program might be developed to determine whether a supported decision-making model could be a viable alternative to New York's current guardianship system. Such a pilot program could provide evidence regarding whether a supported decision-making program could be successful and cost-effective. The workgroup discussed whether funding might be available to develop such a pilot program.

As part of this discussion, we identified systems or models that are in place in other municipalities or countries. One model, for example, is a private supported decision-making agreement. In such a system, a person with a disability has the right to enter into a private legal agreement with one or more agents of his choosing who will provide decision-making support or act as formal decision-making representative(s) to make legally binding decisions.[106] The person with a disability does not thereby lose the legal right to make his/her own decisions.[107] In addition, in at least one model, an individual who would not be deemed to have

the generally accepted level of legal capacity to enter into a general or health care power of attorney could create a legally binding support agreement.[108]

D. Recommendations

The workgroup agreed that, in order to promote alternatives to guardianship, a two-track approach was necessary. Our recommendations therefore focus on promoting alternatives to guardianship within the current guardianship system as well as on reforming the guardianship system. Some members of the workgroup recommended the abolition of guardianship and its replacement with a system based entirely on support. While the workgroup represented a wide range of experiences and opinions, we also recognized that, going forward, the workgroup would benefit from including more people with disabilities, the psychiatric survivor community, self-advocates, peer advocates, government officials, and representatives from disability-rights organizations such as ADAPT.

1. **Existing Alternatives to Guardianship**

   a. Study why people often do not choose the currently available alternatives to guardianship

   b. Study the currently available alternatives to guardianship to determine best practices and the ways in which those alternatives support or undermine individual autonomy and self-determination

2. **Ensuring that People with Disabilities, Attorneys, and Judges are Aware of and Utilize the Alternatives to Guardianship**

   a. Gather advocacy stories about people with disabilities who have successfully utilized the less restrictive alternatives to guardianship

   b. Develop publications that describe the alternatives to guardianship in easy to understand terms

   c. Use success stories and publications to educate judges, court evaluators, and attorneys about the less restrictive alternatives to guardianship

   d. Use success stories and publications to provide community education, including know-your-rights trainings for people with disabilities, regarding the less restrictive alternatives to guardianship

e. Use success stories to lobby to protect access to and strengthen community supports and resources

f. Work with the court system to develop a guardianship diversion program to promote less restrictive alternatives to guardianship

3. Reforming the Guardianship System

a. Determine whether funding might be available for a supported decision-making pilot program

b. Develop a supported decision-making pilot program

c. Develop a lawsuit to challenge the validity of Article 17-A

d. Explore the potential for law reform to comply with the CRPD by replacing substituted decision-making regimes with support that ensures respect for the person's autonomy, will, and preferences

Endnotes

[1] Article 81 was enacted amid a wave of guardianship reform nationally. In 1987, a watershed Associated Press investigation exposed widespread neglect and malfeasance in the guardianship process throughout the country. Fred Bayles & Scott McCartney, *Guardians of the Elderly: An Ailing System*, ASSOCIATED PRESS, Sept. 1987. The following year, the ABA Commission on Legal Problems of the Elderly and the Commission on Mental and Physical Disability Law sponsored a National Guardianship Symposium, known as the "Wingspread Conference." That conference produced an agenda for reform intended to "produce a guardianship system . . . more fair, just and responsive to the needs of the wards." AMERICAN BAR ASSOCIATION COMMISSION ON THE MENTALLY DISABLED AND COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY, GUARDIANSHIP: AN AGENDA FOR REFORM, RECOMMENDATIONS OF THE NATIONAL GUARDIANSHIP SYMPOSIUM iv (1989), *available at* http://www.guardianshipsummit.org/wp-content/uploads/2011/03/Agenda-for-Reform.pdf. Many of these recommendations resulted in state legislative reforms. *See, e.g.*, Sally Balch Hurme & Erica Wood, *Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role*, 31 STETSON L. REV. 867 (2001).

[2] N.Y. MENTAL HYG. LAW § 81.11 (hearing); M.H.L. § 81.09 (court evaluator); M.H.L. § 81.10 (counsel).

[3] N.Y. MENTAL HYG. LAW § 81.02(a)(2).

[4] N.Y. MENTAL HYG. LAW §§ 81.30, 81.31.

[5] The conference focused primarily on Article 81 guardianships. For a helpful description of the different origins of the two guardianship regimes, *see* Rose Mary Baily & Charis B. Nick-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Alb. L. Rev. 807 (2012).

[6] See REPORT OF THE SUB-COMMITTEE ON GUARDIANSHIPS OF THE NEW YORK STATE BAR ASSOCIATION: ELDER LAW SECTION 5 (January 2010).

[7] *See* The Vera Institute of Justice, *Guardianship Practice: a Six-Year Perspective,* 4-5 (December 2011), *available at* http://www.vera.org/download?file=3393/Guardianship-Practice-a-Six-Year-Perspective.pdf (describing how New York's fee-for-service model of guardian compensation excludes many indigent individuals from accessing guardianship care).

[8] REPORT OF THE GRAND JURY OF THE SUPREME COURT, QUEENS COUNTY (March 2004), *available at* http://www.queensda.org/newpressreleases/2004/03-03-2004_Grand_jury.htm.

[9] GOVERNMENT ACCOUNTING OFFICE, GUARDIANSHIPS: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS 13 (Sept. 2010).

[10] *Id* at 25.

[11] *Id.* at 2 (noting that GAO investigators had reviewed cases of alleged abuse in 45 states plus the District of Columbia).

[12] CENTER FOR ELDERS & THE COURTS, ADULT GUARDIANSHIP COURT DATE AND ISSUES: RESULTS FROM AN ONLINE SURVEY 5 (March 2010), *available at* http://aja.ncsc.dni.us/pdfs/GuardianshipSurveyReport_FINAL.pdf

[13] *Id.* at 4, 8.

[14] *Id.*

[15] For a compelling case that substituted decision making systems such as guardianship "violate the [Americans with Disabilities Act's] mandate to provide services in the most integrated and least restrictive manner," *see* Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 157 (2010).

[16] Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, G.A. Res. 61/106 (2007) [hereinafter "CRPD"].

[17] United Nations, Convention on the Rights of Persons with Disabilities, art. 12, May 3, 2008, http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

[18] United Nations, Convention on the Right of Persons with Disabilities, http://www.un.org/disabilities/countries.asp?navid=12&pid=166 (last visited September 14, 2012).

[19] *Id.*

[20] *Cf. Roper v. Simmons*, 543 U.S. 551, 578 (2005) (acknowledging "the overwhelming weight of international opinion against the juvenile death penalty" in holding that "[t]he Eighth and Fourteenth Amendments forbid imposition of the death penalty on offenders who were under the age of 18 when their crimes were committed.").

[21] CRPD, Art 12(4).

[22] Concluding Observations on the report of Spain, CRPD/C/ESP/CO/1, paragraphs 33-34; also with less detail, Concluding Observations on the report of Tunisia, CRPD/C/TUN/CO/1, paragraphs 22-23.

[23] National Guardianship Network, Third National Guardianship Summit Releases Standards and Recommendations, *at* http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_summit_recs_1111.authcheckdam.pdf.

[24] *Id.* at 5.

[25] For more information on the National Guardianship Network and the Summit recommendations, *see* http://www.guardianshipsummit.org.

[26] *See, e.g.*, Report of the Commission on Fiduciary Appointments ("Birnbaum II") 50, *available at* http://www.courts.state.ny.us/reports/fiduciary-2005.pdf.

[27] If standardized judgments are used, extra care must be taken to make sure that the most limited guardianship necessary under the circumstances is imposed and that the powers granted to a guardian are all supported by individualized findings.

[28] These recommendations are consistent with recommendations from Chief Judge Lippman's Access to Justice Task Force, which called for standardizing forms in all types of cases around the state. THE TASK FORCE TO EXPAND ACCESS TO CIVIL LEGAL SERVICES IN NEW YORK, REPORT TO THE CHIEF JUDE OF THE STATE OF NEW YORK 30 (2011), *available a*t http://www.courts.state.ny.us/ip/access-civil-legal-services/PDF/CLS-TaskForceREPORT.pdf.

[29] Minnesota currently accepts all accountings online.

[30] For a discussion of ways in which the courts have read flexibility into the 17-A regime, *see* Rose Mary Baily & Charis B. Nick-Torok, *Should We Be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Alb. L. Rev. 807 (2012).

[31] N.Y. MENTAL HYG. LAW §§ 81.30(f), 81.31(c).

[32] N.Y. MENTAL HYG. LAW §81.32.

[33] *Cf.* Standard #4.6 from the recent national guardianship summit: "The conservator shall value the well-being of the person over the preservation of the estate." THIRD NATIONAL GUARDIANSHIP SUMMIT: STANDARDS OF EXCELLENCE – GUARDIANSHIP STANDARDS (2011), available at http://www.mobar.org/uploadedFiles/Home/Committees/Fall_Committee_Meetings/2011/Course_Materials/summit guardian standards 11-10-11.pdf.

[34] N.Y. MENTAL HYG. LAW § 81.31(b)(10).

[35] *See, e.g.*, *In re Matter of Jones*, 2011 N.Y. Slip Op. 50501U, No. 99008/91 (N.Y. Sup. Ct. Kings Cty. March 31, 2011) (guardian was found to have depleted disabled young man's assets while depriving him of accessible living arrangements). The attorney who uncovered the guardian's abuse and self-dealing in that case stated that one visit from the court or one conversation between court staff and the affected family could have uncovered the abuse long before it came to light.

[36] The pilot project would benefit from the extensive guidance for volunteer monitoring programs developed on the national level. *See* A.B.A COMMISSION ON LAW & AGING, VOLUNTEER GUARDIANSHIP MONITORING AND ASSISTANCE: SERVING THE COURT AND THE COMMUNITY (2011), *available at* http://ambar.org/VolunteerGrdMonitor.

[37] NAOMI KARP & ERICA WOOD, GUARDING THE GUARDIANS: PROMISING PRACTICES FOR COURT MONITORING (2007), *at* http://assets.aarp.org/rgcenter/il/2007_21_guardians.pdf.

[38] The Surrogate's Court in New York County currently sends such reminders to Article 17-A guardians.

[39] These measures are required by Title VI of the Civil Rights Act of 1964, which requires that all courts that receive federal assistance, as New York's do, must provide for adequate language access. The Department of Justice has stated that "[p]roviding meaningful access to the legal process for [limited English proficiency] individuals might require more than just providing interpreters in the courtroom. Recipient courts should assess the need for language services all along the process, particularly in areas with high numbers of unrepresented individuals … ."67 Fed. Reg. 41,455-01 at 41,471 (June 18, 2002).

[40] Rule 36.2(d)(2) of the Rules of the Chief Judge of the State of New York.

[41] Like much of the conference, the Monitoring working group focused on guardianship under Article 81 of the Mental Hygiene Law and did not cover guardianships under Article 17-A of the Surrogate's Court Procedure Act.

[42] *See* M.H.L. § 81.32(b) (authorizing the presiding justice of the appellate division in each department to designate examiners to perform the required court examination of guardians' initial and annual reports). There is no statutory requirement that court examiners be attorneys.

[43] M.H.L. § 81.32(a)(2).

[44] M.H.L. § 81.32(a)(2).

[45] M.H.L. § 81.31(b)(6)(i).

[46] A similar standard was recently adopted at the Third National Guardianship Summit. *See* NATIONAL GUARDIANSHIP NETWORK, THIRD NATIONAL GUARDIANSHIP SUMMIT: STANDARDS OF EXCELLENCE –GUARDIAN STANDARDS AND RECOMMENDATIONS FOR ACTION, Standard 4.6 ("The conservator shall value the well-being of the person over the preservation of the estate.") (October 2011), *available at* http://www.guardianshipsummit.org/wp-content/uploads/2011/11/Final-Summit-Standards-Recommendations-5-122.pdf.

[47] For example, the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program is charged with assisting with problems encountered by individuals and their families regarding developmental disabilities services. *See* http://cqc.ny.gov/advocacy/protection-advocacy-programs/padd.

[48] M.H.L. §§ 81.30(f), 81.31(c).

[49] *See In the Matter of Roy W. Lantigua*, 2011 N.Y. Slip Op. 50501, No. 99008/91 (N.Y. Sup. Ct. Kings Cty. March 31, 2011).

[50] *See In re Mark CH*, 28 Misc 765, 2010 NY MISC. LEXIS 918 (Surr. NY Co. 2010) (holding that due process requires courts to monitor guardianships closely once individuals have been stripped of substantial liberties by being placed under guardianship).

[51] This is consistent with the national movement toward adopting standards for guardians. *See* NATIONAL GUARDIANSHIP NETWORK, THIRD NATIONAL GUARDIANSHIP SUMMIT: STANDARDS OF EXCELLENCE –GUARDIAN STANDARDS AND RECOMMENDATIONS FOR ACTION (October 2011), *available at* http://www.guardianshipsummit.org/wp-content/uploads/2011/11/Final-Summit-Standards-Recommendations-5-122.pdf.

[52] Language access is required by Title VI of the Civil Rights Act of 1964 for all courts that receive federal assistance, as New York's courts do. For the U.S. Department of Justice's detailed guidance on the application of Title VI to state courts, *see* 67 Fed. Reg. 41,455 (June 18, 2002). The guidance notes that "[p]roviding meaningful access to the legal process for LEP individuals might require more than just providing interpreters in the courtroom. Recipient courts should assess the need for language services all along the process, particularly in areas with high numbers of unrepresented individuals … ." 67 Fed. Reg. at 41,471.

[53] *See* Minnesota Judicial Branch, Conservator Account Monitoring Preparation and Electronic Reporting (CAMPER), *at* http://mncourts.gov/?page=4058.

[54] American Bar Association Commission on Law and Aging, *Volunteer Guardianship Monitoring: Serving the Court and the Community,* http://ambar.org/VolunteerGrdMonitor.

[55] M.H.L. § 81.31(c).

[56] M.H.L. § 81.03(e).

[57] M.H.L. § 81.08 (a)(14).

[58] *Id.* § 81.09(c)(5)(vi).

[59] *Id.* § 81.15. In practice, it is common for judges to make findings that do not limit the duration of the guardianship.

[60] *Id.* § 81.36(a). "[T]he guardian, the incapacitated person, or any person entitled to commence a [guardianship] proceeding" can move to discharge a guardian or modify the guardian's powers. Id. § 81.36(b).

[61] *See In the Matter of Chaim A.K.*, 885 N.Y.S.2d 582, 584 ("SCPA Article 17-A as originally enacted in 1969 applied to persons with 'mental retardation' It was revised in 1989 to add to its coverage persons who are 'developmentally disabled'") (internal citations omitted).

[62] SCPA § 1750(1).

[63] *Id.* § 1750-a(1).

[64] *Id.*

[65] *In the Matter of Chaim A.K.*, 885 N.Y.S.2d at 586 (citing *Matter of Maryanne Cruz*, 2001 N.Y. Slip Op. 40083(U), *4, 2001 WL 940206 (2001) and Lawrence R. Faulkner and Lisa Klee Friedman, Distinguishing Article 81 and Article 17-A Proceedings, II Guardianship Practice in New York State, p. 160 (New York State Bar Association 1997)).

[66] SCPA § 1751.

[67] Id. §§ 1750, 1750-a(1); 1754(5).

[68] Id. § 1754(1).

[69] *Id.*

[70] SCPA § 1754.

[71] *In the Matter of Chaim A.K.*, 885 N.Y.S.2d at 587 ("17-A provides no gradations and no described or circumscribed powers.").

[72] 42 U.S.C. § 12132.

[73] *Id.* § 12131(1).

[74] *Id.* § 12131(2).

[75] *Id.* § 12134(a).

[76] 28 C.F.R. § 35.130.

[77] *See, e.g.*, *id.* § 35.130(a) ("No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity . . . ."); 35.130(b)(2) ("No qualified individual with a disability

shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity . . . .").

[78] 28 C.F.R. § 35.130(d).

[79] *Id.* § 35.130(d), App. A, p. 450 (1998).

[80] Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

[81] *Id.* at 157.

[82] *Id.* at 194.

[83] *Id.*

[84] Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL'Y 315, 341 (2009) ("Guardianship is certainly part of the process that results in a person being institutionalized in a nursing home, and perhaps in some cases at least part of the cause.").

[85] Salzman, *supra* note 80, at 161 ("a move to a supported decision-making paradigm is consistent with the ADA, as well as with the recently adopted U.N. Convention on the Rights of People with Disabilities"); *see* 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 (citing CRPD, Art. 12).

[86] Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, G.A. Res. 61/106 (2007) [hereinafter *CRPD*].

[87] United Nations, Convention on the Rights of Persons with Disabilities, http://www.un.org/disabilities/default.asp?navid=14&pid=150 (last visited Aug. 24, 2011).

[88] *CRPD*, art. 42.

[89] United Nations, Convention and Optional Protocol Signatures and Ratifications, http://www.un.org/disabilities/countries.asp?navid=12&pid=166 (last visited Aug. 24, 2011).

[90] *Id.*

[91] *Cf. Roper v. Simmons*, 543 U.S. 551, 578 (2005) (acknowledging "the overwhelming weight of international opinion against the juvenile death penalty" in holding that "[t]he Eighth and Fourteenth Amendments forbid imposition of the death penalty on offenders who were under the age of 18 when their crimes were committed.").

[92] *CRPD*, art. 1.

[93] *Id.*, art. 2.

[94] *Id.*, art. 15(1).

[95] *Id.*, art. 15(2).

[96] Prior to the *CRPD*, "no specific binding international human rights convention exist[ed] to protect explicitly the right of people with disabilities to live in the community or to be free from indeterminate institutionalization." Eric Rosenthal & Arlene Kanter, *The Right to*

Community Integration for People with Disabilities under United States and International Law, in Disability Rights Law and Policy: International and National Perspectives, *available at* http://www.dredf.org/international/paper_r-k.html. However, "[r]eferences to community integration are found in Article 23 of the Convention on the Rights of the Child, and in instruments and documents of the UN General Assembly such as the Declaration on the Rights of Mentally Retarded Persons, the 1991 Principles for the Protection of Persons with Mental Illness, the 1993 Standard Rules on Equalization of Opportunities for Persons with Disabilities, and General Comment 5 to the International Convention on Economic, Social and Cultural Rights, as well as in the Charter of Fundamental Rights of the European Union." *Id.*

[97] CRPD, Art 12(4).

[98] Concluding Observations on the report of Spain, CRPD/C/ESP/CO/1, paragraphs 33-34; also with less detail, Concluding Observations on the report of Tunisia, CRPD/C/TUN/CO/1, paragraphs 22-23.

[99] This workgroup will not address the important issue of the appointment of a guardian for an individual who neither needs nor wants support, but who is at risk of guardianship because a court may disagree with the individual's choices.

[100] *See, e.g.*, *In re May Far C.*, 61 A.D. 3d 680 (App. Div. 2d Dep't 2009) (POA and no evidence of impropriety by appointed agent); *In re Albert S.*, 286 A.D.2d 684 (2d Dept. 2001)(Health care agents acting pursuant to a living will and attorney in fact adequately managing property and previously created trust); *In re Mildred MJ,* 43 A.D.3d 1391 (App. Div. 4th Dep't 2007) (validly executed POA and HCP and no evidence of undue influence). *See also St. Francis Hosp. (Matter of Rose)*, 907 NYS2d 104 (Sup. Ct. Dutchess Co. 2010)(Validly executed POA and HCP); *In re G.S.*, 841 NYS2d 428 (Sup. Ct. Bronx Co. 2007) (POA and HCP were sufficient to provide for AIP's personal needs and property management; that Article 81 was not intended to be used as a nursing home collection mechanism).

[101] This list of existing alternatives to guardianship is descriptive; it is not meant to imply that the workgroup endorses all of these alternatives.

[102] In New York, "supportive housing" refers to a range of housing programs, including: Congregate Treatment, Congregate Support, Community Residence/Single Room Occupancy, Apartment Treatment, and State-Operated Community Residence. See New York State Office of Mental Health, Residential Program Descriptions, http://bi.omh.ny.gov/adult_housing/index?p=res-programs.

[103] In New York, "supported housing" is a "form of housing in which individuals with mental illness live in their own apartments scattered throughout the community and receive supportive services." Disability Advocates, Inc. v. Paterson, 598 F. Supp. 2d 289, 292 (E.D.N.Y. 2009); see also New York State Office of Mental Health, Supported Housing Guidelines, http://www.omh.ny.gov/omhweb/adults/SupportedHousing/supportedhousingguidelines.html.

[104] See *In the Driver's Seat: A Guide to Self-Directed Mental Health Care*, prepared by the Bazelon Center and UPENN Collaborative on Community Integration, April 2008

[105] For example, Tina Minkowitz, who is a member of this workgroup, has pointed out that:

> CRPD Article 12(2) states, "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." This guarantee is the heart of the Convention for people with psychosocial disabilities. All laws directed at restricting our freedom and self-determination are premised on an equation of psychosocial disability with legal incapacity, and legal incapacitation is the primary way that the law deals with persons with psychosocial disabilities. A guarantee of legal capacity on an equal basis with others in all aspects of life should result in the elimination of all such legal regimes.

The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions, 34 SYRACUSE J. INT'L. L. & COM. 405, 408 (2007) (emphasis added).

[106] *See* Representation Agreement Act, R.S.B.C., ch. 405, pt. 1, § 2 (1996) (British Columbia); Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 SASKATCHEWAN L. REV. 75, 84-91 (2010); Decision-making, Support and Protection to Adults Act S.Y.T, ch. 21, pts. 1-2; pt. 2, §§ 7, 9 (2003) (Yukon)(creating two legally distinct options, one of support and one of representation).

[107] *See, e.g.*, Representation Agreement Act, pt. 6, § 36 (1996).

[108] *Compare* Representation Agreement Act, pt. 2, §§ 7-8 (1996) *with* Decision-making, Support and Protection to Adults Act S.Y.T, ch. 21, pt. 1, § 6 (2003) (setting a higher standard for the execution of support agreement). *See generally*, Mildred MJ 43 A.D.3d 1391, 1392 (4th Dept. 2007) (discussing the capacity of an individual with moderate dementia to authorize an individual to act on her behalf).

RETHINKING GUARDIANSHIP

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The Arc Michigan

Summary Statement

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express those choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of her/his right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on tests of competence, makes that person vulnerable and deprives him/her not only of his/her right to self-determination but also of other rights which should be inalienable.

The following is an adaptation of the "Statement of Principles" by the Coalition on Alternatives to Guardianship".

STATEMENT OF PRINCIPLES

SUMMARY STATEMENT

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express those choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of her/his right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on tests of competence, makes that person vulnerable and deprives him/her not only of his/her right to self-determination but also of other rights which should be inalienable.

PRINCIPLES

1. Each individual can choose and make decisions about his/her life

2. Each individual has the right to make decisions (self-determination)

3. Individuals may want help fro other persons of their choosing with whom they have trusting relationships, including family members or friends, to make decisions or have them interpreted, and to communicate them to others. This is called supported decision making.

4. Individuals who have an intellectual disability may communicate choices, whishes, likes and dislikes in non-traditional ways which can include actions rather than language. Friends, family members, or others who are trusted by the individual, can help to interpret these decisions.

5. This natural interdependence of people must be recognized and supported decisions that are made within such trusted, supportive relationships must be given status and validation.

6. All adults have the right to make decisions with support or to name a substitute (e.g. by power of attorney) to make decisions for them.

7. Laws and/or policies that do not recognize supported decision making or that protect other interests at the expense of the individual's right to self-determination discriminate against persons who have an intellectual disability and make them more vulnerable

8. Individuals should never be assessed to determine competency; decisions should be reviewable if there is concern that the will of the individual is not being respected or that the individual is being exploited.

9. Any legal system or proceeding which sets up a test of competency to be used to appoint a substitute decision-maker puts the individual at risk of also losing other rights.

10. A decision that could not have been made by the individual without support, e.g. consent for non-therapeutic sterilization, experimentation or other non-therapeutic procedures which could offend human dignity, should not be made within supported decision making relationships.

*Coalition on Alternatives to Guardianship
180 Duncan Mill Road Suite 600
North York, Ontario M3D 1Z6

People First of Ontario
People First of Canada
Ontario Association for Community Living

Canadian Association for Community Living
Youth Involvement Ontario

TASH RESOLUTION

"Be it resolved that TASH, an international advocacy association of people with disabilities, their family members and other advocates, and people who work in the disability field affirms the rights of persons with disabilities and commits to the promotion and use of alternatives to guardianship rather than the removal of said rights. TASH urges the development and promotion of the use of accommodations and supports people need to make choices and decisions, to have their preferences recognized and honored, and to have their rights to self-determination protected."

Today

- Guardianship
  - What it is and what it isn't
  - What it does do and what it doesn't do
- Ways to address barriers
- Tools that help

Guardianship is a situation, recognized by law, under which one person or entity exercises power over and on behalf of another person.

("a ward")

PAST REASONS FOR SEEKING GUARDIANSHIP?

- Medical reasons
- Contracts
- Decisions about programs, records, etc.
- Administrative convenience
- Financial decisions
- Placement decisions
- Sex and related issues
- What will happen when parents or family are no longer around?

WHY AVOID GUARDIANSHIP?

- Avoid public declaration of incompetency
- Promote independence, dignity, freedom of choice
- People deal with guardian – not person
- Expense – attorneys, hearings, evaluations
- Courts don’t always follow law (partial vs. plenary, promote independence, etc.)

WHY AVOID GUARDIANSHIP? (cont'd)

- Very difficult to modify or terminate
- Attorneys and G.A.L.s – very little training
- Corporate guardian problems – take money & independence
- It simply doesn't do what you want it to do!

Connecticut Supreme Court

"Guardians appointed by the court whether limited or plenary, can be vested with substantial powers over a respondent. Therefore…the appointment of a guardian implicates a respondent's constitutional rights…"

(Oller vs. Oller-Chiang, 1994)

Iowa Supreme Court

Guardianship "…involves significant loss of liberty similarly to that present in an involuntary civil commitment for treatment of mental illness."

(In Re: Hedin, quoting Arizona Court of Appeals)

California Supreme Court

"[A person who has] a conservator [appointed] may be subject to greater control of his or her life than one convicted of a crime"

National Elder Abuse and Guardianship Victims Taskforce

"Too often the very Adult Guardianship and Conservatorship System meant to protect the elderly are being used as instruments to violate their rights, rob them of their lifelong savings and tear them away from their families and loved ones."

"The typical ward has fewer rights than the typical convicted felon – they no longer receive money or pay their bills. They cannot marry – or divorce… it is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception of…the death penalty"

-Claude Pepper, U.S. Representative

1990 Guardianship Filings

STATE	NUMBER OF FILINGS	
	Total	Per 100,000
Alaska	234	51.6
Arkansas	2,871	122.1
Colorado	1,169	35.5
Connecticut	4,313	131.2
Delaware	173	26.0
District of Columbia	106	17.5
Florida	7,641	59.1
Georgia	5,762	88.9
Hawaii	474	40.2
Idaho	463	43.9
Indiana	6,090	109.8
Massachusetts	5, 093	84.7
Michigan	18,870	203.0
Missouri	2,841	55.5
Nevada	837	69.6
New Hampshire	906	81.7
New York	1,597	8.9
Ohio	6,963	63.8
South Dakota	708	101.7
Vermont	968	172.0
Virginia	651	10.5
Washington	2,632	54.1

The United Nations Convention on the Rights of Persons with Disabilities

In the Preamble:

Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices

Article 4
General Obligation

5) The Provisions of the present Convention shall extend to all parts of Federal States without any limitation or exceptions

Defines discrimination, in part as:

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, of all human rights and fundamental freedoms"

Article 3
General Principles

The principles of the present Convention shall be:

A) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

C) Full and effective participation and inclusion in society

Article 5
Equality and Non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

Article 12
Equal recognition before the law

1) States Parties affirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12 (*cont'd*)

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.

The vast majority of those who end up petitioning the court to appoint a guardian for some person are either related to the person or a friend

However, most petitioners do not come to the decision to seek guardianship on their own, but are encouraged to do so by someone else

Iowa Supreme Court

"In making a determination as to whether a guardianship should be established…the court must consider the availability of third party assistance to meet a …proposed ward's need for such necessities…"

(in the Matter of Hedin, 1995)

Utah Supreme Court
(re: "Responsible Decisions")

"…responsible focuses the appointing authority's attention on the *content* of the decision rather than on the ability of the individual to engage in a rational decision making *process*."

(In re: Boyer)

"We have to reject the very idea of incompetence. We need to replace it with the idea of 'assisted competence'. This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision –making that will preserve their rights…"

-Thomas Nerney, Director of Self Determination for Persons with Developmental Disabilities

Pennsylvania Supreme Court

"Persons cannot be deemed incapacitated if their impairments are counterbalanced by friends, family or other support."

In re: Perry, 727 A2d 539 (Ps. Sup. Ct. 1999)

CMS: Centers for Medicare and Medicaid Services

Quality Framework Includes:

- PERSON-CENTERED SERVICE PLANNING AND DELIVERY:

  . . .responses to changing needs/choices and participant directions

- RIGHTS AND RESPONSIBILITIES

  Protection of rights and decision-making authority. . .

www.cms.hhs.gov/HCBS/downloads/qualityframework.pdf

Michigan Mental Health Code

"Guardianship … shall be utilized only as is necessary to promote and protect the well-being of the individual…"

(MCL 330.1602(1))

ALTERNATIVES

- Advisors, Advocates
- Person-centered planning
- Power of Attorney
- Durable Power of Attorney
- Durable Power of Attorney for Health Care or Designation of Patient Advocate
- Protective Orders
- Trusts
- Contracts –

  Void vs. Voidable
- Finances
  - Representative Payee
  - Limited Bank Account
    - Co-signers
    - Ceiling Limit Account
    - Pour-over Account

Person Centered Planning

"'Person-centered planning' means a process for planning and supporting the individual receiving services tat builds upon the individual's capacity to engage in activities that promote community life and that honors the individual's preferences, choices and abilities. The person-centered planning process involves families, friends, and professionals as the individual desires or requires" MCL 330.1700 (g)

Michigan's Long Term Care Group Report and Recommendation, June 2000

PERSON CENTERED PLANNING

A person centered plan assists individuals to create a personalized image of a desirable future. The development of a plan suggests a process tat can organized and guide community change in alliance wit people with disabilities thus building the bridge from both sides.

Essential to all person centered plans are the following characteristics:

Person Directed – The plan for the person is that the person's vision of what he or she would like to be and do. The plan is not static, but rather it changes as new opportunities and obstacles arise.

Capacity Building – Planning focuses on the person's gifts, talents and skills rather than deficits. It builds upon the individuals to engage in activities that promote a sense of belonging in the community.

Person Centered – The focus is continually on the person for whom the pan is being developed, and not on plugging the person into available slots in a program. The individual's choices and preference must be honored.

Network Building – The process brings together people who care about the person, and are committed to helping the person articulate their vision of a desirable future. They learn together and invent new courses of action to make the vision an reality.

Outcome based – The plan focuses on increasing any or all of the following experiences which are valued by the individual:

- Growing in relationships or having friends.
- Contributing or performing functional/meaningful activities.
- Sharing ordinary places or being part of their own community.
- Gaining respect or having a valued role which expresses their gifts and talents.
- Making choices that are meaningful and express individual identity.

Community Accountability – The plan will assure adequate supports when there are issues of health and safety, while respecting and according their full dignity as a fully participating member of the community.

Adopted by the Howell Group of Michigan, October 1994

Person Centered Planning

- Preferences determined by person centered planning process are honored unless harmful to the individual
- This process of determining preferences and choices enhances the dignity and self-determination of individuals
- This process is more reliable than having a court-appointed person to make decisions with or without input from anyone.

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE OF INFORMATION

I, _____ hereby authorize Community Mental Health to release/ exchange information with my parents, _____ _____, which pertains to my services, programs and living situation. I also wish that my parents be invited to any and all meetings about me, and I do not want any decisions made without their input. If CMH has any documents I need to sign, my parents must sign first to acknowledge their receipt of these documents and their concurrence with them, before I will sign. This authorization, unless otherwise revoked by me, is intended to remain in effect for the duration of time I receive mental health services, etc. or until I revoke this authorization, whichever comes first.

_____
(name)

_____
(date)

CONSENT TO AUTHORIZE ADVOCACY AND RELEASE OF INFORMATION

I, _____, hereby authorize _____ Schools to release / exchange information with my parents, _____ _____, which pertains to my school program and placement. I also wish that y parents be invited to any and all meetings about me, and I do not want any decisions made without their input. If the schools have any documents I need to sign, my parents must sign first, before I will sign. This authorization, unless otherwise revoked by me, is intended to remain in effect for the duration of time I receive special education services or until my twenty-seventh birthday, whichever comes first.

_____
(name)

_____
(date)

Michigan Social Welfare Act MCL 400.66h

- Affirms a person's right to provide consent to treatment and have wishes followed when receiving government assistance (i.e., Medicaid).
- If the individual is unable to make medical decisions, then providers are required to obtain written consent of individual's nearest relative, guardian or parent except in emergencies.

Medical Power of Attorney

- Appoint an Agent to handle medical decisions or support you in medical decisions
- Can be effective immediately
- Can be as broad or narrow as desired

Patient Advocate Designations (PADs) for Medical Decisions

- Exercisable only in event the person is unable to make their own medical decisions (certified by two physicians)
- Can be individual 18 or over to exercise powers related to care, custody and medical treatment decisions of the person.
- Includes the individual's preferences regarding care and treatment.
- Necessary for withdrawal of life-sustaining treatment.
- New Michigan law also permits PADs for mental health decisions. This is also a preferred alternative to "Kevin's Law" (court-ordered, outpatient treatment).

(Sample only—revise language or content to reflect the understanding and circumstances of the person signing.)

POWER OF ATTORNEY FOR MEDICAL TREATMENT DECISIONS

I am _____. I live at _____. I want _____ to help me if I am sick and if I need to go to the doctor.

My mother/father read this paper to me before I signed it. I understand what he/she told me about this paper before I signed it.

If I am sick, my mother/father should take me to the doctor. If she/he is not at my house when I become sick, please call her/him to come to the doctor's office. I would like the doctor to talk to her/him and tell her/him what the matter is.

I would like to ask my mother/father what the doctor should do. I would like the doctor to do what my mother/father tells the doctor to do; she/he knows what is best for me.

Sometimes a doctor says that I need to have a shot or some other care. Sometimes a doctor says that I need to take pills or medicine. My mother father will also decide what other care I should have, but she/he will talk to me about what care I need.

I would also like my mother/father to decide if I need to go to the dentist.

If I am very sick, I might need to go to a hospital. My mother/father can decide if I need to go to the hospital. I would like all of the people at the hospital to speak with my mother/father about what the people at the hospital should do for me. I would like my mother/father to decide about my care at the hospital even if I am unable to understand what my doctor says about me. This is very important since I want the people at the hospital to try very hard to care for me if I am sick. If I need to have an operation because I am very sick, I would like the people at the hospital talk to my mother/father. My mother/father will say "yes" or "no" and that is what the people at the hospital will do.

I understand that I want my mother/father to help decide what care I need, and I want people to listen to him or her about my care. If my mother/father is not happy with my doctor, then he or she is able to get another doctor to care for me.

_____ _____
(Signature or Mark) (Date)

_____ _____
(Witness) (Date)

_____ _____
(Witness) (Date)

DESIGNATION FOR DURABLE POWER OF ATTORNEY FOR MEDICAL TREATMENT, RESIDENTIAL PLACEMENT, AND PROGRAM DECISIONS

I am _____ and I live at _____. I want my mother, _____to help me if I am sick and need to see a doctor. I want her to make decisions about my medical care, including medication and surgery.

I also want my mother, _____ to make decisions about where I will live. She can sign any papers needed to arrange for a place for me to live.

I also want her to make decisions about work and other programs that I participate in.

If my mother, _____ is not available, I would like my _____, _____ to make these decisions instead.

If neither of the above are available, I would like my _____, _____ to make these decisions.

I would like these powers to last even if I become unable to understand this form in the future. I understand that if I want to change my mind about who makes these decisions, I can destroy this paper or let people know I want to change my mind.

_____ _____

(Date) (Signed)

STATEMENT OF WITNESSES

We sign below as witnesses. This was signed in our presence. The signer appears to be of sound mind, and to be making this designation voluntarily, without duress, fraud or undue influence.

Signed by witness: _____

_____

(Print full name)

Signed by witness: _____

_____

(Print full name)

Representative Payee

- A person or organization designated through the Social Security Administration to handle a person's Social Security check

- SSA has special paperwork and procedures for appointing a representative payee

- Can be changed or revoked only if SSA consents

Personal Money Manager

Personal Money Managers are individuals or organizations that can handle finances for an individuals. Services include:

- Paying bills
- Managing finances
- Handling Investments
- Troubleshooting

Automatic Bill Paying

- Automatic bill payment can be set up for an individual
- Eliminates the ongoing need for bill payment assistance
- Periodic monitoring is helpful

Two Methods: Opting Out of Credit Card Offers

- **Five Year Opt – Out**

  Complete form online (secure website)

  at: www.optoutprescreen.com

- **Permanent Opt – Out**

  Form must be printed, signed and mailed.

  (Five year opt-out may be completed in the interim)

  Call: (888) 567-8688

Estate Planning for People with Disabilities

Estate Planning for people with disabilities is generally done to preserve eligibility for governmental benefits that provide essential services.

Trusts

- Settlor/Grantor
  - Creates the Trust
- Trustee
  - Manages the Trust
- Beneficiary
  - Receives the beneficial use of the trust

Types of Trusts for People with Disabilities

Support Trust

Medicaid Qualifying Trusts:

- Amenities Trust
- Payback Trust
- Pooled Trust

Fiduciary Duty

- A Fiduciary is someone who has undertaken a relationship of trust and confidence to act on behalf of another person.
- The Fiduciary duty is the highest standard of care in law or equity.
- A Fiduciary must put the person's interest before his or her personal interest.

Support Trust

- Provides for support, care and maintenance of the beneficiary
- Can be created and funded by anyone including beneficiary
- ***Does not preserve eligibility for government benefits (e.g., Medicaid, SSI)***
- Typically established by family members for individuals with special needs who do not need government benefits

Third-Party (Amenities) Trust

- Established and funded with assets of a third party (e.g. family member)
- Provides for amenities or extra items or services only (e.g., advocacy, recreational activities, home furnishings, haircuts, music therapy)
- If properly written, preserves beneficiary's eligibility for government benefits

Benefits of Amenities Trusts

- Preserves Eligibility for Government Benefits
- Provides for an enhanced quality of life for the beneficiary
- Provides for Trustee to Act as an Advocate

Pooled Accounts Trust

- Used to preserve government benefits
- Established and administered by a non-profit organization.
- Sub-accounts are established for the benefit of the individual.
- Remaining assets at death are left with the non-profit organization.

Pay Back (Self-Settled) Trusts

- Established by a family member or designated individual with trust powers
- Funded with the Beneficiary's own funds (e.g., funds awarded from lawsuit)
- To provide for amenities or extra items to promote quality of life and independence
- Primarily used to preserve government benefits
- Requires language in the trust that upon the death of the individual, the State is paid back **first** for any government benefits paid during his/her lifetime before distributing rest of trust assets to anyone else

Trust can be used for:

- Medical treatment beyond Medicaid
- Dental Care
- Educational or Vocational services
- Recreation expenses or outings
- Travel for beneficiary or siblings, etc.
- Books, magazines, cable television, phone calls
- Monitoring expenses
- Non-standard or non-covered personal services
- Can purchase home & rent to beneficiary with or without roommates (payments must cover total cost of home)
- Can make the difference between success & failure of a placement
- Favors consumer choice & inclusion

Exhibit 12.2 A List of Amenities

- Acupuncture/acupressure
- Advocacy
- Appliances (TV, VCR, stereo, microwave, stove, refrigerator, washer/dryer)
- Bottled water
- Bus pass/ public transportation fees
- Clubs and club dues (record clubs, book clubs, health clubs, service clubs)
- Computer (hardware, software, programs, internet service)
- Courses or classes (academic or recreational)
- Curtains, blinds, drapes
- Dry cleaning and laundry services
- Elective surgery
- Fitness equipment
- Furniture, home furnishings
- Gasoline for automobile
- Haircuts/ salon services
- House cleaning/maid services
- Insurance (automobile, home, and/or possessions)
- Linens and towels
- Massage
- Musical instruments (including lessons)
- Nonfood grocery items (laundry soap, bleach, fabric softener, deodorant, dish soap, personal hygiene products, paper towels, napkins, Kleenex, toilet paper, any household cleaning products)
- Over-the-counter medications (including vitamins or herbs)
- Personal assistance
- Pet, pet supplies
- Physician specialists
- Private counseling
- Repair services (appliance, automobile, bicycle, household)
- Retail store charge accounts (gift stores, craft stores, hardware stores, pet stores)
- Sporting goods/ equipment
- Taxi cab scrip
- Tickets to concerts or events (for beneficiary and an accompanying companion)
- Transportation (automobile, motorcycle, bicycle, moped)
- Utility bills (telephone, cable TV, electric, heating)
- Vacation (including paying for a companion to accompany the beneficiary)

Self-Determination Principles

- **Freedom**: The ability to plan a life, rather than purchase a program
- **Authority**: Ability for a person with a disability to control a certain sum of dollars to purchase supports
- **Support**: Arranging resources and personnel, both formal & informal, to achieve meaningful participation
- **Responsibility**: Acceptance of a valued community role, through employment, affiliations, spiritual development and caring for others, as well as accountability for public dollars

Self-Determination

Freedom

- *Liberty*
- *Independence*
- *Autonomy*
- *Sovereignty*

Guardianship

- *Lack of Control*
- *Disparagement*
- *No Power*
- *Loss of Rights*

Self-Determination

Authority

- *Control*
- *Mastery*
- *Power*
- *Rights*

Guardianship

- *Lack of Control*
- *Disparagement*
- *No Power*
- *Loss of Rights*

Self-Determination

Support

- *Livelihood*
- *Independence*
- *Accessibility*
- *Confidence*

Guardianship

- *Dependence*
- *Lack of Freedom*
- *More exclusion from community*
- *Low Self-esteem*

Self-Determination

Responsibility

- *Accountable*
- *Committed*
- *Empowered*
- *Decisive*

Guardianship

- *Lack of Control*
- *Disparagement*
- *No Power*
- *Loss of Rights*

Desired vs. Current

- Person-centered planning
- Life outcomes
- Build on capacities and abilities
- Behavior as communication
- Choice and control
- Supports and Personal Assistance
- Own Home
- Supports Coordination
- Inclusion and self-determination
- Consumer Satisfaction as test of quality

- Interdisciplinary Teams
- Assessments
- Goals Determined by Deficits
- Behavior Management
- Beds and Slots
- Agency and Provider staff
- Congregate /Program
- Case Management
- Medical Model
- Monitoring and Inspection of care

QUALITY OF LIFE

People in your life

- Unpaid and paid
- Of your choosing
- Variety and array of relationships

QUALITY OF LIFE

Control

- Where and how you live
- What you do an where you do it
- What supports, and how they are provided
- Who provides supports

QUALITY OF LIFE

Money

- Direct your budget
- Opportunity to earn money
- Decide how to spend your money

"One of the biggest challenges facing us as we enter the twenty-first century…lies in the overemphasis, even dependency, on power control, paternalism, and, ultimately, coercion."

Rod Copeland
Commissioner of the Vermont Department
of Developmental and Mental Health

In the real world, people die for their freedoms. In the field of [developmental disabilities], they hold conventions or invite each other to conferences. In the real world, people learn from each other, and protect each other. In the field of [developmental disabilities], one must be licensed to teach, certified to treat, and commissioned to protect. That which is considered to be good in the field of [developmental disabilities] is professionally controlled.

Burton Blatt, 1981

What is least restrictive about the real world drives from thousands of years of human discourse under such diverse leaders as Attila and Lincoln, Pharaoh and Moses, George III and George Washington, Martin Luther and Martin Luther King. What's most restrictive about the world of {developmental disabilities} derives from 200 years of professional interest in pathology rather than the universality of people. Professionals have created much of the need to do something about the problem of too restrictive environments forced upon {people with disabilities}. We have created or been much of the problem, and now we seem anxious to do something, but less to rescue {people with disabilities} than to redeem ourselves, less to obtain their freedoms than to establish ours, less because they need us than because we need them"

Burton Blatt, 1981

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express their preferences/choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of his/her right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on test of competence or capacity, makes that person vulnerable and deprives him/her not only of his/her right to self determination but also of other rights which should be inalienable. Our obligation is to find the best ways to provide the accommodations, and supports a person needs to maintain their autonomy and make decisions.

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