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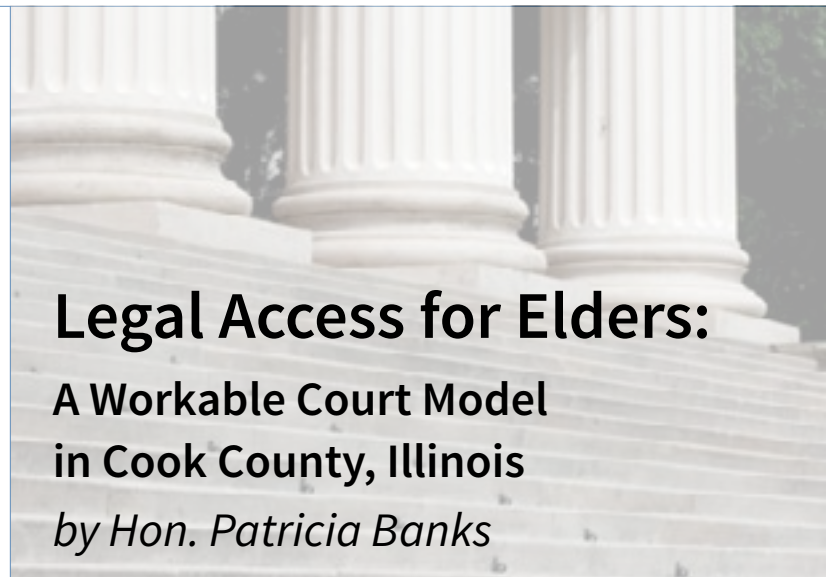
A Journal of the  Commission on Law and Aging
Vol. 37, No. 5, May – June 2016



New ABA Resource

PRACTICAL Tool for Lawyers:

Steps in Supporting
Decision-Making



Legal Access for Elders:

A Workable Court Model
in Cook County, Illinois

by Hon. Patricia Banks

“Stepping in When Help is Needed”

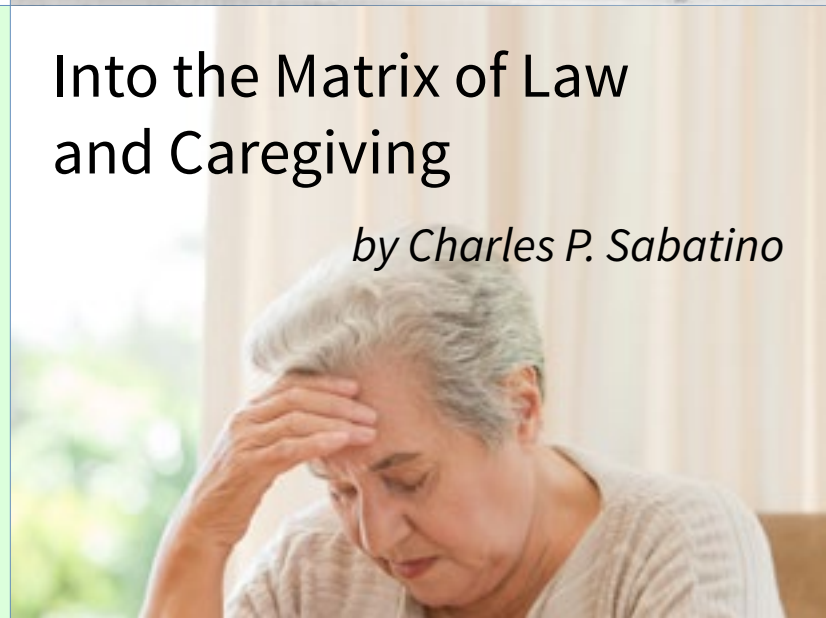
An interactive training video for
family guardians

by John J. Ford



Into the Matrix of Law and Caregiving

by Charles P. Sabatino



Bifocal

Vol. 37, No. 4
May – June 2016

- 95 *New Free Resource*
PRACTICAL Tool for Lawyers:
Steps in Supporting Decision-Making
- 96 Into the Matrix of Law and Caregiving
by *Charles P. Sabatino*
- 105 “Stepping in When Help is Needed”
An interactive training video
for family guardians
by *John J. Ford*
- 108 Legal Access for Elders:
A Workable Court Model
in Cook County, Illinois
by *Hon. Patricia Banks*
- 111 The Commission’s
Summer 2016 Interns
- 111 New Commission Resources
- 112 Core Essentials Track at the 2016
National Aging and Law Conference:
Elder Law Essentials

Bifocal

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Editor

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Questions?

Contact the Commission at
(202) 662-8690, or at:
aging@americanbar.org.

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PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

A new resource guide aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship.

The PRACTICAL Tool is a joint product of four American Bar Association entities—the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making. The project was made possible by the ABA Enterprise Fund, which provides internal grants of seed money to fund innovative, collaborative efforts between ABA entities.

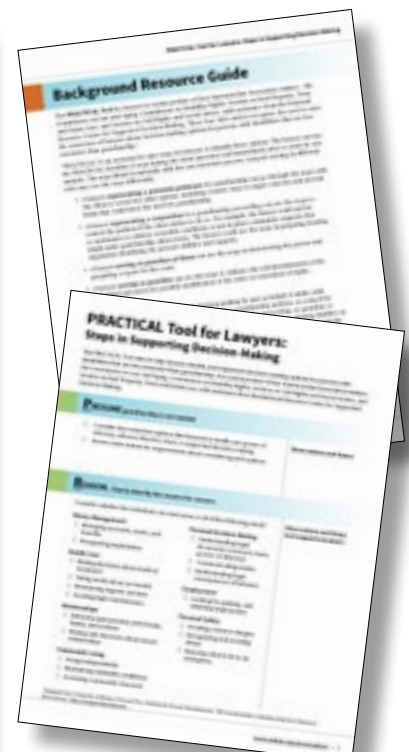
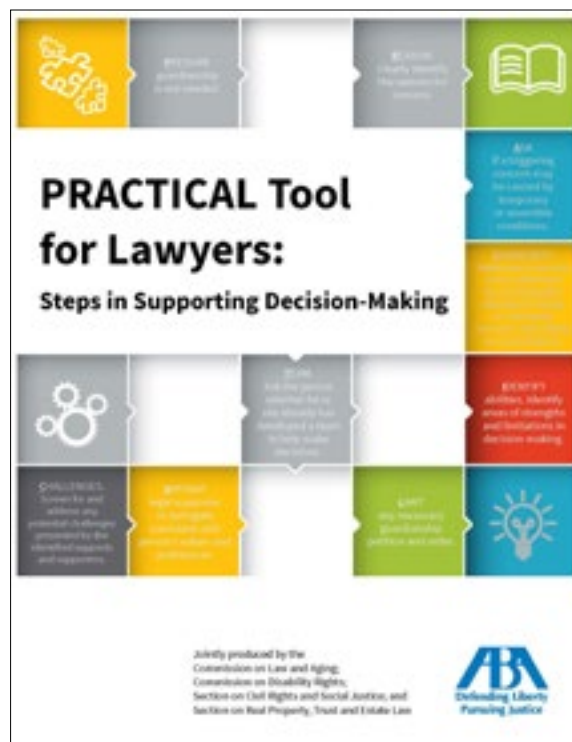
“PRACTICAL” is an acronym for nine steps lawyers can use in case analysis to identify legal and practical approaches to heighten self-determination before moving ahead with guardianship: Presume guardianship is not needed; clearly identify the Reasons for concern; Ask if a triggering concern may be temporary; determine if concerns can be addressed by Community resources; ask if the person already has a Team to help make decisions; Identify the person’s abilities; screen for potential Challenges; Appoint a legal supporter consistent with the person’s values; and Limit any necessary guardianship petition.

Guardianship is one of society’s most drastic interventions, removing fundamental human rights and reducing self-determination. Guardianship is viewed as a last resort, and laws and standards require that less restrictive decision-making options be considered first.

These options address both financial and health care/personal decisions, and include the emergent concept of “supported decision-making”—in which a person uses support from trusted others to help understand choices and make needed decisions on his or her own, rather than relying on a guardian or other surrogate.

“With the aging of the population and increase in the number of individuals with disabilities, lawyers who practice in many areas of the law will encounter the need for decision making by and on behalf of these adults,” said ABA President Paulette Brown. “This new ABA checklist tool offers a working framework to think through these challenging issues.”

PDF and Word versions of The PRACTICAL Tool and Resource Guide are available for no-cost download at <http://www.ambar.org/practicaltool>, where information on accessing the recording from a free June 28 webinar based on the Tool can also be found. ■



Into the Matrix of Law and Caregiving

by Charles P. Sabatino

Among the challenges faced by family caregivers is a tangled matrix of legal and financial issues that surround the practical care issues these caregivers cope with daily. The legal face of everyday caregiving can seem distant, obscure, or discomfiting. But, the key legal challenges are identifiable and manageable when one understands the basics.

Consider the following story. Ann works full time as a clerk at a local grocery store chain, and in much of her free time, cares for her mother and father, with whom she shares a two-bedroom apartment. Ann has one sibling, a brother who lives several hours away. Ann's father has been diagnosed with Alzheimer's Disease, but he is still able to recognize his loved ones most of the time, engage in simple conversation, and perform most daily activities, with some cueing. Her mother suffers from severe arthritis and emphysema and cannot handle most housework, but still adequately manages the couple's finances. While at work, Ann receives a call from her neighbor: Her mother has had a fall in the apartment building's lobby. The neighbor called 911 and Ann's mother has been rushed to the hospital.

Hospital records noted that Ann's mother is married, so when Ann arrives at the hospital, staff share only general information with her and ask how to contact her father. Upon explaining her father's condition, hospital staff become somewhat more forthcoming. Treated for a broken hip, her mother is eventually

transferred to a nursing home for convalescence. During this time, Ann takes extra, unpaid time off (begrudgingly provided by her employer) to care for her father and to manage her mother's transfer to a nursing home, which is a considerable distance from home.

During his wife's absence, Ann's father becomes significantly more confused, agitated, and begins to wander. Ann recruits a neighbor to visit and keep an eye on her father a couple days a week, but one day, when no one is available to monitor him, Ann locks him in the apartment for his own safety while she is at work. When Ann's mother returns home after four weeks, she is very frail physically and, though still fairly mentally capable, needs Ann's help with virtually all household management and personal care tasks, including managing finances. Ann pays bills by writing checks from her parents' bank accounts, on which they had her named as a joint owner. Ann also uses her personal bank account to pay some expenses, but because they are all one household, Ann tends to use the accounts interchangeably.

As Ann is adapting to this new care routine for her parents, she is suddenly fired from her job, because her supervisor assesses her performance as "lackadaisical" and "less competent and committed" to her work than is necessary for employment. In discussing what to do next with her mother, her mother insists that they pay Ann for her caregiving



This article discusses eight key law-related issues affecting family caregivers:

- decisional capacity;
- surrogate decision-making;
- caregiver access to health information;
- abuse and neglect risks;
- designating a financial decision-maker;
- designating a healthcare decision-maker;
- family responsibilities discrimination by employers;
- and, use of personal care agreements to pay family caregivers.

because it is so time consuming, and it is unfair to expect Ann to forego employment. They agree that Ann will be paid \$2,000 per month. Some weeks later, her brother calls, concerned about their parents' status. After an emotionally volatile conversation, he accuses Ann of taking financial advantage of their parents, and insists that both parents need to be in a residential care facility.

The predicament faced by Ann and her parents raises questions about appropriate access to support services, caregiver stress, financial management, and quality of care. But it also raises several legal conundrums and risks that can and should be addressed. This article discusses eight key law-related issues affecting family caregivers: decisional capacity; surrogate decision-making; caregiver access to health information; abuse and neglect risks; designating a financial decision-maker; designating a healthcare decision-maker; family responsibilities discrimination by employers; and, use of personal care agreements to pay family caregivers.

Decisional Capacity

Ann is facing issues regarding her parents' capacity to make decisions for themselves. How does she know where the line lies between respecting a loved one's decision-making autonomy and stepping in as decision maker? The starting point in understanding capacity is grasping the reality that capacity is task-specific and time-specific. One may have capacity to get dressed and prepare meals, but lack the capacity to manage finances. Or, one may have capacity to manage some finances in the morning, but not late in the day, or not after certain medications are taken.¹

Though people can become totally and permanently incapacitated due to advanced illness, most cases fall into a broad and variable continuum. Ann's parents still have some capacities at some times, but are gradually losing others. Ann needs help sorting out decisional capacity as a first step in determining how her parents' needs can be met. This may be especially important in dealing with her brother, who seems to have judged their parents' incapacity as being well beyond Ann's caregiving abilities.

¹ American Bar Association (ABA) and American Psychological Association (APA). 2005. *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*. Washington, DC: American Bar Association.

A second key to understanding capacity is distinguishing between legal and clinical notions. Legal incapacity is not the same as clinical incapacity, yet the concepts often are not clearly distinguished. Clinical incapacity is a functional conclusion based on an assessment of the particular cognitive, emotional, and physical faculties required to accomplish a specific task. Legal incapacity requires a finding by a civil court that the appointment of a guardian or conservator is necessary to manage some or all of one's affairs. Questions of legal capacity normally will not arise if other legal tools have been thoughtfully put into place before one's capacity declined—tools such as powers of attorney for finances and for healthcare decisions. For a court to find legal incapacity, it must be convinced not only that the individual lacks the clinical capacity to perform one or more essential functions, but also that the court's intrusion into the individual's life is necessary (i.e., there are no other options left to support the autonomy and well-being of the individual that are less restrictive than appointing a guardian). For Ann's parents, the law still presumes legal capacity.

It can be daunting to be a caregiver for a loved one whose capacity to handle ADLs [activities of daily living] and IADLs [instrumental activities of daily living] is uncertain. Neuroscience research tells us that financial capacity and judgment with respect to finances often decline before other functions, putting persons with mild impairment at risk for financial exploitation.² It is advisable to get a professional assessment of capacity early on in cases of chronic, progressive illnesses accompanied by dementia. Assessment can help provide a clearer picture of the current level of functioning, underlying diagnoses, and likely progression of the condition(s); identify supports and accommodations to maximize capacity; and confirm when to trigger legal arrangements that have been voluntarily set up for surrogate decision-making, such as powers of attorney.

The ideal resource for obtaining professional assessments is an interdisciplinary team specializing in geriatric assessment. This type of team assessment evaluates multiple issues including physical, cognitive, affective, social, financial, environmental, and spiritual components that influence the older adult's health and

² Widera, E., et al. 2011. "Finances in the Older Patient with Cognitive Impairment." *Journal of the American Medical Association* 305(7): 698-707.

then develops a coordinated plan to maximize health and functioning.³ If such a resource is not available, the most important criteria for an assessment is the professional's (e.g., primary care physician or other clinical provider) depth of experience in geriatric capacity assessment, rather than the particular letters that follow that professional's name. Resources available vary considerably by community. Ann's best starting point for finding the resources available in her community is likely to be her local area agency on aging.

Surrogate Decision-Making

Even though Ann's parents have not yet had a formal assessment of capacity, Ann clearly has stepped into the role of de facto surrogate decision-maker. But what is the basis of Ann's authority to act as their decision maker, and what is the extent of that authority? Ann's authority can come from any of the following three possible sources:

Delegated decision authority

This is accomplished through the use of legal advance planning documents created while the individual still has decisional capacity. The most common devices are powers of attorney that can be created for financial and healthcare decisions. Trusts also are a common planning instrument, but normally used in circumstances where there is a need to manage a significant amount of property, or property across multiple jurisdictions. In Ann's parents' case, none of these legal tools were used.

³ Elsayw, B., and Higgins, K. E. 2011. "The Geriatric Assessment." *American Family Physician* 83(1): 48-56.

Judicially determined decision-making authority

A guardianship or conservatorship proceeding is the vehicle for obtaining this authority. The process, cost, and consequences vary by state, but almost always require legal assistance to navigate and can be expensive, time-consuming, and stressful. It is a solution of last resort. Once established, the individual appointed as guardian has only the authority specified in the guardianship order and serves under the supervision of the court.

Devolution of authority under state law

For health decisions, the majority of states (about forty-four) authorize a close family member to step in as surrogate decision-maker for treatment decisions.⁴ Typically, a next-of-kin hierarchy of permissible surrogates is specified, starting with one's spouse, then adult children, and down to some level of kinship, defined by each state. About half the states include close friends as an alternative if no family members are available.⁵

The trigger for these default surrogate laws is a clinical finding (not a legal finding) of incapacity to make a treatment decision. Assuming Ann and her parents live in a state that includes default surrogacy, she could have authority to make healthcare decisions for her parents when they lose the capacity to make those

⁴ Wynn, S. 2014. "Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States." *Bifocal* 36(1): 10-4. http://www.americanbar.org/publications/bifocal/vol_36/issue_1_october2014/default_surrogate_consent_statutes.html. Retrieved August 4, 2015.

⁵ ABA Commission on Law and Aging. 2015. "Health Decisions Resources" (periodically updated). <http://www.ambar.org/HealthDecisions>. Retrieved June 29, 2015.



decisions, but their incapacity must be determined and documented in the medical record, as prescribed by the health surrogacy law in their state. A complicating factor is that Ann's brother will have equal authority with Ann with respect to healthcare decisions. If Ann and her brother don't get along, it will undermine decision making. If her parents don't live in a state with default surrogacy, then Ann's options are more restricted and the importance of advance planning is all the more emphatic.

There are no equivalent default surrogate laws for financial decisions. Ann has no inherent authority to assume the role of financial decision-maker over her parents' assets, even if she is going to be the beneficiary of those assets after her parents' deaths. The one caveat is the joint bank account. While the money in that account may belong to her parents, her name on the account gives her the same practical control over the money as her parents had. Families commonly use joint financial accounts like this. However, such accounts have major risks. They muddle intended ownership: Ann's parents may have intended her to serve only as helper to make sure bills were paid, and not as an owner of the account. Yet Ann now has the easy means, albeit improper, to use the money as she pleases and even empty the account. And Ann's creditors may have the ability, through legal action, to reach that account to satisfy Ann's debts. The arrangement may also contribute to suspicions and discord with her brother. Using a power of attorney (described later in this article) to manage her parents' finances would have been the preferred course of action.

Caregiver Access to Health Information

Ann has already encountered resistance from healthcare providers in trying to access her mother's health information. That is because most healthcare providers and facilities are bound to very detailed rules intended to protect the privacy of patients' personal health information. The rules were established by the Health Insurance Portability and Accountability Act of 1996⁶ and its regulations, one component of which is known as the Privacy Rule.⁷

⁶ Health Insurance Portability and Accountability Act of 1996 (HIPAA). 1996. PL 104-91.

⁷ 45 C.F.R. Part 160 and Subparts A and E of Part 164 (2013) (The Privacy Rule).

The starting point of the Privacy Rule is that healthcare providers cannot disclose a patient's personal health information without the patient's consent. The HIPAA Rules (specifically, the Privacy Rule) enumerate several exceptions, most of which address the necessity to share information among the providers and suppliers involved in Ann's mother's care, or who regulate or pay for that care. Ann may have access to her parents' health information in one of three ways. First, she could be their "personal representative." This status is given to someone legally authorized to make healthcare decisions for the patient.⁸

As noted above, this can come about by virtue of a healthcare power of attorney (which Ann does not have), or by being appointed guardian with health decisions authority, or by virtue of the default surrogate decision-making law for health decisions under state law. The need to establish this status with documentation and a determination of her parents' incapacity to make healthcare decisions is an extra challenge for Ann, but necessary to be recognized as a personal representative. As her parents' personal representative, Ann would be entitled to the same access and the same rights to consent to, or limit access to, personal health information as each of her parents do themselves.

A second means of access is through a valid HIPAA authorization. There is no standard form for such an authorization, but it must be a document, signed by the patient, that identifies the information to be disclosed, to whom, for what purposes, and for what duration. An example may be found on the health decisions Web resource page of the ABA Commission on Law and Aging at <http://ambar.org/healthdecisions>.⁹ To complete an authorization, the patient must still have the capacity to knowingly and voluntarily execute a HIPAA authorization.¹⁰

The third means by which Ann may access information about her parents' health is the family and friends discretionary rule. Where authority is lacking under the above two options, the healthcare provider may

⁸ 45 C.F.R. § 164.502(g) (2015) (Personal Representatives).

⁹ ABA Commission on Law and Aging. 2015. "Health Decisions Resources" (periodically updated). <http://www.ambar.org/HealthDecisions>. Retrieved June 29, 2015.

¹⁰ 45 C.F.R. § 164.508 (2015) (Uses and Disclosures for which an Authorization Is Required).

share limited information with family and friends who are involved in the patient's health in some way. The simplest way for this to happen is for Ann's mother to tell her healthcare provider, "It's okay to talk to Ann." Or, permission can be implicit by not objecting to the sharing of information in the presence of the provider. However, as is commonly the case, the patient may not always be present or may not have capacity to consent. In that situation, the Privacy Rule gives the provider broad discretion, based on professional judgment, to determine whether it is in the patient's best interest to share information.¹¹

Moreover, the information shared must be limited to the minimally necessary information that the person involved needs to know about the patient's care or payment.¹² For example, if Ann has to depend on the discretionary rule to request copies of diagnostic tests the hospital performed on her mother, the hospital might refuse, saying that summary findings are sufficient for purposes of her involvement in her mother's care. Under the "minimally necessary" guideline providers follow, less is better. This is the situation in which the healthcare provider wields the most control, and where a caregiver may find herself obstructed. Again, this highlights the value of a healthcare power of attorney.

Abuse and Neglect Risks

Ann is desperately struggling to care for her parents, to keep them at home, and to stay employed. While her intent is good and even courageous, Ann may already have stepped over the line of neglect and abuse. Locking her father in the apartment even once

¹¹ 45 C.F.R. § 164.510 (2015) (Uses and Disclosures Requiring an Opportunity for the Individual to Agree or to Object).

¹² 45 C.F.R. § 164.502(b) (2015) (Standard: Minimum Necessary).

and using her parents' bank account interchangeably with her own are both actions that, on their face, raise neglect and financial-exploitation flags. Ideally, long-term services and supports (LTSS) would be available to help Ann understand and implement a plan of care for her parents, while enabling her to remain employed. However, with limited time and a lack of familiarity with available resources and LTSS, Ann did not have those supports at the time of her mother's hospitalization. What is available depends upon where she and her parents live, and the institutions she deals with.

In managing their financial affairs, Ann has stepped into a role in which the law expects her to meet basic fiduciary standards, of which she may be oblivious. For example, she should maintain a strict separation between her money and obligations and those of her parents. As emphasized earlier, relying on a joint bank account is an easy but very risky way of managing another person's money. A better strategy would be to designate a financial decision-maker through a financial power of attorney.

Designating a Financial Decision-Maker

Caregiving for anyone with diminished capacity is always easier when there has been advance care planning before the onset of serious illness. The goal is to have someone trustworthy in place in the event one loses capacity to manage financial and personal affairs. For financial tasks, a financial power of attorney is an essential—but too often misunderstood—legal tool. It often is perceived as a simple, standardized form document. In reality, powers of attorney need to be closely tailored to individual needs and circumstances. Without that, a power of attorney can be a blank check for financial exploitation.

“ For financial tasks, a financial power of attorney is an essential—but too often misunderstood—legal tool. It often is perceived as a simple, standardized form document. In reality, powers of attorney need to be closely tailored to individual needs and circumstances. ”



A well-drafted power of attorney should clearly describe the powers given to the agent (Ann) and meaningful protections for the principal (Ann's mother or father). For example, if there is a possibility that the agent may need to hire herself as a caregiver for the principal, that power should be explicitly stated in the power of attorney; otherwise, it may be seen as selfdealing if Ann were to pay herself.

There are several powers that a principal may be advised to limit or not to confer upon the agent at all, such as the power to make unlimited gifts, to change beneficiaries on insurance policies, to change rights of survivorship on financial accounts, or create or amend a trust. Also, selected safeguards can help avoid financial misdirection, such as requiring a yearly financial accounting to another family member, or requiring the written consent of a designated person to engage in transactions over a specified amount. Powers of attorney are private consensual arrangements, so there is no routine outside scrutiny of them unless such oversight is written into the document.

To the extent that Ann's parents' income consists of Social Security and-or veterans benefits, she will need to make a request to those agencies to be appointed as their representative payee (for Social Security) or VA fiduciary (for veterans benefits) if her parents cannot manage those funds. If approved, her parents' checks would be paid to her, to be managed on behalf of her parents. Monitoring of the appointment is done through an annual report that Ann must file with the agency.

As a designated agent or representative payee or VA fiduciary, Ann would legally be a fiduciary under the law and expected to comply with basic fiduciary duties. However, many (if not most) family members acting as agent have no familiarity with fiduciary duties. The Consumer Financial Protection Bureau makes available four simple, free guides¹³ for family members acting in any fiduciary capacity: one each for agents under powers of attorney, family trustees, guardians or conservators, and representative payees-VA fiduciaries. The guides explain four basic fiduciary duties that would apply to Ann: acting only in her parents' best interests; managing their

¹³ Consumer Financial Protection Bureau (CFPB). 2013. Managing Someone Else's Money: Help for Agents Under a Power of Attorney. <http://www.consumerfinance.gov/blog/managing-someone-elsesmoney>. Retrieved August 4, 2015.

money carefully and avoiding conflicts of interest; keeping their property separate from hers; and keeping good records. Guides are available at www.consumerfinance.gov/blog/managing-someone-elses-money.

Designating a Healthcare Decision-Maker

Just as with financial affairs, healthcare decision-making for anyone with diminished capacity is always easier when there has been planning before the onset of serious illness. For health planning, most people have at least heard of the legal documents that are available to use to direct their care: Living Wills and Health Care Powers of Attorney. These documents are known more generally as Health Care Advance Directives.

A Living Will is a document that spells out wishes or preferences about end-of life care, and a Health Care Power of Attorney is a document that legally appoints someone to make medical decisions for another (the principal), should the principal be unable to make them herself. Depending on the state, the person appointed may be called a "healthcare agent," "proxy," "surrogate," or "attorney-in-fact," among other titles. Both documents can be combined into one healthcare advance directive.

Of the two, the healthcare power of attorney is by far the more essential. Sound decision-making for Ann's parents requires her to understand the medical circumstances and options faced by her parents in real time, and to make decisions in collaboration with their healthcare providers, based upon her parent's most important values, priorities, and wishes. The latter task depends on Ann's intimate knowledge of her parents' wishes, which in turn depends on whether or not she and her parents have had direct and meaningful discussions about their goals and priorities. To that end, a growing number of tools for guiding reflection and conversation about healthcare advance planning are easily available,¹⁴ and can be accessed through the health decisions Web resource page of the ABA Commission on Law and Aging¹⁵ at <http://ambar.org/healthdecisions>. Ann should try

¹⁴ Sabatino, C. P. 2014. "Advance Care Planning Tools that Educate, Engage, and Empower." Public Policy and Aging Report 24(3): 107-111.

¹⁵ ABA Commission on Law and Aging. 2015. "Health Decisions Resources" (periodically updated). <http://www.ambar.org/HealthDecisions>. Retrieved June 29, 2015.

to initiate these conversations, even at her parents' advanced stage of illness.

Family Responsibilities Discrimination

Ann was fired from her job at the grocery store. Perhaps her supervisor's negative assessment of her work performance was accurate. But possibly, Ann's need to take periodic and sometimes unplanned time off to care for her parents was the reason. The latter phenomenon has been called family responsibilities discrimination, or FRD. FRD is employment discrimination against people based on their caregiving responsibilities— whether for children, elderly parents, or ill family members. It arises when an employer treats an employee with caregiving responsibilities based on stereotypes about how the employee will or should behave, rather than on that employee's individual interests or performance.¹⁶ Ann may be perfectly competent and committed to her

¹⁶ Williams, J. C., and Bornstein, S. 2008. "The Evolution of 'FRED' Family Responsibilities Discrimination and Developments in the Law of Stereotyping and Implicit Bias." *Hastings Law Journal* 59: 1311–58.

work, but her supervisor may equate her need to fulfill caregiving responsibilities as equivalent to lack of commitment to work or incompetence.

Surprisingly, most federal and state statutes don't expressly prohibit discrimination based on family responsibility, although there is increasing attention to the topic. FRD-related claims challenging employer actions typically rely on other related discrimination causes of action, such as sex discrimination, hostile work environment claims, or discrimination based on association with a person with a disability. Ann can complain to the Equal Employment Opportunity Commission if she suspects discrimination on these grounds.

The one federal law that directly addresses caregiving is the Family and Medical Leave Act (FMLA), which applies to employers with more than 50 employees. Ann's employer, a grocery chain, is almost certainly covered. Ann has also worked there more than a year, another requirement of the Act, so under the FMLA she is entitled to up to 12 weeks of unpaid, job-protected leave per year to care for her parents or a spouse or child. Unfortunately, less than 60% of the workforce is covered by the FMLA.¹⁷ And, if one is caring for a non-covered relative, such as a grandparent, in-law, or sibling, the FMLA doesn't apply. Violations of the FMLA provide a basis of a legal claim if the employee can establish that the employer interfered with, restrained, or denied the exercise of FMLA rights. The Wage and Hour Division of the U.S. Department of Labor receives FMLA claims. In all instances, the filing of a civil action in state or federal court is likely necessary because administrative enforcement is weak unless the claim is egregious. The Center for WorkLife Law reports that the number of FRD cases filed between 1999 and 2008 (2,207 cases) was nearly five times the number of cases filed between 1989 and 1998 (444 cases).¹⁸

National policy that supports workers with caregiving responsibilities falls far short of today's social realities, given the high prevalence of caregivers in the workforce, as well as the increase in the aging population needing LTSS, and the dependency

¹⁷ Feinberg, L. 2013. *Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies*. Washington, DC: AARP Public Policy Institute.

¹⁸ Calvert, C. T. 2010. *Family Responsibilities Discrimination: Litigation Update 2010*. San Francisco, CA: UC Hastings College of Law, Center for WorkLife Law.



upon family caregivers for the lion's share of care for that population. Proposed solutions abound, such as providing greater flexibility in work hours; expressly prohibiting FRD in federal law; expanding the coverage of the FMLA; requiring paid FMLA; mandating minimum sick leave for all employees; or, establishing paid family and medical leave under a mandatory social insurance model.¹⁹ All of these face obstacles on a national level, even though state-level and private-industry examples have been shown to be successful.²⁰

Personal Care Agreements

Ann was forced into a trade-off between working and caring for her parents. She's not unique in facing that dilemma. A recent survey²¹ by the National Alliance for Caregiving and the AARP Public Policy Institute found that 60% of caregivers were employed at some point in the past year while also caregiving; and, among employed caregivers who are not self-employed, 11% reduced work hours or took less demanding jobs, and 5% gave up working entirely. Without employment, Ann faces not only the loss of income, but also the loss of the Social Security work credit and of employee benefits such as healthcare coverage or future pension benefits, if these were provided by her employer.

¹⁹ Feinberg, L. 2013. Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies. Washington, DC: AARP Public Policy Institute.

²⁰ Bornstein, S., and Rathmell, R. J. 2009. Caregivers as a Protected Class?: The Growth of State and Local Laws Prohibiting Family Responsibilities Discrimination. San Francisco, CA: UC Hastings College of the Law, Center for WorkLife Law. www.worklifelaw.org/pubs/LocalFRDLawsReport.pdf. Retrieved August 18, 2015. See also Equal Employment Opportunity Commission (EEOC). 2009. Employer Best Practices for Workers with Caregiving Responsibilities. www.eeoc.gov/policy/docs/caregiver-best-practices.html. Retrieved August 18, 2015.

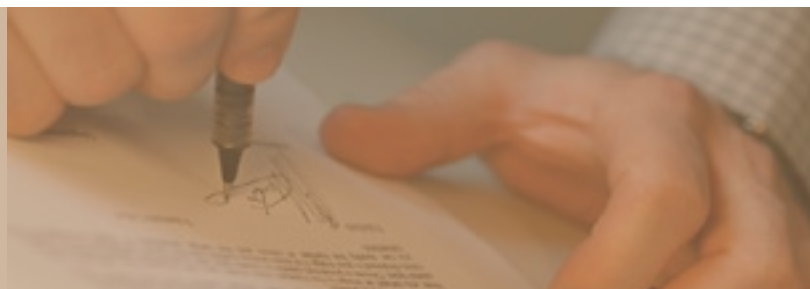
²¹ National Alliance for Caregiving and the AARP Public Policy Institute. 2015. Caregiving in the U.S. 2015. www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html. Retrieved August 18, 2015.

Being paid by her parents to provide personal care services can be a win-win situation for all, because her parents prefer Ann over paid caregivers who are unknown to them, it will enable them to remain at home, and it will provide Ann with an income. However, the legal trap here is trying to do this without a formal personal care agreement (PCA), prepared in consultation with legal counsel. Ann has already run into the wrath and distrust of her brother, as he perceives her to be making up her caregiving role, as circumstances change, without any clear assessment or plan. Forming a PCA provides an opportunity to bring family members together with a professional and the care recipient to discuss and explore options, and devise a plan everyone will support.

The legal issues of a PCA include employment tax and reporting responsibilities, estate-planning issues (because anyone with siblings will face potential disputes over inheritance from the parents' estate), and Medicaid issues. Ann's parents may never have imagined needing to rely on Medicaid, but as their care needs increase, many Americans find that their comfortable middle-class incomes and estates are insufficient to cover long-term-care costs, and they turn to Medicaid. Medicaid rules vary considerably by state, but all states view family PCAs with skepticism and may impose several restrictions.

Unless there is an acceptable PCA in place before services are provided, all states will presume those services were intended to be provided without compensation, and any transfers of money or property to the caregiver will be seen as transfers of assets that disqualify the care recipient from Medicaid coverage for a period of time, tied to the size of the transfers. The transfers also may be viewed as possible financial exploitation by authorities. If care was being provided gratuitously for a period of time, a decision to switch to paying the family caregiver faces even greater scrutiny and distrust by Medicaid officials.

“ Forming a personal care agreement provides an opportunity to bring family members together with a professional and the care recipient to discuss and explore options, and devise a plan everyone will support. ”



At a minimum, the PCA between Ann and her parents must be in writing and signed by the parties before services are rendered. It must define the services to be provided and their duration, and define the compensation to be paid. Care needs change, therefore some process for changing the amount, type, or level of services to be provided should be considered. For example, changes could be triggered by periodic assessments of care needs by a geriatric care manager or other health professional. The involvement of a geriatric care manager at the inception of a PCA will help definitively establish the need for and level of services specified in the PCA. In many states, Ann will also need to compile evidence of the fair market value of the services to be provided, and once services begin, she will need to keep a detailed daily log of caregiving services.²² Guidance on paying employment taxes and income reporting also is important; consult the IRS Publication 926, Household Employer's Tax Guide.²³

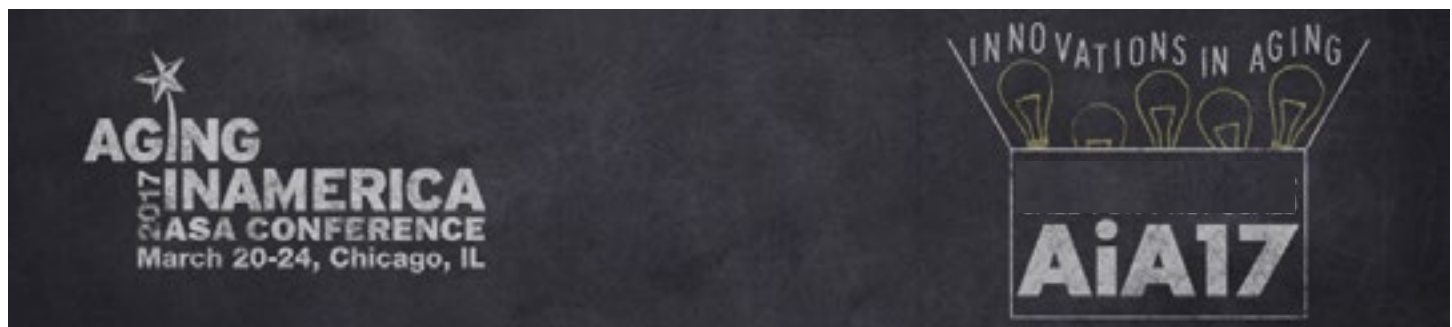
²² Peck, K., and Law, R. L. 2013. *Alzheimer's and the Law: Counseling Clients with Dementia and their Families*. Chicago: American Bar Association.

²³ Internal Revenue Service (IRS). 2014. *Household Employer's Tax Guide*. Publication 926 (revised periodically). www.irs.gov/publications/p926/index.html. Retrieved August 18, 2015.

In the end, Ann's success in balancing her needs and her parents' increasingly demanding care needs requires planning ahead for both health and financial contingencies, connecting with and maximizing available long-term-care services and supports, and getting good clinical and legal guidance. It may be disquieting to find that legal issues so pervasively permeate the world of family caregivers, but that is the world we live in. With determination, it can be mastered . . . or at least help to put Ann, and others like her, on a footing that better serves her parents' and her own needs.

Charles P. Sabatino, J.D., is the director of the American Bar Association Commission on Law and Aging, Washington, D.C.

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Over 3,000 attendees from across the nation and abroad attend the annual ASA Aging in America Conference conference to learn, network and participate in the largest multidisciplinary conference covering issues of aging and quality of life for older adults.

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“Stepping in When Help is Needed”

An interactive training video for family guardians

by John J. Ford

The narrative portion of the training video opens in a hospital room. An older woman sleeps in a hospital bed as a younger woman, her daughter, sits nearby. The older woman wakes.

“How long have I been here?”

“Mama, you can’t walk yet. You broke your hip, remember?”

“How long have I been here? It feels like forever.”

“Just four days, Mama. Now you have to try to get up and start walking a bit.”

“I want to go home.”

Mrs. Mendez is recovering from hip surgery and is confused and having trouble making decisions. Her daughter Espy has stepped in and is trying to assist her mother through this complicated time.

Introduction

Since the 1980s in Massachusetts, advocates of seniors and of people with disabilities have been engaged in the daunting campaign to reform the state’s guardianship laws and procedures. As one of the original 13 colonies, the state is long burdened with archaic legal notions of how to address the needs of mentally or intellectually incapacitated persons. For example, until as recently as 1992, a petition could be filed in Massachusetts probate courts for the appointment of a conservator for an individual on no other reason than the basis of “advanced age.”

An Initial Resource:

“Guardianship: the Hidden Issues” Video

In the 1990s, advocates organized the Massachusetts Guardianship Task Force (MGTF) and, in the environment encouraged by a reform-minded Attorney General Scott Harshbarger, year after year proposed legislation which included concepts of legal due process as well as concepts based on knowledge derived from decades of experience in medicine, psychiatry, and gerontology. When a succession of Legislatures showed no real inclination to embrace meaningful reform, advocates and stakeholders turned their efforts to community education, to build a greater constituency for reforms. The late Judith



Lennett secured funding from the Attorney General's office and led the project to produce a training video that dramatized the lack of due process in guardianship proceedings which stripped respondents of freedom and autonomy. "Guardianship: the Hidden Issues" told the story of Emily Gale, plunked into a nursing home involuntarily because her treating physician described her as "befuddled" and because she was refusing cataract surgery.

The first audience Lennett presented the video to was a group of Probate Court judges at a judicial conference. They learned about the inadequacies of medical certificate forms in use. For example, a medical certificate reciting nothing more than: "Senile dementia. Dr. Jones," highlighted the all-too-common phenomenon where a respondent does not even appear at a guardian or conservator appointment hearing, and situations where the allegedly incapacitated person loses freedom and autonomy without benefit of counsel.

Some sensational press coverage by the Boston Globe's Spotlight Team of overreaching, if not larcenous, fiduciaries contributed to the growing awareness that as a society we are not responding to the needs of an ever increasing cohort of incapacitated seniors and persons with disabilities. Dr. Jennifer Moye, another MGTf member, was engaged at the national level on the failure to assess incapacity in older adults in any meaningful fashion. She, with the support of the American Bar Association (ABA) and American Psychological Association (APA), produced several guides on capacity for lawyers and judges.¹

¹ See http://www.americanbar.org/groups/law_aging/resources/capacity_assessment.html.

Fast-forward to the early 2000s when all the stakeholders (MGTf and other advocates of older or disabled people), the judiciary, and the Massachusetts and Boston Bar Associations joined forces to propose the enactment of the Massachusetts Uniform Probate Code (MUPC), Article 5 of which was the Uniform Adult Guardianship and Protective Proceedings Act (UAGPPA). The proposed legislation enshrined all the due process reforms we had been clamoring for decades: the right to counsel, "limited" guardianship (that is, intervention only where the person lacks capacity), further oversight of the court appointed guardians, etc.

Success came in 2008, when the MUPC was signed into law by Governor Patrick and implemented in 2009, with astounding vigor and commitment under the leadership of Probate Court Chief Justice Paula Carey.

Development of an Updated Video Resource

Even as rule changes, forms, and procedures were being redesigned and the reforms implemented, Judge Carey urged the stakeholders to develop methods of training, educating, supporting, and monitoring family guardians (they are by far the greatest proportion of court-appointed guardians, and take on very serious responsibilities on behalf of their loved ones). She urged advocates specifically to develop interactive videos to introduce the basic concepts of guardianship law and procedures, and to inform the public on how to avoid the drawbacks of guardianship by effective life planning. This approach of educating all to the very real value of executing health care proxy documents and durable powers of attorney documents should obviate the need for court intervention when incapacity occurs.



Judith Lennett and her small non-profit, Northnode, took up the challenge. A seed-money grant from the Massachusetts Guardianship Association, with Judy Flynn as its President, funded her search for resources to make the production of a family guardian training video a reality. She developed a proposal for “Stepping In When Help is Needed” and a budget, and secured a grant from the Attorney General’s office to begin the project in earnest. Northnode staff and the producers wrote a script, and Lennett recruited a talented group of volunteer actors and actresses and hired a professional videographer. Judge Carey agreed to appear in a prologue and epilogue to explain its purpose and encourage its audiences. We secured the locations for the filming with the cooperation of the Suffolk Probate Court and the Milton Hospital, and the video was shot in two days. Post-production was extensive, and credit goes to Northnode and Nesson Video Productions for contributions well beyond their compensation—the production was a triumph of volunteerism.

“Stepping In When Help is Needed” tells the story of Dolores Mendez, a hospital patient recovering from surgery to repair a fractured hip. Her daughter Esperanza (Espy), like many other devoted but overwhelmed family members in such circumstances, must step in to deal with the crisis. The hospital discharge planner tells Espy that Mrs. Mendez is now stable and must move on to a rehabilitation facility where hopefully she will be able to regain the ability to walk. However, Mrs. Mendez is refusing to go to the rehab facility, which she calls a “nursing home.” She has not executed a health care proxy document, and in her confusion, will not sign any documents without first consulting with her husband; Espy tells us that her father died two years ago. The video shows the discharge planner’s ultimatum and Espy’s consultation with a geriatric care manager and an elder law

attorney. The video also details a court hearing on Espy’s motion for appointment of a temporary conservator and appointment of a temporary guardian with a grant of authority to admit Mrs. Mendez to a rehab facility.

The optimal use of the video is a presentation by an experienced facilitator to a group of family guardians, or professionals who deal with such situations. There are several pauses in the action where a facilitator can pose questions or invite comments and assist in the discussion. Judith Lennett developed materials for use by the facilitator, including basic information, mock pleadings, etc.

Handbook Resource Currently in Development

Our next project is a complete re-write of the now-obsolete *2004 Handbook for Guardians of Nursing Home Residents in Massachusetts*.² The *Handbook* gives reader friendly instructions on how to secure a guardianship for an incapacitated nursing home resident, and how to successfully complete the long term care Medicaid application process. The project of re-writing the handbook is already underway by Ellen O’Donnell, who designed the syllabus for the course at the Gerontology Institute at the University of Massachusetts Boston, for which the *Handbook* was the course project. The current plan is to change the identity of the individual nursing home resident and incorporate the story of Mrs. Mendez.

John J. Ford is the Director of the Elder Law Project at the Northeast Justice Center in Lynn, Massachusetts. For further information on this project, Mr. Ford may be contacted at jford@njc-ma.org. ■

² The *Handbook* is still available online at <http://bookstore.iuniverse.com/Products/SKU-000081553/A-Handbook-for-Guardians-of-Nursing-Home-Residents-in-Massachusetts.aspx>.



Legal Access for Elders: A Workable Court Model in Cook County, Illinois

by Hon. Patricia Banks

A 70 year-old woman has a grandson who is running up unauthorized charges on her credit card; an 80 year-old homeowner ignored a city citation for failure to cut his grass, resulting in a money judgment and property lien; a caregiver is overreaching and financially exploiting a 90 year-old man; an 82 year-old woman, with seemingly good health, and cognition is outside in the dark, retrieving throw rugs from a trash bin and looking for contractor nails on the ground to hang her family photos.

Would an Elder Justice Center address these issues?

The Honorable Timothy C. Evans, Chief Judge of the Circuit Court of Cook County, Illinois, created a division of the Court to focus on socio-legal issues of seniors, such as the above described scenarios. He appointed Honorable Patricia Banks as the first Presiding Judge to implement and coordinate the new division, now known as the Elder Law and Miscellaneous Remedies Division (ELMRD). The Cook County Elder Justice Center (“Center”) is a vibrant part of the Division, which also includes multiple elder protection courts. Judges assigned to the elder protection courts hear cases involving abuse, neglect, and financial exploitation of seniors, and routinely rely on the support services of the Center.

The Center is conveniently located in Cook County’s largest courthouse, the Richard J. Daley Center. Cook County residents age 60 and over, and their caregivers, are eligible to receive a multitude of free services. Eligible residents may walk into the Center for services or schedule an appointment. The 192 judges who preside over cases in the Daley Center regularly refer senior litigants to the Center for information, consultation, and other services.

A modest start-up budget was appropriated by the Office of the Chief Judge for the Center. It included approximately 4,000 square feet of space, telephones, office supplies, computers, desks, chairs, and two full-time staff members. Later, an appropriation for a social worker was added. A year prior to the Center’s September 2013 launch, the Presiding Judge recruited a 35-member multi-disciplinary task force.¹ These task force members provide a direct entrée to the supplemental services and agencies that they represent. Task force members are an integral part of the Center’s overall operation. They have assisted in the development of training manuals, brochures, literature, work flow charts, and marketing strategies, as well as with distribution of resource materials and literature. They also participate in senior health

¹ The Task Force proved to be a powerful resource, critical to the creation and ongoing sustainability of the Center. Members of the Task Force include representatives from the offices of the Attorney General, States Attorney, Public Defender, law enforcement, the Clerk of the Circuit Court, the Public Guardian, Directors of the two Area Agencies on Aging, Directors of legal aid organizations, law schools and graduate school of social work deans, bankers, accountants, investment brokers, elder law practitioners, media specialist, real estate brokers and journalists, judges, faith based and community representatives, and law enforcement representatives.

fairs, workshops, and seminars. They identify and recruit personnel, attorneys, law students, community volunteers—and they provide training.

With delivery of legal services to older persons seriously compromised due to budgetary reasons, and education programs designed to protect seniors at a minimum, the Center has emerged as a working model. It shows tremendous promise for those courts wishing to develop an effective response to the proliferation of elderly older litigants in the nations' court systems.

On-Site Legal Clinic: Elder Law & Wellness Initiative (ELWI)

ELWI is a nonprofit legal clinic, sited in the Center since October 2014. The clinic currently provides legal advice and consultations to over 250 seniors monthly on matters such as mortgage foreclosures, benefits, housing, bankruptcy, debt collection, landlord-tenant, guardianships, abuse, neglect, and financial exploitation. Attorney services may also include drafting simple motions; assistance with completing court forms such as fee waivers, appearances, answers; or composing demand letters. Volunteer attorneys range in experience from new admittees to retired judges. Their practices range from sole practitioners to partners in major law firms, with legal knowledge and expertise in many diverse areas of the law. The legal clinic's Executive Director, seasoned attorneys, legal-aid organizations, and Task Force members provide training.



Senior Enrichment Seminar Series

Another significant Center offering is the Senior Enrichment Seminar Series. These seminars are tailored to accomplish multiple goals, such as: problem solving, information, empowerment, awareness, and prevention. They address common issues that cause seniors to come in contact with the court system (e.g., debt collection, reverse mortgages, financial literacy, real estate fraud, housing, substance abuse, benefits, powers of attorney, abuse, neglect and financial exploitation). Law school externs research and provide materials for the seminar attendees. These bi-weekly seminars enjoy a loyal following of seniors, with attendance ranging between 60 to 100 persons per session.

All seminars are widely marketed and listed on the ELMR Division webpage.² The websites of the Illinois Attorney General, Clerk of the Circuit Court of Cook County and Cook County Recorder of Deeds include links to the ELMR Division webpage.

The seminar series has a far-reaching impact. County offices, veterans groups, financial institutions, bar associations, faith-based organizations, senior centers, and entities dealing with seniors have invited seminar panelists to present in other venues, while others ask to participate as panelists or to present seminars as part of the series.

Social Service Resources and Social Security Express Portal

The Center's social worker assists and counsels seniors who present with issues such as abuse, neglect, mental, medical, and housing problems. Benefit check-ups, short-term case management, and assessments are available through the Center's social worker. Since joining the Center's staff, the social worker has upgraded the Center's comprehensive directory, and also has compiled resources for guardians. The Center's extensive reference library and referral network, along with the personal attention provided by trained staff members and volunteers, make it possible to provide wrap-around services.

The Social Security Administration (SSA) initially piloted its Social Security Express portal in the Center and now annually updates its program to allow seniors

² Please see <http://www.cookcountycourt.org/ABOUTTHECOURT/CountyDepartment/ElderLawMiscellaneousRemediesDivision/FreeSeminarSeriesEJC.aspx>.

direct access to apply for and monitor SSA benefits. The Center's staff assists seniors with free email account setup and requesting replacement Medicare cards.

Language Access and Other Assistive Devices

The Circuit Court of Cook County serves many ethnic groups. The Center is equipped to assist limited or non-English speaking as well as visually and hearing impaired customers. This allows for a diverse population of seniors to receive meaningful consultations and to participate in senior enrichment seminars and courthouse tours. Assistive listening devices, Communication Access Real-time Translation (C.A.R.T.) services, and interpreter services are available for this purpose. A Language Line is located in the Center, which provides interpretation services for 20 languages via a double headset telephone. The Center can schedule an in-person interpreter, subject to adequate notice. A number of Task Force members and Center volunteers are bilingual and are available to translate (i.e., Chinese American League and the Coalition for Limited English Speaking Elderly (C.L.E.A.S.E)).

Senior Peer Counselor Program

The Senior Peer Counselors Program assists seniors with navigating the Court system by clarifying and providing information on processes and procedures; connecting seniors to resources and services; lending a supporting ear; and serving as escorts to courtrooms, the Center, and various County offices (e.g., vital statistics, recorder of deeds, sheriff, and clerk). Senior Peer Counselors undergo a rigorous 10-week training program to hone their skills on the art of listening, mindfulness, legal terminology, signs and symptoms of abuse and neglect, and more. Victim advocacy, including role-playing, is part of the curriculum. The Senior Peer Counselors commit to a service term of six to twelve months. While based in the Cook County Elder Justice Center, the counselors are detailed to courtroom floors where senior litigants are more likely to appear, such as landlord-tenant, consumer, housing, mortgage foreclosure, and guardianship. Senior Peer Counselors are volunteers who must be 55 and older. Experts, such as representatives from Adult Protective Services agencies, volunteer their time to train these Senior Peer Counselors.

Senior Courthouse Tours

Senior Courthouse Tours are designed to familiarize seniors with key sites in the courthouse such as where to file cases, serve summons, and request fee waivers. Seniors are shown the locations of certain courtrooms namely debt collection, guardianship and housing. Court tour participants learn to more comfortably navigate the Court system and receive important information about the structure of the Court and the services provided to seniors.

Conclusion

A full-service senior center, providing holistic services, is the best way to describe the Circuit Court of Cook County Elder Justice Center. This Center has witnessed phenomenal growth since its inception. Over 7,000 Cook County seniors have sought and received direct services since the Center opened. This model can be replicated through the role of the court as a convener and mobilizer of multiple stakeholders. An Elder Justice Center in the heart of a courthouse offers a user-friendly setting, giving the genuine appearance of accessibility to justice.

The Hon. Patricia Banks serves on the Executive Committee of the Circuit Court of Cook County and is Presiding Judge of the Elder Law and Miscellaneous Remedies Division of the Circuit Court. She is Chair of the ABA Commission on Law and Aging. ■



The Commission's Summer 2016 Interns



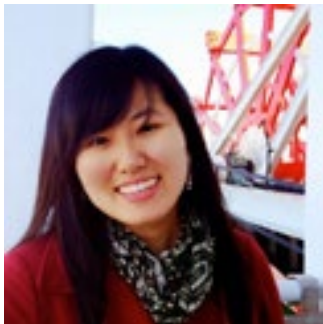
Preston Holmes

Preston Holmes is a rising third-year law student at Penn State Law in State College, PA.

Mr. Holmes received his B.S. from Auburn University in 2013, with a major in Economics. In the summer of 2015, Mr. Holmes worked for the Mecklenburg County 26th Judicial District as a law clerk in the Self-Serve Center in Charlotte, NC. There he taught pro-se clinics and conducted legal research of North Carolina law for criminal expunctions.

Currently at the Commission, Mr. Holmes is working under the supervision of Director Charles Sabatino, to conduct research on health care decision making.

Upon graduation, Mr. Holmes hopes to find work as legislative counsel or an elder law attorney.



Teresa Yao

Teresa Yao is a rising third-year student in the JD/MSW program at Washington University in St. Louis.

Prior to law school, Ms. Yao received her B.A. in Philosophy-Neuroscience-Psychology from Washington University, where she conducted research on various neuropsychological studies for older adults for three years, with an emphasis on discovering biomarkers for Alzheimer's disease. In summer 2015, she worked at a non-profit where she spearheaded an effort to connect global dementia non-profit groups with law firms that provide free legal assistance.

Ms. Yao has served as the public service committee co-chair for her law school's Public Service Advisory Board. Currently, she is an executive editor of the *Washington University Law Review*. This summer, under the supervision of senior attorney David Godfrey, she is working on a project examining surrogate selection in the context of decision-making for incapacitated patients. ■



Substitute Decision-Maker Terminology Under State Law

This new chart details state-by-state terminology (where defined) for substitute decision-maker terminology.

Visit: <http://ambar.org/HealthDecisions>.

State Public Guardianship and Guardianship of Last Resort Citations

This new list provides helpful state public guardianship and guardianship of last resort citations.

Visit: <http://ambar.org/guardianship>. ■

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Core Essentials Track at the 2016 National Aging and Law Conference: Elder Law Essentials

New this year on the agenda for the National Aging and Law Conference (NALC) is a track labeled “Core Essentials.” This track was developed to accommodate a special request from the new Elder Justice AmeriCorps program. In the fall of 2015, the Department of Justice (DOJ) announced its intent to fund the Elder Justice AmeriCorps program and place up to 60 AmeriCorps attorneys in legal aid offices around the country over a two-year period.¹ The goal of the program is to “provide legal assistance and support services to victims of elder abuse, neglect and exploitation.”² The program will be administered by a national host organization, the name of which is expected to be made public soon.

As most of the attorneys participating in Elder Justice AmeriCorps will be new law school graduates or attorneys new to the field of law and aging, DOJ representatives reached out to Commission staff to discuss leveraging NALC as a training venue for these attorneys. To design the Core Essentials track, the

¹ Justice Department and the Corporation for National and Community Service Expand Their Partnership to Provide Legal Aid to Victims of Elder Abuse and Financial Exploitation. DOJ website: <https://www.justice.gov/opa/pr/justice-department-and-corporation-national-and-community-service-expand-their-partnership>.

² *Id.*

DOJ and ABA called on the expertise of experienced advocates from across the country in a series of emails and phone calls. This outreach allowed for the identification of topics for which elder law attorneys should have a foundation, including: Medicare; Medicaid; income basics; elder abuse, neglect, and exploitation; understanding capacity; legal ethics of working with clients across the spectrum of capacity; and more.

Many of the Core Essentials panels cover topics that are always on the agenda at NALC—others, including some fundamentals courses, were created specifically for this effort. The NALC agenda this year has been expanded from four to five concurrent breakout sessions to accommodate the Core Essentials without displacing other content. Many of the Core Essentials will appeal to participants of all experience levels.

Core Essentials is an opportunity to expose attorneys new to the field to issues at the heart of working with older adults with the greatest economic and social needs, and for experienced advocates to refresh their knowledge of these important topics.

We invite you to join us this year at NALC for an exciting agenda of both Core Essentials and advanced issues in law and aging. ■

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Staff contact: David Godfrey
David.Godfrey@Americanbar.org