

## The Policy and Political Challenges of Being Mortal

by Charles P. Sabatino



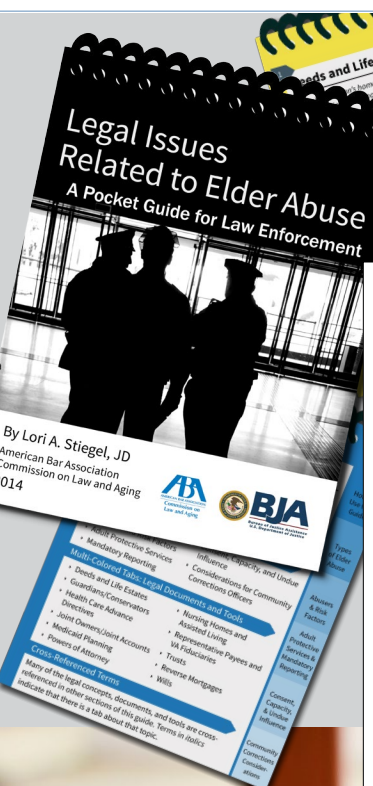
## The Wrong Signals: Shutting Down the Planning Conversation Before It Starts

by David Solie

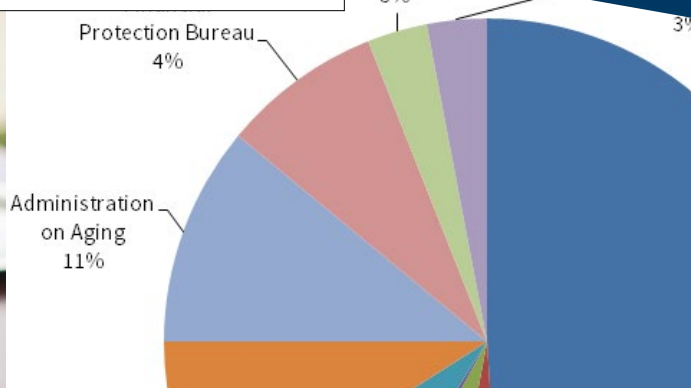
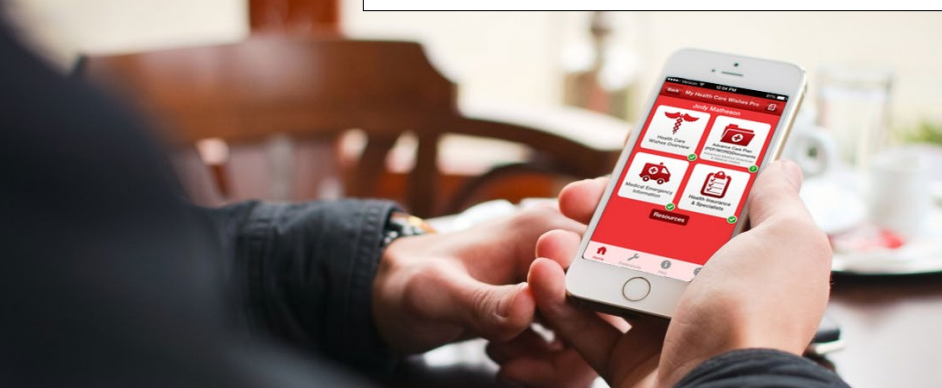
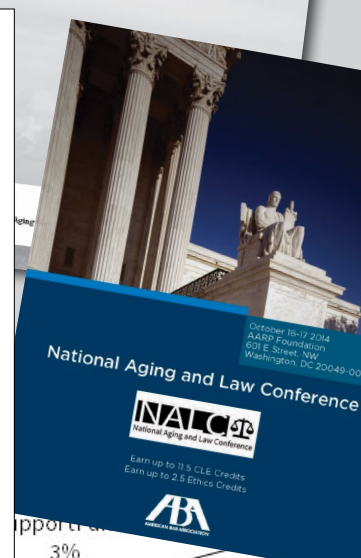
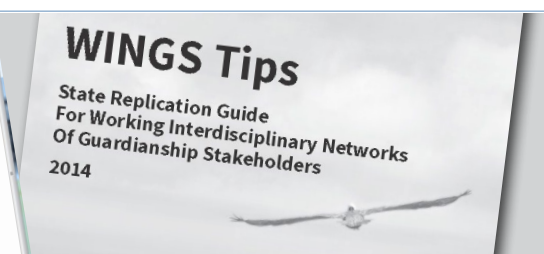


# BIFOCAL

A Journal of the **ABA** Commission on Law and Aging  
Vol. 36, No. 2, November – December 2014



## Commission on Law & Aging 2014 in Review



# BIFOCAL

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Commission on Law and Aging

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Erica F. Wood, Ass't Director  
Lori A. Stiegel  
David M. Godfrey  
Sonia M. Arce  
Trisha Bullock

### Editor

Andrea P. Amato

### Questions?

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

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# Commission on Law & Aging

## The Work and Accomplishments of 2014

by David English

In this, its 35th year, the Commission has continued to leverage the cumulative expertise of its members and staff in its pursuit of its mission: to serve as a collaborative, interdisciplinary leader of the Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons. It is this unique focus on law *and* aging that enables the Commission's singular impact.

This issue of *Bifocal* is our 2014 Year in Review issue, providing a snapshot of the Commission's work over the past year.

Given the pace required to achieve what we have in the past year, it's easy to forget to step back and appreciate the breadth and depth of the Commission's work. In the past 12 months, the work of the professional staff and Commissioners has impacted the legal profession, public policy, and the public at large in several ways.

The Commission's work has impacted the legal profession:

- Through our law and practice publications, such as our capacity assessment handbooks and tool kits, our bi-monthly e-journal *BIFOCAL*, our elder-friendly law-office guide, our elder law ethics brochure, and topical articles;
- Through our new leadership role organizing the annual National Aging and Law Conference in partnership with the Center for Professional Development;
- Through our leadership as a partner in the National Legal Resource Center, funded by the Administration for Community Living;
- Through our quarterly "Elder Law Essentials" CLE webinars and more than 50 professional education presentations by staff and Commissioners;
- Through our support of programmatic efforts of all ABA sections and divisions that seek to target law and aging issues, including cross publication with the Senior Lawyer's Division and providing faculty to other section and division CLE programs;
- Through our new educational initiative, funded by the Investor Protection Trust and Investor Protection Institute, to train lawyers how to identify potential financial exploitation of their clients and respond effectively;
- Through our ABA "Enterprise" grant collaboration with other ABA entities to develop guidance for lawyers about decision-making options less restrictive than guardianship.

The Commission's work has impacted public policy:

- Through responding to requests for technical assistance (over 2,000 per year from multiple disciplines, policy-makers, and the media) and online tracking charts summarizing the status of state legislation on guardianship, elder abuse, health care decision-making, and other subjects;
- Through our advisory participation in policy, advocacy, and training efforts related to state health care decisions, guardianship, and elder abuse laws; support for state enactment of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act and the Uniform Power of Attorney Act; and federal laws including the federal Elder Justice Act and the Older Americans Act, among others;"
- Through our advisory role with the National POLST Paradigm Task Force, particularly in developing a POLST Legislative Guide for states;
- Through our hosting, in collaboration with the National Guardianship Network, the 3<sup>rd</sup> convening of the World Congress on Adult Guardianship, as well as funding and supporting coordinated, court-community partnerships in the states to drive changes in the ways courts and guardians practice;
- Through our liaison work with the United Nations Open-Ended Working Group on Ageing, which is weighing the need for an international convention on the rights of older persons;
- Through our policy development and advocacy efforts within the ABA and at the state and federal level in conjunction with ABA Government Affairs, particularly the August 2014 adoption by the ABA House of Delegates of the Commission's resolution on rebalancing the OASDI and Disability Trust Funds.

The Commission's work has impacted the public:

- Through our educational materials for the general public, addressing financial exploitation, health care powers of attorney, and other publications developed under foundation grants;
- Through our collaboration with other groups in promoting National Health Decisions Day, April 16, including release of a new smartphone app that enables individuals easily to store and share their advance directives and related information on their smartphones.

A considerable and successful undertaking this year was the publication of *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement*. This pocket-sized, tabbed reference book was developed with the support of the Bureau of Justice Assistance, an entity of the U.S. Department of Justice. Twenty-three thousand copies of the Pocket Guide have been printed and a pdf of the publication is available at the Commission's website at: [www.ambar.org/ElderAbuseGuides](http://www.ambar.org/ElderAbuseGuides). A companion Desk Guide is due to be released soon in digital format.

And, work on the Commission-authored booklets for the Consumer Financial Protection Bureau continues into 2015 with a set of six state-focused guides in process and a replication guide in the works, as well. The series, entitled *Managing Someone Else's Money*, has been widely praised and more than 450,000 copies of the booklets have been disseminated.

I'm proud of our successes and accomplishments and look forward to continuing success in helping to shape an effective response of the legal profession in meeting the law-related needs of older individuals.

I encourage you to get involved: through participating on one of our excellent discussion lists, through interacting with us through our social media accounts, or by contacting us to discuss a donation or a potential opportunity to partner with us on a project.

Sincerely,



David English  
Commission Chair  
2014–2015 ■



# Revenue & Funding

## 2014 Review

The Commission's operating budget is made up of core funding from ABA general revenues that provide about half of the funds needed to run the Commission. The remainder comes from grants, contracts, and donations. Looking back over six years, the annual Commission revenues have ranged from \$930,000 to a high of \$1.3 million, depending on the number and size of outside funding sources in any given year. Total revenues for a given calendar year are hard to quantify because each grant has a different fiscal year. Taking September 2014 as a snapshot, revenues for the year stood at approximately \$1,055,000, including ABA funds.

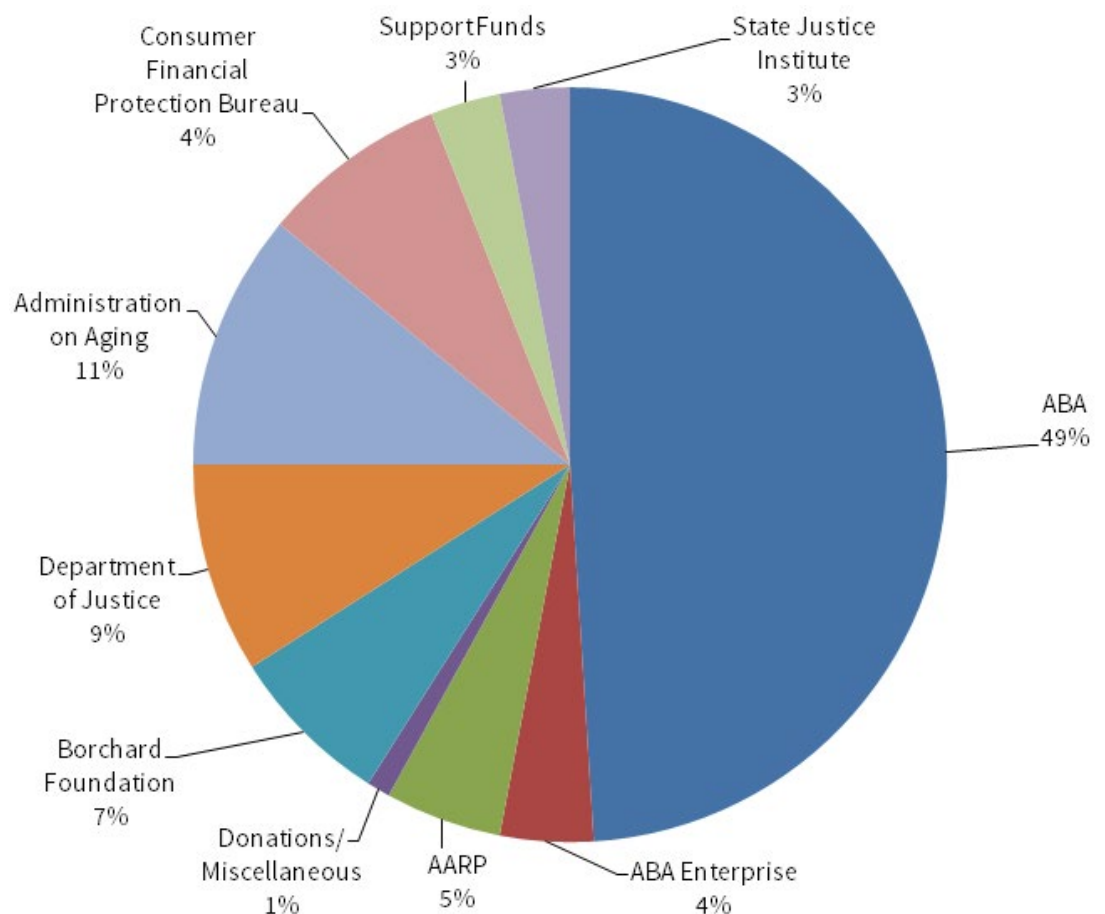
The prospects for future grants are never certain, so planning for the future is always challenging. The solicitation of private donations continues to be a priority for the Commission. As a program of the ABA Fund for Justice and Education, a 501(c)(3) charitable organization, the Commission is able to receive tax deductible donations.

The pie chart below shows the breakdown of revenues for the past year as of September 1, 2014. ■

### Commission Revenue Sources

Total: \$1,055,000

(as of 9/1/14)



# Advance Care Planning & Advanced Illness

2014 Review  
by Charles P. Sabatino



Advanced care planning and the care of persons with advanced, progressive conditions has been a major priority in Commission work for several years. This article takes a look at Commission accomplishment during 2014 in areas of policy, research, product development, and education.

## Policy Accomplishments

The Commission was a principal co-sponsor of the ABA resolution, adopted in February 2014, urging Congress to enact legislation that requires that any days an individual spends in the hospital under “outpatient observation status” be counted as inpatient days with respect to satisfying the three-day inpatient hospital stay requirement for Medicare coverage of skilled nursing facility care after hospitalization. Anyone who goes to the hospital can be placed on observation status so that doctors can determine what’s wrong and determine whether hospitalization is needed. Observation patients may receive diagnostic tests, medications, treatments, and other services just like an in-patient, so they may not know they are on observation status. If their doctor then orders a period of skilled nursing home care after discharge, they discover that Medicare will not cover their care, because they were never officially admitted to the hospital for three days. The use of observation status by hospitals has increased substantially in recent

years, so many more patients and their families are being negatively affected by it.

The practice was unsuccessfully challenged in court by the Center for Medicare Advocacy, so the best hope for a solution has been a bill that the ABA supports, called the *Improving Access to Medicare Coverage Act of 2013*, which would require observation days to be counted toward the three-day qualifying hospital stay required for nursing home coverage. The bill had substantial support with 161 co-sponsors in the House and 28 co-sponsors in the Senate at the end of 2014 but was not taken up on the floor of either body. The Commission will continue to support the effort when the bill is reintroduced in 2015. In the meantime, three states enacted legislation requiring hospitals to give patients clear notice when they are placed on observation status. The state laws don’t solve the problem but they at least make to practice visible.

The ABA, through the Commission, has continued to support legislation that would strengthen the federal Patient Self-Determination Act, such as, *Personalize Your Care Act* (HR 1173), introduced by Rep. Earl Blumenauer (D-OR). Commission staff also played a role as expert reviewer for the major new report released by the Institute of Medicine, National Academy of Sciences, titled *Dying in America: Improving Quality and Honoring Individual Preferences*

*Near the End of Life*. The report included major findings and recommendation addressing advance care planning and caregiver issues, along with payment and delivery reform challenges for the care of persons with advanced illness as they near the end of life.

### **Advanced Illness Care**

Commission staff continue to collaborate on an individual level with the Coalition to Transform Advanced Care (C-TAC) toward the goal of ensuring that all people with advanced illness receive high-quality, coordinated, and compassionate care consistent with their personal goals and values. In late 2014, C-TAC released a new book, the *Path Forward: A Blueprint for Reforming Advanced Illness Care in America*, with one chapter on policy and advocacy co-written by Charlie Sabatino.

The Commission has also lead ABA support for broadening supportive services to persons in the community who would otherwise have to be placed in nursing homes. A key 2014 bill targeting that goal was the *Community Integration Act of 2014*, introduced by Sen. Tom Harkin (D-IA). The bill would have amended the Social Security Act to require state Medicaid plans to give an individual with disabilities needing an institutional level of care the choice and opportunity to receive such care in a home and community-based setting. The bill did not progress in Congress but, nevertheless, represents a policy goal that will only continue to rise in importance – that of ensuring the availability of effective home and community-based care resources when people need them and in the place they wish to receive them.

The Commission also provided technical assistance on the *Care Planning Act* (S 1439), introduced by Senators Mark Warner (D-VA) and Johnny Isakson (R-GA). The bill would create a new Medicare and Medicaid benefit for advanced illness planning services by interdisciplinary teams and authorize a 5-year advanced illness care coordination services demo for patients in need of assistance with two or more activities of daily living.

In late 2014, the Institute of Medicine commenced a new Committee on Family Caregiving of Older Adults, with an ABA Commission staff appointed as a member of the Commission. The Committee will work intensively through 2015 with a report expected in 2016.

### **My Health Care Wishes Smartphone App**

In April, the Commission released its new *My Health Care Wishes* smartphone app in connection with National Healthcare Decisions Day. The app gives individuals and their family members the ability to store their own and each other's health care advance directives, key health information, and health care contacts on their Apple or Android smartphones, and to send advance directive documents directly to health care providers by email or Bluetooth connectivity. The goal is to enable people to have advance directives available whenever and wherever needed, without having to rely on 3<sup>rd</sup> party cloud-based advance directive registries.

Initial publicity and distribution plans included an ABA National Healthcare Decisions Day Radio News Release, featuring ABA President Bill Silkenat, and a media report picked up by several publications, including the New York Times *New Old Age* Blog. The app is a particularly useful resource for lawyers to recommend to their clients when they prepare advance directives for their clients.

### **Physician Orders for Life-Sustaining Treatment (POLST)**

The Commission has served as the legislative/legal consultant to the National POLST paradigm Task Force which is made up of representatives from states that have established POLST programs in conformity with endorsement standards adopted by the Task Force. See [www.POLST.org](http://www.POLST.org). The number of states that have adopted POLST authorizing legislation reached 23 this year, with 15 of those states and one sub-state program (in Wisconsin) having programs endorsed by the National POLST Paradigm Task Force. The majority of remaining states have POLST programs in various stages of development. The Commission provides technical advice not only to the Task Force but also to individual states working through legislative and regulatory issues related to PLST. Staff succeeded in completing the research and writing for a *POLST State Legislative Guide* with several collaborators, released in mid-2014, along with a comparative state chart of POLST legislation. Noteworthy this year was the fact that the Institute of Medicine's major report and recommendations, *Dying in America*, recommended the use of POLST for patients with advanced care. The IOM report will likely increase state interest in implementing POLST.



## National Health Decisions Day

The ABA, through the Commission, is one of the original co-sponsors of *National Health Decisions Day* (April 16). This year the Commission tied the release of *My Health Care Wishes* smartphone application to the day and also produced a radio news release and an op-ed piece on advance care planning by ABA President Jim Silkenat. Both promoted the need for all adults to engage in advanced care planning. The radio news release was picked up by an estimated 1,969 radio stations and heard by an estimated audience of 8.4 million listeners. The op-ed was picked up by 18 newspapers, including international outlets.

## Educational Efforts

Educational efforts on health decisions and advance care planning are ongoing. This year, they included 10 professional conference presentations; publication of the article “Advance Care Planning Tools That Educate, Engage, and Empower,” in the *Public Policy & Aging Report*; and continued service as a consultant to the AARP Caregiving Resource Center. The Commission publication, *Consumer Tool Kit for Health Care Advance Planning*, continues to be one of the most visited pages on the Commission website. ■

# National Aging and Law Conference

October 29–30, 2015

Hilton Arlington • [www.hiltonarlington.com](http://www.hiltonarlington.com)

*Save the Date!*



### Conference attendees will enjoy:

- Low registration rates and a two-day agenda to minimize travel time and costs
- An anticipated 4 plenary sessions and 24 workshops
- A focus on core substantive legal issues affecting older Americans with the greatest economic and social needs
- Programming on legal service development and delivery
- High-quality written materials

### Interested in presenting?

- Watch for the call for workshop proposals in early 2015.

### The 2015 Conference hotel boasts:

- Direct access to the Ballston Metro Station with restaurants and shopping within walking distance
- Larger space to accommodate more attendees, sessions, and faculty than last year
- On-site hotel rooms, with a negotiated room rate (limited in quantity)

**INALC**   
National Aging and Law Conference



Facebook:  
<http://t.co/fWDko0uL1R>



Twitter: [@NtlAgingLawConf](https://twitter.com/NtlAgingLawConf)



Staff contact: David Godfrey  
[David.Godfrey@Americanbar.org](mailto:David.Godfrey@Americanbar.org)



## Your Health Care Wishes Just a Finger Tap Away

With some very creative people, the Commission has created version 1 of a smartphone app called My Health Care Wishes to give individuals and their family members the ability to store their own and each other's health care advance directives, key health information, and health care contacts on their Apple or Android smartphones, and to send advance directive documents directly to health care providers by email or Bluetooth.

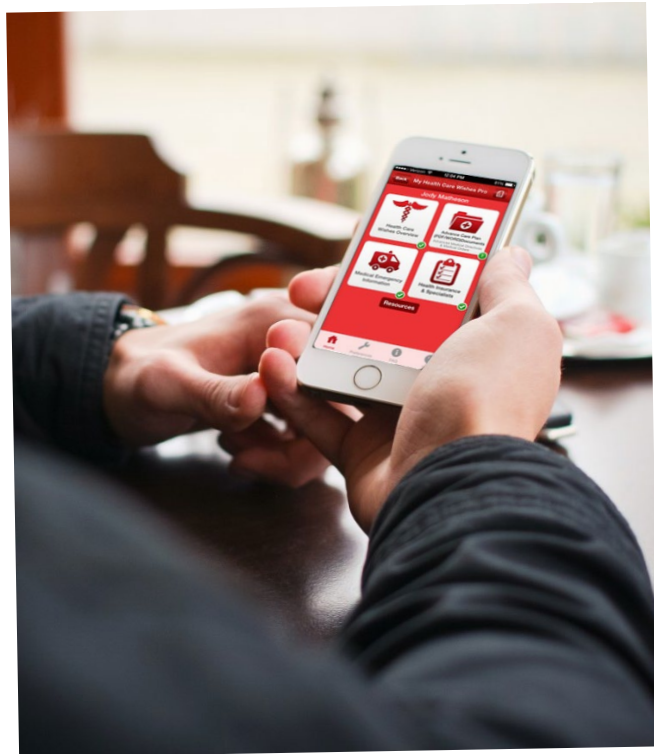
You can learn more about the app and download it by going to [www.MyHealthCareWishes.org](http://www.MyHealthCareWishes.org). We think the app is a great product, but to reach its potential it needs several new capabilities that I'll describe below.

### **That's why we are fundraising.**

The Commission has promoted health care advance planning and the use of advance directives for decades. Advance directives are documents such as a health care power of attorney or living will that can provide instructions for how decisions are to be made and also legally authorize another person to make health care decision for the individual, if the individual loses the ability to make decisions. While all adults should have an advance directive, one universal problem they still face if they have one is ensuring that their advance directive is available and in the medical record at the time and place it actually becomes needed.

Advance directive registries have attempted to solve that problem. Many private enterprises as well as state governments have tried to develop successful electronic registries over the last 25 years. These registries offer to keep a copy of the advance directive and provide a digital copy of it quickly to any authorized health care providers on their request. These systems are generally managed via cloud-based computing. In reality, none have ever attracted a truly critical mass of participants. We concluded that one of the reasons for this is that people are reluctant to give up control of such personal documents to a third party and an electronic environment you do not control.

The My Health Care Wishes app essentially allows you to create your own personal registry with content and access controlled by you. The app can store and share the directives of multiple loved ones. While just about any smartphone can store a document, there is little available to make storage, sharing, and revising convenient, focused on the rights documents and information, organized, and truly portable electronically.



### Here's what we need to do to make this app reach its potential:

1. The app is useful now only for people who have already completed a health care advance directive. We have created a multi-state health care power of attorney form and want to digitize it on the app so it can be completed and electronically signed.
2. There are currently no desktop versions or tablet versions of the app. We want to create both desktop and laptop versions to make it as convenient as possible for people to enter and change data and complete the multi-state health care power of attorney.
3. Another capability we can add when we create a desktop version is the ability for users to share their complete file with other family member in one step, and vice versa. The app does enable family members share mom's and dad's and each other's health wishes information, but sharing the complete set of data from one smartphone to another has to be done in a few steps.

We believe that at its full capability, app sales will be able to cover the cost of maintaining it and providing ongoing customer service and even produce additional income that will go back into our public interest law work. We've set the price of the app at \$3.99, and we think it can make a big difference in ensuring your health care wishes are known and honored.



Charlie Sabatino



Visit:

<http://www.gofundme.com/i54s44>

# Legal Services & Education

2014 Review  
by David M. Godfrey

There were three major projects for the ABA Commission on Law and Aging's work on legal services in the past year: creating and hosting the 2014 National Aging and Law Conference; a major update and redesign of the National Legal Resource Center website; and continuation of our Elder Law Essential Webinar Series. The Commission has a long history of working to empower aging and legal services providers to meet the needs of older clients. We do this in part by "research, policy development, technical assistance, advocacy, education, and training."<sup>1</sup>

## National Aging and Law Conference

In 2014 the Commission assumed responsibility for hosting the National Aging and Law Conference (NALC). NALC 2014 held October 16<sup>th</sup> and 17<sup>th</sup> in the Brickfield Center at AARP, and was a smashing success. We sold the space out six weeks before the program, ending 145 registrations, total attendance of over 150 and sadly turning away people on the registration waiting list because of a lack of space. The agenda featured four plenary sessions and 19 workshops over two days. We hosted a listening session for the planned 2015 White House Conference on Aging over lunch on the first day. AARP generously supported NALC by supplying space, audio visual services and underwriting the conference reception. The Borchard Foundation Center on Law and Aging underwrote a block of staff time making it possible for Commission to devote significant time to planning and organizing the Conference.



The Commission has a long history of being involved in national conferences on aging and law, starting about 30 years ago with the Joint Conference on Law and Aging, followed by the AARP organized National Aging and Law Conference, and later by the NAELA hosted National Aging and Law Institute. The NAELA Institute was held for the last time in 2013, leaving no one organizing a national elder law conference for public interest advocates. In looking for a successor conference we talked to the ABA Center for Professional Development and the collaborators who had been active in past conferences. The consensus was that there was a need for a conference on poverty elder law. There are other great conferences on estate planning and elder law, what was missing was a conference focusing on the legal needs of low income and at risk seniors and the advocates that develop and deliver legal services to them. From this we decided to bring back the National Aging and Law Conference with a renewed focus on these issues.

We recruited a planning committee representing over a dozen outside co-sponsors and eight ABA co-sponsor entities. The planning committee reviewed over 50 workshop proposals to create a sharply focused agenda with over 70 speakers on 23 programs. The speakers submitted voluminous written materials, over 1,150 pages that have been edited into a book that is available on the ABA webstore (visit <http://shop.americanbar.org/eBus/Store/ProductDetails.aspx?productId=130950230> and enter code: ALCCOR60 for a 60% discount when ordering this book).

<sup>1</sup> Mission of the ABA Commission on Law and Aging [http://www.americanbar.org/groups/law\\_aging/about\\_us.html](http://www.americanbar.org/groups/law_aging/about_us.html).

Planning is underway for the 2015 National Aging and Law Conference to be held at the Hilton Arlington on October 29 & 30. The new venue will allow us to accommodate up to 220 attendees and allow us to expand the agenda with 4 plenaries and 24 or more workshops.

### NLRC Website Update

The Commission is a partner in the Administration for Community Living, National Legal Resource Center (NLRC). We are one of five grantees in the NLRC with our role being to create, collect and disseminate resources on aging and law and facilitate coordination of the activities of the Center partners to support the aging and legal services community in meeting the needs of older Americans with the greatest economic and social needs. The other partners in the NLRC are the Center for Elder Rights Advocacy, National Consumer Law Center, National Senior Citizens Law Center and The Center for Social Gerontology. The NLRC is in its seventh year.

The virtual home of the NLRC is the webpage at [www.NLRC.ACL.gov](http://www.NLRC.ACL.gov). Over the course of the past year, the website underwent a total redesign with a line-by-line review of all content and the addition of new sections on emerging issues and concepts. The first step was a reexamination of the purpose and goals of the website. The new website focusses on the user experience. When we asked “what do visitors come to the site for?” the answer was clear from looking at the website analytics that visitors come seeking information in eight primary areas. The new website focusses on

those eight with “accordion tabs” that are clickable and linked to a randomizer so each time you visit the page a different one is featured. The menu bar was redesigned to modern standards. All existing content was reviewed with the help of law student pro bono volunteers from Stetson University College of Law to assure that the content is current, that content matches the description, and that the links work. New content was added in supported decision-making and in legal service development and delivery. Website maintenance involves about 300 additions and updates per year and is part of the Commission’s ongoing work on the NLRC project.

### Communication and Dissemination

Our communications tools have two goals, to spread awareness of our work and to provide a forum for discussion of issues in aging and law. We use a series of electronic tools to spread the word about our work. *Bifocal* is the e-journal of the ABA Commission on Law and Aging; this free bi-monthly publication goes out to nearly 1,600 subscribers. We host three email discussion lists: *Elderbar* is the a discussion list for professionals in law and aging with over 950 members, *Collaborate* is a discussion list for professionals in elder mediation with nearly 500 members, and *Elderlink* is a discussion list for ABA members and staff interested in law and aging with over 120 subscribers. Each of these media has a different purpose, with overlapping audiences. All are offered without charge.

Connect with Us • Connect with Us • Connect with Us • Connect with Us



#### Twitter

Follow us:  
[@ABALawandAging](https://twitter.com/ABALawandAging)



#### Facebook

We are listed as:  
[ABA Commission on Law and Aging](https://www.facebook.com/ABACommissiononLawandAging)

#### Discussion Lists

- *Elderbar*, an open discussion list for professionals in law and aging, and
- *Collaborate*, a discussion list on aging, disability, and dispute resolution.

Visit the [www.americanbar.org/aging](http://www.americanbar.org/aging) for more information on how to sign up.





## **COLA Webinar Series**

### **Elder Law Essentials**

The COLA Elder Law Essentials webinar series continues as a way for the Commission staff and our network of experts to provide education and training on essential issues in law and aging. This year we hosted five programs:

- *Fundamentals of Family Caregiver Agreements: Taking Care of Those Who Care for Others.* This program was inspired by a chapter on this important topic in the book *Alzheimer's and the Law* written by Commissioner Kerry Peck. Commissioner Peck teamed up with Dianna Law for this excellent program.
- *Health Care Decisions and the F Word: Counseling Clients about Medical Futility.* The idea for this program came from two cases in the news at the time, one family fighting to discontinue life support and another fighting to continue it. Robert Fine, MD; Bernard Hammes, Ph.D; and Thaddeus Mason Pope, JD, explored the legal and ethical issues of modern medical technology.
- *Social Security Retirement Strategies: Helping Your Clients Maximize Benefits.* Featuring William Meyer, of Social Security Solutions and John Whitelaw, of Community Legal Services in Philadelphia this program explored the complex

issues of when to start Social Security benefits, the impact of working after retirement with a focus on strategies for drawing the entire benefit a worker has earned. (Unfortunately, an audio recording of this webinar is not available for purchase.)

- *What is a Good Guardian? Understanding and Using National Guardianship Standards.* Sally Hurme of AARP and Erica Wood, Assistant Director of the Commission explored how to applying the standards of practice of the National Guardianship Association can improve guardianship and enhance the quality of life persons with a guardian.
- *Ethical Issues of Representing a Client with Diminished Capacity.* COLA Commissioners Judge Patricia Banks and Kerry Peck, with Professor Rebecca Morgan explored the ethical and practical challenges of working with clients with diminished capacity. The faculty explored the obligation to maintain a normal attorney client relationship, confidentiality, while being a zealous advocate and protecting clients from harm.

The programs offer continuing legal education credit. Recordings of four of the five programs presented this year are available for purchase. Plans are underway for webinars in 2015. ■



# Guardianship & Capacity

2014 Review  
by Erica Wood



The 2014 year has seen a kaleidoscope of actions and ideas on the guardianship and capacity front. The Commission, as part of the 11-member National Guardianship Network (NGN)—and in close collaboration with organizations such as AARP and the National College of Probate Judges—is at the cusp of important changes. The Commission, with its partners made great progress in protecting the rights of older persons.

## **Creating an infrastructure for real state level reform**

During 2014, the Commission with its NGN partners has worked with four states that established Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) through a grant from the State Justice Institute and the Borchard foundation Center on Law and Aging. New York, Oregon, Texas and Utah each have used WINGS to begin driving changes in practice, such as increased use of decision-making options less restrictive than guardianship, exploration of supported decision-making approaches, better monitoring and enhanced data collection.

In addition, four other states—Indiana, Missouri, Ohio, and West Virginia—have created similar WINGS groups to work collaboratively for change. NGN produced a replication guide for other states to follow. The pdf publication can be downloaded from the Commission's Guardianship Resources page: <http://ambar.org/guardianship>. In October, NGN received additional funding from the State Justice Institute to boost two more state WINGS court-community partnerships. Lift-off is imminent!

## **Progress toward effective coordination between state courts with guardianship jurisdiction and the Social Security representative payee program**

During the past decade, the U.S. Government Accountability Office has highlighted the need for greater coordination between the federal representative payment system and state courts with guardianship cases. Both systems involve appointment of fiduciaries to make financial decisions on behalf of the same or similar populations, but there has been little interaction. In 2013, the federal interagency Elder Justice Working Group called for coordination of guardianship and representative payee systems as a way to reduce financial exploitation by fiduciaries.

During 2014, the Commission has participated in a series of calls spearheaded by the Social Security Administration (SSA) as part of the WINGS initiative. The quarterly calls bring together state WINGS leaders and key SSA staff to explore problems and solutions concerning guardianship and representative payment. SSA has created a subgroup to draft cross-training modules so each system can better understand and work with the other.

## **Helping to make the emergent concept of “supported decision-making” a reality**

Supported decision-making focuses on promoting ways that people with cognitive disabilities can make their own decisions about their own lives, rather than being placed under a guardianship in which a surrogate makes life decisions on their behalf.

The concept stems from the United Nations Convention on the Rights of People with Disabilities. Supported decision-making around the world was highlighted at the World Congress on Adult Guardianship; and in October the U.S. Administration on Community Living designated The Quality Trust as grantee to establish and operate a National Resource Center on Supported Decision-Making. The Commission is pleased to be a partner in the five-year National Resource Center project.

### **Developing more effective strategies in guardianship cases marked by a high level of family conflict**

A substantial number of high conflict guardianship cases feature family/sibling feuds or extreme tension between or among family members or with guardianship professionals in care situations involving an older person. These egregious cases erode court time and resources, use up scarce estate funds, delay needed care, often fail to focus on the real desires and needs of the individual, and seem intractable.

“Eldercaring Coordination” is a concept modeled after the successful “parenting coordination” programs currently used by some courts in high conflict child custody cases. The Association of Conflict Resolution (ACR) created a broad-based working Task Force to consider and refine the idea, and Commission staff have participated over the past year. In October, ACR unanimously approved the eldercaring coordination guidelines created by the Task Force. The guidelines target adult guardianship and related cases in which high conflict family dynamics may interfere with the well being and safety of an older person and with adherence to court orders. The new ACR Guidelines are posted at <http://acrelldersection.weebly.com/documents.html>.

### **Progress towards better resolution of jurisdictional conflicts in guardianship between states**

The Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA) sets out ways to resolve multi-state adult guardianship jurisdictional issues. See <http://uniformlaws.org>. The Act addresses the transfer of a case to a different state, recognition and enforcement of a guardianship order in another state, and determination of which state will have initial jurisdiction to hear a case if more than one state is involved. The Act saves judicial and family time and

expenses, and greatly simplifies multi-jurisdictional cases—without changing substantive state guardianship law, and without cost to the state.

Because it is jurisdictional in nature, the Act can’t work as intended unless it is adopted by all of the states. Currently, a total of 40 states plus the District of Columbia and Puerto Rico have adopted the Act, leaving 11 jurisdictions remaining. The ABA has policy supporting the Act, and the Commission has vigorously advocated for its adoption by states—working closely with AARP during the last two years.

### **Educating professionals and the public about termination of guardianship and restoration of rights**

Guardianship is one of society’s most drastic interventions, resulting in the loss of basic human and civil rights. All individuals deserve an opportunity to have a guardianship terminated and have their rights and self-determination restored. Yet very little is known about the process of restoration in practice.

In 2013, Jenica Cassidy, then a Commission intern, produced a detailed paper about restoration statutory provisions. In 2014, Ms. Cassidy returned to the Commission as a law graduate fellow (the Commission’s first!) and has been collecting and analyzing restoration case law, as well as spearheading online inquiries to judges and attorneys. She is pulling all of this information together in a comprehensive article, helping to shed light on a key aspect of rights and supported decision-making for older individuals and adults with disabilities. Stay tuned!

### **Helping lawyers operationalize the “least restrictive alternative” principle and routinely build it into the practice of law**

Because guardianship is so intrusive and results in extreme loss of rights, guardianship laws and standards generally require that less restrictive options be considered before petitioning for a court order. However, use of the least restrictive alternative principle in practice appears uneven at best. Not infrequently guardians are appointed when other approaches might have sufficed.

In 2014, the Commission, along with three other ABA entities, received an American Bar Association collaborative Enterprise grant that aims to raise the awareness of the legal profession about decision-making options that are less restrictive



than guardianship. The project will develop a practical screening tool to identify options, with a guide for attorneys to explain the tool and its use. This challenging 18-month project offers great potential to avoid unnecessary and overly broad adult guardianship orders, thus preserving self-determination as much as possible.

### **Producing our annual review of guardianship state legislation**

The Commission has tracked the passage of state adult guardianship legislation every year since 1988. As of October, we found 17 successful state enactments in 15 states for the 2014 year. Both Oregon and Nebraska passed landmark public guardianship bills. Massachusetts, Mississippi, and California enact the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act. Oregon authorized court appointment of volunteer visitors. Idaho revised procedures for guardian and conservator reports to court. Additional states tweaked various provisions in existing law. The Commission presented a summary of these enactments as part of the 2014 National Guardianship Association's annual Legal and Legislative Review; and will be updating and finalizing the 2014 list in December.

### **Teaching physicians how to perform better capacity assessments**

In 2012, the Commission and the Rush University Medical Center completed an online curriculum for physicians and other clinicians on capacity assessment of older adults. During the 2014 year, the Commission and Rush worked to disseminate information about the course, including a recent presentation to a range of clinicians at a palliative care conference in New York City. See [www.rush.edu/decisionalcapacity](http://www.rush.edu/decisionalcapacity).

### **Networking with guardianship stakeholders worldwide**

As a member of the National Guardianship Network, the Commission in 2014 played a substantial role in planning the highly successful 3<sup>rd</sup> World Congress on Adult Guardianship, convened May 28-30. The event was funded through the Borchard Foundation Center on Law and Aging, the American College of Trust and Estate Counsel Foundation, and the National Guardianship Network organizations, as well as registration fees.

Final attendance at the World Congress totaled 373 participants, including 268 from the U.S. and 105 from 24 other countries. The program included 120 presenters representing 21 countries across six continents. World Congress participants came, speaking many languages, from Europe, Asia, North America, and Australia—as well as first-time representatives from Africa (Nigeria) and South America (Argentina). All were eager to learn from each other and compare practices. The lively three-day event offered those involved in guardianship and decision-making a rare opportunity to share problems and solutions with peers from other countries. An International Resource Library of materials from the Congress is now available at <http://www.guardianship.org/IRL/>.

### **Where is further information?**

For the latest on all of the above guardianship fronts, see the Adult Guardianship Law and Practice page on the Commission's website at: <http://ambar.org/guardianship>. ■



## **Get Connected, Stay Connected, on Elderbar**

Join **Elderbar**, the discussion list that brings together public and private sector legal advocates and the aging network.

**Elderbar** gives you the opportunity to communicate across the boundaries of the law and aging networks and the public and private legal sectors. Share ideas and information about programs, bar section and committee activities, and learn how others are responding to the increasing demand and finite funding for legal services for seniors.

To get connected to **Elderbar** send your name, e-mail address, and professional affiliation to [david.godfrey@americanbar.org](mailto:david.godfrey@americanbar.org). ■



# Elder Abuse & Neglect

2014 Review  
by Lori A. Stiegel



Since 1993, the Commission has been at the forefront of efforts to expand and improve the justice system's role in preventing, detecting, and remedying the devastating problem of elder abuse, neglect, and exploitation (which we'll just call elder abuse for short). This year those activities were concentrated in four areas.

## **Educating and Providing Tools to Justice System Professionals**

Criminal justice professionals (law enforcement and community corrections officials, and prosecutors) are the target audience for two new Commission publications released in October: *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement* and *Legal Issues Related to Elder Abuse: A Desk Guide for Law Enforcement*.

Victims, advocates, and adult protective services and other professionals have long bemoaned a lack of responsiveness by criminal justice professionals to allegations of elder abuse. Training opportunities in many states and communities have helped raise awareness. The pocket guide supplements those efforts by explaining legal concepts, documents, and tools that may be misused to commit elder abuse or used properly to remedy it. It is a small, durable, user-friendly tabbed quick-reference tool that may be carried in a pocket or attached to a patrol car visor. The more comprehensive desk guide can serve as a training resource.

The Bureau of Justice Assistance, an entity of the U.S. Department of Justice, supported the development, printing, and dissemination of 23,000 laminated

pocket guides. A PDF of the pocket guide is available and a desk guide PDF will be available soon.

Visit [www.ambar.org/ElderAbuseGuides](http://www.ambar.org/ElderAbuseGuides) for more information. The Commission is actively seeking funding to produce more laminated pocket guides and to create an app for mobile devices.

Lawyers can play a critical role in preventing, detecting, and remedying elder abuse. They also can unwittingly facilitate it or, even worse, deliberately participate in it. To facilitate the former and to help prevent the latter, the Commission has entered into a partnership with the Investor Protection Trust (IPT) and Investor Protection Institute (IPI), which are nonprofit organizations devoted to investor education and protection. The initiative is known as the *Elder Investment Fraud and Financial Exploitation Prevention Program – Legal* (EIFFE—Legal). Its goal is to educate lawyers to:

- recognize clients' possible vulnerability to exploitation due to mild cognitive impairment,
- identify signs of exploitation affecting their clients, and
- report suspected exploitation to appropriate authorities.

To do this, EIFFE—Legal will develop and pilot test in six states a model national continuing legal education (CLE) curriculum that is intended for practitioners in a wide array of specialties, such as elder law, trust and estate law, family law, general practice, business law, tax law, and administrative and government law.

Additionally, the Commission will provide an ABA CLE webinar during 2015. Once the pilot phase is complete, the program will be rolled out nationwide.

EIFFE—Legal was successfully kicked-off at the ABA Annual Meeting in August with a Showcase CLE program titled *The Epidemic of Elder Financial Exploitation: Ethical Traps for Lawyers & Skills Every Lawyer Needs*. It was one of 32 Showcase programs selected from over 200 proposals and was co-sponsored by thirteen other ABA entities. It was moderated by Commission chair David M. English and featured a panel of national experts who covered an array of topics:

- **Lori Stiegel**, EIFFE—Legal director and Commission senior attorney, provided an overview of the many forms of elder financial exploitation.
- **Patricia D. Struck**, a Commission member, Wisconsin's state securities regulator, and a former IPT trustee, spoke about investment fraud and the role of securities regulators in educating and protecting investors.
- **Dr. Daniel C. Marson**, clinical neuropsychologist and professor in the Department of Neurology at the University of Alabama at Birmingham, discussed research on financial decision-making capacity that explains vulnerability to fraud and financial exploitation.
- **Bruce S. Ross**, used his experience as a member of the legal team representing Mickey Rooney against his exploiter, to illustrate relevant ethical issues and to provide practice tips.
- **Elizabeth Loewy**, a lead prosecutor of the Brooke Astor case, discussed what her office considers when investigating attorneys involved in questionable trust and estate matters related to older or impaired clients.

### **Educating Other Professionals about the Law**

The Commission continued striving to raise awareness among non-legal professionals about the laws relevant to elder abuse and the ways in which the justice system can help victims or punish perpetrators. Highlights included presentations at various national and state conferences including the Corporation for Enterprise Development's Assets Learning Conference and the annual meetings of the Gerontological Society of America, the North American Securities

Administrators Association, and the National Adult Protective Services Association. Topics included the growing role of the legal system in combating elder abuse, the relationship between diminished financial capacity and financial exploitation, power of attorney abuse and the benefits of the Uniform Power of Attorney Act, and undue influence committed by professionals.

### **Educating Older Persons and Lay Fiduciaries**

The *Managing Someone Else's Money* guides that the Commission produced for the Consumer Financial Protection Bureau (CFPB) Office for Older Americans last year have been extremely successful. More than 450,000 print copies of the national guides (for agents under powers of attorney, court-appointed guardians of property and conservators, representative payees and VA fiduciaries, and trustees under a revocable living trust) have been disseminated. The guides may also be downloaded online for free. The guides have received very favorable media attention. *Forbes* blogger Carolyn Rosenblatt wrote "About Aging Parents: Something The Government Got Right (For A Change)" on October 1<sup>st</sup>, saying:

*I think they did a fine job on this. Maybe that's not the way I would comment on a lot of other confusing or poorly written government efforts at educating the public. And they don't teach you this stuff in school. My hat's off to the CFPB.*

### **Advocating for Stronger Laws and Policies**

Supported by ABA policy, the Commission engaged in numerous efforts to strengthen federal and state laws and policies. These activities included participation in the Elder Justice Roadmap steering committee and implementation efforts; technical assistance to federal agencies including the Administration for Community Living, CFPB, Department of Justice, Federal Trade Commission, Securities and Exchange Commission, and Social Security Administration on financial exploitation issues; technical assistance to and trainings for multiple states on power of attorney abuse, elder abuse fatality review teams, and court-focused elder abuse initiatives; participation in national policy roundtables, forums, and summits; and collaboration with the ABA's Governmental Affairs Office to send letters to Congress in support of appropriations for the Elder Justice Act as well as for expansion and reauthorization of elder abuse-related provisions in the Older Americans Act. ■

# Featured Successful Partnership

## New Guide Helps Law Enforcement Detect and Respond to Elder Abuse

The Commission on Law and Aging recently published *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement*. Development, production, and dissemination of the pocket guide was funded through a cooperative agreement from the U.S. Department of Justice's Bureau of Justice Assistance (BJA). The guide was written by Lori Stiegel, senior attorney and elder abuse expert.

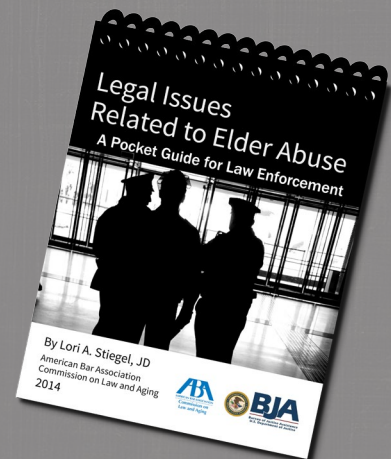
The 55-page guide is coil-bound, tabbed, color-coded, and cross-referenced for ease of use. It is laminated for durability and small (4" by 5") so that it may be carried in a pocket or attached to a patrol car visor.

The guide provides brief explanations of:

- legal concepts, documents, and tools that may be misused to commit elder abuse or used properly to remedy it, and
- issues and actions that justice system professionals should consider if they suspect elder abuse has occurred.

Specific topics include:

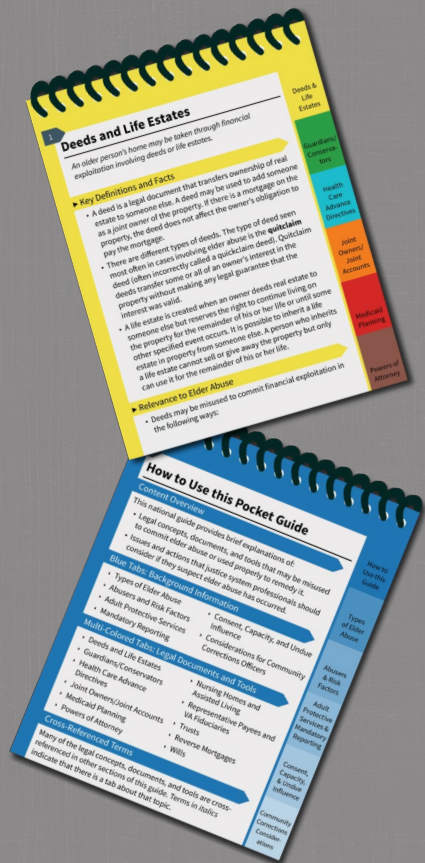
- Types of Elder Abuse
- Abusers & Risk Factors
- Consent, Capacity, & Undue Influence
- Adult Protective Services & Mandatory Reporting
- Considerations for Community Corrections
- Deeds & Life Estates
- Guardians/Conservators
- Health Care Advance Directives
- Joint Owners/Joint Accounts
- Medicaid Planning
- Nursing Homes & Assisted Living
- Powers of Attorney
- Representative Payees & VA Fiduciaries
- Reverse Mortgages
- Trusts
- Wills



**Commission on  
Law and Aging**

**&**

**U.S. Department of  
Justice's Bureau of  
Justice Assistance**





Stiegel was assisted by an advisory committee composed of representatives from law enforcement, community corrections, prosecutors, and victim advocates. Members included:

- The Honorable John Conery, a judge in Louisiana
- Robert Fleming, an elder law practitioner in Arizona
- Dale Gillette, a retired law enforcement officer and TRIAD program coordinator in Ohio
- Trudy Gregorie, a victim advocate from Washington, DC
- Nancy Halverson, a community corrections official from Minnesota
- Ricker Hamilton, formerly an adult protective services administrator in Maine
- Tristan Svare, an elder abuse prosecutor from California
- Randy Thomas, a retired law enforcement officer/academy instructor in South Carolina

More than 23,000 guides were printed. BJA's policy advisor for the project, Linda Hammond-Deckard, distributed 2,000 copies at the International Association of Chiefs of Police annual conference in October. As a result, numerous law enforcement agencies and prosecutors already have requested several thousand more copies.

Information about ordering the pocket guide or downloading the PDF of the guide can be found online at: [www.ambar.org/ElderAbuseGuides](http://www.ambar.org/ElderAbuseGuides). ■

## Three options are available:

1. Pocket Guide print edition
2. Pocket Guide pdf download
3. Desk Guide pdf download



*“My colleagues and I need to know that when we’re told ‘I could spend dad’s money because I have his power of attorney’ we shouldn’t just say ‘Oh, OK’ and walk out.”*

*—Dale Gillette, Lt. (ret.), Ross County Ohio Sheriff’s Office and Triad Coordinator  
Pickaway County, Ohio Sheriff’s Office*



# International Human Rights & Older Persons

2014 Review  
by Charles P. Sabatino



This year the Commission continued to participate in what has become an annual meeting of the U.N. Open-Ended Working Group on Ageing through our liaison Bill Pope. The meeting took place July 30 to August 1. The Working Group has continued to engage in extensive inquiry and debate about whether the U.N. should pursue a separate convention on the rights of older persons; or instead, seek to strengthen the enforcement of existing international normative standards as they may apply to older persons. That question remains a threshold sticking point to consensus.

The Commission cosponsored an important side event at the Working Group's meeting this year. The event presented the work of John Marshall Law School and Roosevelt University in the drafting of a model international convention, referred to as the *Chicago Declaration*. The authors see this draft as an evolving work, based on continuing input from experts and stakeholders internationally, including the ABA Commission. The hope is that this declaration will stimulate concrete thinking about what the terms of an actual convention might look like.

After the summer meeting, Bill Pope finished his successful tenure as liaison and Commission member and welcomed a new liaison to the U.N. Working Group, Professor William Mock of John Marshall Law School in Chicago. Bill Mock and his colleagues have been the driving force behind the *Chicago Declaration*. At John Marshall, Bill founded the Center for International & Comparative Studies and the school's LL.M. programs in Comparative Legal Studies and International Business & Trade Law. Bill also serves in a leadership position in the Section on International Law. In looking ahead at prospects for action by the U.N. on aging issues, Bill is optimistic that the U.N. will eventually accept the need for an international convention on the rights of older persons and proceed with a convention process.

The Commission also continued to monitor the efforts of the Organization of American States (OAS), which has been moving ahead with stops and starts to draft a free-standing OAS convention on the rights of older persons. The convention drafting process has been extended into 2015. ■

# The Policy and Political Challenges of Being Mortal

by Charles P. Sabatino



*At the ABA Midyear Meeting in February 2015, the Commission on Law and Aging and the Health Law Section will cosponsor a resolution “to support legislation and regulation that promotes access to comprehensive long-term supportive services and care for persons with advanced illness.” In this article, Commission Director Charles P. Sabatino describes the resolution and the reasons therefor.*

Two recent publications suggest that as a society we may be getting closer to recognizing and doing something about how we treat our sickest and most vulnerable citizens and their families as they cope with illness near the end of life. The first is the release of a landmark report from the Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preference Near the End of Life*. The other is the publication of a powerful book by physician surgeon Atul Gawande, *Being Mortal: Medicine and What Matters in the End*.

The report by the Institute of Medicine (IOM) starts with a recognition that for patients and their loved ones, no care decisions are more profound than those made near the end of life. But our healthcare and payment system, despite the efforts of dedicated health professionals, largely fails to provide care for those nearing the end-of-life that is compassionate, coordinated, affordable, and of the best quality possible.

Consider this story, one of many submitted to the IOM:

*As my 88-year-old father-in-law was in decline with eight different chronic conditions, he had more specialists than we could keep track of, and nobody was steering the ship. Most of all, his pain was poorly managed, but finding an outpatient palliative care physician was impossible, even in a city like Los Angeles. He resisted hospice mainly because he thought that meant he was giving up, so he continued to suffer and experience recurring runs to the emergency room. When he finally agreed to home hospice, his care and condition improved dramatically, and during the final month he lived under hospice he was comfortable, he had heartfelt conversations with all 11 of his children, and he died in peace and dignity in his home. It was a good death, but the period of serious, progressive illness before hospice was a nightmare, because hospice-type care is kept out of reach until the last moments of life.*

Atul Gawande's book, *Being Mortal*, grippingly portrays Dr. Gawande's personal evolution as a surgeon and pillar of Western medicine into a humble awareness of what really matters to individuals nearing the end of life and how our health systems tragically miss the mark:

*You don't have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. They are spent in institutions—nursing homes and intensive care units—where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.*

The IOM report presents a substantial body of evidence showing how broad improvements to the care of those with advanced illness are within reach. They make the case persuasively that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system. Dr. Gawande makes the same case through his personal experience with patients, family, and innovative leaders in palliative care and gerontology.

From the perspective of the ABA Commission, these issues are not just matters of improving the quality of care. They are ultimately human rights issues, since we see access to dignified, person-centered, coordinated care consistent with the values and preferences of individuals as a fundamental right.

The Commission on Law and Aging and the Health Law Section have taken a first step to respond to the status quo by proposing a resolution that will go to the ABA's House of Delegates in February 2015. The resolution supports legislation and regulation that promotes access to and financing of high-quality, comprehensive long-term supportive services for persons with advanced illness. It supports a system with six characteristics, based upon elements identified in existing innovative models of advanced care that have been shown to work. The key elements are reflected in the principles and policy framework articulated both by the IOM as well as the Coalition to Transform Advanced Care (C-TAC), a diverse alliance of more than 100 patient and consumer advocacy

groups, healthcare professionals and providers, private sector stakeholders, and faith-based organizations.

The resolution identifies six key elements needed to create a high quality system of care for persons with advanced illness. Advanced illness is defined as the stage at which one or more conditions become serious enough that general health and functioning decline, treatment aimed at cure begins to lose its effect, and quality of life increasingly becomes the focus of care. A person with advanced illness has entered the "gray zone" between treatable and terminal illness and may need both chronic care and acute care, as well as palliative care and eventually end-of-life care.

### **A High-Quality System of Care for Persons with Advanced Illness**

#### **Element 1: Finance and payment mechanisms that support access to person-centered care coordination and care management across all care settings, providers, medical conditions, and time.**

Care options are currently determined more by various payment incentives and resources available than by the personal goals of individuals, families, and caregivers. The current fee-for-service payment method does not encourage efficient use of services or proper care coordination and encouraged reimbursement for quantity over quality. Fee-for-service also tends to isolate episodes of care over time and location, leading providers to treat recurring medical events in isolation of one another. There is little incentive to integrate treatment over the course of time and place in order to treat the whole person, rather than discrete problems.

Care coordination and care management that reaches across care settings and treatments and provides continuity over time has been shown to be an essential component of quality chronic care. It can be provided through multiple modalities, but its success depends on its engagement with the patient and its ability to break down the system and payment silos that separate treatment settings and home and community-based services.

In its landmark 2001 report, *Crossing the Quality Chasm*, the IOM defines *person centered* as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions." The concept has become a pivotal precept in health



systems reform and has also been incorporated in Medicaid regulations for home and community based services.

**Element 2: Advance care planning through counseling, disclosure and meaningful discussion of prognosis, goals of care, personal values, and treatment preferences, including planning for family caregivers' needs.**

Effective advance care planning depends on an ongoing, informed, shared decision-making process among the patient, family, and providers. At its best it takes place within a community-wide health system that organizes itself to engage patients and those closest to them about their values and their healthcare goals. The ultimate goal is to make sure that patients receive just the treatment they want based on informed decisions and documentation of their preferences.

Planning models based on this framework have been shown to effectively elicit and document patient goals of care and preferences and comply with them in the final stages of the patient's life. The IOM describes the ideal model as a "Life-Cycle Model of Advance Care Planning" beginning in adulthood as part of primary care and continuing as an evolving discussion through changing health and life circumstances, diagnoses of chronic conditions, declining health, and one's final stage of life. The discussion changes according to the stage.

**Element 3: Access to palliative care, community-based supportive services, and caregiver support to enable persons with advanced illness to remain in the home and community in accord with their preferences and needs.**

The Department of Health and Human Services' Centers for Medicare and Medicaid Services (DHHS CMS) and the National Quality Forum (NQF) both provide a definition to characterize palliative care in the United States:

*Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.*

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team.
- Patients, families, palliative and non-palliative healthcare providers collaborate and communicate about care needs.
- Services are available concurrently with or independent of curative or life-prolonging care.
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.
- Palliative care is provided by a team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Most people with advanced illness want to remain at home and, when the time comes, to die at home. So, access to palliative care in the community is important, along with community-based support services to help individuals and their caregivers. Palliative care has also been shown to increase patient and family satisfaction with care, lower costs, and, in some cases, increase longevity for dying patients.

**Element 4: Expanded research to improve care delivery and payment practices that will benefit individuals and families facing advanced illness.**

So-called *pay-for-quality* initiatives have become an increasingly important policy strategy for improving quality performance and reducing health care costs. While some measures of quality exist for homebound elders and individuals in hospice programs, a great gap still exists in developing measures that capture the experience of the advanced illness population across care settings, across providers, and over time.

There has been progress through the National Quality Forum which in 2012 released its report endorsing 14 measures for accountability and quality improvement in palliative and end of life care, but these still fall short. NQF has a current project to review potential measures of person- and family-centered care, including health-related quality of life, functional status, and experience with care. It is also working to identify appropriate measures for care coordination,



a challenge that requires taking into account multiple providers and care settings.

**Element 5: A strong healthcare workforce educated and equipped with the clinical and social skills to serve people with advanced illness and their families and caregivers.**

The existing workforce is simply insufficient to care adequately for the growing number of Americans with advanced illness for several reasons, including:

- We now face a looming shortage of nurses, primary care physicians, chaplains and other spiritual advisors, direct care workers, and social workers. This places increased burdens on family caregivers, who currently provide the vast majority of long-term care and, increasingly, complex care with inadequate training.
- Existing Medicare and Medicaid regulations and payment rules often limit providers from optimizing efficiencies, using emerging technologies fully, and enabling interdisciplinary teams to provide appropriate supportive care to individuals and families living with advanced illness, especially for individuals who are eligible under both Medicare and Medicaid (called *dual eligibles*).
- Advanced illness training and protocols are lacking. There is little incentive to communicate or to coordinate services among health care providers, especially across care settings. Care professionals need training in the provision of certain caregiving and basic supportive services that can be helpful with individuals with advanced illness. Training needs include person-centered decision-making skills, care planning and transitions, palliative care knowledge and skills, and medication management.

**Element 6: Health information technology that promotes advanced care planning and effective information sharing across time, place, and provider.**

Health information technologies hold great promise for quality and efficiency. But there are also great challenges to its meaningful use and interoperability across care systems and locations. Paper records are too tied to their physical location and vulnerable to loss and disorganized accumulation over time. Technology efforts will also have to develop standards,

protocols, and incentives to ensure quality and efficacy across settings and providers.

Consistent with this position is the IOM recommendation urging policy and payment systems to:

*require the use of interoperable electronic health records that incorporate advance care planning to improve communication of individuals' wishes across time, settings, and providers, documenting (1) the designation of a surrogate/decision maker, (2) patient values and beliefs and goals for care, (3) the presence of an advance directive, and (4) the presence of medical orders for life-sustaining treatment for appropriate populations.*

**Challenges in Realizing the Vision**

The task of creating a system with the above characteristics requires broad-based advocacy from many sectors. The ABA brings a unique human rights voice to the debate; it can speak for the interests of patients and families without the inherent conflicts of interests born by providers of care. So far, Congress has failed to address the issue comprehensively or even incrementally. Instead, it has in the past fallen into baseless debates about death panels.

Policy makers have to face up to the fact that dying is not what it used to be. Most Americans will die in old age after an extended period of decline caused by multiple chronic conditions. Within our current health non-system, there are numerous regulatory barriers—as well as clinical, social, and financial barriers—that reinforce fragmented, uncoordinated, and unsupportive care. Without solutions, the last stage of life will be characterized by financial stress, life-extending interventions that may degrade the quality of life with little benefit, and care in settings individuals hoped to avoid.

Adoption of the resolution affords an opportunity for the ABA to recharge its role in raising the consciousness of policy makers about the serious needs of vulnerable populations and reminding them that access to health, long-term, and end-of-life care is a human rights as well as a clinical and social issue. More importantly, in the end, everyone in the ABA is, or will be, profoundly affected by these issues personally if not professionally.

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*Charles P. Sabatino is the Director of the American Bar Association Commission on Law and Aging in Washington, DC. ■*

# The Wrong Signals:

## Shutting Down the Planning Conversation Before It Starts

*by David Solie*



As advisors, how do we communicate good ideas to older clients that could improve their quality of life? These might include suggesting:

- Support services to enhance aging in place,
- Lifestyle changes to protect and improve health,
- Living accommodations to reduce isolation and loneliness, or
- Planning options to manage incapacity.

Many times, attempts to discuss these and other planning topics are met with indifference, rejection, and even hostility. Despite the constant media prompting to have “the talk” with older adults, it’s easy to send out the wrong signals that create barriers instead of conversation starters. Why is this happening and, as important, how can it be avoided?

It is tempting to blame these false starts on the eccentricities of aging. But is there more going on in these conversations? New research<sup>1</sup> on the psychology of aging indicates there is: outdated assumptions.

Despite good intentions, outdated assumptions about older clients may lead advisors to inadvertently send out the wrong message--and it is this poor signaling, not the eccentricities of aging, that proves to be a primary cause of communication setbacks. The good news is that by understanding the psychology of aging, advisors can fine-tune their communication skills to resonate with the unspoken agenda of older clients.

<sup>1</sup> William R. Miller and Stephen Rollnick, *Motivational Interviewing: Preparing People for Change*, second edition (New York: The Guilford Press, 2002).

## The Psychological Agendas of Older Clients

Consider the psychological landscape of older clients—it is a world embedded with two dominant agendas posing significant resistance to change. Together, these psychological currents create a deep inertia to disrupting the status quo.

### *Ambivalence and the “Righting Reflex”*

An understanding of one of the agendas comes from new research on the psychology of change.<sup>2</sup> While not unique to the old, its presence has profound implications for older clients. This underlying psychological mechanism categorically resists unsolicited advice. Not surprisingly, its defining feature is ambivalence.

A deep current of ambivalence lies behind client conversations that involve unsolicited advice about change. Attempts to inform or direct clients about change typically involve phrases such as “You need to get outside help” or “It is important to develop a long-term care plan.” However, this aggressive phrasing can provoke a push-pull of ambivalent thoughts—“I want to change, but I don’t want to change”—that defaults into resistance. An advisor’s attempts to counter this resistance through prescribing, persuading, or convincing may only entrench clients into defending the status quo. This a response aptly called the “righting reflex”—a client uncomfortable with change may push back, reflexively preferring the status quo to the off-kilter feeling that the suggestion of change may bring. No matter how logical or beneficial the advice appears, ambivalence-tainted conversations can quickly shift from cordial to gridlocked.

It’s not that older clients are opposed to change or fail to appreciate its necessity or benefits. They do. But the magnitude of the underlying psychological reaction to unsolicited advice may short circuit even the best ideas. By itself, this communication challenge poses a daunting obstacle to advisory conversations. And, rapport with older clients proves to be even more complicated in the face of an equally powerful tension: developmental tasks present later in life.

### *Development Later in Life: A Need for Control*

Developmental stages in life are characterized by sets of oppositional tasks. These tasks are the drivers of personality growth--the internal engine that propels a person forward. While well-documented in children and teenagers—for example in the development of the ability for independence and for intimacy--their identification and impact on psychological development in old age has only recently been considered.<sup>3</sup>

Beginning in their late 60s, older adults are confronted with two seemingly paradoxical tasks that provoke conflict and resistance to change:

1. Preserve control in a world where physical and cognitive functioning is declining.
2. Create a legacy in a world where time is running out.

One task requires hyper-vigilance to guard against an unending series of losses that threaten to push life out of control. The other task requires a reflective pause, a review of life’s events and an eventual letting go. Each task is pulling in a different psychological direction, one struggling to last and one preparing to leave.

In addition to the loss of control associated with changes in health and physical strength, older adults are experiencing equally painful losses in other areas of their lives that intensify the scope and complexity of the battle for control. These losses can include:

- Family
- Peer group
- Status
- Identity
- Driving privileges
- Home
- Financial independence

As the losses mount and control is involuntarily surrendered, older adults run out of options. Underestimating the intensity and impact of these losses can derail the best intentions of an advisor to be helpful. Good advice may be rejected by an older person in favor of illogical or shortsighted choices because, from a developmental perspective, the need for control is greater than the need for medical, financial or social correctness.

<sup>2</sup>*Id.* at 1.

<sup>3</sup>David Solie, *How To Say It To Seniors: Closing the Communication Gap with Our Elders* (New York: Prentice Hall Press, 2004).



Given this communication landscape, how do advisors navigate these two psychological agendas to establish and sustain rapport with older clients? What strategies have proven effective for framing critical planning conversations and improving receptivity to new ideas?

### **Suggested Approaches**

Confronted with an older person's ambivalence and a need for control, it is essential for advisors to learn how to send signals that minimize resistance while respecting choice.

#### *Open-Ended Questions*

One effective strategy for accomplishing this is open-ended prompts that contain key words that resonate with losing and preserving control. Words like *independence, dependence, choice, loss, manage, and control*, may enhance an older person's receptivity to open-ended questions. Here are some examples:

- Tell me more about your choices for his care.
- How will you manage your loss?
- What's your living situation like?
- How will you preserve your independence?

Open-ended questions invite clients to discuss their lives as well as reveal concerns and priorities. As important, they soften ambivalence by offering a non-judgmental venue that invites disclosure. While an effective first step in creating rapport, open-ended questions need facilitation to advance the dialogue. This requires the use of another complimentary communication strategy called reflective listening.

#### *Reflective Listening*

Reflective listening prompts are how advisors signal to clients: "here's what I heard you say." They can be simple reflections of what the client has said, paraphrasing of a topic, or identifying feelings surrounding people and events. Here are some examples:

- Your choices regarding his care are becoming more complex and confusing.
- You're still trying to come to terms with the sudden loss of your sister.
- You feel that your living situation is slipping out of control.
- Let me see if I understand how you plan to preserve your independence based on what you have said so far.

As with open-ended prompts, the reflective listening examples above are embedded with key words that resonate with losing and preserving control.

#### *Thoughtful Word Choice*

Advisors can also integrate a similar developmental resonance in the "why" of planning with older clients. Here are some examples:

- We plan in order to preserve choice.
- We have found lack of planning results in loss of control

The continuity of preserving control could be further be expanded by renaming familiar planning techniques. Long-term care planning might be recast as long-term control planning. A simple alteration in language can help create a control-focused conversation that reinforces the perception that the advisor is both a confidant and a facilitator.

The overriding goal with these approaches is to create a conversational precedent that minimizes resistance and signals a "control friendly" environment. It allows older clients a safe venue for disclosure, a process that helps them make connections between their behaviors and values and goals. It is a context in which clients become aware of discrepancies that may eventually catalyze change. However, it is an organic, client-driven process that should not be forced or manipulated. The advisor's role is to plant seeds and wait for new signals.



## “Change Talk” and Opportunities for Advice

These signals come with the client’s movement towards talking about change or taking small steps towards making it happen. This client-generated motivational shift is called “change talk.”

Change talk comes in many forms ranging from cautious consideration to statements of commitment. Here are some examples:

- I wish things were different.
- I know what I have to do. I just need to do it.
- It would be nice if I didn’t have to worry about it.
- I can’t go on this way.
- I’m going to do it.

Recognizing these shifts in motivation offers advisors the opportunity to use open-ended questions to advance the dialogue. Here are some examples:

- Suppose you do nothing?
- What would be the advantages of downsizing?
- How would that make things better?
- How would you like things improve?
- What’s next?

Change is a non-linear process in which clients advance and retreat based on circumstances and motivation. It is important to remember that change talk is a signal not a directive. While advisors need to be supportive of motivational shifts, they need to resist the temptation to prematurely advance them. They also need to accept the fact that resistance is a normal part of the process. Instead of attempting to prematurely mobilize a motivational shift, it is better to allow discrepancies between the client’s behavior and their values drive the pace and direction of change.

This shift also signals a change in the client’s receptivity to information about peers who have faced similar challenges. At this point, parallel stories are an effective adjunct to open-ended questions and reflective listening. They offer strategies and lessons on how others have navigated the predictable dilemmas aging. As important, this approach affirms the advisor’s commitment and experience to working on these issues with older clients.

## Conclusion

Older clients are looking for good ideas on how to preserve dignity and independence. Unfortunately, their psychological agenda may create communication obstacles that incline them to resist taking unsolicited advice and surrendering control. Advisors who understand the thematic and linguistic implications of this agenda are able to fine-tune their messaging to resonate with their client’s needs. By doing so, they open up the planning conversation before it starts.

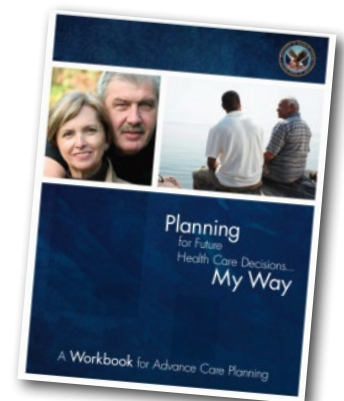
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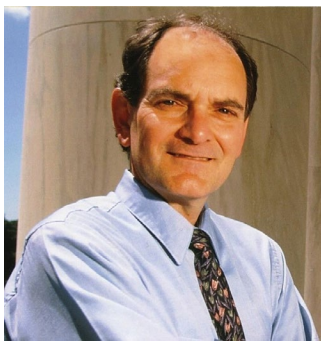
*David Solie, MS, PA, is an author, educator, speaker, and thought leader on the developmental psychology of the second half of life. His research offers unique insights and proven, practical communication strategies that help professionals and laypersons alike interact more compassionately and effectively with older adults. He is a graduate of the University of Washington, University of Manitoba, University of Colorado Medical School, and practiced a number years in family medicine as a licensed physician assistant.*

*Additional information about his work can be found at [www.davidsolie.com](http://www.davidsolie.com). ■*

## U.S. Department of Veterans Affairs Releases Health Decisions Planning Resource Website

The National Center for Ethics in Health Care within the U.S. Department Veterans Affairs (VA) health care system has released a health care decisions planning resource called *Planning My Way*. Resource components include worksheet and documents on a variety of topics. The publication was designed with Veterans in mind, but is a useful tool for anyone—veterans and non-veterans alike. Anyone can benefit from *Planning My Way*. To access the digital publication and the other tools available, visit: [http://www.ethics.va.gov/pmw\\_web/what-matters.htm](http://www.ethics.va.gov/pmw_web/what-matters.htm). ■





## Commission Director Invited to Join Expert Group

Commission Director Charlie P. Sabatino has been invited to join and has accepted

membership to the National Academy of Social Insurance (NASI). Over 900 of the nation's leading experts on social insurance are members of NASI. Membership is an honor for which individuals are nominated by at least three active NASI members.

Members' affiliations include universities, think tanks, business, labor, legislative and executive branches of the federal or state governments, and interest groups. Members include policy analysts in income security and health care financing, economists, political scientists, physicians, actuaries, administrators of public and private benefit programs, social workers, sociologists, historians, journalists and scholars and practitioners in related fields.

Learn more about NASI at [www.nasi.org](http://www.nasi.org). ■

## Commission Liaison Receives Award

Mary Joy Quinn, a Liaison to the Commission from the National College of Probate



Judges (NCPJ), has been presented with the Treat Award for Excellence by the NCPJ. Established in 1978, the Treat Award is presented annually to one who has made "a significant contribution to the improvement of the law or judicial administration in probate or related fields." The award is named in honor of Judge William W. Treat, founder and President Emeritus of the National College of Probate Judges.

Mary Joy Quinn has served as the director of the Probate Court of San Francisco Superior Court since 1989, and previously served as a conservatorship investigator for 12 years. She has authored numerous articles and books focusing on elder abuse and neglect, as well as on adult guardianships. ■

## ABA Senior Lawyers Division

### John H. Pickering Award of Achievement Call for Nominations



The ABA Senior Lawyers Division (SLD) is accepting nominations for the 2015 John H. Pickering Achievement Award. The award honors the life and accomplishments of John H. Pickering, an outstanding lawyer who was involved in various pro bono activities and law-related societal issues affecting the elderly.

The award nominees shall have attained the age of 55 years; must be a lawyer or judge (not necessarily a member of the American Bar Association); shall have demonstrated throughout his or her career outstanding legal ability; shall have compiled a distinguished record of dedicated service to the profession and the community at large; and made significant contributions to the furtherance of access to justice for all.

The deadline for nominations is February 27, 2015. The award will be presented at the SLD dinner, on July 30, 2015, held during the ABA Annual Meeting in Chicago, IL.

For more information, visit <http://www.americanbar.org/groups/seniorlawyers.html> and scroll to Awards to download the requirements and nomination form. ■