Getting Our Priorities Straight

Using priority-setting and data analysis to understand and meet the high-impact needs of older Americans.

by David M. Godfrey
Inside the Commission

Find these resources, and more, online at: http://ambar.org/COLA.

ABA Annual Meeting Updates

- The Commission welcomed the 2013-2014 Commissioners at the ABA’s Annual Meeting. Joining us this year are four new Commission members: William Hopkins, Robyn Shapiro, Susan Shapiro, and Patricia Struck. The October issue of Bifocal will feature biographical information about our new Commissioners!

- The Commission’s two resolutions before the ABA’s House of Delegates were passed. You can find out more about the resolutions at: http://bit.ly/1d6FKDk and http://bit.ly/17Nc2gO.

- The Commission cosponsored two panels at the recent ABA Annual Meeting: “More than an Equal Sign: DOMA, Prop 8, the Supreme Court, and Your Practice” (on 8/9) and “Why Traditional Planning Fails Seniors” (on 8/10).

Staff Updates

- An updated version of our useful Health Decisions Resources handout is now available: http://bit.ly/1895E9Q.


- Commission Director Charlie Sabatino is on the AARP Caregiving Advisory Panel. Questions can be submitted to the Panel via the online form here: http://bit.ly/11HYi8f.

- Senior Attorney Lori Stiegel presented on the legal duties of fiduciaries at the Adult Protection and Advocacy Conference. You can view the panel slides online: http://bit.ly/16gW69x.

- The New York Times blog The New Old Age featured a post titled “Unable to Cope, Unwilling to Accept Aid” with insight from Commission member Dr. XinQi Dong. It is available at: http://nyti.ms/1aaWNSf.

- Potential interns, we’ll be interviewing at the Equal Justice Works Conference and Career Fair in October. You can find out more online: http://bit.ly/15wdHcU. See you there!

ABA Updates

- The ABA’s Division of Public Education announced that the Law Day 2014 theme is “American Democracy and the Rule of Law: Why Every Vote Matters.” Start your program planning now!

- The Senior Lawyers Division presented the 2013 John H. Pickering Award of Achievement to U.W. Clemon, retired chief judge of the U.S. District Court for the Northern District of Alabama.

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The Administration on Aging has announced funding of 11 new Model Approaches to Statewide Legal Assistance Systems (Model Approaches) projects to “help states develop and implement cost-effective, replicable approaches for integrating low cost service mechanisms into the broader tapestry of state legal service delivery networks.” This continues work begun in 2006. To date, 31 jurisdictions have been funded to complete Model Approaches projects. Fundamental work under the projects include: assessing the legal needs of older clients, assessing legal service delivery systems capacity, development of statewide service delivery standards, examination of priority legal issues, and developing linkages with the full spectrum of aging services providers.

Funding has been awarded to Oklahoma, Oregon, Montana, and Washington to begin Model Approaches projects. For the first time, funding has also been awarded to continue, enhance, and expand the work of previous Model Approaches projects. These projects are now known as Model Approaches Phase 2. The Model Approaches Phase 2 awardees are California, District of Columbia, Nebraska, Iowa, Michigan, Idaho, and Maine.

Congratulations to the 11 new awardees. We look forward to working with these projects through the Commission on Law and Aging’s partnership with the National Legal Resource Center. Competition for this funding was fierce for the limited number of awards available. Additional rounds of funding are anticipated.

More information is available on the Administration on Aging’s website: http://www.aoa.gov/AoARoot/AoA_Programs/Elder_Rights/Legal/model_approach.aspx.

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The 3rd World Congress on Adult Guardianship will be convened on May 28–30, 2014, in the Washington, DC, Metropolitan Area. It is sponsored by the National Guardianship Network in affiliation with the International Guardianship Network. The theme of the conference is “Promising Practices to Ensure Excellence in Guardianship Around the World.” For more information, see http://worldcongressguardianship.org/.

The World Congress on Adult Guardianship is an unparalleled international gathering of guardianship advocates to examine problems from new perspectives and offer solutions from multiple viewpoints and cultures. Each World Congress offers opportunities to learn and collaborate by bringing together those involved in adult guardianship, as well as aging, disability, and elder rights from around the globe. All participants bring a commitment to examine the best ways to shape guardianship systems so that they consistently treat vulnerable populations with dignity and respect.

Approximately 400 delegates, including academics, attorneys, court officials, judges, disability advocates, government officials, guardians, and fiduciaries from 20 countries have participated in previous Congresses.
The April issue of *Bifocal* included quantitative data on legal service delivery to older adults in eight jurisdictions.¹ This article goes a step further to explore what the data may tell us about how well we are meeting the priority legal needs of older Americans with the greatest economic and social needs—to see if we have our priorities straight.

### Setting Priorities

Virtually all civil legal aid programs rely on priority-setting to focus limited service capacity on the legal issues that are most critical to clients. Most programs engage in a formal priority-setting process to define the legal issues and case types on which they will focus. Some programs set priorities informally—deciding what cases to take and what cases as they come in. Still others limit their focus overall, choosing to make their mission a specific legal issue.

A formal priority-setting process is required of all Legal Service Corporation (LSC) grantees.² The board of every LSC-funded program must adopt written priorities based on an assessment of the needs of potential and current clients. LSC suggests priority issues as a starting point, but individual program priority-setting must consider the needs of their eligible clients and should include “all significant segments of that population with special legal problems or special difficulties of access to legal services.”³ The overlapping capacity of all legal service providers must be considered in LSC priority-setting. Priorities ration limited resources to provide legal assistance to the most critical legal issues.

Priority-setting needs to include provisions for flexibility. Unexpected legal challenges can emerge very rapidly. Programs must be able to adjust priorities as needed. LSC requires that a program’s board review priorities at least annually—and as needed—based on emerging client needs.⁴ When needs change and requests for cases outside established priorities rise, priorities can change as fast as a board meeting can be held.

While the Older Americans Act (OAA) does not mandate a formal priority-setting process the way that Legal Service Corporation regulations do, the Act does require state agencies to provide assurances that the area agencies on aging will “give priority to legal


³ Id. at § 1620.3(c)3.

⁴ 45 CFR § 1620.5.
In assessing an area’s needs, it is important to look at the needs of eligible clients and not just current clients . . .

. . . are there segments of the population not yet being reached by your services?

assistance related to income, health care, long-term care, nutrition, housing, utilities, protective services, defense of guardianship, abuse, neglect, and age discrimination” as part of their State Plans.5

Identifying and Understanding the Client

The first step in priority-setting is to understand the legal needs of clients in the service area. Most legal aid programs have guidelines for client eligibility based on definable characteristics such as geographic location, age, income, and assets. For OAA-funded programs, eligible clients are persons age 60 and older; services are targeted to those with the greatest economic need (under the poverty level) and the greatest social need (as defined in the Act).6 In assessing an area’s needs, it is important to look at the needs of eligible clients and not just current clients; are there segments of the population not yet being reached by your services? The assessment of the legal needs of potential client can be done by survey, interview, or focus group.7 Effective assessment requires more than asking clients about their legal needs, it requires understanding the lives of those in the service area, the day-to-day challenges they face, and the legal needs that arise.

What Makes an Issue a Priority?

The key to priority-setting lies in weighing the relative importance of legal problems, sometimes a difficult calculation. Some issues, such as establishing eligibility for income-based housing, result in clearly quantifiable outcomes—you can place a dollar value on the benefit to the client. Other issues, such as avoiding or terminating an unnecessary guardianship, make a huge difference in the life of the client but do not have a clear dollar value. Both quantifiable and non-quantifiable issues need to be included in effective priority-setting and need to be valued in outcomes based on the difference they make in the life of the client.

To be a priority, an issue must have a viable legal solution.8 Some issues, such as basic applications for income-based housing are best resolved with a non-legal approach. The issue must have a resolution that can be accomplished with available resources.9 The old wisdom of picking your battles applies to complex cases;10 cases requiring complex litigation must be very carefully selected based on priority issues, likelihood of success, and the residual impact on other similarly situated clients.

Priority issues should also be ones that make the biggest difference in the life of a client. Successful priority-setting should not just be about generating increased numbers of cases closed or clients served. For example, helping a client collect a judgment for $100 against a former landlord makes a modest difference in the life of that client; helping a client establish eligibility for $100 in monthly rental assistance has a larger and long-term impact. When faced with this choice, the sound choice is the one that has the greater and longer-lasting impact.

Priority-Setting Under the Older Americans Act

As mentioned earlier, the OAA does not mandate a formal priority-setting process; rather, it focuses on agency assurances that priority needs are being met. However, for

5 42 USC 3026 § 307(11)(E).
6 Older Americans Act § 102 (25–26).
7 For legal needs assessment reports and survey examples, see http://www.cerare-source.org/.
8 45 CFR § 1620.3(a)(8).
9 Id. at (8), (9), and (10).
10 45 CFR § 1605.3 requires LSC programs to have a review process for potential appeals.
the assurances to be meaningful and to truly focus on the priority issues and sub-issues, legal service developers, area agencies on aging, and legal aid programs must engage in active priority-setting.

The categories listed in the Older Americans Act are far too broad for effective issue prioritization; this scrutiny needs to be done at the subcategory level. For example, legal issues in long-term care can run the spectrum from private long-term care insurance to Medicaid benefits to caregiver abuse to unlawful discharge. Of older Americans with the greatest economic and social needs, few can afford private long-term care insurance—Medicaid is more likely to be a real legal need. Even within Medicaid cases there are many sub-issues; refinement in priority-setting will likely focus on core eligibility issues for the poorest of clients, rather than complex asset planning of use to clients with greater resources.

It is important to concentrate on the needs of the clients and not on the capacity or interests of staff. Talented staff can develop expertise in the issues that need to be priority issues for clients.

When setting priorities on a statewide level, it is important to consider regional differences. The priority legal needs of the target client population can vary significantly from area to area. For example, in a city with rent control, a primary housing issue may be keeping clients in affordable rental housing; in a nearby rural area without rent control and a high level of home ownership by very low income older adults, the primary housing issue may be qualifying older clients for property tax exemptions and deferrals. Priorities need to take into account the varying needs of clients at the local level.

➡ What Does the Service Data Tell Us?

What does the legal service data tell us about how well we are meeting the priority legal needs of the neediest of older clients? In April we published legal service data we collected from eight jurisdictions last year. While the sample contains over 38,000 cases, the sample should not be construed as representing a national picture, only a report on the services from the reporting states. Here is the core data again, followed by an analysis.

<table>
<thead>
<tr>
<th>Problem Code Area</th>
<th>Number of Cases Reported</th>
<th>Percentage of Total Reported Codes</th>
<th>Subcategory Standouts (% of Total Reported Codes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>29</td>
<td>0.0075%</td>
<td></td>
</tr>
<tr>
<td>Juvenile</td>
<td>230</td>
<td>0.06%</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>785</td>
<td>2.04%</td>
<td></td>
</tr>
<tr>
<td>Individual Rights</td>
<td>864</td>
<td>2.25%</td>
<td>Social Security (0.70%) SSDI (0.46%) SSI (0.59%)</td>
</tr>
<tr>
<td>Income</td>
<td>1,555</td>
<td>4.04%</td>
<td>Medicaid (3.09%)</td>
</tr>
<tr>
<td>Health</td>
<td>2,376</td>
<td>6.125</td>
<td>Homeownership (6.3%) Private LL Tennant (4.8%)</td>
</tr>
<tr>
<td>Family Law</td>
<td>2,657</td>
<td>6.91%</td>
<td>Divorce (2.50%) Guardianship (2.22%)</td>
</tr>
<tr>
<td>Housing</td>
<td>6,383</td>
<td>16.6%</td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td>7,347</td>
<td>19.12%</td>
<td>Collections (10.19%)</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>12,920</td>
<td>33.63%</td>
<td>Wills &amp; Estates (14.61%) Advance Directives (12.72%)</td>
</tr>
<tr>
<td>None reported</td>
<td>3,277</td>
<td>8.52%</td>
<td></td>
</tr>
</tbody>
</table>

11 The states are: Alaska, DC, Kansas, Nebraska, Michigan, New Mexico, North Dakota, and Wyoming.
12 Categories are sorted by number of cases, not in order of LSC reporting codes.
Education and Juvenile Cases
Education cases represent a negligible number at 29 cases out of over 38,400 cases reported. Some of these may be access to education in later life, locating educational records, or grandparents raising grandchildren. Juvenile cases are also insignificant at far less than one percent of total cases reported. Grandparents raising grandchildren likely account for juvenile cases being included in Older Americans Act services.

Employment Cases
While the majority of older adults are retired, employment cases still come in at 2.04%, very much in line with the 2.9% reported by LSC for overall legal aid services. Continued employment is an important source of income for an increasing number of older adults and their employment issues and discrimination may account for this parity with the LSC percentage.

Individual Rights Cases
Individual Rights cases break down into subcategories of immigration, mental health, disability rights, civil rights, human trafficking, and other. At 2.25% of reported cases, it is slightly above the LSC report of 1.90% of cases. Looking at the data, there is not a noticeable source for the difference.

Income Cases
Income Maintenance case numbers are surprisingly low in comparison to LSC numbers (4.04% of Title III-B cases as compared to 12.7% of LSC cases). Breaking it down further, our data shows Social Security at 0.7% as compared to 0.3% of cases reported to LSC. Social Security retirement benefits are the cornerstone of income for lower-income retirees—accounting for more than 50% of income for more than 50% of seniors. Given this fact, one would expect legal aid programs serving older clients to be doing more work in this area. The data for Title III-B cases shows

Health Cases
Health cases including Medicare and Medicaid seem low at 6.125%. For the overall legal aid population, LSC reports 3.1% of cases in the Health Care grouping. I would expect this number to be higher for the older population with the added complications of Medicare and Medicaid (as well as dual-eligibility for these two programs), and long-term services and supports.

Family Cases
Family Law cases at 6.91% is reasonably in line with expectations.

It is not easy to turn a case away, but the reality is that legal aid programs are forced to turn cases away when they reach capacity.
This is much lower than the 34.4% of cases reported by LSC grantees. Older client populations are less likely to face divorce issues. When older clients do divorce, they are much less likely to have child custody and child support litigation, issues that contribute to higher LSC numbers.

Housing Cases
Census data tells us that homeownership peaks with the age group of 70-74 with more than 4 in 5 older adults owning a home. This is going to impact the kind of housing issues presented by Older Americans Act clients and, as expected, the data shows that the most common housing issues were related to homeownership. Overall Housing cases were a much smaller factor for this sample than for the general LSC legal aid population (16.6% for the Title III-B data compared to 26% for the general LSC population). Home owners face fewer legal challenges than renters. Low income homeowners will need help with foreclosure, tax exemptions, tax deferrals and home repair and modification programs essential to remaining in their home. Older renters, while smaller in number, will still need legal assistance with the challenges of being a tenant. While the numbers of cases will be smaller for older clients, legal assistance aimed at maintaining stable housing should be considered for the program priority list. The numbers reported by the Title III-B providers appear to be in line with expected needs.

Consumer Cases
Consumer law cases coming in at over 19% comprised a surprisingly large percentage. By comparison, LSC data for 2011 shows that consumer law issues were 11.7% of reported cases. Unless supported by evidence that older clients have a higher than average incidence of consumer law issues, the data could be interpreted to suggest the need for closer scrutiny in the amount of resources allocated to consumer cases.

Miscellaneous Cases
LSC includes wills and estates, and advance directives and powers of attorney in the broad category of Miscellaneous. You need to look at the sub-problem codes to see the details for these important issues for older clients. For an aging client base this will always be a high-demand area and some inheritance and planning for incapacity issues should be considered a priority. But, at 33.63% of services, with 14.61% for wills and estates, this number seems high. By contrast, in the general legal aid population, LSC reports only 5% of all cases fall into the Miscellaneous category.

Some estate planning and probate work is necessary to retain housing or income that would otherwise be at risk. Successful advance directives and powers of attorney can minimize the need for guardianship. While some advance health care directives can be done by consumers, powers of attorney are a very complex area of the law that benefit greatly from legal counsel. Even taking into account these factors, the numbers here seem high. It is easy to say that older clients want wills, but priority-setting requires focusing on the legal needs as opposed to legal wants of clients.

Parsing out under what circumstances a legal provider serving seniors should draft a will or probate an estate for a client requires detailed priority-setting. An example from my earliest legal aid clerkship

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20 Id.
22 See http://www.americanbar.org/publications/bifocal/vol_34/issue_4_april2013/legal_services_oaa.html for more detail on the Title III-B data.
24 For the issues included in the category, see http://www.americanbar.org/publications/bifocal/vol_34/issue_4_april2013/legal_services_oaa.html.
days is instructive. Because of limited capacity, the legal aid program I was working with only accepted divorce cases if a domestic violence restraining order had been filed and the couple had lived separately for more than 30 days.

The logic behind this was two-fold. An important priority was assisting victims of domestic violence. The law required a minimum 30-day separation before a hearing could be scheduled on a divorce case. By applying this detailed priority process, the program focused on helping victims of domestic violence with cases that could be scheduled immediately in the courts. Following this example, a program could limit writing wills or probating estates to cases essential to retaining housing, access to health care, or income. It is not easy to turn a case away, but the reality is that legal aid programs are forced to turn cases away when they reach capacity. When we can focus on the highest impact issues, we are getting our priorities straight.

A Gap in the Data
The increased focus on elder abuse, neglect and exploitation reveals a weakness in the LSC data reporting categories, a lack of a clear category for the tracking of cases relating to elder abuse, neglect, and exploitation. Domestic abuse is included as a sub-category of family law, but many elder abuse cases do not fit easily into the category of domestic violence. Some abuse, neglect, and exploitation issues are addressed through adult guardianship or via powers of attorney or advance directives, or even contract or real property. But without a clear reporting category, these cases are merged into the data for those issues. I encourage LSC to create reporting subcategories to measure the legal aid communities’ work to prevent and respond to the abuse, neglect and exploitation of vulnerable adults.

➡️ Conclusion
Priority-setting and data analysis work hand-in-glove to help us understand the high-impact needs of older Americans and how well we are meeting them. Data from Legal Service Corporation provides a starting point for data comparison, adjusting for differences between the priority needs of the general legal aid population and the unique needs of older clients. While data from eight states does not provide a perfect picture for the entire Title III-B legal service delivery system, a pool of over 38,000 reported cases give us a feel for how well we are meeting the priority legal needs of older clients. Every state and each provider needs to examine, at least annually, the priority legal needs of current clients and of potential clients and review the services being delivered. Comparing the two will tell us if we are meeting the most critical needs of clients, if we have our priorities straight.

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- **Elderbar**, an open discussion list for professionals in law and aging, and
- **Collaborate**, a discussion list on aging, disability, and dispute resolution (jointly sponsored by COLA and the Association for Conflict Resolution’s Elder Decisions Section).

Visit the Commission’s homepage for more information on how to sign up.
From the time I began work as a young lawyer in a senior citizens law project in 1979 through more than 25 years at the ABA Commission on Law and Aging, one ever-present challenge in the field of aging has been how to ensure that the care individuals receive at the end of life is the care they want and expect. Advance care planning is a key tool for reaching that goal. (I use the term “advance care planning” because that’s the core process in which advance directives are merely one tool.) A lot has changed over the years, and research, law, policy, and practice experience have nudged me toward a perspective I’d like to share in the form of eight advance care planning lessons. This list may be of interest to you both personally, as you consider your plans for the future, and professionally, as you reflect on the role that lawyers play in the planning for others. And, if I’ve learned anything in my career, it’s that the only constant is change. These lessons will continue to evolve with changing medical science, health systems, and social mores.
Most Advance Directives Aren’t Worth the Paper on Which They Are Written

I’ve written about the shortcomings of advance directives elsewhere (see, e.g., The Evolution of Health Care Advance Planning Law and Policy, 88 Milbank Q. 211 (2010)), so here, let me just give a very simplified summary of the research literature. Only a minority of adults take the time to create a health-care advance directive, and they generally use a standardized form that doesn’t provide much useful clinical guidance. Even after completing a directive, a patient cannot be confident that it will be followed. Healthcare providers typically don’t know that the directive exists, or if they know, it’s not in the medical record or easily accessible in the record. Agents acting under a health-care power of attorney typically have inadequate knowledge of the principal’s goals and wishes and are too often unprepared to act as an effective surrogate decision maker.

The Real Legal Task of Advance Care Planning Is Appointing and Informing a Health-Care Agent

The authority of an agent to act for an incapacitated principal didn’t exist at common law. It is a power created by statute, so understanding and following the legal requisites of state law is important.

However, everything else is a communication task, not well accomplished through legal documents. Yet, the documentation of treatment instructions—usually in the form of a living will—has been the focus of most legislative and public attention.

In the popular mind, creating a living will to communicate treatment wishes in the face of serious and eventually fatal disease is the most important legal task in advance care planning. The creation of state “living will” laws going back to the 1970s has given the public and sometimes the bar the mistaken belief that you must use a particular legal document to express your future health-care wishes, but that is not the case. Statutes did not create the right to have one’s wishes honored. That right originates in both constitutional and common law principles. More importantly, treatment-specific instructions just don’t work well, except for persons facing fairly known and imminent decisions. We lack a crystal ball to tell us what challenges we will face in our final days. Having a surrogate decision maker is far more valuable, but only if the surrogate is adequately informed and educated.

Ambivalence Is Our Middle Name

Not only do we have a right to change our mind, we often do so. In one study of 189 community-dwelling elders with advanced chronic conditions, researchers found that when participants were asked about their willingness to risk physical disability in order to avoid death, almost half changed their minds over a two-year period, and almost half changed their minds about their willingness to risk cognitive disability. And those participants whose health varied over time were somewhat more likely to have inconsistent trajectories. See Terri R. Fried et al., Stages of Change for the Component Behaviors of Advance Care Planning, 58 J. Am. Geriatrics Soc’y 2329 (2010).

These results shouldn’t be surprising to anyone. Most of us are ambivalent about the prospect of dying, and our deeply held human inclination to hang onto life, even through a progressive decline, often means that we are willing to redraw the line at which enough is enough. A doctor colleague of mine captures it best with what he tells me is an old Spanish proverb: The bull looks different from inside the ring.

Advance Care Planning Has Stages

As our lives change, so does the nature of advance care planning. Planning is just as important for a young, healthy Freddie at age 18 as it is for a Frederick at age 85 who has a serious progressive chronic condition. Freddie isn’t likely to think about end-of-life priorities
and goals.

But Freddie can and should think about whom he wants to make decisions for him were he to become temporarily or permanently indisposed. By the time Freddie reaches his 40s or 50s, he will likely have had personal or family experiences with chronic illness or death and dying; at that stage, his more seasoned values and priorities can be a part of his advance care planning discussion. Frederick, on the other hand, is in a position to be very specific about his preferences, priorities, and treatment decisions—that is, if someone takes the time to talk meaningfully with him. We know that the likelihood of engaging in advance care planning is directly proportional to age, but the need is just as high at all ages.

The Best Trait in a Health-Care Agent: A Drive to Research Relentlessly

Anyone who has counseled clients about naming a healthcare agent knows that a relationship of true love and intimacy doesn’t necessarily translate into a relationship of good surrogate decision making. Sometimes that person is too emotionally invested to make objective decisions. I used to emphasize most strongly the need for an agent to be a strong advocate for the patient’s preferences in the face of resistance. But I’ve concluded that even more important is a drive to know and discover.

The ideal agent should want to understand a client’s values and thinking as thoroughly as possible, and he or she should also be inclined to approach medical decisions as a research task. What are the facts and options, and how do values and goals lead to a choice in that circumstance? This is not PhD-level research; it is often informed common sense.

Some excellent handbooks for healthcare agents are available. But, as a short course, I have found that the following four questions, suggested by Dr. Pat Bomba, a nationally recognized geriatrician, can bring needed clarity to any critical decision an agent must make. See Patricia A. Bomba, Marian Kemp & Judith S. Black, *POLST: An Improvement over Traditional Advance Directives*, 79 Clev. Clinic J. Med. 457, 459 (2012).

1. Will the proposed treatment make a difference?
2. Do the burdens of treatment outweigh its benefits?
3. Is there hope of recovery? If so, what will life be like afterward?
4. What does the patient value? What is the patient’s goal of his or her care?

An Advance Directive Does Not Equal a Plan of Care

Formal legal documents have an aura of authority about them that doesn’t always stand up to scrutiny. Advance directives are an example. Even if a directive is perfectly clear about a particular decision (e.g., “Under no circumstances do I want anyone to attempt resuscitation if my heart or breathing stops.”), it is not a medical order and may never see the light of day in the medical record.

Consider what drives behavior in hospitals and other institutions. It is doctor’s orders and standard clinical protocols. Advance directives simply don’t integrate well with current hospital practice. Moreover, even if the treating physician is aware of your directive, every state permits health-care providers to raise conscience objections and refuse compliance, as long as required notice and some level of assistance in transferring to another provider is given.

Some very insightful clinicians in Oregon in the 1990s began to think about how to bridge this gap between the treatment goals and wishes of seriously ill patients and medical orders that actually govern care and treatment. The effort gave birth to the Physician Orders for Life-Sustaining Treatment (POLST) program. POLST programs have developed in more than a third of the states under a variety of names: Medical Orders for Life-Sustaining Treatment (MOLST), Physician Orders for Scope of Treatment (POST), Medical Orders for Scope...
of Treatment (MOST), and others. They all have in common four important tasks:

- A discussion takes place between the treating physician and patients with advanced progressive illness, or their surrogate. The discussion explores the range of end-of-life care treatment options and seeks to discern the wishes of the patient in light of his or her current condition. If the patient has an advance directive, it is relevant and potentially helpful to this discussion, but the POLST program is available to all patients with advanced illness regardless of whether they have previously engaged in advance care planning.

- The patient’s wishes are incorporated into a set of doctor’s orders recorded on a highly visible, standardized POLST form that serves as a cover sheet to the medical record or is easily accessible in the electronic health record.

- Providers must ensure that the POLST form travels with the patient whenever he or she transfers from one setting to another.

- Providers comply with POLST across care settings and reevaluate the orders with the patient or surrogate as appropriate.

POLST programs are taking hold in the majority of states and represent a real sea change in learning how to elicit and honor patient preferences and goals of care. A substantial research base shows that POLST substantially improves the documentation of patient preferences in the medical record and compliance with them at the end of life. A research bibliography on POLST can be found at www.polst.org/educational-resources/939-2.

However, the beating heart of POLST, as well as its Achilles heel, is the quality of the conversation between provider and patient. Of course, this is true of all forms of advance care planning. Developing valid and feasible quality measures to ensure the quality of these conversations is still a work in progress.

Good Advance Care Planning Requires More Than Just Better Education—It Requires System Change

Healthcare delivery in the United States is extremely complicated and fragmented. While medical orders and standard clinical protocols may drive what happens in a particular setting, many more factors affect quality of care across the continuums of time, place, and disease. As patients and their agents travel across these continuums, they too often find little support in making good decisions, and are left on their own to navigate a maze of care providers, settings, and confusing information. POLST offers one paradigm for improving care planning for those with advanced progressive illnesses. Better education of healthcare providers and the public is also essential.

However, person-centered care and care planning across the age span also requires fundamental system change. Doing the right thing has to be built into the system.

At least one health system in the Midwest has figured out how to do this with advance care planning: Gundersen Lutheran Health System in La Crosse, Wisconsin. The Gundersen system covers 19 counties and has 6,300 employees. They have built advance care planning into the system design, ensuring that all adults encounter advance care planning opportunities multiple times, at different times, and in a way that is appropriate for their stage of life. Staff members are trained in advance care planning skills, and the healthcare system goes outside hospital walls to educate and engage the community in advance care planning. Finally, the systems put in place are subject to a process of continuous quality improvement.

As a result, data from a retrospective study of deaths across all settings in La Crosse County, Wisconsin, during a seven-month period revealed that 90% of the deceased individuals had an advance directive. Of those with an advance directive, it was available in the medical record 99.4% of the time. In addition, 67% of decedents had a completed

With respect to conformity of treatment to preferences, the study found that expressed preferences regarding CPR and hospitalization were consistent with treatment in 99.5% of the cases. These outcomes far surpass any similar measures seen elsewhere. While Gundersen may be smaller than many health systems, less urban, and more homogenous, the results are still astounding and demonstrate that it is possible to fashion effective advance care planning environments. La Crosse has set a high bar, but it’s one that makes me extremely optimistic about the future of advance care planning.

8 Lawyers Will Continue to Have an Important, Though Changed, Role in Advance Care Planning

Almost every general practitioner, estate planner, and family law attorney includes advance directives in their armament of products. Unfortunately, advance directives are often a stock add-on, produced in rote fashion, and signed with minimum explanation. This is somewhat understandable, given that meaningful counseling about goals of care, values, and treatment options is time intensive and, thus, likely cost-prohibitive for most clients.

A better role for lawyers is that of provocateur and facilitator. There are many good advance care planning tools and workbooks now available that can be given to clients to jump-start their thinking, provoke meaningful conversations with family and clinicians about future medical decision making, and educate future surrogate decision makers about their role.

For a list of tools and resources, see the webpage of the ABA Commission on Law and Aging: www.ambar.org/HealthDecisions. The tools can also become additional, important documentation of the individual’s thinking, values, priorities, and wishes. These conversations don’t come easily, but with your encouragement and some tools to help them along, clients are more likely to engage in the process effectively. Then you can customize their advance directive—a document that they will now understand to be part of a continuing conversation, not the end of a discussion.

Conclusion

In the end, the mantle of responsibility for tough decisions falls on the shoulders of the patient, agent, family or friends, and healthcare providers. Good advance care planning is good person-centered care. And good person-centered care is the Holy Grail of health reform, long-term care, and end-of-life care. I’m 30 years and eight lessons into my quest for this ideal and am cautiously encouraged by what I have seen so far.

Charles P. Sabatino is the Director of the Commission on Law and Aging. This piece was originally published in Experience, Volume 23, Number 1, 2013. © 2013 by the American Bar Association. Reproduced with permission. All rights reserved. This information or any portion thereof may not be copied or disseminated in any form or by any means or stored in an electronic database or retrieval system without the express written consent of the American Bar Association.
For better or worse, Twitter can change the world. I got a whiff of that potential last spring, while participating in a regular Twitterchat (#eldercarechat), someone raised (Tweeted?) the question of what we want government to do to improve the lives of the nation’s 60 million caregivers, and added that we needed something like a Peace Corps for family caregivers.

That idea resonated with me—and with what I myself need at this juncture in my life. My young adult children, five between the ages of 19 and 23, struggle to find work—regular work, much less meaningful work—so that they can pay their bills, including college tuition and loans. My 92-year-old grandmother has moved to Alaska to be with my aunt, and spends many of her days alone, her mind still longing for human connections, her body unable to get her there.

What if we could build something akin to the Peace Corps, a national program that could simultaneously address a spectrum of issues, such as workforce development, economic security, intergenerational respect, skill-building, and national service? What if a program existed that could, for instance, employ my 20-something kids, rely on the skills and experience of retirees, like my own 69-year-old parents, and provide companionship to my grandmother?

What if we had a Caregiver Corps? I tweeted. Within a day, I had launched a petition to the White House calling for America to create such a Corps. Within a month, the New Old Age blog of The New York Times had featured the idea. Even now, late summer, the idea continues to be discussed: mentioned in the Times, and talked about online.

Moving from something as ephemeral as a Tweet to something as enduring as a national program, of course, will take more than a season. To that end, I have spent subsequent months writing about the idea for various online platforms, and networking with individuals and organizations who are intrigued by the possibility. Anne Montgomery, my colleague at the Center for Elder Care and Advanced Illness at Altarum Institute and a veteran Hill staffer, has done the same. Making a reality of my “I’d like to teach
the world to sing” vision will
require engaging the support of
stakeholders nationwide, learning
more about current national
service programs aimed at serving
vulnerable people, and attending
to the myriad political and public
policy concerns the program
engenders.

**Why We Need a Caregiver Corps**

Several demographic trends
point to a future that will leave
families and their beloved elders
overwhelmed, exhausted, and
bankrupted by the challenges of
living with old old age—that is,
living past 80—with multiple
chronic conditions that will,
no matter what they do, kill
them. In any given year, some
60 million Americans serve as
family caregivers to another
adult, someone who is either old,
disabled, or both. (And millions
more care for children and young
adults who live with serious
disabilities, and face even more
challenges in terms of education,
employment, and so on.)

These families will run square
into a medical system that is
not prepared to care for them in
the ways they need most. These
individuals might sometimes need
rescue and cure—but they will
more often need long-term supports
and services, and help with things
like transportation, hygiene, and
food. And while they’ll have plenty
of access to ICUs and new hips
and knees—they will be shocked
and disheartened by the costs of all
the things they will need to pay for
on their own: private-duty nurses,
for instance, and home care;
transportation and food; and skilled
nursing care.

Unless these families spend-
down to become Medicaid
beneficiaries or have adequate
long-term care policies, their costs
will be out of pocket. And those
costs will be beyond reach for most
middle-class Americans.

In the meantime, the social
services agencies meant to serve
aging Americans continue to be
devastated by short-sighted budget
cuts. Sequestration alone, one
estimate suggests, will eliminate
800,000 Meals on Wheels in the
State of Maryland.

Demographics will stymie our
ability to respond to these needs.
In short, the future will include
fewer people to provide the hands-
on care that aging adults will
need. The nation faces a profound
shortage of people trained in
geriatric care, from geriatricians
to nurses to direct care workers.
These shortages stem, in part, from
the relatively low pay geriatricians
earn, and the outright unlivable
wage direct care workers receive.
By one estimate, by 2030, when
all of those Boomers are in
their dotage, there will be one
geriatrician for every 20,000 older
adults.

**A Caregiver Corps:
Hope—and Help—for Us All**

What’s a country to do? Launch
a Caregiver Corps, a program
modeled on similar valuable,
successful, and long-lived
efforts, such as the Peace Corps,
AmeriCorps, VISTA, and Teach
for America. The program could
recruit volunteers: high school
graduates not trained for the
workforce; college graduates
facing a tough economy and huge
undergraduate debt; and older
adults, those healthy enough to
want to remain in the workforce
and contribute to others’ well-
being.

Volunteers could sign up for a
year or two. In exchange for their
service, they could earn tuition
credits to cover the cost of college;
they could receive some degree of
loan forgiveness, to lessen their
burden of debt; they could be paid
a stipend that acknowledges the
value of their work. They could
be assigned to community-based
organizations that serve older
adults, such as Area Agencies
on Aging, non-profit health
care institutions, social services
agencies, and others. They would
not have to travel far, or even leave
home, to serve as volunteers: Every
community in America will face
the inescapable challenge of caring
for its frail elders.

In fact, every community could
tailor its volunteer opportunities
to meet its own most pressing
needs—it could recruit volunteers
whose specific skills and interests
align with what the community
wants. Volunteers could apply
for positions that appeal to their
own interests, strengths, and
experiences, for instance, and
develop accordingly.

While volunteers could offer
enthusiasm, compassion, and
insight, they could also learn the
kinds of skills required to care for
an older adult and his or her family.
They need not ever actually apply
those skills in their real-world, day-
to-day assignment, but they could
certainly come to understand the
extent of what it means to have
those skills, and what it takes to
work in a position that requires so
much of its workers.

Some volunteers could learn
about the public policies that affect
that care. Others could acquire
medical and nursing skills—the
kind of skills family caregivers
use routinely in their daily routine.
Many could be exposed to older
people, and bridge the generational
gap that splits our country on this demographic. In the end, they might even be inspired to pursue a career in one of the caring professions whose workers will be essential to how we collectively experience aging.

In many ways, we will have to make it up as we go along—we simply do not have any experience of living with so many old people, all at one time, all over America. In the past, few of us had any experience with this phase of life. In the future, almost all of us will. Transforming personal experience into something upon which to build programs that serve a collective good is essential to forging a future we can live with.

Finding ways to engage and support people who have the skills, resources, and motivation to help us in everyone’s self-interest. The question before us is simply how.

In months ahead, Anne Montgomery and I will continue to explore ideas, issues and challenges in conversation with many colleagues around the country. We are beginning to collect stories and information about the myriad community-based organizations now underway nationwide, and would be delighted to learn more about what your organizations are doing.

To join this conversation, please email me at Janice.lynchschuster@altarum.org, or simply “Like” Caregiver Corps on Facebook, the easiest way (for now) to keep pace with what we are doing. To learn more about this project in the context of our larger organization, please visit our website at http://altarum.org/research-centers/center-for-elder-care-and-advanced-illness.

Guardianships\textsuperscript{1} are designed to protect the interests of incapacitated adults. Guardianship is the only proceeding in American courts in which adults can be permanently deprived of rights solely in order to protect their well-being when they are unable to care for themselves.\textsuperscript{2} Due to the seriousness of the loss of individual rights, guardianships should always be a last resort. An adult under guardianship who has regained capacity has the right to restoration and to manage his or her person and estate. While it is most common for a guardianship to end upon the death of the individual, in all jurisdictions, the court has the power to terminate a guardianship upon finding that the individual has regained capacity sufficient to manage his or her personal affairs.

Unlike an appointment of a guardian, the statutory legal procedure for restoration is often unclear, ambiguous, and inconsistent.\textsuperscript{3} The procedural process and the duties of the court and of the guardian vary significantly by state, court, and judge. Due to the inconsistency among state statutes, variations in practice, and lack of hard data on restoration proceedings, it is unclear whether current law adequately protects the right to restoration.

This paper examines state statutory provisions concerning restoration of rights\textsuperscript{4} in four areas: (1) general procedure for restoration; (2) the presence or lack of evidentiary standard provided for in the statute; (3) the procedural barriers and safeguards in restoration proceedings; and (4) the role of the guardian and of the court upon termination.

**Procedural Process in a Petition for Restoration**

The Uniform Guardian and Protective Proceedings Act (UGPPA), revised by the National Conference of Commissioners on Uniform State Laws (currently the Uniform Law Commission)
in 1997, stipulates that guardians must encourage the protected individual to participate in decisions and to regain capacity, and courts must limit the scope of guardianship orders where possible. Since its enactment, 15 states have adopted the official language or language substantially similar to the official UGPPA provisions concerning restoration of rights.

The primary issue before the court in a restoration proceeding is whether the protected individual has capacity. A determination of restored capacity can be made only after an adjudication, wherein the court determines any change in circumstance and improvement in capacity of the individual. The manner in which this is accomplished depends on the jurisdiction. In 18 jurisdictions and the UGPPA, the statute simply states that in a petition for restoration and termination, the same procedures apply as in an appointment of a guardianship.

Many states and the UGPPA require that a respondent seeking termination be afforded the same rights and protections that are provided in the establishment of the guardianship. Such rights might include the right to notice, the right to personally attend the hearings, the right to counsel or a guardian ad litem, the right to examine witnesses, and the right to appeal.

Most states provide very broad permission to the protected individual or any interested party to seek restoration. Three states, Connecticut, Iowa, and Wyoming, limit the authority to petition for restoration to the individual under guardianship. New Jersey limits authority to the individual and the guardian.

Upon the filing of a petition for restoration, the court will provide notice and schedule a hearing on the issue of capacity, pursuant to the state requirements. Some courts conduct a hearing immediately upon filing, so long as they find sufficient cause to warrant further proceedings. Other courts schedule a hearing only after they receive a medical examination report from a court-appointed expert. Notice of the hearing is given to the guardian and the protected individual, and to other interested parties as required by the statute.

After the hearing, the court may restore the individual’s rights and terminate the guardianship if the burden of proof for capacity is met and the court deems restoration to be appropriate. The adjudication of restoration is grounds for terminating the guardianship. The discharge of the guardian ends all rights and responsibilities of the guardianship, except for those involved in the winding up of the guardianship.

**Evidentiary Standard**

The evidence considered in a guardianship hearing depends upon the guardianship laws of the state. The petitioner has the burden to show that the protected individual has capacity such that guardianship is no longer necessary. The burden then shifts to the party opposing restoration to prove the continuation of incapacity. Unlike in a petition for appointment of a guardian where the burden of proof is generally clear and convincing evidence, the standard in termination

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7 Conn. Gen. Stat. Ann. § 45a-660(a)(1); Iowa Code Ann. § 633.679(1); Wyo. Stat. Ann. § 3-3-1105(a) (stating that “At any time, not less than six (6) months after the appointment of a guardian or conservator, the individual may petition the court alleging that he is no longer a proper subject of the guardianship or conservatorship and asking that the guardianship or conservatorship be terminated).
9 This is also possible upon the court’s ruling *sua sponte*, although this is rare.

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proceedings varies greatly and is often unclear. Under the UGPPA, once the petitioner establishes a prima facie case for termination the court shall order the termination unless the opposing party establishes by clear and convincing evidence that continuation of the guardianship is in the best interest of the protected individual.12 The lower evidentiary standard for termination is consistent with the Act’s philosophy that a guardian should be appointed only for as long as necessary. Only two states, Minnesota and Maine, have adopted the UGPPA’s prima facie evidentiary standard for restoration.13 Seven states require the petitioner to prove by a preponderance of the evidence that the individual has sufficient capacity to manage his or her own affairs. Eight states use the higher standard of clear and convincing evidence. Mississippi requires “such proof as the chancellor may deem sufficient.”

Thirty-three states do not provide a specific evidentiary standard. There is little case law in the area of restoration and it is not entirely clear what standard of proof should apply. Courts have taken different approaches. A circuit court case in Florida suggests that the standard is a preponderance of the evidence.14 Cases in Ohio have found that the evidence presented need not be clear and convincing but need only ensure that the guardian’s removal will serve the individual’s best interests.15 New Jersey cases suggest that the burden be clear and convincing.16 Rhode Island does not set out an evidentiary standard. Rather, it requires the court to remove any guardian upon finding that the individual, based on a decision-making assessment tool directly in the statute, has the capacity to make decisions regarding his or her personal affairs.17

In states without an express burden of proof, a court may simply use the same evidentiary standard that it uses in a petition for guardianship, which is generally the high standard of clear and convincing evidence. But there is no research to substantiate this. Courts may be more inclined to use the same evidentiary standard when the statute expressly requires the court to follow the same procedural standards as in a petition for guardianship.

Of the 18 states that require the court to follow the same procedural standards as in a petition for guardianship, only four expressly state an evidentiary burden of proof. Minnesota requires prima facie,18 Hawaii and Oregon require clear and convincing evidence after the petitioner establishes a prima facie case for termination,19 and Louisiana’s standard is a preponderance of the evidence.20 The remaining 13 states that require the same procedures as in a petition for guardianship do not state an evidentiary standard. The legislative intent is unclear. In spite of the variation and ambiguity, it is clear that at least eight states require courts to use a lesser burden of proof (either prima facie or preponderance of the evidence) in a petition for termination than in an initial petition for guardianship. There is no research to determine whether courts in these states may grant

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14 In re Guardianship of Branch, 10 FLW Supp. 23, 25 (20 Cir. 2002) (citing Beal Bank, SSB v. Almand & Associates, 780 So. 2d 45 (Fla. 2001) (establishing the presumptions and burden of proof required by banks to execute on accounts titled in the name of husband and wife who claimed the accounts were held as tenants by the entirety and therefore not subject to execution by the husbands judgment creditors).

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restoration more frequently. Due to the nature of the issues and the presumptions to be overcome, codifying an evidentiary standard can be an additional tool for states to protect the autonomy of the protected individual.

Moratorium Periods on Filing Requests for Review

States may enact procedural bars to petitions for restoration. Eleven states permit courts to specify a minimum time period after the issue of the order adjudicating incapacity during which a petition for a review of the order may not be filed without special leave. Of these states, eight require that the period not exceed one year, two require that it not exceed six months, and Michigan sets the maximum period at 182 days. While this may reduce frivolous and hasty attempts to remove a guardian, it could at the same time delay legitimate petitions for removal and restoration of rights.

Four states specify a period during which a petition for reconsideration of an adjudication of incapacity cannot be filed, regardless of what the original order says. Arizona precludes an interested person, other than the guardian or protected individual, from filing such a petition within one year of the order adjudicating incapacity unless the court believes that the individual is no longer incapacitated. Texas expands the one-year period to apply to any person. Iowa and Wyoming preclude such a petition within six months of the denial of a former petition. Other states don’t place any limitations on the time in which a petitioner may file a request for restoration.

Procedural Safeguards

As a practical matter, the only way an individual can end a guardianship against the wishes of the guardian is by initiating a contested court proceeding. Under the UGPPA and in similar jurisdictions, once a guardian has been appointed, the court will ordinarily act only if a moving party so requests. Twenty states and the UGPPA expressly permit a request for restoration to be made informally to the court. In these states, the petitioner may informally communicate with the court instead of filing a formal application. This makes the judicial process more accessible by reducing procedural barriers to filing, such as cost and time, which may deter interested parties from taking action. However, it would be critical for the individual to secure counsel should the petition proceed further. As an additional safeguard, 17 states expressly bar willful interference with a request for restoration to the court. The court may hold any person who knowingly interferes with the transmission to be in contempt of court.

Colorado specifically targets the guardian, stating that the fiduciary shall not take an active role opposing or interfering with a proceeding for restoration initiated by the protected individual. However, the guardian may file a report on matters relevant to the termination proceeding, and may file a motion for instructions regarding the appointment of an attorney or visitor, investigations to be conducted, and the guardian’s involvement in the proceedings. The UGPPA does not contain a similar provision.

These procedural safeguards—permitting informal requests for restoration and sanctions for interference with such requests—increase accessibility to the judicial process independent of the statutory legal procedure for restoration. Unlike an appointment of a guardian, the statutory legal procedure for restoration is often unclear, ambiguous, and inconsistent.

24 Cavey, supra note 40, at 29.
27 See Patricia M. Cavey, Realizing the Right to Counsel in Guardianship: Dispelling Guardianship Myths, 2 Marq. Elder’s Advisor 5 (2000).
28 See Colorado Revised Statutes Annotated § 15-14-318(3.5)(c).
29 See id. § 15-14-318(3.5)(a).
guardian. Seventeen states have codified both protections. Thirty-one statutes do not include either protection. General statutory provisions requiring guardians to act in the best interest of the individual and the common law likely apply in this context. The common law impliedly allows a guardian to oppose a petition for restoration so long as the guardian acts reasonably and in good faith.\(^{30}\) The guardian’s general duty of loyalty may require the guardian to oppose a petition for restoration where it is clear the individual has not regained capacity.\(^{31}\)

Following appointment of a guardian, courts have an on-going responsibility to ensure that the terms of the order remain consistent with the respondent’s needs and conditions.\(^{32}\) Three states, Connecticut, Missouri, and New Mexico, require the court to periodically analyze whether the individual’s circumstances have changed sufficiently to justify termination and restoration.\(^{33}\) In Connecticut, the court must conduct a review “not later than one year after the conservatorship was ordered and not less than every three years after such initial one-year review.”\(^{34}\) Missouri requires that the court inquire into the status of every protected individual at least annually, to determine whether the incapacity may have ceased.\(^{35}\) New Mexico requires the court to hold a hearing to review the continued need for a guardian “at any time following the appointment of a guardian, but not later than ten years after the initial appointment, and every ten years thereafter.”\(^{36}\) In these states, the individual is regularly assessed by the court, regardless of whether a petition for restoration is filed.

**Duties of the Guardian and Rights of the Individual**

While states require a periodic status report from the guardian, some states impose additional reporting duties upon a change in the individual’s capacity. Three states expressly require the guardian to immediately notify the court if the incapacitated individual’s condition has changed.\(^{37}\) This is consistent with existing standards that call attention to a guardian’s duty to report to the court should a change in capacity occur.\(^{38}\) The UGPPA, the National Guardianship Association Standards of Practice, and Rule 6 of the Model Code of Ethics for Guardians require the guardian to promptly seek termination of the guardianship upon any change in capacity of the person that warrants termination. While not law, these standards are in line with guardianship policy to protect autonomy and work towards the regaining of capacity.

Every individual under guardianship has the right to petition for restoration. Three states have codified that right in the guardianship statute. Florida, Georgia, and Michigan expressly state that the individual has the right to have their autonomy and rights restored at the earliest possible time.\(^{39}\) But what is the “earliest possible time”? And what do courts do in practice to de-

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31 See id.
38 These standards include the National Probate Court Standards (NPCS), the Uniform Guardianship and Protective Proceedings Act (UGPPA), and the National Guardianship Association Standards of Practice (NGA).
termine the earliest possible time? There is little data or literature to provide an easy answer.

**Conclusion**

This statutory review is an initial examination of current state law on restoration of rights in the termination of adult guardianships. In light of the findings in this paper, there is a compelling need for additional research and data collection to determine which state practices adequately protect the individual’s right to restoration. It’s unclear whether more restorations occur in states that codify detailed restoration procedure and protections. Further, it is unknown in practice whether such detailed procedural requirements lead to more petitions for restoration. A second phase of this study, including a restoration case law summary and intensive reviews of probate court procedure in jurisdictions with exemplary practices, is necessary to document and articulate restoration practices for replication across the United States.


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Telephonic Signatures: An Essential Tool for Enrollment

by Rachel Meeks Cahill

The Affordable Care Act (ACA) envisions a single, streamlined, electronic application and verification process for health coverage that remedies many of the challenges and inefficiencies that exist in today’s public benefits system. The law also ensures that individuals and families can obtain coverage in multiple ways by requiring states to accept applications online, in person, by mail, and by telephone.¹ This policy brief focuses on the critical role that telephonic signatures, or “spoken signatures,” can play in the success of each state’s telephone application process. States must prioritize the adoption of telephonic signatures now to ensure that new state IT systems will be able to develop this technology for use by exchange call centers, navigators, and assisters before open enrollment begins in October 2013.

Background

A recent three-state study conducted by Lake Research Partners found that nearly as many low-income people want assistance by telephone as in person, and almost twice as many want help over the phone compared to those who want help online.²³ This research suggests that phone applications will be especially important to supporting enrollment in health insurance that will be available to individuals and families in 2014 (Medicaid, the Children’s Health Insurance Program (CHIP), and coverage through a health insurance exchange).

¹ The Affordable Care Act (ACA), § 1413.
A telephonic signature is a type of electronic signature that uses an individual’s recorded verbal assent in place of an ink signature, and it is considered legally enforceable in both the private and public sectors under certain conditions.4

In addition to significant use of telephonic signatures in the private sector, the federal government has been testing various ways to implement telephonic signatures since the 2008 Farm Bill, which allowed state agencies to accept “spoken signatures” for the Supplemental Nutrition Assistance Program (SNAP, formerly the Food Stamp Program).5 The goal of this rule change was to develop a more efficient and cost-effective application process for individuals and government agencies by allowing SNAP applicants to avoid the lengthy and often unreliable mail exchange to submit ink signatures.

A review of various approaches to implementing telephonic signatures approved by the U.S. Department of Agriculture (USDA) provides useful insight into the kinds of technology that work best for consumers (see table opposite).

What’s Changing?

While the federal government has allowed states to accept electronic signatures for Medicaid and CHIP for several years, the Affordable Care Act will require states to accept electronic signatures in 2014.6 Subsequent regulations from the Centers for Medicare and Medicaid Services (CMS) confirm that “electronic, including telephonically recorded, signatures and handwritten signatures transmitted via any other electronic transmission must be accepted.”7 Because the law requires exchanges, Medicaid, and CHIP to use a single, streamlined application, and because the exchanges must accept applications via telephone, the telephonic signature requirement also extends to the exchanges.8

CMS is expected to issue detailed guidance around the use of telephonic signatures in the coming months, and it has stated that forthcoming regulations will allow states significant flexibility. Even so, CMS will likely require states to ensure that telephonic signatures are transferable to and among relevant entities (i.e., from the exchange to the Medicaid or CHIP agency, and vice versa). Such a requirement would ensure that all relevant application information travels between agencies in a single case file and that applicants are never required to submit duplicate information.9

It is important to note that states with federally facilitated exchanges (FFEs) may implement the telephonic signature provision differently than those with state-based exchanges, since the responsibility for collecting and accepting telephonic signatures will fall primarily on the federal government and its exchange call center. That being said, states with FFEs must still prepare to accept telephonic signatures into their Medicaid and CHIP eligibility systems, since states will maintain control over both programs.

Conclusion

Effective assistance over the phone will play a key role in ensuring that health reform reaches the millions of Americans who will be newly eligible for coverage in 2014. Whether states are operating their own exchanges or partnering with the federal

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4 Government Paperwork Elimination Act (GPEA), § 1707; Electronic Signatures in Global and National Commerce Act (E-SIGN), § 105(5).
5 The Food, Conservation, and Energy Act of 2008 (FCEA), § 4119. Proposed regulations were issued on May 4, 2011, but they have not been finalized.
6 The Affordable Care Act (ACA), § 1943(b)(1)(A).
7 42 CFR § 435.907(f).
8 45 CFR § 155.405(c)(2)(ii).
9 The Affordable Care Act (ACA), § 1943(b)(1)(C).
government, they can benefit from seeking out best practices in telephonic assistance and engaging diverse stakeholders to make the most of state IT development.

Rachel Cahill is Director of Policy at Benefits Data Trust in Philadelphia, PA. She can be reached at 215-207-9108 or rcahill@bdtrust.org. Benefits Data Trust is a national not-for-profit organization committed to transforming how people in need access public benefits. To meet this mission, Benefits Data Trust partners with diverse stakeholders to implement cost-effective and scalable outreach and enrollment strategies and delivers data-driven solutions to create a more coordinated benefits enrollment system.

### Three Different Approaches to Telephonic Signatures

<table>
<thead>
<tr>
<th>Implementing Agency</th>
<th>Type of Recording</th>
<th>Lessons Learned</th>
</tr>
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</table>
| **Pennsylvania**10   | Nonprofit organization, in collaboration with Pennsylvania Department of Public Welfare | Full phone calls were recorded and stored by non-profit organization and made available to SNAP agency on request | **Pro**: Successfully streamlined application process  
**Con**: Different technology solution needed to allow SNAP agency to accept and store telephonic signatures |
| **Wisconsin**11      | Wisconsin Department of Human Services | Only the signature portion of each phone call was recorded and stored by SNAP/Medicaid agency with specialized software | **Pro**: Successfully streamlined application process  
**Con**: More consumers could have accessed the streamlined application if the technology design had included community-based organizations |
| **Florida**12        | Florida Departments of Elder Affairs and Children and Families, in collaboration with Area Agencies on Aging | Interactive voice response (IVR) system | **Pro**: Successfully streamlined application process for some households  
**Con**: Applicants with diminished hearing had difficulty using automated IVR system |

A Brief Survey of State POLST Form Distribution Practices

by Jenica Cassidy

The POLST form is an advance care planning tool that documents the “Physician’s Order for Life Sustaining Treatment” process. It is a way to translate the wishes of a patient with an advanced, progressive illness into physician orders that must be followed by emergency personnel and other health care providers across all settings of care. The POLST form is based on an effort to make end-of-life health care planning for seriously ill individuals more person-centered, better coordinated across care settings, and focused on key critical decisions relevant to the patient’s current condition. At the same time, the process places a high priority on protecting vulnerable individuals for whom life and death decisions are made. POLST supplements other health care planning documents specifically for patients with advanced, progressive conditions. POLST is in use or under development in over thirty states. Each state adheres to its own POLST document and procedures. While all states require a valid POLST form to be signed by a health care provider, they vary as to who qualifies as “health care provider.” In addition, the use of POLST requires a discussion between the treating health care provider and the patient or the authorized surrogate about end-of-life care treatment options. The nature and use of POLST poses an access challenge. In whose hands are POLST forms placed and how? Providing unlimited access to the POLST form—for example, by posting it online—is simple, cost effective, and in accordance with the POLST policy of patient autonomy and independence. However, providing unrestricted access to the POLST form may increase the likelihood of improper or ill-informed use. Making the form accessible to the general public without limitation may also increase the risk of confusing the form with other health care planning documents such as advance directives. Whether these concerns in connection with distribution of POLST forms have any merit has never been explored in research.

To acquire a baseline understanding of how POLST forms are distributed, this brief survey examined state policies and procedures regarding POLST form accessibility in the 16 states where the POLST program is either mature or endorsed as of July 2013. The survey examined program web sites and requested information on distribution policies and practices from state key contacts identified by the National POLST Paradigm Task Force.

The survey found that distribution requirements and procedures varied significantly across the states but generally fall into one of two categories: those that provide general public access to the POLST form without limitation, and those

3 California, Georgia, Hawaii, Louisiana, New York, Tennessee, and West Virginia stipulate that the patient’s physician is the only health care provider authorized to sign and validate the POLST form. Colorado, Delaware, Idaho, Minnesota, Montana, New Jersey, North Carolina, Oregon, Rhode Island, Pennsylvania, Utah, Vermont, and Washington permit the patient’s physician, nurse practitioner, or physician assistant to sign and validate the POLST form. In Maryland, the physician or nurse practitioner may sign and validate the POLST form.
4 Sabatino, supra note 1, at 231.
5 Endorsed and mature POLST program status is conferred by the National POLST Paradigm Task Force to states that meet standards set by the Task Force and apply for the certification. The standards can be reviewed at: http://www.polst.org/develop-a-program/program-requirements/.
6 See individual state profiles at www.polst.org.
states that limit access to health care professionals only.

Of the sixteen states with a mature or endorsed POLST program, eleven offer the POLST form to the general public, without any restrictions, via a free-of-charge download off of the state’s participating website. Five states limit distribution to health care professionals. POLST is so new in some states, such as Georgia, that the state may not have developed a formal protocol for distribution of POLST form. Open accessibility of the form on a website may be the natural default option.

Design and color requirements also affect distribution options. One of the earliest hallmarks of the POLST paradigm is the use of a unique, brightly colored and easily visible document in a patient’s record. A POLST form printed on plain white, indistinguishable paper lacks that hallmark but simplifies access, copying, and use. States that mandate a specific color and paper type for printing purposes may provide greater assurances of form validity, integrity, and visibility, but they make access potentially more onerous and costly. In addition, as medical records move toward all-electronic formats, paper characteristics become increasingly archaic.

Currently, of the 16 states, only North Carolina, Wisconsin, and West Virginia restrict distribution to mail order shipments of the form printed to the state’s color specifications.

The chart on the following pages summarizes the states’ distribution and access characteristics.

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Jenica Cassidy is a third-year law student at Wake Forest University School of Law in Winston Salem, NC, and served as a 2013 summer intern with the Commission on Law and Aging.

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[^7]: These 11 states are: California, Colorado, Georgia, Hawaii, Idaho, Montana, New York, Pennsylvania, Tennessee, Utah, and Washington.

[^8]: These five states are: Louisiana, North Carolina, Oregon, Wisconsin, and West Virginia.


[^10]: In contrast, Oregon, the first state to create a POLST program, has had a program since the early 1990s.

<table>
<thead>
<tr>
<th>State</th>
<th>How and by whom POLST forms are distributed</th>
<th>Who has access to POLST forms</th>
</tr>
</thead>
</table>
| Colorado| 1. Download the Colorado MOST form free of charge off of the Colorado Advance Directives Consortium and Life Quality Institute websites at: [www.coloradoadvancedirectives.com/page04.html](http://www.coloradoadvancedirectives.com/page04.html) and [www.lifequalityinstitute.org](http://www.lifequalityinstitute.org)  
  - Astrobrights Vulcan Green Smooth Finish 65lb paper is recommended but not required                                                                                         | Forms are available to the general public. There are no restrictions                                              |
| Georgia | 1. Download the Georgia POLST form free of charge at: [www.dph.ga.gov/POLST/](http://www.dph.ga.gov/POLST/)                                                                                                                                   | Forms are available to the general public. There are no restrictions                                              |
| Hawaii  | 1. Download the Hawaii POLST form free of charge at: [www.kokua-mau.org/professionals/polst](http://www.kokua-mau.org/professionals/polst)                                                                                                         | Forms are available to the general public. There are no restrictions                                              |
|         | 2. Obtain a POLST form in-person at some hospitals, nursing homes, health and hospice providers, who can provide some assistance in understanding the form and filling it out.                                                              |                                                                                                                                                                           |
| Idaho   | 1. Download the Idaho POST form free of charge at: [www.idahoendolifecoalition.wildapricot.org/Default.aspx?pageId=775419](http://www.idahoendolifecoalition.wildapricot.org/Default.aspx?pageId=775419)   | Forms are available to the general public. There are no restrictions                                              |
| Louisiana| 1. Download the LaPOST document free of charge at: [http://lhcqf.org/lapost-for-health-care-providers/lapost-document](http://lhcqf.org/lapost-for-health-care-providers/lapost-document)                                                                 | Forms are available to health care professionals as well as consumers, patients, and caregivers. The document is a physician’s order and must be signed by both the physician and the patient and travel with the patient across care settings. |
|         | 2. Louisiana Physician Orders for Scope of Treatment (LaPOST) is an initiative of the Louisiana Health Care Quality Forum. The LaPOST documents are available on their website. Most of the education and distribution is done through the website and other state organizations such as Louisiana State Medical Society, Louisiana Hospital Association, and the Louisiana Nursing Home Association. |                                                                                                                                                                           |
  POLST forms, envelopes and bracelets are also available at: Department of Public Health and Human Services  
  EMS & Trauma System Section  
  P.O. Box 202951  
  Helena MT 59620  
  Phone: (406) 444-3895  
  E-mail: [emsinfo@mt.gov](mailto:emsinfo@mt.gov)                                                                 | Forms are available to the general public.                                                                        |
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<tr>
<td>New York</td>
<td>1. Download or order the New York MOLST form free of charge at the central repository for information on New York’s MOLST program: <a href="http://www.compassionandsupport.org">www.compassionandsupport.org</a></td>
<td>Forms are available to the general public. There are no restrictions</td>
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<td>2. The DOH-5003 is also available to download free of charge off of the DOH website at: <a href="http://www.health.ny.gov/professionals/patients/patient_rights/molst/">www.health.ny.gov/professionals/patients/patient_rights/molst/</a></td>
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<td></td>
<td>• Printing on to bright “pulsar” pink heavy stock paper is recommended but not required.</td>
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<td>NY is working on implementation of eMOLST, a secure web-based application that allows enrolled users to complete the eMOLST form, MOLST Chart Documentation Form (CDF) and mandated OPWDD Checklist for persons with developmental disabilities who lack capacity. CDFs document the MOLST discussion including the patient’s values, beliefs and goals for care, the ethical framework for medical decisions regarding withholding and withdrawing life-sustaining treatment, and legal requirements. Forms are created as pdf documents that can be printed for the patient and paper-based medical records, stored or linked to from an EMR, and become part of the NYS eMOLST registry. The New York eMOLST Registry is an electronic database centrally housing MOLST forms and CDFs to allow 24/7 access in an emergency.</td>
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<td></td>
<td>2. Obtain a MOST form in-person from DHHS in Raleigh. The forms cost four cents each. The clinician or health care organization is responsible for the cost.</td>
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<tr>
<td></td>
<td>3. If a physician or health care provider is not familiar with the MOST form, the patient can ask them to contact the North Carolina Medical Society for additional information at <a href="http://www.ncmedsoc.org">www.ncmedsoc.org</a> or email or call Varsha Gadani at <a href="mailto:vgadani@ncmedsoc.org">vgadani@ncmedsoc.org</a> or 919-833-3836.</td>
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<tr>
<td>Oregon</td>
<td>1. POLST hard copy forms are distributed to health care professionals by the Center for Ethics in Health Care at Oregon Health &amp; Science University.</td>
<td>Forms are available to the general public, but only health care providers are authorized to print the form for medical use. A POLST Form requires a signature from an MD, DO, PA, or NP to be valid and should only be filled out and signed after an in-depth conversation between the patient and health care provider about the patient’s goals of care.</td>
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<tr>
<td></td>
<td>2. Order Oregon POLST forms at: <a href="http://www.orpolst.org">www.orpolst.org</a></td>
<td></td>
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<td></td>
<td>An invoice is placed in with the shipped order. The recipient has 30 days to pay. If a smaller clinic requests a small quantity, often for individual patients, forms will be shipped free of charge. Forms are not shipped directly to patient.</td>
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<tr>
<td></td>
<td>Price list:</td>
<td></td>
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<tr>
<td>Forms</td>
<td>Price</td>
<td>Forms</td>
</tr>
<tr>
<td>50</td>
<td>$15.50</td>
<td>500</td>
</tr>
<tr>
<td>100</td>
<td>$29.00</td>
<td>1000</td>
</tr>
<tr>
<td>250</td>
<td>$53.50</td>
<td>2000</td>
</tr>
<tr>
<td>The Oregon POLST form is a copyright-protected document.</td>
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<td>State</td>
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</tbody>
</table>
| Pennsylvania | 1. Download the Pennsylvania POLST forms free of charge at: [www.aging.pitt.edu/professionals/resources-polst.htm](http://www.aging.pitt.edu/professionals/resources-polst.htm)  
   • Printing on to pulsar pink card stock 65# paper is recommended but not required.  
   Users are asked to print copies of the form on pulsar pink card stock (65#). The POLST Wallet Card should be printed on both sides of page | Forms are available to the general public. There are no restrictions. |
| Tennessee  | 1. Download the Tennessee POST form free of charge off of the Department of Health’s website at: [www.endoflifecaretn.org](http://www.endoflifecaretn.org)  
   • The POST may be printed on any color of paper according to policy of the facility. | Forms are available to the general public. There are no restrictions. |
   2. Sample POLST Forms and additional information available at: [www.leaving-well.org/polst.php](http://www.leaving-well.org/polst.php) | Forms are available to the general public, but the form must be completed after counseling by a physician or physician’s representative (social worker, nurse) then signed by both the patient and the physician. |
| Washington | 1. Obtain a Washington POLST form by sending a self-addressed, stamped envelope to WSMAn, Attn: POLST, 2033 Sixth Avenue, Suite 1100, Seattle, WA 98121.  
   2. Download Washington POLST forms in bulk and patient brochures free of charge off of the Washington State Medical Association at: [www.wsma.org/POLST](http://www.wsma.org/POLST)  
   • Printing on to 8-1/2” x 11” Astrobrights terra green card stock (smooth finish), 65 lb (#22781) paper, front and back, is recommended  
   Non-members are charged a fee to cover administration costs. | Forms are available to the public, but patients are encouraged to ask their physicians for the form. |
| Wisconsin  | 1. Copies are distributed by Gundersen and are sold to participating health organizations for cost plus shipping and handling. Each organization must pay for its own forms. Call 608-775-9139 to request an order form and mail to:  
   Gundersen Health System  
   Bereavement and Advance Care Planning Services  
   1900 South Ave, AVS-003  
   La Crosse WI 54601 | Forms are not distributed to the public. They are completed only in a patient/health professional interaction. Typically the only time a patient gets a form is when the form has been signed by the provider and the patient is going home. |
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<tr>
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</table>
| West Virginia | 1. The West Virginia Center for End-of-Life Care distributes POST forms: [www.wvendoflife.org](http://www.wvendoflife.org). A readable only copy of the form is available on the website.  
2. Health care providers can request copies of the POST form or a step-by-step manual on the completion of the form by calling 877-209-8086.  

The West Virginia Center for End-of-Life Care is funded through the West Virginia Department of Health and Human Resources. It is a line-item in the budget proposed by the governor and passed by the legislature | Forms are available to treating health care providers. The general public can request copies of the forms they have submitted. Annually, each person in the WV e-Directive registry receives a letter inquiring if the forms the registry has for the patient are current.  

The online registry has all required HIPAA protections including username and password and secure database. Access to the WV e-Directive registry is through the West Virginia Health Information Network at: [www.wvhin.org](http://www.wvhin.org) |

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Screening and Working with Older Clients with Diminished Capacity – A Practical How-To Webinar

Presenters:
Charlie Sabatino, Commission Director, will present this webinar with Daniel C. Marson, Professor of Neurology at the University of Alabama, Birmingham.

Background:
America is graying and this means lawyers increasingly encounter more clients with age-related cognitive impairments caused by Alzheimer’s disease and other forms of dementia. These clients pose special challenges to representation, and lawyers are increasingly faced with the challenge of making accurate assessments of clients’ legal capacity to make decisions and engage in legal transactions.

This program will:
• Provide a practical approach and process for capacity screening by attorneys.
• Describe “warning signs” of diminished capacity in elderly clients.
• Clinical background on the nature, variations, and progression of cognitive impairments.
• Strategies for maximizing clients’ capacity.
• Practical guidelines for utilizing mental health professionals effectively.

The webinar is scheduled for October 24. To be placed on a notification list for when more information is available, please email Andrea Amato at andrea.amato@americanbar.org.

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