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Nursing Home Deregulation Jeopardizes Residents’ Health and Safety

By Richard Mollot and Dara Valanejad

Nursing home residents are some of the most vulnerable individuals in the United States. Given that about half of all older adults will need nursing home care at some point in their lives,\textsuperscript{1} the quality and safety of our nursing homes are matters of importance to virtually every family in the United States. Sadly, serious problems such as insufficient staffing, abuse, and neglect are persistent and widespread.

A recent Senate subcommittee hearing, as well as government studies, have focused on the clinical care and safety of residents in our nursing homes—and much-needed efforts to improve them. The Trump administration is moving in a different direction. It has advanced efforts to deregulate nursing homes at the risk of placing even more residents in harm’s way. In July, more than a year after the nursing home industry asked for relief from what it called regulatory burdens, the Centers for Medicare and Medicaid Services (CMS) issued a proposed rule that would roll back many of the minimum standards of care in the federal regulations known as the Requirements of Participation.\textsuperscript{2} CMS offered no meaningful explanation as to how rolling back these resident protections would improve resident health, safety, or welfare. Rather, the agency said the proposed rule would enable nursing homes (which are increasingly run by for-profit enterprises) to decrease staffing and reduce costs associated with resident care and compliance with minimum standards.

The proposed rule rolls back requirements related to:

- Keeping residents informed about their primary care professionals
- Responding to resident grievances
- Protecting residents from inappropriate transfer or discharge
- Bed rail safety
- Posting of care staff on duty
- Behavioral health services
- Reducing antipsychotic drugging
- Food and nutrition management
- Facility assessments
- Quality assurance and performance improvement programs
Perhaps most shockingly, the proposed rule guts the requirement that nursing homes provide a meaningful response to grievances by residents and their families. As it stands, concerns voiced by residents, families, and their representatives are not always addressed by care staff or facility administration. This can result in extended suffering or discomfort, and often leaves residents and their families deeply frustrated. In 2016, CMS required facilities to have a designated grievance officer to whom complaints could be made. To ensure that nursing homes were not burdened by this requirement, the rule only requires the designation of a specific staff member; facilities do not have to hire additional staff. The grievance officer is responsible for investigating the complaint and responding in a timely manner.

Now, CMS is proposing changes that would gut the value of this important regulation to residents and their families. The proposed rule creates a new distinction between what CMS calls “feedback” (or complaints) and grievances. CMS states that feedback or complaints “stem from general issues that can typically be resolved by staff present at the time a concern is voiced, while grievances are more serious and generally require investigation into allegations regarding quality of care.” The proposed rule allows facilities to determine whether a resident’s concern rises to the level of a grievance. The likely effect: an increased risk that resident abuse and neglect will go undocumented.

The proposed rule also would make it easier to administer antipsychotic drugs to residents, which too many nursing homes use as a form of chemical restraint: to sedate them for the convenience of staff. In fact, the Inspector General of the Department of Health and Human Services (HHS) stated in 2011 that “[g]overnment, taxpayers, nursing home residents, as well as their families and caregivers should be outraged—and seek solutions” to remedy widespread and unnecessary antipsychotic drugging.

Since that time, CMS created initiatives resulting in the modest reduction of antipsychotic drugging. Nursing homes around the country received a comprehensive training package on improving dementia care and reducing the use of antipsychotics. State surveyors (inspectors) were provided a mandatory training to improve oversight. In 2012, CMS promised that these various training efforts would be accompanied by vigorous enforcement of the longstanding prohibitions against use of chemical restraints. Unfortunately, as our analyses of enforcement
data indicate, promised improvements to enforcement never materialized.\textsuperscript{6} As a result, close to one in five residents still receive these dangerous drugs today.\textsuperscript{7}

To improve efforts to address this problem, in 2016 CMS limited the administration of these drugs PRN (\textit{pro re nata} or “as needed”) to a maximum of 14 days, but this can be extended if “the attending physician or prescribing practitioner evaluates the resident for the appropriateness of that medication.”\textsuperscript{8} According to CMS’s current Interpretive Guidelines, evaluation “entails the attending physician or prescribing practitioner directly examining the resident and assessing the resident’s current condition and progress to determine if the PRN antipsychotic medication is still needed.”\textsuperscript{9}

CMS now proposes to revise the regulations so that the attending physician or prescribing practitioner can, without a direct examination and assessment of the resident, extend PRN orders beyond 14 days. There is no medical indication for any antipsychotic to be given PRN and no legitimate basis, in our view, for extending a time limit on something that is not the standard of care. Furthermore, the standard of care is for doctors to see a patient when prescribing a medication. We cannot imagine that any other insurance company would accept the argument that a doctor did not want to see a patient in person before prescribing a drug. We must not allow nursing homes and residents’ doctors to circumvent this standard of care.

These are just two examples among many of how the administration’s proposal would put U.S. nursing home residents at higher risk of abuse, neglect, and even unnecessary death.\textsuperscript{11}

\textbf{Background on the Nursing Home Standards}

Congress passed, and President Reagan signed into law, the Nursing Home Reform Law as part of the Omnibus Reconciliation Act of 1987. Passage of the Reform Law was a watershed event in our country’s approach to nursing home care. Following an Institute of Medicine report to Congress that identified widespread abuse, neglect, and inadequate care, the Reform Law was promulgated to protect nursing home residents and to put an end to unnecessary suffering.

The Reform Law established national standards for care and residents’ rights for those in nursing homes. At the heart of the law is the requirement that each resident be provided with services sufficient to attain and maintain his or her highest practicable physical, mental, and psycho-social wellbeing.\textsuperscript{12} Importantly, “highest practicable” relates to a resident’s potential abilities and personal goals as identified through an individualized, comprehensive assessment. “Highest practicable” does not mean what is practical, or preferable, for the facility based on its profit margin or other priorities.
To realize the Reform Law’s mandate, many new federal standards were established:

- A resident assessment process leading to the development of an individualized service plan
- Residents’ right to organize and participate in family or resident councils
- Residents’ right to be free of unnecessary restraints, physical or chemical
- Specific requirements for those most responsible for resident care (including direct care staff and those responsible for overseeing medical, food, and therapy services)
- Assurances by state survey agencies (usually the state health department) that the minimum standards are implemented

Additionally, the Reform Law requires the Health and Human Services Secretary to ensure that the nursing home requirements and their enforcement are “adequate to protect the health, safety, welfare, and rights of residents and to promote the effective and efficient use of public monies.”

Unfortunately, 32 years after passage of the Reform Law, many nursing home residents are not fully protected by, or benefitting from, these standards due to the persistent failures at the state and federal levels to adequately enforce them. Numerous studies over the years have identified lax oversight by the government agencies charged with protecting residents (not to mention safeguarding the fiscal integrity of the public programs which pay for a majority of nursing home care).

For instance, a 2014 study by the HHS Office of the Inspector General (OIG) found that an astonishing one-third of residents who were in a nursing home for short-term care were harmed within an average of two weeks of admission (15.5 days). Almost 60 percent of the injuries were identified as preventable and attributable to poor care. Six percent of those who were harmed died, and more than half were rehospitalized at an annualized cost of $2.8 billion in 2011.

In July of this year, a report by the U.S. Government Accountability Office (GAO) found that the number of abuse deficiencies more than doubled between 2013 and 2017. Almost half of all violations were identified at the highest levels of severity. Similarly, an OIG report in June found that one in five high-risk Medicare claims for hospital emergency room services in 2016...
indicated potential abuse or neglect of nursing home residents. An OIG analysis of a sample of those claims revealed that nursing homes failed to report 84 percent of the potential abuse and neglect incidents to state survey agencies. Representatives from the GAO and OIG testified about these reports at a July hearing before the U.S. Senate Committee on Finance.

The Long Term Care Community Coalition’s (LTCCC) analyses of federal records and data over the last 25 years corroborate these grim accounts of nursing home care. For example, health inspection reports indicate that states and CMS too often fail to properly cite a nursing home for any pain or suffering a resident experienced as a result of a violation. In fact, the vast majority of violations of minimum health standards cited by the states are identified as causing neither harm nor immediate jeopardy to a resident’s health and safety. A few examples of these “no harm” deficiencies that our organization has come across include a live maggot infestation on a resident, a sexual assault of a resident with dementia by another resident, and a 30-day wait for a resident to be bathed.

The failure to identify when residents are harmed is, perhaps, the most pernicious dereliction of duty by the state survey agencies and CMS, which directs and oversees the state agencies. A facility is unlikely to face any penalty for violations when harm or immediate jeopardy is not documented. As a result, too many nursing homes get paid for care that is abusive, neglectful, or, essentially, “worthless.”

The public is also being misled. The failure to identify harm and care problems, including substandard care, enables too many nursing homes to enjoy high ratings in the federal Nursing Home Compare Five-Star Rating System. To make matters worse, the Trump administration is now advocating for Congress to decrease the frequency of standard nursing home inspections for so-called “top-performing” facilities from annually to every three years. This likely would be disastrous for residents and their families.

**Nursing Home Resident Advocacy**

LTCCC and other advocates are responding to these challenges through advocacy and education of the public, news media, and policy makers. It is particularly important that state and federal representatives are educated about the prevalence of substandard care and demeaning conditions in our nursing homes, and that they hear from their constituents about their experiences with nursing home care. We encourage individuals and families to speak out to their representatives. To help residents, families, and advocates understand their rights and effectively advocate for better care, we offer these resources on [www.NursingHome411.org](http://www.NursingHome411.org).
• Fact sheets on key nursing home standards
• Abuse, Neglect, and Crime Reporting Center
• Dementia Care Advocacy Toolkit
• Elder Justice “No Harm” Newsletter
• The latest staffing information for all U.S. nursing homes
• Searchable state files on facility citations and ratings based on key indicators
• Webinars and podcasts on key issues and developments

1 See Michael D. Hurd, Pierre-Carl Michaud, & Susann Rohwedder, Distribution of lifetime nursing home use and of out-of-pocket spending, 114 Proceedings of the National Academy of Sciences 9,838 (Sept. 2017), https://www.pnas.org/content/pnas/114/37/9838.full.pdf (“We found that 56% of persons aged 57–61 will stay at least one night in a nursing home during their lifetimes . . . .”).


3 Id. at 34,740-41.


6 See, for examples, Left Behind: The Impact Of The Failure To Fulfill The Promise of The National Campaign To Improve Dementia Care (2014) and Safeguarding Nursing Home Residents & Program Integrity: A National Review of State Survey Agency Performance (2015), both available at https://nursinghome411.org/.


8 42 CFR § 483.45(e)(5).


10 Id. at 34,743-44.

11 For the full text of our comments on the proposed rule, see https://nursinghome411.org/consumer-comments-proposed-nursing-home-requirements-2019/.


13 Id. at § 1395i–3(f).


15 Id.

16 Id.


18 See id. at 15 (“Specifically, 42.6 percent of the 875 abuse deficiencies were categorized as causing actual harm or posing immediate jeopardy to residents in 2017, compared to 31.9 percent of the 430 abuse deficiencies in 2013.”).


20 Id. at 12.


About the Authors:

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- We are available as collaborators on grant-funded research & education.
- Contact us at aging@americanbar.org.
Report: Improvements Needed for New York Guardianship and Decision Supports for People Indigent and Alone

By Erica Wood

More than 25 years after New York enacted a guardianship law to best serve individuals’ needs and preserve rights, a significant gap remains between its implementation and practice. Now a new report cites the urgency in addressing these challenges for an often-overlooked population of needy adults with no one to help.

The report, *Incapacitated, Indigent, and Alone: Meeting Guardianship and Decision Support Needs in New York*, was released in September by The Guardianship Project at the Vera Institute of Justice in New York City. It was funded by the New York Community Trust and authored by Pamela Teaster (Virginia Tech Center for Gerontology); Erica Wood (American Bar Association Commission on Law and Aging); John Holt and Kimberly George (The Vera Guardianship Project). For the full report with recommendations, see [https://www.vera.org/publications/incapacitated-indigent-and-alone](https://www.vera.org/publications/incapacitated-indigent-and-alone).

Several key factors set the stage as to the urgency and complexity of the New York scenario and the need for the report:

First, like many states, New York is aging. A 2019 report by the Center for an Urban Future found that the number of New Yorkers ages 65 and over increased by 26 percent over the past decade. The number of 85-plus New Yorkers has also increased by 26 percent since 2007. As the state’s older adult population grows, the number living in poverty has increased by 11 percent since 2007. According to the Alzheimer’s Association, New York has 400,000 people with an Alzheimer’s diagnosis.
That figure is expected to climb by 15 percent by 2025.ii The cases profiled in the Vera study show a population with a troubling combination of mental health problems, dementia, abuse and exploitation, and difficult family dynamics. A recurring theme was that for this target population of adults who are “incapacitated, indigent and alone,” housing plays a huge role in guardianship cases, and that eviction is a gateway to guardianship that may be overbroad or unnecessary.

Second, in 2005 the Vera Institute of Justice and New York State’s Office of Court Administration launched The Guardianship Project (TGP) in New York City to serve as court-appointed agency guardian for the largely indigent target population at risk of falling through societal cracks. The intent was to enable these individuals to live as independently as possible, often in a home or community-based setting. Vera has been a bright spot on the scene but has not had a rigorous assessment.

The new report provides that assessment and analyzes whether TGP is an appropriate model for expansion to other areas of the state, where the target population lacks services.

Third, New York has no statewide public guardianship program. In 2008, a national public guardianship studyiii found that 27 states had statutorily established explicit public guardianship programs. Since that time, two additional states enacted public guardianship legislation, bringing the total to 29.iv While New York has a piecemeal approach in which, as described below, various entities serve as guardians of last resort, there is no statewide system nor funds providing for such a system. The study in the report updated information on selected state public guardianship programs and sought perspectives on establishing such a program in New York.

The study included online surveys of guardians, judges, court evaluators and court examiners as well as in-depth telephone interviews with judges, court examiners, mental hygiene legal services, Vera Guardianship Project staff, and others. Five topics in the study are summarized below:v
Who Needs Guardianship and Decision-Support Services? What Services Are Needed?

While data are lacking, the Vera study uncovered a compelling unmet need for guardianship and related decision support services for individuals in New York who are indigent, have been named by a court as “incapacitated,” and who have no one to help. The need is especially pressing for individuals facing or at risk of eviction, and for those with a combination of chronic conditions including mental illness. Often these are the most resource-intensive cases, yet these are the cases where no fee is available.

The study noted that frequently guardians place individuals in nursing homes because it is difficult to find and arrange for the care they need in the community. Such community-based care is less expensive for the state than Medicaid-based nursing home care and is usually what people want. The study recommended that New York fund comprehensive home and community-based care for older adults and people with disabilities, including low-income housing.

Guardianship is a legal proceeding and attorneys make up a large proportion of guardians appointed by the court for no-fee or low-fee cases when there is no one else to serve. However, the needs of the target population are not strictly legal in nature; instead, they are a complex mix of legal and social services. The skills of social workers, nurses and occupational therapists often are required to find solutions that will help to keep older adults at home or in the community.

While the target population of individuals who are indigent and alone needs more available and skilled guardianship services, guardianship is not always the best solution. There is also a need to screen for less restrictive options. The report recommended legal and judicial training on screening for these options, including a range of decision-supports and supported decision-making. Forms that emphasize screening and tracking the use of these options could help to avoid unnecessary appointments, making guardianship a last resort. Additionally, the study noted that New York court procedures should increase access for requests to end the guardianship and restore rights when it is no longer needed.
Who Serves as Guardian for the Target Population?

New York has four “guardian of last resort” schemes. While each helps to meet the need, they are all stretched thin, and taken together, there is still a gaping hole in serving the target population.

New York law and regulations provide for local commissioners of social services to act as the guardian of last resort. In some but not all areas of the state, the commissioner names adult protective services (APS) to fulfill guardianship responsibilities. The study found that APS guardianship practices vary throughout the state. In some areas of the state, particularly upstate, APS not only investigates the need for guardianship and petitions but serves as guardian as well – a role the study noted is an inherent conflict of interest. While APS is responsible for investigating reports of abuse, neglect, and financial exploitation, the study did not find any such APS investigations of suspected abuse by guardians, which would provide an outside eye and assist the court with monitoring. New York law also provides for “community guardian programs” funded by local social services offices.

New York City has three such programs. Community guardian programs must relinquish cases when a person enters a nursing similar residential facility, leaving a serious and sometimes life-threatening gap where there is no one to make health and personal decisions or to monitor facility care. Moreover, the community guardian programs are overwhelmed with cases, and require additional resources, as well as consideration of a staff to client ratio.

New York Judicial Rules Part 36 provides for appointments by the court, including appointments of guardians. The Part 36 list of potential guardians is predominantly composed of lawyers. The number of professionals on the list willing to serve as guardians in no-fee/low-fee cases (as opposed to court evaluators, court examiners, or other roles) for this challenging population has dwindled. Many professionals cannot afford to take no-fee/low-fee cases because of the enormous complexity and time intensity required. Even though the cap on compensation recently was raised, judges cannot rely on the list to fully meet the growing number of cases.

Finally, New York also has scattered not-for-profit agencies that take guardianship cases. Such agencies are vastly under-funded to serve as guardian and do not exist throughout the state. Individuals we interviewed agreed that funding for additional nonprofits, especially those with a multidisciplinary team model and an emphasis on community-based settings, would help to curb the unmet need.
There was widespread recognition by those we surveyed and interviewed of a need for increased funding to provide for guardians in low fee/no fee cases where there is no one else to serve, and where no less restrictive option exists. Many, but not all, supported a statewide public guardianship system with flexibility to meet local needs. Two pilot programs are underway, and evaluation of their experiences will offer critical input toward addressing the unmet need in other areas of the state.

New York Court Processes: Barriers to Effective Service

Complicating attempts to address unmet needs are barriers in court guardianship processes that may needlessly hamper efforts to get people the help they need. In the development of New York’s primary guardianship system, Mental Hygiene Law Article 81, maximizing self-determination and expediting guardianship cases were both prominent features. The report noted that “while it is important to comply with time deadlines set out in the law, it is also important to focus on the individual and support his or her rights.” This balance is challenging. The Vera study examined issues of timing in court processes and in the monitoring to find solutions that streamline procedures yet preserve rights.

An earlier study in 14 counties by the Brookdale Center for Healthy Aging at Hunter College (as summarized in BIFOCAL in 2016) found that, on average, it takes 211 days -- significantly longer than the Article 81-mandated 50 days -- from the filing of a petition for guardianship to the commissioning of a guardian. The Brookdale study found additional delays and backlogs for other stages of the proceeding. Some delays are inherent in the very nature and complexity of the cases – time for needed accommodations, investigation, and evaluations. Other delays may be addressed through solutions such as uniform, plain-language forms, as well as additional court clerks to move the process ahead. Several of the study’s respondents cited “bottlenecks” at various stages and offered practical solutions. New York’s Article 81 requires the guardian to file an initial report after 90 days and an annual report thereafter. The Brookdale study found the average time to the filing of a first report is 237 days. The Vera study confirmed that a substantial number of reports and accountings are not submitted on time. Often lay guardians don’t have the experience and training in filing reports and accountings, and the study’s survey respondents urged ways of making filing easier. They emphasized the need for a uniform statewide template for initial and annual reports. An additional issue pointed out by interviewees was the need for a guardianship complaint procedure or ombudsman function.
The TGP Model -- Assessment of Effectiveness and Replicability

The TGP model in New York City was supported both internally by the staff members and externally by stakeholders in the study’s surveys and interviews. The study found that TGP’s team system is a holistic “one-stop shopping” approach to the provision of services, and the low ratio of staff to individual allows for high quality, person-centered services. TGP is especially outstanding in its efforts to either keep people living in community settings or to return people from institutions to community settings.

Although the TGP team model is a promising one, it is costly, and respondents in the study raised this important point. The program struggled for many years to find a sustainable funding model. Recently it obtained a sizable, multi-year contract from the Office of Court Administration. The study found that “TGP’s struggle to sustain itself is not due to its programmatic model, however, but rather, due to its mix of high-fee and low-fee, no-fee cases that the court orders TGP to take. Often, it is the most resource-intensive cases that are very low or no fee. Hence the need for programs (and alternative funding sources) specifically to serve indigent persons.”

While TGP is successful in a city with a high-density population such as New York City, the model may need to be modified in more rural areas. The study recommended that replication and adaptation should be piloted to determine feasibility, including requirements for technology, training, oversight, and partnerships to access services.
Top Ten Tips for Writing Funding Proposals

By David Godfrey

In order to provide critically needed services to older adults, aging services and legal assistance programs must secure funding to do their important work. Writing funding proposals is a core activity for most non-profit organizations, but many of us have little formal training in this key activity. These ten tips are designed to help you apply for both outside funding and requests for internal budget allocations.

1. Fully Respond to the Call for Proposals or Solicitation.
   » Be sure that you are actually answering the questions in the solicitation and responding to specific requests for information. It can be helpful to create an initial checklist with the information and answers that are required. Carefully review the request for proposals or funding opportunity, read background information on the funding provider, and look at the project through the eyes and ears of the funder.

2. Define Your Goals, Activities, and Outcomes.
   » Early on, concisely describe what you are going to do, how you are going to do it, and what the outcome will be. Condense the initial description into three sentences, stating what you will do, why it is needed, and the expected outcome or result.

3. Allocate Space and Resources Based on Scoring.
   » If the request for proposals includes scoring or evaluation criteria, let the criteria be a guide for how much elaboration, space, and focus should be placed on each element. Don’t overlook any element, but distribute your efforts and time in proportion to the review criteria.

4. Cite to Pages in the Call for Proposals.
   » Citing to page numbers in the request for proposals makes it easier for the reviewer and shows that you are being responsive to what was asked for.

5. Include Letters of Commitment when Collaborating.
   » Letters of commitment are critically important if the collaboration of another person, organization, or entity is required to carry out any element of the proposal. Letters of commitment are stronger than letters of support because they convey specific actions that will be taken to commit to the success of the project. However, if the solicitation does not specifically request letters of commitment or support, check the instructions to be sure that you are permitted to include letters or extra supporting documents in your proposal.

6. Minimize the Use of Acronyms.
   » Start by defining all acronyms or abbreviations. Beyond that, use a shortened name, if practical, instead of an acronym. For example, if you are working with “Last Chance Legal Aid of Mid-America” you could refer to it as LCLAMA, but you could also refer to them as “Legal Aid” or “Mid-America.”
7. Define Roles and Activities.
   » Make it clear in the narrative and project work plan, who will do what, and how they plan to do it.

8. The Budget Counts.
   » Read and follow the directions on budget planning. The budget needs to fund the work you are proposing, not just fill budget gaps in your office. Reviewers look to see that the time and funds allocated to key people is sufficient to cover the work they are committing to and is not excessive. If you commit to travel or material costs in the narrative, describe how it will be paid for in the budget.

9. Submit Early!
   » The rule of thumb is to plan to submit at least two working days before the deadline. If things can go wrong, and if you are submitting your proposal a few days early, you should have time to fix any problems that may arise. Submitting late or encountering a technical issue might result in a rejection.

10. Don't Shortchange Evaluation.
    » Describe how you will report the work you have done and the impact of that work. Plan to report both quantitative and qualitative data showing the impact of the work in terms of experiences or changes. Build in surveys or interviews to gather information about how the work has impacted the lives of people. Consider including an independent outside evaluator (if there is a cost, cover it in your budget). It is important for evaluation to go beyond the numbers to describe how the work changed something.

   [This article first appeared on the National Center on Law & Elder Rights website]

Additional Resources

- NCLER Chapter Summary: Creating Effective Legal Outreach Programs
- NCLER Issue Brief: The Older Americans Act in Action: Building & Cultivating Your Elder Law Program
- NCLER Issue Brief: The Essential Role of the State Legal Assistance Developer
- Many more trainings on program development and legal services capacity building on the NCLER website

Please contact ConsultNCLER@acl.hhs.gov for free case consultation assistance. Sign up for our email list and access more resources at NCLER.acl.gov.
Seven Slip-Ups to Avoid When Applying for Funding

By David Godfrey

Certain mistakes can ruin your chance to secure funding. Know these proposal-busting blunders so you can avoid them:

1. Don’t wait until the last minute to write or submit a request for funding.

A friend of mine submitted a major funding proposal just 30 minutes before a midnight deadline, then shut down his computer and went home for the night. The next morning, he turned on his computer to find an email error message saying one of the attachments had failed to upload properly. It was too late to fix. The deadline had passed.

2. Don’t use an expensive overnight delivery service when your submission explains your dire need for funds.

An officer at a private foundation said his office received a desperate plea for additional funding from an organization they had supported for some time. That plea was delivered by FedEx, even though the office was just three blocks away. The executive director looked at the envelope and immediately said, “Reject it. If they can spend $20 to send that instead of $2 to mail it, or simply walk over here with it, they really don’t know how to manage money.”

3. Don’t have all the letters of support or commitment read the exact same way.

The same reviewers will read each letter, meaning that it could raise questions if they all sound the same. While it is common to send draft suggestions when requesting a letter, it is important that the letters specifically address how the outside organization understands your work, how they understand the project, and how they will help you accomplish the goals of the project you are proposing.

4. Don’t hide in the budget what you really intend to do with the funding.

The work plan, narrative, and budget should agree on what work is to be funded. The goal needs to fund the work that is being proposed, not to fill funding gaps in your budget.
5. Don’t create a plan that is unreasonable for the time or funding available.

Unreasonable goals or expectations are a red flag for reviewers. Make the goals of the project reasonably fit the time and funding available. If you promise the sun, the moon and the stars, but your budget can barely get you to Cape Canaveral, you’re in trouble.

6. Don’t write a proposal without talking with the individuals who will actually do the work.

Writing a proposal should be a collaborative effort between the grant writer, the frontline staff, and the person who will be keeping the books and filing reports. Everyone needs to be on board for the project to be a success.

7. Don’t ignore the suggested templates for budgets or work plans. If an application checklist is included, use it.

Using the checklist will assure that you don’t accidentally overlook a required element. You might think that you can organize a submission better than what the checklist suggests but having things in the expected order makes it easier for the reviewers to find what they are looking for. If there are templates for the budget or workplan, use them. Uniformity of these elements helps the readers understand the proposal.

In every proposal, tell the funding organization what your project will do, how you’re going to do it, and the impact it will create.

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**Webinar on Issues Involving Social Security and Medicare**

Social Security benefits and Medicare benefits are closely intertwined, and most people who receive one also receive the other. The close connection means that a problem with one benefit will sometimes cause problems with the other benefit. It can be difficult to figure out which agency is responsible and where to go for relief.

This webcast on October 8, 2019, at 11:00 a.m. PT/2:00 p.m. ET, will focus on why cross-program issues occur and what advocates can do to resolve them. Register here:

https://register.gotowebinar.com/register/2136243741789324034?source=Salsa&eType=EmailBlastContent&eId=5bdf2c4f-a2dc-4e1d-b37a-9c3a47c9a046
Meet the New Commissioners

The ABA Commission on Law and Aging welcomes five new appointments for the 2019-2020 term. We are thankful for the contributions of those whose terms have ended, and we look forward to continuing and advancing meaningful work with our new and current commissioners.

We’d like our readers to get to know our new commissioners: Judith Feder; Hon. Lauren Holland; Jason Karlawish, MD; Casey Ross; and Dominic Vorv.

Judith Feder

Judith Feder is a professor of public policy and, from 1999 to 2008, served as dean of what is now the McCourt School of Public Policy at Georgetown University. Professor Feder is a nationally-recognized leader in health and Long-Term Services and Supports (LTSS) policy. She is a widely published scholar, staff director of the congressional Pepper Commission (1989-1990), HHS deputy assistant secretary of planning and evaluation (1993-1995), Democratic nominee for Congress in VA-10 (2006, 2008), and member of the congressional Long-term Care Commission (2013). She is an elected member of the National Academy of Medicine, the National Academy of Public Administration, and the National Academy of Social Insurance; a former chair and board member of Academy Health and former board member of the National Academy of Social Insurance; and a member of the Center for American Progress Action Fund Board and of the Hamilton Project’s Advisory Council; and an Urban Institute Fellow. Professor Feder is a political scientist, with a B.A. from Brandeis University, and a master’s and PhD from Harvard University.

Why did you decide to join the Commission?

Promoting solutions to address the long-standing inadequacies of the nation’s financing for long-term services and supports becomes increasingly important as baby boomers age and need care. Participation in the Commission offers an opportunity to advance effective policies that are sorely needed.

What do you hope to bring to the Commission, and what do you hope to accomplish?

I bring to the Commission decades of experience in developing, evaluating, and promoting policies that improve access to affordable LTSS. I hope my policy and political experience can advance the Commission's efforts to educate policymakers and the public on why and how to achieve that goal.

Has the Commission impacted your work, and if so, how?

The Commission's voice--and Charlie Sabatino's leadership--contribute mightily to advancing public and policymaker understanding of LTSS policy. I have benefited from and partnered with Charlie and the commission as a researcher, policymaker, and advocate throughout my career.
Hon. Lauren Holland

Judge Lauren Holland is a Circuit Court Judge in Oregon and the current president of the Oregon Circuit Court Judges Association. She is a leader in identifying and implementing standards and best practices for protective proceedings in her own court and throughout the state. She instituted a court-appointed attorney list from which to appoint experienced attorneys to represent persons subject to protective proceedings. She developed a mandatory fiduciary education class for guardians and conservators and established a monitoring program utilizing trained volunteers to conduct independent investigations for the court in ongoing guardianships and conservatorships. Born and raised in Chicago, she attended the University of Illinois. She moved to Oregon in 1972, where she graduated from the University of Oregon. Judge Holland earned her JD Order of the Coif at the University of Oregon Law School in 1978. She was elected to the bench in 1992.

Why did you decide to join the Commission?

The Commission provides judges, lawyers, legislators and other system leaders resources and tools to ensure that seniors have the best opportunity and protections to lead autonomous, respected, and valued lives. In Oregon, I have led successful efforts to do that for the people who appear before me and statewide, testifying before the legislature this session on a bill to codify fiduciary standards of decision-making and rights of protected persons to associate with others. When people who are serving our most vulnerable collaborate and learn from each other’s practices, we extend the reach of our impact. The Commission connects us, across the country, to expand successes and ensure we continue to strive to improve our system of service to seniors.

What do you hope to bring to the Commission and what do you hope to accomplish?

As Chair of the Oregon Circuit Judge Conference in 2018, I organized this statewide judicial education conference, presenting, along with national speakers, the keynote session on Protective Proceedings. I have listened to and collaborated with protective proceeding stakeholders to ensure we include diverse voices and members of the community at the table. I have also worked with the University of Oregon Law School conducting a Probate Mediation Clinic and trainings for law students. I have had personal experience with family members whose capacities were questioned and the challenges and obstacles they faced being respected and heard. I bring passion, enthusiasm, experience and a willingness to learn as I join the Commission in continuing its influence and reach in the service of seniors and vulnerable members of our communities.

Has the Commission impacted your work, and, if so, how?

The policies and resources of the Commission have allowed me to look beyond state borders to access and discuss ideas implemented elsewhere to protect vulnerable persons. I have been Co-Chair of Oregon WINGS since its inception. Under a grant from the ABA and NCSC, Oregon WINGS has completed a mapping project to determine and close gaps in services thereby allowing less restrictive alternatives to guardianships for vulnerable persons. From that project, we are now creating a “Train the Trainer” program and pursuing a public service presence. The commitment and dedication of those who serve with the Commission and in support of the Commission has been an inspiration.
Jason Karlawish is a professor of medicine, medical ethics and health policy, and neurology at the University of Pennsylvania, and cares for patients at the Penn Memory Center, which he co-directs. He leads the Penn Program for Precision Medicine for the Brain (P3MB), which developed standards for Alzheimer’s disease biomarker disclosure and investigates the clinical impact on individuals and their families. He has investigated the development and translation of Alzheimer’s disease treatments and biomarker-based diagnostics, informed consent, quality of life, research and treatment decision-making, and voting by persons with cognitive impairment and residents of long-term care facilities. He is the author of Open Wound: The Tragic Obsession of Dr. William Beaumont, a novel based on true events along the 19th century American frontier. He is currently writing a book on how Alzheimer’s disease became a crisis and the steps needed to address it. Dr. Karlawish studied medicine at Northwestern University and trained in internal medicine and geriatric medicine at Johns Hopkins University and the University of Chicago.

**Why did you decide to join the Commission?**

The Commission is the nation’s thought leader on the important, and sometimes vexing, issues at the intersections of law and aging. As a physician dedicated to the care of older adults with disabling cognitive and behavioral problems caused by diseases such as Alzheimer’s, the Commission is a marvelous opportunity to help these persons and their families. Besides, working with Charlie Sabatino and his team is consistently a blast.

**What do you hope to bring to the Commission, and what do you hope to accomplish?**

I bring an open mind and a hope to learn and to contribute.

**Has the Commission impacted your work, and if so, how?**

The Commission’s work on voting rights, capacity assessment and guardianship have been critical to advancing my ideas and boosting the impact of my work.
Casey Ross

Casey Ross is the University General Counsel for Oklahoma City University. She also serves as a clinical professor and the director of the American Indian Law and Sovereignty Center at Oklahoma City University School of Law, where she oversees the American Indian Law program, teaching clinical and doctrinal courses in Tribal Law, American Indian Wills and Probate, Indian Gaming Law, and Federal Indian Law. Prior to joining the faculty at Oklahoma City University School of Law, Professor Ross served as the Senior Legislative Officer for the Cherokee Nation, in its Washington, D.C., office. She is also the founder of an all-native-female-owned consulting firm, Advocates for Native Issues, LLC. Her firm provides consulting services to tribes, tribal organizations, and other stakeholders with an interest in Indian Country policy. Professor Ross is a citizen of the Cherokee Nation.

Why did you decide to join the Commission?

I'm very excited to join the Commission to work alongside the nation's foremost experts, to advance scholarship and the practice of law, with an informed focus on the unique needs of elder populations.

What do you hope to bring to the Commission, and what do you hope to accomplish?

I hope to provide the Commission with an understanding of the unique legal issues facing American Indian elders, with a deepened appreciation for various tribal cultural values related to elders.

Has the Commission impacted your work, and if so, how?

The Commission continues to provide leadership for development in our profession by engaging in thoughtful dialogue, legal analysis, and policy advocacy that improves services to clients. The resources developed by the Commission are very helpful for lawyers serving clients and professors teaching future lawyers.
Dominic Vorv is the president of the Bar Association of the District of Columbia (BADC) and has been a member since the early 2000s. He leads the voluntary bar of the District of Columbia, with programs ranging from intellectual property to child abuse and neglect, reflecting the rich diversity of the nation’s third oldest voluntary bar. Mr. Vorv also served as a member of the Board of Directors of the Hispanic Bar of the District of Columbia, and president of the Maryland Hispanic Bar Association. He is founder and principal of the Vorv Firm, PLLC. In his practice, Mr. Vorv has served elder clients in a variety of matters, including foreclosure, probate, wills & estates, personal injury, and divorce. As court-appointed counsel, Mr. Vorv has represented grandparents in their efforts to gain custody of their grandchildren in the District of Columbia’s foster care system. Mr. Vorv received his law degree from the University of the District of Columbia David A. Clarke School of Law.

Why did you decide to join the Commission?

I decided to join the Commission because having been a member of the other bar associations and the American Bar Association, I wanted to contribute and be productive in supporting the Commission’s leadership work.

What do you hope to bring to the Commission, and what do you hope to accomplish?

I hope to bring my experience and contacts so that I can contribute as a team player with others at the Commission in assisting elder persons in legal advocacy, education and everyday complications.

Has the Commission impacted your work, and if so, how?

Yes, I have utilized the Commission's materials.
ABA Calls for Dental Coverage in Medicare

The ABA is urging Congress to include dental and oral health coverage for beneficiaries of Medicare. A resolution, sponsored by the ABA Commission on Law and Aging and the Senior Lawyers Division, passed overwhelmingly by the ABA House of Delegates at the ABA annual meeting in San Francisco in August. It calls for lawmakers to support legislation that would repeal the statutory exclusion of dental care and dentures from Medicare and add coverage of comprehensive dental and oral health services to the program.

Louraine Arkfeld, chair of the Commission on Law and Aging, told the House of Delegates that oral health is critical to the overall health and wellbeing of older adults. Yet many go without dental insurance because they can’t afford it. Studies show that poor dental health can lead to or worsen medical conditions, including cardiovascular disease and diabetes.

“How many of you know that 70 percent of all seniors have no dental care coverage?” she said. “It is very expensive. We need to continue to stand behind our seniors in need.”

Medicare does not cover dental and oral health benefits for beneficiaries in most cases. The Medicare Dental Benefit Act of 2019 was introduced in the Senate to repeal the exclusion and expand Medicare Part B benefits to cover dental and oral health care services. A related bill, the Medicare Dental, Vision and Hearing Benefit Act of 2019, was introduced in the House and also would increase Medicare dental benefits.

Another resolution that passed overwhelmingly encourages attorneys who provide estate planning services to include counseling for advance care planning that conforms with principles developed through a John A. Hartford Foundation-funded project. As part of the project, the Commission on Law and Aging tasked more than 30 legal and clinical experts with examining how advance care planning practices of lawyers and clinicians could better align. The resolution encourages attorneys who provide advance care planning to consider greater collaboration with medical providers and the health care system.

Arkfeld said the COLA project could better ensure that clients and patients make their values, goals and wishes known and honored near the end of life.

“How many of you know that 70 percent of all seniors have no dental care coverage?” said Commission Chair Louraine Arkfeld. “It is very expensive. We need to continue to stand behind our seniors in need.”
More States Pass Supported Decision-Making Agreement Laws

By Zachary Allen and Dari Pogach

Supported decision-making is gaining national recognition as an alternative to guardianship, potentially affecting thousands of Americans and their families. Four states this year have passed laws that define supported decision-making agreements as legally enforceable arrangements. They join five other states since 2015 to enact such laws. In a supported decision-making model, individuals with disabilities -- whose decision-making autonomy might otherwise be limited or removed -- make and communicate their own decisions in any number of informal arrangements, with support from trusted family and friends. A growing number of advocacy groups, social services organizations, and state agencies assist with implementing supported decision-making arrangements by documenting and formalizing the process with supported decision-making agreements.

Indiana, North Dakota, Nevada, and Rhode Island are the latest states to pass supported decision-making agreement laws in 2019. They follow Texas, Delaware, the District of Columbia, Alaska,
and Wisconsin. State laws vary widely on requirements for supported decision-making agreements, including who may serve as a supporter, the role of third parties, and the scope of agreements.

Supported decision-making is often defined as supports and services that help an adult with a disability make his or her own decisions by relying on trusted friends, family members, professionals, and others. While many individuals will continue to engage in an informal supported decision-making arrangement, others are documenting various provisions in an agreement. These include the names and roles of supporters and details about the scope of their assistance, authority, and duties.

Agreements may include whether the supporter has access to confidential information pertaining to the decision-maker. Agreements also typically outline the terms of revocation or termination.

There is no one-size-fits-all supported decision-making agreements law. States take different approaches to addressing the risk of exploitation or manipulation of decision-makers at the hands of supporters. For example, Texas, Wisconsin, Nevada, and North Dakota place no restrictions on who may act as a supporter.

Some states, like Delaware, Alaska, the District of Columbia, and Rhode Island, restrict who may serve as a supporter. This includes employers/employees, anyone against whom the decision-maker has a restraining order, and individuals directly providing paid support services to the decision-maker.

Among the advantages of having legally recognized supported decision-making agreements in your state:

- They can specify the duties of supporters, prohibiting supporters from making decisions on behalf of the decision-maker.
- They can indemnify third parties such as financial and healthcare institutions from liability for relying on a supported decision-making agreement and require them to honor supported decision-making agreements.
- They can provide structure and accountability.
Conversely, there are concerns about supported decision-making agreement laws, including:

- Supporters could use an agreement to unduly influence or exploit a decision-maker.
- Supporters could use an agreement to justify their authority to a third party. For example, supporters could insist an agreement provides them with the authority to consent to medical care on behalf of decision-makers.
- These agreements may unnecessarily formalize a decision-making model that works better as an informal arrangement.

As supported decision-making agreement laws gain momentum, and recent state laws are likely to serve as models for future legislation, it is important to evaluate whether these laws are effective in promoting supported decision-making -- and supporting individuals with disabilities to make their own choices.

For more information on supported decision-making, go to https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/

In its first enforcement action involving its Right of Access Initiative, the Office of Civil Rights (OCR) at the U.S. Department of Health and Human Services cited a Florida hospital in September for failing to give an expectant mother timely access to her unborn child’s medical records. Under Health Insurance Portability and Accountability Act (HIPAA) rules, providers have a maximum 30 days to comply with these requests. It took more than nine months for the hospital, Bayfront Health St. Petersburg, to provide the mother with her requested prenatal health records.

OCR Director Roger Severino said in a statement: “We aim to hold the health care industry accountable for ignoring peoples’ rights to access their medical records and those of their kids. Providing patients with their health information not only lowers costs and leads to better health outcomes, it’s the law.”
The Health Insurance Portability and Accountability Act first mandated the creation of privacy standards for personally identifiable health information in 1996. The set of privacy regulations promulgated under HIPAA, known as the Privacy Rule (45 CFR Part 164), defines the types of uses and disclosures of an individual’s health information that are permitted by health care providers and health plans. That same rule guarantees access to one’s own information through multiple pathways. The Act provides for a right to access. Nevertheless, almost all enforcement actions by the OCR, the designated enforcer, have been for improper disclosures and breaches of information security by health care providers and related business covered by the Act.

The latest OCR enforcement action and settlement against Bayfront is the first of its kind since OCR announced the Right of Access Initiative earlier this year, promising to vigorously enforce the rights of patients to receive copies of their medical records promptly and without being overcharged.

Bayfront has agreed to pay $85,000 to OCR and has adopted a corrective action plan to settle the alleged violation of the right of access provision of HIPAA. Bayfront, based in St. Petersburg, is a Level II trauma and tertiary care center licensed as a 480-bed hospital with over 550 affiliated physicians. Here’s the resolution agreement and corrective action plan.

OCR said it initiated its investigation into HIPAA violations based on a complaint from the mother. “This right to patient records extends to parents who seek medical information about their minor children, and in this case, a mother who sought prenatal health records about her child,” it said.

This case is an important reminder of the need to understand the information access rules that apply to you, your health care representative, and your family members or friends. OCR’s website provides an excellent overview of those rights, including helpful videos.

You have a right to have your health care provider send your medical information to anyone you choose. While the provider must give you more than one way to make this kind of request, one alternative is to use a tool created by the ABA Commission on Law and Aging, a Right to Access Form.
Borchard Foundation Offers Academic Research Grants for 2020

Legal, health sciences, social sciences, and gerontology scholars and professionals are invited to submit research proposals to the Borchard Foundation Center on Law & Aging. The objective of the Academic Research Grants is to advance research about new or improved public policies, laws, and/or programs that will enhance the quality of life for older adults, including those who are poor or otherwise isolated by language, culture, disability, lack of education, or other barriers.

Up to four grants of a maximum of $20,000 each will be awarded to grantees who, through individual or collaborative research projects, do either of the following:

- Analyze and recommend changes to one or more important existing public policies, laws, and/or programs relating to older adults, or
- Anticipate the need for and recommend new public policies, laws, and/or programs necessitated by changes in the number and demographics of the country’s and the world’s elder populations, by advances in science and technology, by changes in the health care system, or by other developments.

It is expected that the research product will be publishable in a first-rate academic journal. Applicants are encouraged to disseminate research findings through additional channels such as conferences, stakeholder meetings, and white papers.

Proposals must be submitted by one or more individual researchers who will be responsible for carrying out the project. Collaborating researchers may be affiliated with the same or different institutions. Grant funds must be administered by an academic, government, or other non-profit organization. Evidence of federal tax-exempt status is required before funds will be released.

The online application form on the Borchard Center’s website, www.borchardcla.org, will be available after September 15, 2019. Applications should be submitted no later than October 15, 2019. Selections will be made on or about December 15, 2019.

Proposals should include a description of the research project (five pages maximum), including proposed research activities, how the research meets the objective of the center’s grant program, why the project is otherwise important, a description of the intended written research product(s), the journal(s) to which the work product(s) will be submitted for publication, and a statement regarding IRB approval. For details, go to the center online or contact Catheryn Koss, ck@borchardcenter.org.
Get Ready for the 2019 National Aging and Law Conference!

Come join us at the 2019 National Aging and Law Conference and feel empowered! This year, empowerment is the theme of the conference, and by the end of the event, you will be empowered with the knowledge you’ve gained and the people you’ve met. It’s happening on Thursday, October 31, to Friday, November 1.

In the agenda, you will find four plenary sessions and 30 workshops, with a mix of sessions on elder abuse, consumer law, legal ethics, supporting decision making, health care, benefits, and legal service development and delivery. There’s something for everyone.

By popular request, NALC returns to the Crystal Gateway Marriott, in the Crystal City area of Arlington, Virginia, for the first time in more than a decade. We are just one subway stop from Ronald Reagan Washington National Airport. An enclosed walkway takes you directly from the subway station to the hotel lobby. The hotel provides free shuttle service to and from the airport.

A pre-conference on Wednesday, October 30, on Supplemental Security Income (SSI) will focus on challenges to obtaining and retaining benefits and emerging issues such as special needs trusts and ABLE accounts. This full-day program includes lunch and CLE credits and requires a separate registration from the main conference. Join us to explore and celebrate Empowerment in our work and in supporting and helping our clients.

Register now at [https://www.americanbar.org/events-cle/mtg/inperson/349894122/](https://www.americanbar.org/events-cle/mtg/inperson/349894122/).

We’re looking forward to seeing you soon!

David Godfrey
Program Chair

This booklet offers a simple durable power of attorney for health care, designed to meet the legal requirements in nearly all states. Research over the last 30 years has shown that instructions about end-of-life treatment choices, provided by relatively healthy adults long before they face serious illness, are often dated and too vague to be of guidance when tough decisions need to be made. This booklet and form focus on the single most important legal task—that of appointing a health care agent.

https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/power_atty_guide_and_form_2011/

Toolkit for Health Care Advance Planning. Thinking of making a health care advance directive such as a living will or durable power of attorney for health care? This toolkit helps you to understand, clarify, and communicate what is important to you in the face of serious illness. It has nine tools, including “How to Select Your Health Care Agent or Proxy,” “Personal Priorities and Spiritual Values Important to Your Medical Decisions,” and “How Do You Weigh Odds of Survival?

https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning/

Practical Tool for Lawyers: Steps in Supporting Decision-Making. The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. “PRACTICAL” is an acronym for nine steps for lawyers to identify these options. Lawyers can use the PRACTICAL checklist of steps during the client interview and immediately after to assist in case analysis.
Here's what a few people had to say about us!

The expertise of the Commission’s staff is unparalleled, particularly in the areas of guardianship and conservatorships. The research, knowledge base, and coordination efforts of the Commission have been critical in the advancement of guardianship reform.

The Commission is a leader in promoting both the expansion of supported decision making as an alternative to guardianship and in efforts to enable individuals to retain or regain legal rights.

--Curtis L. Decker, Executive Director, NDRN

In this leadership role, the ABA Commission has fundamentally changed the landscape for the betterment of Americans who are elderly, disabled, or legally incapacitated.

--Terry W. Hammond, Chair, National Guardianship Network

Learn more about our work at americanbar.org/aging

Assessment Of Older Adults With Diminished Capacity: A Handbook For Lawyers

This handbook for lawyers offers elder law attorneys, trusts and estates lawyers, family lawyers, and general practitioners a conceptual framework and a practical system for addressing problems of client capacity, in some cases with help from a clinician.