September 30, 2015

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–3260–P
P.O. Box 8010
Baltimore, MD  21244

Re:  Department of Health and Human Services Proposed Rule on Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities; File Code CMS-3260-P; RIN 0938-AR61; 80 Fed. Reg. 42168 (July 16, 2015)

Dear Sir/Madam:

On behalf of the American Bar Association (ABA), which has over 400,000 members, I write to express our views regarding the above-referenced proposed rule (Proposed Rule) by the Department of Health and Human Services’ Centers for Medicare & Medicaid Services (CMS) and the proposed regulations contained therein (Proposed Regulations) that would establish new requirements for long-term care facilities. The ABA, especially through its Commission on Law and Aging, has been an advocate for the rights of nursing home residents for more than 30 years. Overall, the Proposed Regulations represent a substantial step forward toward the goal of protecting the rights of residents, improving their quality of care and quality of life, and ensuring resident-centered care. However, as more fully explained below, we have identified several areas in which we believe further revisions are needed to accomplish these important goals.

1. Definition of Resident Representative

Section 483.5 of the Proposed Regulations would define “resident representative” as:

an individual of the resident’s choice who has access to information and participates in healthcare discussions or a personal representative with legal standing, such as a power of attorney, legal guardian, or health care surrogate appointed or designated in accordance with state law. If selected as the resident representative, the same-sex spouse of a resident must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated.

The first sentence of the definition is likely to cause confusion, because the distinction between (1) “an individual of the resident’s choice who has access to information and participates in healthcare discussions” versus (2) “a personal representative with legal standing” is insufficiently articulated. In conventional legal theory, the two parts of the definition are tautological, i.e., one who has access to the resident’s information and participates in healthcare decisions is normally a person with the legal standing to do that, conferred typically by a power of attorney or guardianship. Also, “access to information” is quite vague, because the authority for access under the HIPAA Privacy Rule
involves a few different avenues of access with very different requirements and limitations. The very term “representative” implies all the conventional legal bases of decision-making authority.

The first option appears to be an attempt to recognize a process of supported decision-making that is initiated or agreed to by the resident. This is an option that derives from principles articulated in the U.N. Convention on the Rights of Persons with Disabilities, a convention which the ABA has strongly endorsed. Supported decision-making can be an effective, less restrictive alternative to transferring decision-making authority to someone else. It is a process that uses trusted friends, family members, and advocates to give people with disabilities the help they need and want to understand the situations they face and the choices they must make so they can make their own decisions. Supported decision-making shows great promise for increasing self-determination and improving quality of life outcomes (The National Resource Center for Supported Decision-Making (NRC-SDM), www.supporteddecisionmaking.org).

To incorporate this concept into the nursing home regulations is a worthy goal but will need new terminology to break from the entrenched concept of “representative” in the conventional legal sense. We suggest a term such as “resident enabler” replace “resident representative” and that it include the following definition:

For purposes of this subpart, the term resident enabler means an individual or individuals chosen by the resident to participate in healthcare discussions and assist the resident in making decisions or a personal representative with legal standing, such as a power of attorney, legal guardian, or health care surrogate appointed or designated in accordance with state law.

Since even appointed agents and guardians would now be called “resident enablers,” this approach would have the beneficial effect of introducing supported decision-making to their understanding of their decision-making duties.

2. Residents’ Right to Vote

The proposed enumeration of resident rights in §483.10(a) of the Proposed Regulations begins with the statement that:

(1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.

(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights and to be supported by the facility in the exercise of his or her rights as required under this subpart.

While the ABA strongly supports this statement, it unfortunately specifies nothing that a nursing facility can or must do with respect to supporting residents’ exercise of this most fundamental right of civil society, the right to vote. Since 1986, Americans age 65 and older have voted at higher rates than all other age groups. In 2014, the voting rate for those 65 and older was 59.4 percent, nearly 10
percentage points above the next highest age group. Indeed, voting increases steadily with age and thus is particularly important in old age. Yet, residence in a nursing home poses enormous obstacles to exercising this right, including isolation, mobility limitations, and impaired capacity. Of the approximately 1.5 million nursing home residents, estimates of the prevalence of some level of dementia range from a quarter to two-thirds of the population. But these statistics also mean that somewhere between one-third and three-quarters of nursing home residents do not suffer from dementia. In addition, even those with less severe levels of dementia have the ability to vote competently with some assistance.

We know that nursing home regulations cannot address the policies or practices of election officials, but they can and should ensure that an active and informed effort is made by nursing home staff to support the right of nursing home residents to vote. The few studies that have been done of nursing home voting practices show enormously variable facility practices for registration and voting, in staff attitudes, and in the estimated proportion of residents who vote. Many residents who want to vote may be unable to vote. Evidence suggests gate-keeping by facility staff, including arbitrary judgments regarding residents' ability to vote. Current procedures in many facilities fail to protect voting rights and fail to protect against voting irregularities. Facilitating access to the election system is not a priority for facility staff, and of those that express interest in the topic at all, many state that the best suited organization to provide assistance to their clients would be the Elections Department.

The ideal model for assisting nursing home residents involves a collaboration between election officials and nursing homes in a process referred to as “mobile polling” in which election officials, trained in assisting individuals with cognitive and other brain impairments, bring the vote to residents and make assistance available. Voting may be conducted using an absentee ballot, or portable voting machines may be transported to facilities and even to residents’ rooms. In a pilot of the model, it has been shown to be feasible and generally well accepted by long-term care staff, residents, and election officials. It reduced concerns of voter fraud and manipulation and enhanced residents’ dignity and rights.

The Election Assistance Commission (EAC) has recognized this model in its own guidelines:

Election officials can develop and implement policies and practices that facilitate registration and voting processes for residents of nursing homes, assisted-living facilities, and long-term care facilities, and especially for people with cognitive and other brain impairments. One such practice, known as mobile polling, entails having election officials bring ballots to convenient and accessible locations, such as long-term care facilities, while

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skilled, nonpartisan election workers provide assistance when needed, and—where permitted—register voters.\(^5\)

The U.S. Government Accountability Office (GAO), reporting on election practices affecting long-term care facilities in 2008, found that in their survey of 92 localities, 78 self-reported taking actions to facilitate voting for long-term care facility residents; but, practices varied widely. The most common action was merely providing information or guidance (e.g., a brochure on voting rights), but close to one-half of the localities reported that they brought election officials to facilities to assist with the voting process in long-term care facilities.\(^6\) While not a universal practice, it is one that requires the informed collaboration of nursing home staff.

The ABA is committed to supporting voter rights and, in connection with voting by persons with disabilities, has extensive policies calling for supported access to voting by residents of long-term care facilities. Long-term care facilities should play an active and constructive role in supporting the right to vote by residents. To accomplish that, we recommend the following changes to the Proposed Regulations:

1. **Expressly include the right to vote as among the resident rights respected under 42 CFR §483.10 (“Resident Rights”).** As the most fundamental right of a democratic society, it needs and deserves explicit recognition, especially because of its vulnerability to loss and abuse in an institutional environment.

2. **Require facilities to develop policies and procedures to support voting.** These should include:
   - a process for informing new residents about voting registration or change of address procedures;
   - assistance in registering as needed and desired by the resident;
   - procedures for informing residents of elections, including date, time, and location of voting places and community resources available to provide assistance;
   - assistance with transportation to polling places;
   - processes for reaching out to election officials to develop a plan for officials to come to the facility to register residents and conduct voting to the maximum extent election officials have the ability to do this;
   - the designation of staff charged with assisting with voting;
   - training of designated staff in how to help a resident who requires assistance to vote where election officials are unable to provide that service to the extent needed.

An ancillary task that DHHS should consider to enable the above recommendations to have a meaningful impact is to clarify the ability of election officials to obtain resident names and former addresses under the HIPAA Privacy Rule in connection with their authority to conduct and monitor

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elections. Such sharing of information is essential to determine the registration status and an official address for voting purposes of residents.

3. Advance Care Planning

We applaud CMS for expressly incorporating advanced directives in several provisions of the Proposed Rule. However, referencing only advanced directives as the tool for incorporating a resident’s health care preferences into care plans and as part of transition planning and discharge planning paints a too narrow a picture of advance care planning.

The Proposed Regulations overlook the recent clinical and legal advances in advance care planning reflected in the Institute of Medicine’s recent report, *Dying in America: Improving Quality and Honoring Preferences Near the End of Life.* That report properly recognizes advance directives as just one component in a life-long process of advance care planning that changes according to the stage of life and stage of illness of the individual. The later stages of life fall into the period of advanced and eventually fatal illness, a stage experienced by most nursing home residents. Advance care planning at that stage necessarily becomes more specific, especially with regard to addressing critical care decisions that may have to be made in crisis situations and addressing the balance between curative versus palliative care. One of the best practices recognized by the IOM Committee for this stage of advance care planning is the use of Physician Orders for Life Sustaining Treatment or POLST.

According to the IOM:

The POLST paradigm is an approach to advance care planning designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and will be honored in an emergency. POLST is a clinical process designed to facilitate communication between health care professionals and patients, their families, their health care agents, or their designated surrogates. The process encourages shared, informed medical decision making. The result is a set of portable medical orders, POLST forms, that respects the patient’s goals for care with regard to the use of cardiopulmonary resuscitation; artificially administered nutrition; and other medical interventions, such as intubation and future hospitalization. Medical intervention options generally are described as “comfort measures only,” “limited additional interventions,” and “full treatment” and align with the intensity of the desired interventions. *(references not included)*

The POLST model has been given various names in the states that have adopted it, including Medical Orders for Life-Sustaining Treatment (MOLST), Provider Orders for Scope of Treatment (POST), and Medical Orders for Scope of Treatment (MOST). These may all be described generically as portable medical orders. They are not a substitute for advance directives, but rather a timely complement to advance directives.

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7 Institute of Medicine, “Dying in America: Improving Quality and Honoring Preferences Near the End of Life” (National Academies of Science, 2014).
Regardless of the label used, POLST programs include the following key components: (1) a discussion between the medical provider and patient (or resident’s representative) to ensure that the resident’s condition and treatment and care options are understood and that the provider understands the resident’s goals of care, preferences, and values with respect to care; (2) the completion of a POLST form, with the individual’s consent, that translates the resident’s goals of care and preferences into standardized medical orders; (3) an obligation of the provider to ensure portability of the medical orders across medical settings; and (4) review of the medical orders whenever the patient’s condition or wishes change or the resident is transferred.8

The ABA adopted a policy in support of POLST programs in 2008 and, since then, has worked to ensure the design and implementation of these programs in a way that achieves the goals of maximizing personal autonomy and high quality person-centered care. A national voluntary certification of POLST programs is overseen by the National POLST Paradigm Task Force (see www.POLST.org) under which 17 states currently have achieved the status of “endorsed” programs as of this writing, and most of the remaining states are in various stages of operating POLST programs. At that rate of development, virtually every state will have a POLST program within the next five years. Therefore, it is important for CMS to recognize and incorporate this model clinical practice into its regulation. POLST plays a key role in comprehensive care planning and discharge planning.

Accordingly, we recommend that the Proposed Regulations incorporate recognition of POLST in the following way:

1. In Proposed Regulation §483.5 (“Definitions”), include a definition of “Portable Order for Scope of Treatment” as follows:

   A “Portable Order for Scope of Treatment” means a set of medical orders in standardized format (such as physician orders for life-sustaining treatment or similar portable medical orders) that address key medical decisions consistent with the patient’s goals of care and results from a clinical process designed to facilitate shared, informed medical decision making and communication between health care professionals and patients with serious, progressive illness or frailty.

2. In Proposed Regulation §483.15 (“Transitions of Care”), at subsection (b)(2)(i), documentation in the resident’s medical record should include, if applicable and with the resident’s consent, updated Portable Orders for Scope of Treatment.

3. In Proposed Regulation §483.21(a) and (b), both Baseline Care Plans and Comprehensive Care Plans should include, if applicable and with the resident’s consent, reviewed and updated Portable Orders for Scope of Treatment.

4. In Proposed Regulation §483.21(c), the Discharge Planning Process should include, if applicable, a review and update of the resident’s Portable Orders for Scope of Treatment.

4. Pre-Dispute Binding Arbitration Provisions

Section 483.70(n) of the Proposed Regulations sets out conditions on any binding arbitration agreements between the facility and its residents, including requirements that the facility explain the provision and that the explanation be acknowledged by the resident, that the agreement be voluntary, that the agreement provide for selection of a neutral arbitrator and convenient venue, and that admission not be contingent on signing the agreement. The ABA submits that such conditions, while helpful as far as they go, are clearly insufficient because they fail to expressly prohibit pre-dispute arbitration agreements between long-term care facilities and their residents. Therefore, Section 483.70(n) of the Proposed Regulations may actually worsen the current situation by allowing facilities to use the rule as a shield for actions for which they should be liable.

In 2009, the ABA House of Delegates adopted policy that “opposes the use of mandatory, binding, pre-dispute arbitration agreements between a long-term care facility and a resident of such facility or person acting on behalf of such resident.” The policy also “supports enactment of . . . regulations that would invalidate such arbitration agreements.” Therefore, we urge CMS to revise proposed Section 483.70(n) to expressly prohibit pre-dispute agreements for binding arbitration between the facility and its residents while permitting voluntary, post-dispute arbitration agreements so long as the other conditions in the Proposed Regulation noted above are met and the residents or their loved ones have provided informed consent, as demonstrated by the parties’ compliance with the four requirements outlined below.

Arbitration is a method of dispute resolution in which a neutral decision-maker is selected by one or both parties to resolve a dispute. In an arbitration agreement, a party agrees to waive the rights to sue and to a trial by jury, to participate in a class action lawsuit, or to receive any type of judicial review apart from the very limited grounds applicable to setting aside arbitration decisions, all theoretically in return for a speedy and cost-effective settlement. Recent court decisions have applied the Federal Arbitration Act, 9 U.S.C. §2, which was enacted in 1925, to a multitude of different types of disputes. Arbitration can be a viable means of resolving nursing home resident-facility disputes – but only after the dispute has arisen and its contours and seriousness are known.

The growing use of pre-dispute arbitration provisions for nursing home residents is fundamentally unfair. Nursing home admission is an extremely emotionally and physically challenging event for both resident and family. CMS should realize that it is virtually impossible for a resident or their surrogate decision-maker to give fully informed, voluntary consent to such arbitration provisions in connection with facility admission. The resident and family may not understand the provision, which is generally couched in legal phrases and included in a much larger set of confusing admissions material. Even if the provision is explained and set out separately from the rest of the admission agreement, as proposed in the Proposed Regulations, prospective residents are frail, have chronic health conditions, are frequently coming directly from the hospital, and they and their loved one are usually under severe pressure to culminate admission. Today, refusing to agree to the arbitration clause in most cases means that care will be denied; the nursing home staff typically have no authority to negotiate or waive the provision. Under the Proposed Regulations, refusal to

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agree to a “voluntary” pre-dispute arbitration provision risks creating unwanted tension with the nursing home from the start, no matter how much the document says it is voluntary.

Moreover, anticipating the possibility and nature of future disputes with the facility is the last thing on a resident or family’s mind when seeking nursing home care. They are not thinking of future litigation for receipt of poor care, and they cannot fathom becoming involved in disputes about pressure sores, choking, dangerous bedrails, dehydration, sexual assault, or even death. Yet the arbitration provision covers every aspect of the resident’s care in the facility, jeopardizes the enforcement of federal and state law, and bars access to the courts if something goes wrong. No matter how egregious, facility practices would not be subject to public scrutiny.

When a resident and his or her family are seeking nursing home care, there is generally no time to seek the advice of a lawyer to address such secondary issues as methods of resolving future disputes. In addition, there may be no other beds available for the same level of care and payment source within the geographic area. Consequently, residents and families typically feel compelled to sign the pre-dispute arbitration provisions that are presented to them, and this would continue to be so even if the provision is explained and technically not connected to the admission agreement.

Post-dispute arbitration in many circumstances can be advantageous, and residents should continue to have the choice to use them to resolve disputes after a dispute has arisen. At that point in time, options are tangible and understandable, and an informed choice becomes achievable. Indeed, arbitration is often a preferred course for many disputes, and residents and their loved ones may opt for it. In other cases, they may choose not to do so. If the right to resident-centered care means anything, it means maximizing residents’ and their loved ones’ ability and opportunity to make an informed decision about matters that are important to them.

In the context of arbitrating disputes between long-term care facilities and residents, informed consent can only be achieved by:

(1) postponing the presentation of an arbitration agreement to a resident until after a dispute has arisen;

(2) limiting the scope of such agreement to the dispute that has arisen, and not making it applicable to “all disputes”;

(3) requiring a written disclosure that signing the agreement is entirely discretionary and the resident will not suffer retaliation for refusing to sign it; and

(4) requiring that any such agreement must be signed by either:

(a) a legal guardian or court-appointed official acting on behalf of the resident, or

(b) in the absence of such person, the resident, but only after an independent and neutral "patient advocate" or ombudsperson (not appointed solely by the facility) explains the agreement to the resident, concludes that the resident’s written consent is informed and voluntary, and keeps a record of the signing event.
A strong and welcome theme throughout the Proposed Regulations is resident-centered care and maximizing the voice of the resident. Yet the proposed arbitration provisions in Section 483.70(n) directly contravene this emphasis by continuing to allow forced choices without genuine consent, which in turn will undercut the very quality-of-care and quality-of-life requirements the Proposed Rule sets out.

The importance of banning pre-dispute nursing home arbitration provisions has been recognized by leading organizations in the field, as well as by congressional initiatives.

- In 1997 and 1998, the American Bar Association, American Medical Association, and American Arbitration Association jointly developed the Health Care Due Process Protocol: A Due Process Protocol for Mediation and Arbitration of Health Care Disputes. The ABA subsequently approved the key principles contained in the Protocol in 1999, including Principle 3 (“Knowing and Voluntary Agreement to Use ADR”), which stated that:

  The agreement to use ADR should be knowing and voluntary. Consent to use an ADR process should not be a requirement for receiving emergency care or treatment. In disputes involving patients, binding forms of dispute resolution should be used only where the parties agree to do so after a dispute arises.

(http://www.americanbar.org/content/dam/aba/directories/policy/1999_my_114.authcheckdam.pdf)

- In 2003, the American Arbitration Association issued a policy statement consistent with the Protocol, confirming that the Association “would not administer healthcare arbitration between individual patients and healthcare service providers that relate to medical services, such as negligence and medical malpractice disputes, unless all parties agreed to submit the matter to arbitration after the dispute arose” (http://bit.ly/1M9ofmW), although practice may not consistently adhere to this policy.

- The American Health Lawyers Association Alternative Dispute Resolution Service Rules of Procedure for Arbitration, revised in 2012, state that the Service will administer a “consumer health care liability claim” only if “all of the parties have agreed in writing to arbitrate the claim after the injury has occurred” or if a judge orders it (http://bit.ly/1OtG1Ua).

- In 2008, U.S. House of Representatives and Senate “Fairness in Nursing Home Arbitration Act” bills were approved by the Judiciary Committees in both chambers but did not reach the House or Senate floors. The legislation would have provided that “a pre-dispute arbitration agreement between a long-term care facility and a resident . . . shall not be valid or specifically enforced.”
Allowing the use of pre-dispute arbitration clauses by certified facilities would directly undermine the comprehensive new care requirements contained in the Proposed Rule. Breaches of these requirements resulting in resident injury or death or violations of duly enacted laws would rarely come to public light and facilities would not be held accountable. Thus, the ABA urges CMS to amend Section 483.70(n) of the Proposed Regulations to expressly prohibit pre-dispute arbitration agreements between long-term care facilities and residents and to permit post-dispute arbitration of such disputes only when the other conditions in the Proposed Rule noted above have been met and the resident or their loved ones have provided informed consent, as demonstrated by the parties’ compliance with the four requirements outlined above.

5. Abuse, Neglect, and Exploitation

The proposed CMS regulations on long-term care facilities contain numerous positive provisions related to elder abuse, neglect, and exploitation. Among them are:

- Proposed Rule §483.5 includes new definitions of abuse, neglect, exploitation, and other relevant terms
- Proposed Rule §483.12 includes:
  - Prohibitions of the hiring or use of staff, contractors, or volunteers who have had a court or administrative/licensure finding regarding elder abuse;
  - Requirements that facilities develop and implement new policies and procedures about prohibiting, preventing, and investigating elder abuse;
  - Requiring facilities to develop policies indicating that staff are required to comply with state reporting laws if elder abuse by a resident representative (which includes guardians and agents) is suspected; and
  - Requiring facilities to allow residents to file complaints related to elder abuse directly with state survey and certification agencies
- Proposed Rule §483.95 requiring ongoing staff training about elder abuse

We commend CMS for including these provisions. We believe they will improve the federal and state governments’ response to elder abuse by strengthening federal and state oversight related to elder abuse in long-term care facilities. The Proposed Regulations also strengthen a nationwide structure (e.g., federal and state oversight) for training long-term care facility staff about elder abuse. The ABA supports such efforts.

6. Psychotropic Drugs

The ABA supports the goal of reducing the use of unnecessary psychotropic medications in long-term care facilities, but we are concerned that the Proposed Regulations stretch the definition of psychotropic drugs so far that it will result in under treatment of pain and other distressing symptoms that reduce the quality of life of residents. The ABA supports the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care, even if such pain and symptom
management may result in analgesic tolerance, physical dependence, or as an unintended consequence, shorten the individual’s life.

Proposed § 483.45 defines psychotropic drugs as follows:

A psychotropic drug is any drug that affects brain activities associated with mental processes and behavior. These drugs include, but are not limited to, drugs in the following categories:

(i) Anti-psychotic;
(ii) Anti-depressant;
(iii) Anti-anxiety;
(iv) Hypnotic;
(v) Opioid analgesic; and
(vi) Any other drug that results in effects similar to the drugs listed in paragraphs (c)(3)(i) through (v) of this section.

The inclusion of both antidepressants and opioid analgesics in this definition will inevitably cause nursing homes to avoid the use of such interventions, because they will be looked at with the same restrictive scrutiny as antipsychotics which have too often been misused in long-term care settings.

Expert treatment of pain and symptoms such as nausea and shortness of breath are essential components of palliative care. The proposed regulation will potentially cause not only under treatment but also unnecessary hospitalizations. Furthermore, the regulation would require that these medications be subject to gradual dose reduction – which may be directly contrary to the resident’s therapeutic goals.

This section on psychotropic drugs should be revised to eliminate the inclusion of antidepressants and opioid analgesics. CMS should instead take steps to develop palliative care quality indicators focused on the concordance of care received with resident and family priorities.

Thank you for considering the views of the ABA on these important issues. If you have any questions regarding the ABA’s position on the Proposed Rule, please contact me at (202) 662-1765, or Charles Sabatino, Director of the ABA Commission on Law and Aging, at (202) 662-8686.

Sincerely,

Thomas M. Susman