AMERICAN BAR ASSOCIATION

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STATEMENT

of

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AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING

on behalf of the

AMERICAN BAR ASSOCIATION

presented to the

SPECIAL COMMITTEE ON AGING

of the

UNITED STATES SENATE

on

HOW TO RESPECT AMERICANS' CHOICES AT THE END OF LIFE

September 24, 2008

Mr. Chairman and Members of the Committee:

I appreciate this opportunity to present the perspective of the American Bar Association on the development of state and federal health care advance directive policy. I currently chair the ABA's Commission on Law and Aging, which has followed and provided technical assistance and education on health care advance planning for over 20 years. I would like to describe how advance directives for health care decisionmaking have evolved in the last three decades, highlighting some of the implications that has for present and future policy options at the state and federal level.

Incremental State Evolution

The first advance directive – popularized by the term *living will* – was proposed by the Luis Kutner, a human-rights lawyer from Chicago. He proposed it in a 1969 *Indiana Law Journal* article as an instrument by which an individual could refuse treatment prior to losing capacity, even if such treatment would prolong life.

Borrowing this concept, California adopted the first living will statute in 1976 (although it used the term "directive to physicians" rather than the popular "living will"). The paradigm offered individuals a standardized tool to express their wishes about life-sustaining treatment – usually to withhold or withdraw it – in the event of a terminal condition or permanent unconsciousness; and to physicians it offered statutory immunity if they complied with the patient's wishes in good faith. This legal model for directing decisions focused on conventional legal formalities or procedural protections was intended to protect vulnerable populations from harm, specifically the premature termination of life due to lack of understanding, or diminished capacity of, or undue influence upon, the signor of the living will.

In the ten years after 1976, a *first wave* of advance directive legislation rolled through the states, so that by the end of 1986, 41 states had adopted living will laws. But it was not long before the shortcomings of living wills became apparent to policymakers, especially with respect to the narrow range of decisions it applied to. Policymakers turned to validating and reshaping the use of durable powers of attorney to apply to health care.

The conventional view of powers of attorney is that they can be used for any purpose not contrary to law or public policy of a given state. Their use as a health care decision-making tool had an obvious advantage over the living will, but many also expressed concerns that durable power statutes, focused on property matters, lack rigorous procedural protections that may be needed to deter potential misuse of these instruments in the context of serious decisions about life-support.

To address these concerns while encouraging their use, states began crafting special durable power of attorney for health care statutes or, alternatively, adding proxy provisions to their living will statute. This *second wave* of advance directive legislation took place roughly from the mid-1980s to the mid-1990s, with California again leading the pack with its 1983 law. By the end of 1988, only twelve states had such statutes, but by the end of 1997, the District of Columbia and every state had enacted some version of a health care power of attorney statute.

A *third wave* of legislation began in the early 1990s, triggered by a growing awareness of unwanted cardio-pulmonary resuscitation attempts of terminally ill patients living at home or in nursing homes or hospice, occurring when the expected medical crisis arises and someone on the scene calls 911. Absent an out-of-hospital do-not-resuscitate protocol, emergency medical services personnel are obligated to do everything possible to resuscitate a patient whose heart or breathing has stopped unless the patient himself or herself refuses help. An advance directive does not normally trump that obligation. To address these unwanted medical encounters, states began enacting out-of-hospital DNR legislation or regulations. These protocols, also called Comfort Care Orders or CPR directives usually require the signing of a DNR order by both physician and patient (or patient surrogate) and the use of a specially designed identifier, such as a bracelet, to be kept on or near the patient. By the end of 1999, 42 states had statewide protocols in place, most frequently created by legislation.

A *fourth wave* of legislation was not so much a wave as a slowly rising tide, going as far back as the 1960's and continuing to the present. Unlike the advance directive waves, this trend addressed the other side of the decision-making coin – how decisions are to be made *in the absence of an advance directive*. An awareness that the great majority of Americans were not utilizing advance directives fueled interest in this subject. As is still the case today, most decisions relating to end-of-life care for persons lacking decisional capacity are made without the guidance or authority of a health care advance directive. State law frequently failed to identify

who, in the absence of an appointed agent or guardian, was authorized to make decisions in these instances.

Default surrogate consent or family consent laws provide an answer to that question. These exist is some 40 states and the District of Columbia, although they vary significantly in scope of decision-making and limitations on surrogate authority. All create a list of permissible surrogates, usually in a priority order starting with spouse and covering next-of-kin. Twenty-one states include "close friend" or its equivalent in the list of permissible surrogates, usually at or near the end of the order of priority.

A significant *fifth wave* of state legislation began as a merging of the separate health care decisions acts states had already enacted. This was driven, in part, by the public's lack of understanding these legal tools and their lack of use. Most estimates of completion rates in the early 1990's hovered around 20 percent or less. And, a substantial lack of awareness and misunderstanding of advance directives persisted.

New Jersey enacted the first combined statute in 1991, merging the living will (called an "instruction directive") and the durable power of attorney for health care (called "a proxy directive") into a single "advance directive for health care," N.J. Stat. Ann. §26:2H-53 to –81 (West 2007). By the beginning of 2000, some 16 states had comprehensive or combined advance directive statutes, which at a minimum, combined living wills and proxies in the same law. Today, that number has risen to 26 states. During the 1990s, interest also grew in establishing special advance directives for mental health decisions, but because these focus on a distinctive set of issues not directly related to end-of-life decision-making, they are not covered in this review.[1]

The primary model for a flexible combined advance directive and default surrogate law has been the *Uniform Health-Care Decisions Act*. The *Uniform Act* was promulgated as a national model by the Uniform Law Commissioners in 1993, and recognized by the American Bar Association in 1994. The Act establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive. Even unwitnessed documents are valid under the Uniform Act. However, states that have adopted the *Uniform Act* have almost always added more to the Act's baseline requirements. Indeed, all states that have adopted it have added

[1] For more information on psychiatric advance directives, see the web page of the National Resource Center on Psychiatric Advance Directives at < http://www.nrc-pad.org/index.php>.

at least a witnessing requirement. The Act provides a comprehensive, sample form with options for instructions, appointment of an agent, organ donation, an option to name a primary physician, and the recognition of default surrogates in the absence of an advance directive.

Our Commission's provides summary charts of current health decisions legislation and annual legislative updates. These can be found at: http://www.abanet.org/aging/legislativeupdates/home.shtml.

The Federal Role

The federal legislative role in the above evolution of advance directives has been fairly minimal. The primary congressional foray into this subject is the Patient Self-Determination Act, enacted as part of the Omnibus Budget Reconciliation Act of 1990.[2] The Act was a fairly modest amendment to federal Medicare and Medicaid law, spearheaded by Missouri's then Senator John Danforth. It was hoped that the Act would encourage adults to think about and plan for health care decisions. It also legislatively affirmed the use of the term "advance directive". At its heart, it is an information and education mandate. It did not create or change any substantive right to health care decision-making. Rather, it requires all Medicare and Medicaid provider organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things:

(1) provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives;

(2) maintain written policies and procedures regarding advance directives and make them available;

(3) document whether or not the individual has executed an advance directive;

(4) comply with the requirements of state law respecting advance directives; and

(5) provide staff and community education on advance directives.

The Act specifically prohibits any form of discrimination based on advance directives. To promote the dissemination of accurate public information, the Act further mandated states to develop written descriptions of state law for distribution by providers or organizations.

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[2] The Patient Self-Determination Act was enacted as part of the Omnibus Budget Reconciliation Act of 1990, signed by the President on November 5, 1990. Omnibus Budget Reconciliation Act (OBRA) of 1990, Pub. L. No. 101-508, §§4206 and 4751 (Medicare and Medicaid, respectively), codified in part at 42 U.S.C. §§1395cc(a)(1)(Q), 1395cc(f), 1395mm(c)(8), 1396a(a)(57), 1396a(a)58, 1396a(w).

Finally, the Act required the U.S. Department of Health and Human Services (DHHS) to undertake a public education campaign.

Because health-care decision making has traditionally been considered a province of state law, federal law generally defers to state substantive law in this area, including the selection and authority of appointed agents and default surrogates. However, with respect to one group of citizens, military personnel, Congress in 1996 enacted a federal advance directive that explicitly pre-empts state law:

> 10 U.S.C.A. § 1044c. **Advance medical directives of members and dependents: requirement for recognition by States**
>
> (a) Instruments to be given legal effect without regard to state law.--An advance medical directive executed by a person eligible for legal assistance--
>
> (1) is exempt from any requirement of form, substance, formality, or recording that is provided for advance medical directives under the laws of a State; and
>
> (2) shall be given the same legal effect as an advance medical directive prepared and executed in accordance with the laws of the State concerned.
>
> (b) Advance medical directives.--For purposes of this section, an advance medical directive is any written declaration that--
>
> (1) sets forth directions regarding the provision, withdrawal, or withholding of life-prolonging procedures, including hydration and sustenance, for the declarant whenever the declarant has a terminal physical condition or is in a persistent vegetative state; or
>
> (2) authorizes another person to make health care decisions for the declarant, under circumstances stated in the declaration, whenever the declarant is incapable of making informed health care decisions.

More recently, Congress added end-of-life planning to the "Welcome to Medicare" exam for Medicare beneficiaries. More about this is included under the options for action below.

The Paradigm Shift in State Law

Historically, the state legal landscape of advance directive law has emphasized standardized legal formalities with procedural requirements or limitations intended to serve as protections against abuse or error. For shorthand, this may be referred to as a *legal transactional approach* to advance directive policy. However, state policy has been in a very gradual state of flux and moving toward an approach that more strongly acknowledges an ongoing and flexible process of communication-- which may be referred to as a *communications approach.*

The *legal transactional framework* focuses on the formal steps of creating and implementing specific legal tools to direct or delegate health care decisions in advance of decisional incapacity. In this light, the creation of an advance directive is treated much like conventional conveyances of interests in property or contracts that establish important rights and obligations. The validity of the transaction focuses on required legal formalities and standardization of the process.

Because states anticipated that these legal tools typically would be commonly signed and used without the advice of legal counsel, detailed standardized formalities were relied upon to ensure the voluntary, knowing, and competent execution of the transaction— the same elements central to medical informed consent. However, completing an advance directive is clearly not the same as giving medical informed consent, because advance directives address simple future hypothetical situations, not here-and-now, complicated medical decisions. Standardization was also driven by the assumption that it would enhance the recognition of and compliance with advance directives by health care providers.

Conventional legal formalities for execution of advance directives have included requirements such as:

- Standardized statutory forms.
- Required disclosures or warnings for anyone completing an advance directive.
- Prescribed phrases or words or even font size for authorizing certain wishes.
- Required witnessing or notarization and restrictions on who may be a witness.
- Limitations on who may serve as agent or proxy.

The legal transactional approach also utilizes an array of mandatory procedures or other limitations intended as protective safeguards. A recent review of the limitations on surrogate decision-making conducted by our Commission identified the following examples occurring in varying frequency:

- Living will statutes typically impose medical diagnosis prerequisites before taking action (usually a diagnosis of terminal condition or permanent unconsciousness); but a dozen states also require a diagnostic precondition before an appointed agent may make decisions about life-sustaining procedures.
- A majority of states impose limitations on implementing advance directives if the patient is pregnant.

- Twelve states include limitations that prohibit a surrogate from consenting to controversial medical interventions such as sterilization or abortion or psycho-surgery.
- Thirty-three states have special limitations on consent by agents, default surrogates, or guardians to forgo artificial nutrition or hydration. These range from an absolute bar on default surrogates to required diagnostic preconditions.

Despite its legitimate goals, the legal transactional approach to advance care planning may have served to impede rather than promote effective advance care planning. An ample body of research, summarized by Fagerlin and Schneider and others,[3] reveals that conventional advance directives, especially living wills, have had relatively little impact on end-of-life decision making. Tersely summarized, some of the significant reasons for the lack of impact include the following:

(1) Too few people make use of the legal tools;

(2) When they do, they do not understand the forms they complete nor the future decisions that might have to be made;

(3) The forms themselves don't provide much guidance;

(4) Patent's goals and preferences for care may change;

(5) When principals name an agent or proxy, the agent seldom understands the principal's wishes;

(6) Even if they have done all the above, health care providers usually don't know about the directive;

(7) And even if providers know one exists, it does not affect patient care.

The Institute of Medicine in its 1997 report on improving care at the end of life likewise

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[3] Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 The Hastings Center Report 30-42 (March-April 2004). A sampling of related literature includes: Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 Arch. Intern. Med. 1501-06 (July 26, 2004); Peter H. Ditto, *et. al*, *Advance Directives as Acts of Communication*, 161 Arch. Intern. Med. 421-430 (2001); Joan M. Teno, Marguerite Stevens, Stephanie Spernak & Joanne Lynn, *Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data*, 13(7) J. Gen. Intern. Med. 439-447 (1998); E.J. Larson and T.A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 Wake Forest L. Rev. at 278 (1997); J. Teno *et al*, *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. of the American Geriatrics Society 500-507 (1997); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101-2104 (1992); Diane E. Hoffmann, Sheryl I. Zimmerman & Catherine J. Tompkins, *The Dangers of Directives or the False Security of Forms*, 24 J. of Law, Medicine & Ethics 5 (1996); Rebecca Dresser, *Confronting the 'Near Irrelevance' of Advance Directives*, 5 J. Clin. Ethics 55-56 (Spring 1994).

questioned the wisdom of conventional advance directives:

> The committee, while recognizing the value of advance directives, questions the urgency of intensive efforts to universalize their use. In this area of decision making at the end of life, the law's favorite product—the legally binding document – may sometimes stand in the way of, rather than ease, the process, especially if these documents are naively viewed as ultimate solutions to the difficulties of decision making. Rather, the documents known as advance directives should be seen as a set of tools useful in the ongoing process of advance care planning.[4]

In response to the experienced shortcomings of the transactional approach, an alternative paradigm has emerged – a *communications approach*. This paradigm derives from the concept of *advance care planning* described by the Institute of Medicine as follows:

> [A]dvance care planning is a broader, less legally focused concept than that of advance directives. It encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions..., and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families.[5]

Advance care planning involves an iterative process over time to discern the individual's priorities, values, and goals of care and to engage a proxy and others who will participate in the health-care decision making process at any time in the future when the individual is no longer able. This revised approach to health care advance directive policy is by no means new, but only fairly recently has its implications for public policy, as reflected in advance directive laws, been taken seriously. A review of current trends in advance directive laws reveals incremental but real steps toward simplification of state law, especially with respect to mandatory forms or language. The 1993 Uniform Health-Care Decisions Act represented the first major milestone in this redirection by offering a model of simplicity that prompted many states to combine disparate pieces of health care decision-making provisions into simpler, comprehensive acts.

One instructive measure of simplification is the extent to which state law has become uncomplicated enough to enable a single advance directive form to meet the statutory requirements of all 50 states and the District of Columbia. The *Five Wishes* advance directive provides one such measure. In the last ten years, the *Five Wishes* advance directive, created by

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[4] Institute of Medicine, Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life* 203 (Marilyn J. Field & Christine K. Cassel, eds., Natl. Acad. Press 1997).
[5] *Id.*, at 198-199.

the organization Aging with Dignity, Inc., has been the only form affirmatively marketed nationally.[6] Five Wishes aspires to be a personal, easy-to-use, and non-legalistic instrument. When *Five Wishes* was released in 1998, it claimed to meet the statutory requirements of 33 states and the District of Columbia.[7] The most prominent barriers to the statutory compliance of *Five Wishes* were statutory requirements for substantial compliance with statutory forms along with prescribed phraseology or requirements for including prescribed notices or warnings. By 2007, the number of state laws friendly to *Five Wishes* had grown to 40. The increase was made possible by the trend toward simplification by state legislators.

Another indicator of simplification is a trend toward the statutory recognition of oral advance directives documented in the patient's record. Prior to the 1993 Uniform Health-Care Decisions Act which permitted oral directives, no state recognized oral advance directives. Today, 15 states recognize some form of oral directive. Most of these states follow the approach of the *Uniform Act* which recognizes an oral "instruction" documented in the record as valid and the appointment of an orally designated "surrogate" where the appointment is personally communicated to the supervising health care provider.

Apart from legislation, one aspect of advance directive practice in the field deserves notice. The tools available to the public under the legal transactional paradigm have primarily been statutory forms and the instructions for completing them and related fact sheets. Beginning in the late 1990s, self-help tools began to appear intended to help the user to understand the process of planning, the values and goals to be considered, and how to discuss these matters with family, friends, proxy, and health care providers. These are essentially workbooks for advance care planning. The written directive is still an intended outcome, but the primary emphasis is placed on the process, not the form.

Robert Pearlman and others at the Veterans Administration Medical Center in Seattle produced one of the first of these in 1998, entitled *Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will.* A small sampling of others that have appeared include:

- *Caring Conversations Workbook,* published by the Center for Practical Bioethics (1999).

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[6] Aging With Dignity, Inc., is a non-profit group that assists families with end-of-life issues. *See* http://www.agingwithdignity.org.

[7] Charles P. Sabatino, *National Advance Directives: One Attempt to Scale the Barriers*, 1 NAELA Journal 131-164 (Spring 2005).

- Finding Your Way: A Guide for End-of-Life Medical Decisions, by Sacramento Healthcare Decisions (1998).
- The Critical Conditions Planning Guide, by Georgia Health Decisions (1998).
- *The Lawyer's Tool Kit for Health Care Advance Planning,* and the *The Consumer's Tool Kit for Health Care Advance Planning* by the ABA Commission on Law and Aging (2000).

The *Lawyer's Toolkit* is significant in its targeting of the legal profession which assists a sizeable proportion of individuals to complete advance directives. The *Toolkit* does not provide guidance in drafting, but instead gives lawyers tools they can provide to clients to help them understand the planning process, self-reflect, and discuss the subject with family, physician, and others. Use of resources such as these by no means marks the end of the transactional legal model, but it is indicative of the growing awareness of the communication process as the ultimate goal of advance directive public policy.

An Emerging Next Step – the POLST Paradigm

As law and practice move toward a less standardized, more flexible, communications approach, questions remain as to whether more flexibility in communication will have any greater impact on actual treatment decisions than do standardized advance directive forms. An emerging strategy that began in Oregon has an impact in bridging this gap between patient goals and preferences – expressed directly, through an advance directive, or by a proxy – and the actual plan of care as reflected by physician orders.

Oregon and a growing number of other states have concluded that patient wishes, no matter how communicated, must be systematically factored into or translated into the medical decision-making engine. In the early 1990s, Oregon experimented with a protocol for seriously chronically ill patients, called *Physicians Orders for Life-Sustaining Treatment*, or POLST. There are several ways to describe the POLST process, but relevant to this review are three key tasks it aims to accomplish.

- One, use of POLST prompts a discussion between health care providers and patients with life-limiting medical conditions about high-probability treatment scenarios. The objective is to discern the wishes of the patient in light of his or her current condition and the available care options as explained by the treating health care provider.

- Two, the patient's wishes are incorporated into doctor's orders that are recorded on a unique, visible (bright pink in Oregon) form. The form covers several key decisions that are common for seriously chronically ill patients, for example: cardiopulmonary resuscitation; the level of aggressive care desired in the event of emergency (full treatment; limited; or comfort only/do not hospitalize); use of antibiotics; and the use of artificial nutrition and hydration.
- Three, providers must ensure that the POLST form travels with the patient whenever transfers from one setting to another are made, thus, promoting continuity of care in decision making. At the same time, the orders are reviewed periodically and as needed.

POLST is not an advance directive in the conventional sense but it is an advance care planning tool that reflects the patient's here-and-now goals for medical decisions that could confront the patient in the immediate future. It builds upon one's advance directive but can also benefit those patients -- still a majority -- who refrain from using advance directives. Research on the Oregon experience with POLST has shown positive outcomes.

The precursor of the POLST paradigm is the out-of-hospital do-not-resuscitate order, now common in virtually every state. POLST is a similar process, except that it is not limited to the single decision of resuscitation, and it does not presumptively call for withholding medical interventions. It permits a full range of intervention options.

Since Oregon's development of the POLST form, Washington, West Virginia, Utah, North Carolina, New York, Maryland, and most recently, California have authorized the use of various versions of the POLST paradigm statewide, often using different nomenclature for the paradigm. Parts of several other states have implemented similar protocols locally, and other states are considering following suit. Detailed information on POLST can be found at http://www.polst.org.

Options for Federal Action

If Congress wished to encourage the policy and practice shift towards a communications model of advance care planning, several options exist. Eight are enumerated here in no particular order of priority. These are offered as thought experiments, not as policy prescriptions

1. Overcoming the Balkanization of State Law.

Congress could give consideration to the appropriateness of addressing the problems posed by confusing interstate differences in the law by creating a federal advance directive that would be deemed valid in all states. The strategy would likely face political resistance on states' rights grounds. In addition, the effect of a federally sanctioned advance directive form does not avoid the very same problems states have encountered in creating their own statutory forms. One size does not necessarily fit all, and an unintended consequence could be to further legalize and formalize a task that is very personal and private at heart.

2. Affirming the Principle of Self Determination.

One of the unintended consequences of statutory advance directive forms, even those that are expressly optional, is that practice often embraces the statutory form as the only safe alternative, thus exacerbating the one-size-fits-all shortcoming of advance directives. That perception can exist even though both the common law and constitutional law principles clearly require health care providers to respect the known wishes of their patients, no matter how communicated. Some suggest that a simple strategy to promote a communications model of advance planning might be to affirm this principle in federal law. Idaho provides an example of this strategy. The concluding sentence in the statement-of-purpose section of Idaho law states simply: "Any authentic expression of a person's wishes with respect to health care should be honored."

The statement does not create any new rights or obligations in Idaho; it merely recites in simple terms a fundamental principle of the common law and constitutional law. Applied to any clinical setting, it focuses the inquiry on accurately determining the person's wishes and goals rather than on whether the individual accurately complied with legal formalities. The principle often gets buried under the legalistic formalities of state laws. By expressly communicating and applying this principle to those providers who participate in Medicare and Medicaid and other federal health care programs, the Congress could clarify the proper role of statutory advance directives as one means of communication but not the only. Affirmation of the principle could also encourage the development and use of a variety of nationally distributed advance directive tools without creating a federal model form.

3. Affirming Portability.

While portability of advance directives across state borders has not been shown to be a major problem, it does persist in perception because of the variability of state laws. This is a

concern that has been targeted in several proposed amendments to the Patient Self-Determination Act over the last few years, although none of these proposals has been enacted.

4. Encouraging the POLST Paradigm

Some have suggested that Congress could encourage all states to adopt protocols with goals similar to that of Physicians Orders for Life-Sustaining Treatment. This could be done by adding to proposed PSDA language a requirement that states, or providers under Medicare and Medicaid, have a process to convert treatment goals and preferences of persons with life-limiting illness into medical orders (e.g. the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Initiative) to ensure that the information is transferable and applicable across all care settings.

5. Physician Reimbursement.

Payment for physician advance planning consultations has been a recurring recommendation as a strategy for enhancing advance planning. However, the potential price tag for physician reimbursement of a new service has posed a fatal barrier to such legislation in the past. Current bills before Congress scaled back the idea to one end-of-life planning consultation as part of the initial preventive physical examination to Medicare (sometimes called the "welcome to Medicare exam"). This past July, Congress enacted the Medicare Improvements for Patients and Providers Act of 2008", PL 110-275 (HR 6331), which adds "end-of-life planning" to the initial preventive physical exam that Medicare beneficiaries are entitled to when they enroll in Medicare. "End-of-life planning" is defined as:

> verbal or written information regarding--
> (A) an individual's ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and
> (B) whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive.[8]

[8] Medicare Improvements for Patients and Providers Act of 2008", PL 110-275 (HR 6331). Section 101 of that Act amends 42 U.S.C.A. §1395x(ww).

The language acknowledges the physician's central role in prompting advance planning, although it is a minimal requirement that on its face can be complied with by handing patients another piece of paper with more information.

6. Public Education and Information

Several proposals have been made in the last few Congresses to require that the Department of Health and Human Services conduct various kinds of public education campaigns to raise awareness of the importance of planning for care near the end of life, or to create a national information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications. Both the clearinghouse and public education campaign represent helpful and familiar strategies for encouraging behavior change, even though most education intervention efforts examined in the literature have not been shown to have much effect on advance planning behavior. Nevertheless, federal resources for such efforts would be welcomed by many. A more ambitious role for the federal government would be to fund research and demonstration efforts for a more intensive social marketing campaign to engage the public in the communication process of advance planning.

7. Supporting Advance Directive Registries.

Not a great deal is known about the effectiveness of registry strategies, although the states are showing strong interest in developing advance directive registries as a way to enhance provider access to advance directives. It is unclear what effect the transition to electronic records, strongly supported by the federal government, will have on the need for separate registries. These questions invite a role for the federal government either to support research financially on these strategies or to support them directly through reimbursement of state costs for creating registries. Alternatively, the government could focus on the goal of a national registry, either through financial incentives or the creation of a federal registry. All these options pose administrative challenges and privacy issues that would have to be carefully addressed.

8. Cultural Diversity

Finally, an underlying social reality that is not touched upon by this review is how and whether advance planning as currently framed in public policy is either effective or appropriate across the wide array of cultures and special populations represented in our society. The values of equal protection and equal opportunity would argue for a strong federal role in supporting

research and demonstration efforts to ensure culturally inclusive public policy with respect to health care decision-making. The legislative trends towards simplification of advance planning, including the use of oral directives, appear to fit well with the goal of greater cultural sensitivity.

In conclusion, if Congress chooses to consider taking action in this area, it is important to think about options in the context of the central trends in state advance planning policy – i.e., the movement of the states away from a legal transactional mode of advance planning toward a communications model. While, much of the evaluative scholarly literature is supportive of that trend, many questions persist. In some respects, the work of this transition has been to get the law out of the way of good planning – i.e., making it simpler, less legalistic in requirements, and more adaptable to modes of communicating and decisionmaking natural to a wide variety of individuals and cultures. At the same time, concerns about potential abuse cannot be blithely discarded. While no significant patterns of abuse have been identified in the research literature, the fact that these decisions do indeed involve life and death consequences, the protection of vulnerable persons will remain a challenge.

Thank you for giving me this opportunity to submit the American Bar Association's perspective to you on this important subject.