

## **Office of the Assistant Secretary for Planning and Evaluation Report to Congress on Advance Directives**

*The Report to Congress on Advance Directives will provide a set of recommendations based on findings from the literature review, in-depth commissioned papers and the roundtable discussions on how best to improve advance directive use and advance care planning as a means of expressing wishes for end-of-life care.*

### **Lead Agency:**

Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services

### **Agency Mission:**

The Assistant Secretary for Planning and Evaluation advises the Secretary of the Department of Health and Human Services on policy development in health, disability and aging, human services, and science and data policy, and provides advice and analysis on economic policy. The Office of the Assistant Secretary for Planning and Evaluation (OASPE) leads special initiatives, coordinates the Department's evaluation, research and demonstration activities, and manages cross-Department planning activities such as strategic planning, legislative planning and review of regulations. Integral to this role, OASPE conducts research and evaluation studies, develops policy analyses, and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

### **Principal Investigator:**

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### **Partner Agency:**

ABA Commission on Law and Aging  
Center for Practical Bioethics  
Yeshiva University

### **General Description:**

**Report to Congress on Advance Directives**

Over the past century, the experience of dying has changed tremendously. At the beginning of the 1900s, the majority of people died at home, usually from a sudden illness or injury. Now, the majority of Americans die of chronic, progressive illnesses often with prolonged periods of physical dependency (Peres & Kaplan, 2002). Over a decade of research has documented that dying in America is painful, isolating and costly (SUPPORT, 1995; IOM, 1997; Hogan et al., 2001). A key predictor of good end-of-life care is whether people have articulated about their preferences ahead of a crisis. This is known as advance care planning. Advance directives are the cornerstone of advance planning and these directives consist of a person's oral and written instructions about his or her future medical care in the event that he or she becomes unable to communicate or becomes incompetent to make health care decisions. There are two types of advance directives: a living will and a health care power of attorney/health care proxy. Living wills (sometimes called medical directives) are written instructions for care in the event that a person is not able to make medical decisions for him or herself (Fagerlin, 2004). The health care proxy or surrogate is a document by which the patient appoints a trusted person to make decisions about his or her medical care if he or she cannot make those decisions.

Congress enacted the Patient Self-Determination Act (PSDA) in 1990 to encourage competent adults to complete advance directives. The PSDA requires all health care facilities receiving Medicare or Medicaid reimbursements to ask if patients have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record (PSDA, 1990). Unfortunately, waiting until the crisis of admission to a facility is not the ideal setting for developing an advance care plan.

In recognition of the need for greater understanding of advance care planning, the Health Education and Labor Committee 2006 Appropriations provided for the Secretary of Health and Human Services (HHS) to develop a Report to Congress on advance directives. As provided, Public Law 109-149 "...directs the Secretary to conduct a study to determine the best way to promote the use of advance directives among competent adults as a means of specifying their wishes about end-of-life care and provide recommendations to Congress on changes to federal law needed to ensure appropriate use of advance directives." The Secretary is instructed to involve persons with disabilities and identify options for people with cognitive disabilities as well.

The Office of the Assistant Secretary for Planning and Evaluation contracted with RAND to commission a literature review, topic-specific papers on: (1) the historical and current legal issues with advance directives; (2) advance care planning among persons with intellectual and physical disabilities; and (3) public engagement with advance directives. In addition, we held Roundtable Discussion meetings with advance care planning experts, and included an emphasis on people with disabilities. This background work will form the basis for the report from the Secretary of HHS to Congress outlining the recommendations on how best to promote advance directives.

***Excellence:*** What makes this project exceptional?  
***Significance:*** How is this research relevant to older persons, populations

- and/or an aging society?
- Effectiveness:*** What is the impact and/or application of this research to older persons?
- Innovativeness:*** Why is this research exciting or newsworthy?

The literature review examines the empirical evidence about the degree to which advance directives and advance care planning have met their intended goals. The report is one of the most comprehensive reviews of what the medical literature reports concerning the use of advance directives and advance care planning, disparities among groups in their use, and interventions to enhance the use and value of advance directives and advance care planning.

Of the 2.5 million people who die in the US each year, about 85 percent are Medicare beneficiaries (Hogan et al, 2001). A recent Centers for Medicare and Medicaid Services (CMS) report on Medicare spending in the last year of life indicated that expenditures have steadily increased from 26 % of total expenditures in 1994 to 29% in 1999 (CMS, 2005). Although considerable sums are spent on prolonging life, relatively little is spent for pain relief, quality of remaining life and emotional support for older persons and their families.

In addition, the concerns, perspectives, and values of people with disabilities have often been overlooked in the research, programs, and policies regarding advance directives, advance care planning, and end-of-life care more generally. While the process for advance care planning for people with physical and intellectual disabilities is the same as for non-disabled people, there are unique community perspectives and issues to be addressed in policies seeking to promote such plans.

The Patient Self –Determination Act (PSDA) requires that all health care facilities receiving Medicare or Medicaid reimbursements must inform patients of their rights to make choices about the treatment they receive and to prepare advance directives. Advance directives are not only focused on what treatments one does not want, they are equally applicable and viable to indicate all of the treatments that one wants. Our Report to Congress will recommend strategies to help strengthen the advance care planning process for elders, people with disabilities and their families.

Generally, the research suggests that even when advance directives are executed, physicians are frequently unaware of them, advance directives are not easily available to surrogates when needed, advance directives are too general and/or are inapplicable to clinical circumstances, and/or they are invoked late in the dying process or are at times over-ridden by providers and families. Only in the context of a comprehensive community effort do advance directives and advance care planning appear to substantially change care at the end of life. Despite the weakness of advance directives as an individual intervention, research points to promising interventions.