

APPENDIX H:

**SUMMARY OF THE ROUNDTABLE
DISCUSSIONS ON
ADVANCE DIRECTIVES AND ADVANCE
CARE PLANNING**

ASPE/RAND Roundtable meetings were held in Washington, DC on October 22 and 23, 2007 to discuss needs concerning advance directives and advance care planning and to provide in-depth review and comment on the RAND advance directive literature review and ASPE/RAND topic-specific commissioned papers. The discussions included targeted consideration of legal and social marketing issues, as well as advance directive use and advance care planning for persons with physical, intellectual and cognitive disabilities. Expert participants discussed numerous underlying assumptions (assembled below) and ideas for improvement to help inform the Secretary of Health and Human Services Report to Congress on "...how best to promote the use of advance directives...". Below is an attempt to capture and categorize the expert discussion.

1. Key Underlying Assumptions Derived from the Discussion

1.A. Individual Perspective

- A person's values and goals and choices regarding health care must be elicited and respected. Particular attention must be paid to populations who have not had the opportunity or experience of having their choices or preferences requested, understood or honored.
- Effective and respectful advance care planning requires recognition that both overtreatment and undertreatment may be concerns of individuals contemplating future care.

1.B. Advance Care Planning Process

- Advance care planning should be a values and goals-driven, iterative process.
- Person and family-centered treatment should be the standard for advance care planning and shared decision making in the context of an ongoing clinician-patient relationship should be the model form of healthcare communication.
- Advance directive documents alone have been ineffective in improving care toward the end of life, and should instead be part of an iterative process of advance care planning.
- Advance care planning should focus more on designation of a proxy decision maker and elicitation of goals and values rather than attempts to elicit treatment-specific preferences.
- Advance care planning can be a complex, fear-provoking and unusual experience, but the process can be facilitated by supportive processes to enhance a person's capability and participation. Facilitation of advance care planning is a skill that health care providers and others can master by practice.

- Beyond appeals to personal autonomy, the advance care planning process can better reflect the goals of diverse groups by also attempting to elucidate *how* a person would determine what would constitute desirable care in future medical situations.

1.C. Capacity and Decisions

- Individuals may have impaired decision making capacity for a variety of reasons, some long-standing and some acute. Decision making and ascertainment of treatment goals requires evaluation of a person's capacity to make decisions. For incapable people, decision making should incorporate information from existing advance directives and communication with proxy decision makers. Person and family-centered planning concerning decisions about life-sustaining treatment should be carried out in a culturally appropriate fashion.
- Early advance care planning is ideal because a person's capacity to make decisions may diminish over time and he/she may suddenly lose the ability to participate. Advance care planning should be "routine" community and clinical practice and plans should be periodically revisited to reflect a person's changes in values and perceptions at different stages/circumstances of life.

1.D. Quality of Life Perspectives

- Different perceptions and judgments of quality of life among providers, proxies and persons with disabilities and other underrepresented groups (e.g., racial/ethnic minority groups) have historically resulted in usually performed life-sustaining treatments not being offered.
- Quality of life is a person-centered concept affected by one's health history, everyday life experiences, values, goals, and cultural perspective. Quality of life depends on one's personal assessment of meaning, not value judgments made by another. For this reason, it is essential that goals of care be reassessed as circumstances change and ascertained before individuals lose the ability to communicate their perceptions of quality of life.
- People with disabilities have a unique and valuable perspective to offer to providers and to the general public about quality of life perceptions.

1.E. Proxy Decisions and Conflicts

- The depth of relationship and commitment of family, others, caregivers and assistants should be recognized and their views respected, in the context of a person's goals, in treatment decisions.

- Proxy decision making may be limited by family, friends and health care providers not knowing what a person would want when life-sustaining treatment decisions need to be made. These perspectives should be elicited before he/she loses the ability to communicate them.
- Conflicts that arise concerning decisions about life-sustaining treatments and other major health decisions should be resolved using an ethics-based mechanism such as principle-based ethics consultation or mediation.

1.F. Voices of Persons with Disability and Diverse Groups

- The inclusion of the voices of persons with disability in developing processes and materials for advance care planning, especially for people with intellectual disabilities, would have outcomes that are beneficial for many others (e.g., quality of life discussions, simpler materials, a variety of communication styles, and supported decision making processes).
- Health care providers must recognize the profound isolation and the lack of personal support experienced by some persons with disabilities and other marginalized groups.
- Diverse perspectives, including those of underrepresented groups, should be incorporated in the development of “standards of practice” such as clinical pathways and clinical consensus statements.

2. Discussion of Ways to Improve Advance Care Planning and Advance Directive Use

A wide-ranging and robust discussion of advance directives and advance care planning is reflected in the following categories. Experts often spoke of failed attempts to create solutions over the last several decades. A call for simplifying processes and being inclusive of all persons’ views is reflected in this discussion.

2.A. Advance Care Planning Models

- Change the focus of advance care planning from formal written forms to a developmental discussion process.
Interventions to facilitate discussion might include workbooks and other aids that help elicit values and goals over time and that engage proxies in the process.
- Build on demonstration projects testing promising advance care planning methods.
Structured advance care planning at the community level (e.g., the *Respecting Choices* program) can induce the expectation that health care providers will

elicit and attend to patient preferences in a timely manner, and affect the process and outcomes of care. Community-based, clinically-oriented demonstration projects that incorporate advance care planning into routine and specialized care, and that evaluate the effects of these efforts are being studied. Models that remove advance care planning from the medical setting may engage individuals who have not connected with their providers.

- Alternatives to the default decision making model.
For individuals with limited or no decision making capacity whose wishes are not known, and for whom substituted judgment is not possible and no proxy decision maker is specified, the process of “best respect” should be employed. In this model, health care decisions are made by an individual or a group of individuals most familiar with the patient’s life and values. In group decision making, informed dialogue permits “shared decision making” in the context of the person’s “community of care or support” that strives to achieve a consensus on treatment decisions.
- Tools to facilitate choice of best proxy and to prepare proxies for decision making.
People who have capacity need help understanding proxy decision making so that they can choose the most appropriate person to make health care decisions for them, if necessary, at the end of life. Proxies need training to: (1) understand their role in decision making; (2) prompt discussions with patients while they can communicate; and (3) participate fully as advocates for patients facing the end of life. Court-appointed proxies and “stranger” surrogates may require special preparation.
- Tools to facilitate decisions from patients without full capacity.
Aids to facilitate the elicitation of goals or preferences and strategies of assisted capacity to maximize the participation of persons with impaired decision making capacity are needed. Studies should examine the effectiveness of these methods of advance care planning and decision making and also evaluate whether these approaches unintentionally influence decisions that are made.
- Tools to facilitate culturally relevant advance care planning.
Advance care planning as currently framed in public policy is not well suited to many cultures and special populations in American society. The values of equal protection and equal opportunity argue for a culturally inclusive public policy with respect to health care decision making. For example, advance care planning tools that are linguistically sensitive should be created to meet the needs of culturally diverse communities. Simplification of advance directives laws, along the lines of the Uniform Health Care Decisions Act, will permit greater cultural adaptability of the advance care planning processes, including, for example, oral directives.

- Create a better array of advance directives.
Standardized statutory advance directive forms often do not foster effective advance care planning or meet the needs of persons with disabilities underrepresented and other groups.
- Develop and test health care decision making mechanisms for “unbefriended” individuals without capacity.
Approaches are needed to handle decision making for people without capacity who have no family or friends even potentially available to act as surrogates. Research and demonstrations of judicial and non-judicial mechanisms of health care decision making for “unbefriended” people should be carried out.

2.B. Education

- Educate social workers, case managers, lawyers, guardians, and care providers about advance care planning, advance directives and the person-centered approach to care.
These individuals interact most with persons in need of assistance and should understand options for advance care planning and participation in decision making. The curriculum should include the perspective of persons with disability.
- Develop a disability curriculum to teach health care and social service professionals and trainees to provide person-centered care that maximizes capabilities and takes into account the experiences of many who, due to personal characteristics, have received inadequate or inappropriate care.
A disability curriculum should incorporate the variety of perspectives of people who live with disability everyday and/or have studied disability and should apply to people who acquire disability at any stage in life. Students and current professionals should learn how to employ strategies and services to support people with disabilities and others with need.
- Medical and other relevant professional schools should hire persons with disabilities and persons with varied cultural backgrounds to teach trainees and to serve as advisors and role models.
A diverse faculty would help trainees to understand the capability of many persons with disabilities to live a full life and facilitate openness to quality of life judgments.

2.C. Health System Issues

- Create and promote mechanisms to ensure that patient preferences are translated into care decisions and are transmitted across care settings.
Protocols such as Physicians Orders for Life-Sustaining Treatment (POLST) that translate the goals of patients with serious chronic illness into easily identifiable, portable and reviewable medical orders that follow the patient

across care settings should be promoted. Such protocols should address resuscitation and other key interventions that the patient may or may not want, such as decisions about venue of care, ICU care, antibiotics and artificial nutrition. One mechanism would be to require use of such protocols by providers accepting Medicare/Medicaid funds. State laws and local policies can also establish such programs.

- Match health care benefits with treatments and support that will maximize clinical outcomes. Medical necessity standards should reflect clinical realities and home and community-based services should strive for persons with disabilities to live outside institutions.

Inadequate care that does not adequately facilitate functional recovery can lead to decisions for less aggressive care that anticipate a self-fulfilling poor prognosis. Rules for payment of medical services often do not match the services or equipment needed by patients to maximize functional recovery or maintain optimal function. With appropriate supports and services, many persons with disabilities live independent, productive lives outside of institutions. Insurers and public-funding systems should ensure appropriate home and community-based services to maximize the potential for persons with disability and illness to remain in their homes.

- Link funding to facilitation of advance care planning and outcomes.
Create payment incentives through existing reimbursement systems and pay-for-performance mechanisms to promote evidence-based best practices to achieve increased participation of patients in advance care planning and to reward patient outcomes that reflect an integration of their goals with the treatment they receive.
- Encourage proxy designation from all persons enrolling in Medicare/Medicaid programs and advise them about the availability of advance directives.
New enrollees can be notified about the importance of appointing a health care proxy. An opt-out provision must be available, but persons choosing not to specify a proxy should be aware of mechanisms that will be used to make decisions on their behalf if they cannot participate in decision making.
- Hospitals collect and maintain advance directives for their patient population.
The hospital must retain advance directives and make them available whenever and wherever the patient requires care within the care system. Hospital electronic health information systems could be repositories of advance directives for persons within their catchment area.
- Inclusion of persons with disabilities and from marginalized communities on ethics committees.
Health care professionals and consumers with disabilities and from marginalized communities should be recruited to participate on hospital ethics committees.

2.D. Measurement

- Grade hospitals on advance care planning processes and outcomes.
Adapt current measures and develop additional measures of the process of goal elicitation, surrogate designation and implementation of advance care planning in care in order to be able to measure advance care planning processes and outcomes at the health care setting (e.g., hospitals, nursing homes, etc.) and health plan levels. These measures could be used in payment incentive initiatives.
- Recognize poor advance care planning as a medical error.
Develop programs in hospitals and other health care settings, standard bearing organizations, professional societies and physician training programs that label inadequate advance care planning and lack of incorporation of patient goals and preferences into care plans as medical errors that require remedy.
- Evaluate advance care planning in diverse populations and investigate outcomes.
Clinically-oriented, community-based research should evaluate current incorporation of advance care planning into health care and evaluate the outcomes of care with identification of groups of clinicians and patients that need to be targeted for improvement.
- Measure processes and outcomes of care for persons with disabilities.
While a wide variety of measures of the quality of care exist, these are not targeted at the care received by persons with physical, intellectual and cognitive disabilities. Quality of care for persons with disabilities should be measured in the same fashion as other persons, but specific specialized measures may be needed. Evaluation of care should be undertaken to determine if disparities exist.

2.E. Legislation

- Federal legislation to ensure portability of advance directives across states.
Federal law could eliminate ambiguity about the validity of other states' advance directives in those states that do not have explicit portability provisions.
- Federal legislation to ensure that, in the absence of a statutory advance directive, any authentic expression of the patient's wishes is respected.
This would permit non-statutory advance directives including clearly expressed oral plans to be on par with statutory advance directives and would free up the format of advance directives to better suit varied audiences.

- Federal legislation concerning default surrogate identification for states without such laws.

Federal law generally defers to state law in defining and authorizing surrogate decision makers. However, the absence of default surrogate legislation in ten states leaves doubt about who may act as an appropriate surrogate for individuals lacking decision making capacity. Within the context of the Medicare and Medicaid programs, the Federal Government could provide a default rule in the absence of state legislation that defines who is an authorized decision maker, following the priority model used by most states or some other approach. A default rule would eliminate uncertainty in those states without legislation, while allowing states to craft their own protocols.
- Advance care planning information clearinghouse.

Establish a clearinghouse to track and disseminate information and analysis of advance care planning policy and practice, and advance care planning models, tools and curricula.
- Modify Patient Self-Determination Act language to require health care facilities to describe their mechanisms to: (1) elicit patients' goals for care; and (2) to honor patients' wishes.

The PSDA does not prompt health facilities to create mechanisms to elicit and follow patient goals for care. The legislation could be modified to include these components to push health care facilities to advance the state of advance care planning.
- Incorporate Advance Care Planning discussion into "Welcome to Medicare" Consultations

The opportunity for thoughtful and thorough discussion with beneficiaries is frequently non-existent. Studies have shown that discussing advance care planning and directives with their doctor increased patient satisfaction among patients age 65 years and over. Include advance care planning as part of the "Welcome to Medicare Physical," an initial preventive examination for all new Medicare beneficiaries. Study effective communication and documentation of components of end-of-life discussions in advanced care planning.

2.F. Public Engagement

- Create a social marketing "case" for advance care planning.

Work with social marketing experts to develop and implement a campaign that communicates the health and social benefits of advance care planning.
- Create advance care planning messages appropriate to the different developmental stages in a person's life.

Tailored messages and approaches to planning should aim to meet the varied advance care planning needs of different groups at different stages of health and at different ages.

- Promulgate advance care planning through grassroots efforts.
Efforts might include collaboration with a variety of groups, including community-based aging and social service providers. Engage communities (e.g., faith, workplace, living, and social groups) by providing them with free, easily usable materials for dissemination. Review growing efforts for establishing a national awareness day/week to increase recognition of and need for advance care planning.
- Target Baby Boomers and their elderly parents.
The emerging bulge of baby boomers caring for their aging parents represents an opportunity to promote the importance of advance care planning across multiple generations and to change social norms.

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

APPENDIX A. Methods

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendA>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-A.pdf>

APPENDIX B. Literature Review on Advance Directives

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-B.pdf>

APPENDIX C. Advance Directives and Advance Care Planning: Legal and Policy Issues

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-C.pdf>

APPENDIX D. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-D.pdf>

APPENDIX E. Commissioned Report: Advance Care Planning and Public Engagement

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-E.pdf>

APPENDIX F. Roundtable Materials

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendF>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-F.pdf>

APPENDIX G. Adrienne Asch's Comments at the October 2007 ASPE Roundtable

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendG>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-G.pdf>

APPENDIX H. Summary of the Roundtable Discussions on Advance Directives and Advance Care Planning

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendH>

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