

APPENDIX F:
ROUNDTABLE MATERIALS

Pre-Meeting Materials

- Letters to invite Roundtable panelists
 - Issues of concern to persons with disabilities
 - Legal and policy issues
 - Public engagement and social marketing
- Project scope of work

Roundtable Meeting Materials

- Introduction letters
 - Issues of concern to persons with disabilities
 - Legal and policy issues
 - Public engagement and social marketing
- Agenda
- List of panelists

July, 2007

<<Panelist>>
<<Affiliation>>
<<Address>>

Dear <<Dear>>:

The U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) and RAND Health are pleased to invite you to a Roundtable Discussion on advance care planning. The purpose of the Roundtable Discussion is to inform the *Secretarial Report to Congress* on how best to promote the use of advance directives as a means of specifying wishes about end-of-life care. The *Report to Congress* focuses on three key areas of inquiry: 1) legal and policy issues; 2) public engagement and social marketing; and 3) attention to the concerns of persons with disabilities. We are convening national experts to provide advice on each of these topics.

We invite you to participate in the Roundtable Discussion on **Issues of concern to Persons with Disabilities**. Participation in the Roundtable Discussion involves attending a meeting in Washington, DC on Monday, October 22nd, 2007 from 9:30AM to 1PM and reviewing draft project reports and rating potential recommendations before attending the meeting. We will use a unique format to increase cross-fertilization and understanding of the issues. We also hope you will participate as an observer in the other Roundtable Discussions being held following your designated Roundtable. All participants will be included in the Wrap-up session from 1 to 3PM on Tuesday, October 23rd. We are pleased to offer you coverage of your travel expenses to the Roundtable Discussion meeting and a \$500 honorarium for your time. A brief summary of the project and tentative agenda are enclosed.

We hope that you will join us as a Roundtable Discussion participant for this important project. Please respond to Patty Smith at RAND (psmith@rand.org or 310-393-0411 x 6794). If you have any questions please feel free to contact Neil Wenger or Lisa Shugarman at RAND or Judith Peres, the ASPE expert consultant for this project.

Sincerely,

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Enclosures

July, 2007

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We invite you to participate in the Roundtable Discussion on **Legal and policy issues**. Participation in the Roundtable Discussion involves attending a meeting in Washington, DC on Monday, October 22nd, 2007 from 2 to 5PM and reviewing draft project reports and rating potential recommendations before attending the meeting. We will use a unique format to increase cross-fertilization and understanding of the issues. We also hope you will participate as an observer in the other Roundtable Discussions being held prior to and following your designated Roundtable. All participants will be included in the Wrap-up session from 1 to 3PM on Tuesday, October 23rd. We are pleased to offer you coverage of your travel expenses to the Roundtable Discussion meeting and a \$500 honorarium for your time. A brief summary of the project and tentative agenda are enclosed.

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We invite you to participate in the Roundtable Discussion on **Public Engagement and Social Marketing**. Participation in the Roundtable Discussion involves attending a meeting in Washington, DC on Tuesday, October 23rd, 2007 from 8:30AM to 12 noon and reviewing draft project reports and rating potential recommendations before attending the meeting. We will use a unique format to increase cross-fertilization and understanding of the issues. We also hope you will participate as an observer in the other Roundtable Discussions being held prior to your designated Roundtable. All participants will be included in the Wrap-up session from 1 to 3PM on Tuesday, October 23rd. We are pleased to offer you coverage of your travel expenses to the Roundtable Discussion meeting and a \$500 honorarium for your time. A brief summary of the project and tentative agenda are enclosed.

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CONGRESSIONAL REPORT on ADVANCE DIRECTIVES
The Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Washington, DC

Congress enacted the Patient Self-Determination Act (PSDA) in 1990 to encourage competent adults to complete advance directives. Since then, the role of advance directives and advance care planning in improving end-of-life care has been widely debated. While advance directives are an important legal tool for patients to state their treatment preferences and to name a proxy, research conducted on the impact of advance directives has generally concluded that ADs have not improved the match of patient goals and clinical circumstances with medical treatments received at the end of life. In contrast, more comprehensive and longitudinal advance care planning interventions have demonstrated positive results on patient and caregiver satisfaction, utilization, and completion of an advance directive. There is a need to consolidate the evidence about the value of advance directives and advance care planning, and to garner insights from experts, advocates, providers, consumers and their families in order to generate consensus on the “best practices” concerning advance care planning in end of life care, the applicability of advance directives in special populations (e.g., people with intellectual and physical disabilities and multicultural groups), and to identify legal, policy and public engagement interventions to promote advance care planning and advance directives.

RAND Health is working with the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) to prepare the *Secretarial Report to Congress* on this issue. The specific aims of this project are to:

- 1) Produce a focused literature review on the evidence concerning advance care planning and advance directives, including the identification of best practices and the role of health information technology
- 2) Commission discussion papers identifying and discussing current policy relevant to:
 - Intellectual disabilities, physical disabilities and advance directives and advance care planning
 - legal and ethical issues concerning advance directives and advance care planning
 - public engagement and the social promotion of advance directives and advance care planning
- 3) Conduct a Roundtable Discussion to inform the *Secretarial Report to Congress* on how best to promote the use of advance directives as a means of specifying wishes about end-of-life care. This meeting will focus on legal and policy issues, public engagement and social marketing, and give special attention to the concerns of persons with disabilities.

RAND will synthesize the information gathered from the above activities in order to inform the *Secretarial Report to Congress* that will suggest efforts to improve advance directive use and advance care planning in order to improve end of life care.

October 9, 2007

<<Panelist>>
<<Affiliation>>
<<Address>>

Dear <<Dear>>:

We are delighted that you will join us for the Roundtable Discussion on October 22 and 23 at the RAND Corporation in Arlington, Virginia. Your participation will help inform the *Secretarial Report to Congress* on how best to promote the use of advance directives as a means of specifying wishes about end-of-life care. The purpose of this mailing is to provide additional information about the meeting, to offer background reading material and to elicit your preliminary thoughts on how best to promote advance directives and advance care planning in the U.S. This package contains the following materials in preparation for the Roundtable Discussion:

- Wilkinson A, Wenger NS, Shugarman LR. RAND Literature Review on Advance Directives.
- Sabatino CP. Advance Directives and Advance Care Planning: Legal and Policy Issues.
- Stein GL. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities.
- Christopher MJ, Carney JG. Advance Care Planning and Public Engagement.
- Roster of Roundtable participants
- Roundtable meeting agenda
- Meeting logistics page
- Rating sheet of possible strategies to improve advance care planning

You will be participating in the **Roundtable Discussion on Issues of Concern to Persons with Disabilities**. In preparation for the meeting, we ask that you read in particular the paper *Advance care planning for people with intellectual and physical disabilities* by Gary Stein and also the section of the *RAND Literature Review* on this topic on pages 21-26. Of course, you are encouraged to read the other two papers and the remainder of the literature review as well. Then we ask that you ponder what changes would be of value in improving advance directive use, advance care planning and end-of-life care. On the enclosed rating sheet we provided several suggestions and we would like you to rate their importance and their feasibility. Please rate every suggestion. We are also interested in your additional thoughts concerning interventions to improve advance directive use and end-of-life care that should be considered and discussed at the Roundtable.

Please complete the enclosed rating sheet and **FAX it to Lance Tan at RAND at 310-260-8161 by October 16th**. If you have any questions or additional suggestions, please feel free to contact Neil Wenger or Lisa Shugarman at RAND or Judith Peres, the ASPE expert consultant for this project.

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You will be participating in the **Roundtable Discussion on Legal and Policy Issues**. In preparation for the meeting, we ask that you read in particular the paper *Advance directives/Advance planning legal issues* by Charles Sabatino. Of course, you are encouraged to read the other two papers and the remainder of the literature review as well. Then we ask that you ponder what changes would be of value in improving advance directive use, advance care planning and end-of-life care. On the enclosed rating sheet we provided several suggestions and we would like you to rate their importance and their feasibility. Please rate every suggestion. We are also interested in your additional thoughts concerning interventions to improve advance directive use and end-of-life care that should be considered and discussed at the Roundtable.

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You will be participating in the **Roundtable Discussion on Public Engagement and Social Marketing**. In preparation for the meeting, we ask that you read in particular the paper *Advance Care Planning and Public Engagement* by Myra Christopher and John Carney and also the section of the *RAND Literature Review* on this topic on pages 31-36. Of course, you are encouraged to read the other two papers and the remainder of the literature review as well. Then we ask that you ponder what changes would be of value in improving advance directive use, advance care planning and end-of-life care. On the enclosed rating sheet we provided several suggestions and we would like you to rate their importance and their feasibility. Please rate every suggestion. We are also interested in your additional thoughts concerning interventions to improve advance directive use and end-of-life care that should be considered and discussed at the Roundtable.

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RAND ROUNDTABLE DISCUSSIONS

Monday and Tuesday, October 22-23, 2007

AGENDA

Monday, October 22 9:00 AM - 5:00 PM		
9 AM	Continental Breakfast	
9:15 AM	Introductions Setting the Stage: Steven J. Tingus, <i>Deputy Assistant Secretary for Planning and Evaluation -- Disability, Aging, and Long-Term Care Policy</i>	
10 AM	Disability Issues Roundtable <ul style="list-style-type: none"> ▪ Panel: How would end of life care and ACP be different if persons with disability were engaged from the start ▪ Findings on how persons with disabilities receive end of life care and engage in ACP ▪ Discussion of suggested interventions 	<i>Participant observers:</i> <ul style="list-style-type: none"> ▪ Legal/Policy participants ▪ Public engagement participants
1 PM	Lunch	
2 PM	Legal/Policy Roundtable <ul style="list-style-type: none"> ▪ Findings about current laws ▪ Discussion, needs assessment ▪ Discussion of suggested legal/regulatory interventions 	<i>Participant observers:</i> <ul style="list-style-type: none"> ▪ Disability issues participants ▪ Public engagement participants
6 PM	Dinner and Discussion, Location TBD	

Tuesday, October 23 8:00 A.M. - 3:00 P.M.		
8 AM	Continental Breakfast	
8:30 AM	Introduction	
8:45 AM	Public Engagement/Social Marketing Roundtable <ul style="list-style-type: none"> ▪ Findings about social marketing and public engagement efforts ▪ Discussion, needs assessment ▪ Discussion of suggested public engagement interventions 	<i>Participant observers:</i> <ul style="list-style-type: none"> ▪ Disability issues participants ▪ Legal/Policy participants
12 noon	Lunch	
1 PM	Wrap-up -- all participants <ul style="list-style-type: none"> ▪ Discussion of conclusions of each Roundtable ▪ Novel interventions 	

ASPE ROUNDTABLE PARTICIPANTS

Secretarial Report to Congress on Advance Directives

October 22-23, 2007

Panelists

Issues of Concern to Persons with Disabilities

Adrienne Asch
Ira Byock
Julie Carroll
Stephen Drake
Marty Ford
Ruth Freedman
Bill Gaventa
Angela King
Leigh Ann Kingsbury
Gary Stein

Legal and Policy issues

William Colby
Nancy Dubler
Michelle Grant Ervin
Joe Fins
Bud Hammes
Naomi Karp
Alan Meisel
Gloria Ramsey
Charlie Sabatino
Jack Schwartz
Jane Tilly

Public Engagement and Social Marketing

Kathy Brandt
John Carney
Myra Christopher
Lex Frieden
Marge Ginsburg
Jim Healy
Richard Payne
Mike Perry
Arlyn Riskind
Bill Smith
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Office of the Assistant Secretary for Planning & Evaluation

Ruth Katz

Deputy to the Deputy Assistant Secretary for Planning & Evaluation, Office of Disability, Aging & Long-Term Care Policy

Gavin Kennedy

Director, Division of Long-Term Care Policy

William Marton, PhD

Director, Division of Disability & Aging Policy

Judith R. Peres, LCSW-C

Expert Consultant, Long-Term Care & Palliative Care

Susan Polnieszak

Task Order Monitor

Steven J. Tingus, MS, CPhil

Deputy Assistant Secretary for Planning & Evaluation, Office of Disability, Aging & Long-Term Care Policy

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*Health Policy Researcher, RAND
Project Director, Co-Principal Investigator*

Patty Smith

Project Administrative Staff, RAND

Lance Tan

Project Administrative Staff, RAND

Neil S. Wenger, MD, MPH

*Senior Natural Scientist, RAND
Co-Principal Investigator*

Jeremy Wolland

Project Administrative Staff, RAND

Roy Young, MD

Moderator

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>

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