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Roundtable on Quality Care  
for People with Serious Illness

# Integrating Health Care and Social Services for People with Serious Illness

A Workshop | July 19, 2018

 #SeriousIllnessCareNASEM

Keck Center of the National Academies  
500 Fifth Street, NW  
Room 100  
Washington, DC 20001

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**ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS**

July 19, 2018

Dear Colleagues:

Welcome to the workshop on *Integrating Health Care and Social Services for People with Serious Illness* hosted by the Roundtable on Quality Care for People with Serious Illness at the National Academies of Sciences, Engineering, and Medicine.

Workshop sessions include: a patient-family caregiver perspective; an overview of the challenges, gaps, and opportunities in integrating health care and social and supportive services; an indepth exploration of the unique role of caregivers; perspectives of organizations providing integrated services and their lessons learned, and a discussion about policy opportunities to support integration of health care and social services for people with serious illness.

The workshop also includes a Lunch and Learn activity that brings together representatives of a small sampling of organizations so that workshop participants might engage with them in informal discussion to learn about the services each organization provides.

We hope you will find the presentations informative, thought provoking and inspiring, and that you will be able to incorporate the lessons learned here today into your vital work focused on improving care for people living with serious illness and their families.

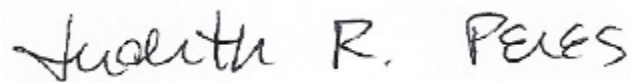
A major goal of the workshop is to facilitate discussion about integration of health care and social services, and each session includes a question and answer/audience discussion period. We encourage you to participate actively in workshop discussions. Proceedings of this workshop will be published by the National Academies Press and may incorporate your comments and ideas. In addition, the workshop will be webcast, and a video archive will be available at:  
<http://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2018-JUL-19.aspx>

We invite you to share your insights throughout the workshop using the Twitter hashtag: **#SeriousIllnessCareNAEM**.

Sincerely,



Joanne Lynn, MD  
Director, Center for Elder Care  
and Advanced Illness  
Altarum Institute  
Workshop Planning Committee Co-Chair



Judith R. Peres, LCSW-C  
Long Term and Palliative Care Consultant  
Clinical Social Worker and Board Member  
Social Work Hospice and Palliative Care Network  
Workshop Planning Committee Co-Chair

**Roundtable on Quality Care for People with Serious Illness**

**WORKSHOP NOTES**

- This workshop is being recorded. Please identify your name and affiliation prior to asking questions at the microphone.
- A live webcast of this workshop is available online at:  
<http://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2018-JUL-19.aspx>
- Please use the hashtag **#SeriousIllnessCareNASEM** to tweet about the workshop.
- An archive of the video webcast and presentation slides will be available at:  
<http://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2018-JUL-19.aspx>
- Proceedings of the workshop will be published following National Academies procedures. Rapporteurs will compose the proceedings from the workshop transcript, and external reviewers will examine the proceedings to make sure it accurately reflects workshop discussions and conforms to institutional policies.
- Interested in receiving updates from the Roundtable on Quality Care for People with Serious Illness or the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division?

Sign up for the **Roundtable** listserv at:

<https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>

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# Agenda

## ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

### Integrating Health Care and Social Services for People with Serious Illness

#### Workshop Agenda

The Keck Center of the National Academies  
500 Fifth Street, NW - Room 100  
Washington, DC 20001  
July 19, 2018

**Thursday, July 19, 2018**

| Thursday, July 19, 2018 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 8:00 am                 | <b>Registration and Breakfast</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| 8:30 am                 | <p><b>Welcome from the Roundtable on Quality Care for People with Serious Illness</b><br/>Leonard D. Schaeffer, University of Southern California (Chair) and<br/>James Tulsky, MD, Harvard Medical School (Vice Chair)</p> <p><b>Overview of the Workshop</b><br/>Joanne Lynn, MD, Director, Center for Eldercare and Advanced Illness, Altarum, and<br/>Judith R. Peres, LCSW-C, Long Term and Palliative Care Consultant, Social Work Hospice<br/>and Palliative Care Network<br/><i>Workshop Planning Committee Co-Chairs</i></p>                    |
| 8:45 am                 | <p><b>Patient and Family Caregiver Perspective</b><br/><i>Moderator: Judith R. Peres, LCSW-C</i></p> <p>MaryAnn, Frank, and Andi Spitale<br/><i>The Patient and Family Caregiver Experience</i></p>                                                                                                                                                                                                                                                                                                                                                      |
| 9:30 am                 | <p><b>Session 1: Framing the Issues of Integrating Health Care and Social Services for People with Serious Illness: Gaps, Challenges, and Opportunities</b><br/><i>Moderator: Lynn Friss Feinberg, MSW, Senior Strategic Policy Advisor, AARP Public Policy Institute</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> <li>— Lauren A. Taylor, MDiv, MPH, Doctoral Candidate, Harvard Business School</li> <li>— Robyn Stone, DPH, Senior Vice President of Research, LeadingAge</li> </ul> <p><b>Panel Discussion/Audience Q &amp; A</b></p> |
| 10:45 am                | <b>Break</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |

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|          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 11:00 am | <p><b>Session 2: Providing Supportive Services - Exploring the Key Role and Unique Needs of Caregivers</b><br/> <i>Moderator: Jeri Miller, PhD, Chief, Office of End-of-Life and Palliative Care Research and Senior Policy Analyst, National Institute of Nursing Research/NIH</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> <li>– Richard Schulz, PhD, Professor of Psychiatry, School of Medicine, Director, University Center for Social and Urban Research, University of Pittsburgh</li> <li>– Debra Parker Oliver, MSW, PhD, Paul Revere Family Professor of Family Medicine, University of Missouri</li> <li>– Courtney Van Houtven, PhD, Research Scientist in Health Services Research and Development in Primary Care, Durham VA and Associate Professor, Duke University Medical Center</li> <li>– Sarita Gupta, Co-Director, Caring Across Generations</li> <li>– Jennifer L. Wolff, PhD, Professor, Johns Hopkins University</li> </ul> <p><b>Panel Discussion/Audience Q &amp; A</b></p> |
| 12:30 pm | <p><b>Lunch and Learn</b></p> <p>E Street Conference Room<br/> Workshop Participants pick up lunch and then meet for informal discussions with a range of organizations involved in providing social and supportive services.</p> <p>The George Washington Institute for Spirituality &amp; Health ♦ HomesRenewed ♦ LeadingAge ♦ Meals on Wheels ♦ National Association of Area Agencies on Aging ♦ National Hispanic Council on Aging ♦ National Hospice and Palliative Care Organization</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| 1:45 pm  | <p><b>Session 3: Integration of Services - Innovative Partnerships and Collaborations</b><br/> <i>Moderator: Peggy Maguire, JD, President, Cambia Health Foundation</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> <li>– Gwendolyn Graddy-Dansby, MD, Chief Medical Officer, Program of All-Inclusive Care for the Elderly (PACE) Southeast Michigan</li> <li>– June Simmons, MSW, President and CEO, Partners in Care Foundation</li> <li>– Will Kennedy, DO, Senior Medical Director for Advanced Illness, CareOregon</li> <li>– Sarah Szanton, PhD, Director, Center for Innovative Care in Aging, Johns Hopkins University School of Nursing, Community Aging in Place – Advancing Better Living for Elders (CAPABLE)</li> </ul> <p><b>Panel Discussion/Audience Q &amp; A</b></p>                                                                                                                                                                                                                   |
| 3:15 pm  | <p><b>Break</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |

## ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

|         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|---------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 3:30 pm | <p><b>Session 4: Policy Challenges and Opportunities for Integrating Health Care and Social Services Nationwide</b></p> <p><i>Moderator: Joanne Lynn, MD</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> <li>– Kathy Greenlee, JD, Vice President of Aging &amp; Health Policy, the Center for Practical Bioethics</li> <li>– Bruce C. Vladeck, PhD, Senior Adviser, Greater New York Hospital Association</li> <li>– Gail Wilensky, PhD, Senior Fellow, Project HOPE</li> </ul> <p><b>Panel Discussion/Audience Q &amp; A</b></p> |
| 4:30 pm | Wrap-up and Adjourn                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

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*Integrating Health Care and Social Services for People with Serious Illness: A Workshop*

**WORKSHOP PLANNING COMMITTEE ROSTER**

**Joanne Lynn, MD (Co-Chair)**

Director, Center for Elder Care  
and Advanced Illness  
Altarum Institute

**Judith R. Peres, LCSW-C (Co-Chair)**

Long Term and Palliative Care Consultant  
Clinical Social Worker and Board Member  
Social Work Hospice and Palliative Care  
Network

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**Robert A. Bergamini, MD**

Medical Director, Palliative Care Services  
Mercy Clinic Children's Cancer and  
Hematology  
*Representing the Supportive Care Coalition*

**Sharon Scribner Pearce**

Vice President, Policy  
National Hospice and Palliative Care  
Organization

**Amy J. Berman, BSN, LHD**

Senior Program Officer  
The John A. Hartford Foundation

**JoAnne Reifsnyder, PhD, RN, FAAN**

Executive Vice President, Clinical Operations  
and Chief Nursing Officer  
Genesis Healthcare  
*Representing the Hospice and Palliative Nurses  
Association*

**Haiden Huskamp, PhD**

30th Anniversary Professor of Health Care  
Policy, Department of Health Care Policy  
Harvard Medical School

**Katrina M. Scott, MDiv, BCC-HPCC**

Oncology Chaplain  
Massachusetts General Hospital  
*Representing the Association of Professional  
Chaplains*

**Kimberly Johnson, MD**

Associate Professor of Medicine  
Duke University School of Medicine  
Member of the Duke Cancer Institute

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Regional Medical Director  
VITAS Hospice Care  
*Representing the American Geriatrics Society*

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Program Officer  
Gordon and Betty Moore Foundation

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UnitedHealthcare, Retiree Solutions

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Chief, Office of End-of-Life and Palliative  
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Senior Policy Analyst  
HHS/NIH/NINR/Division of Extramural  
Science Programs

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*Integrating Health Care and Social Services for People with Serious Illness: A Workshop*

**SPEAKERS AND MODERATORS ROSTER**

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Co-Director  
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@CaringAcrossGen

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Senior Medical Director for Advanced Illness  
Housecall Providers  
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@medicaring

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@MaguirePeggy

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Senior Policy Analyst  
HHS/NIH/NINR/Division of Extramural  
Science Programs

**Debra Parker Oliver, MSW, PhD**

Paul Revere Family Professor of Family  
Medicine  
University of Missouri

**Judith Peres, LCSW-C**

Long Term and Palliative Care Consultant  
Clinical Social Worker and Board Member  
Social Work Hospice and Palliative Care  
Network

**Richard Schulz, PhD**

Professor of Psychiatry,  
School of Medicine  
Director, University Center for Social and  
Urban Research  
University of Pittsburgh

**June Simmons, MSW**

President and Chief Executive Officer  
Partners in Care Foundation  
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**MaryAnn, Frank, and Andi Spitale**

Patient and Family Caregiver Experience

**Robyn Stone, DrPH**

Senior Vice President of Research  
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*Integrating Health Care and Social Services for People with Serious Illness: A Workshop*

**LUNCH AND LEARN ORGANIZATIONS**

**National Hospice and Palliative Care Organization**

Lori Bishop, MHA, BSN, RN, CHPN  
Vice President of Palliative & Advanced Care  
@NHPCO\_news

**National Hispanic Council on Aging**

Yanira Cruz, DrPH  
President and Chief Executive Officer  
@NHCOA

**LeadingAge**

Janine Finck-Boyle  
Vice President, Regulatory Affairs  
@LeadingAge

**Meals on Wheels**

Marci LeFevre, MA  
Senior Director, Strategy and Impact - Care Coordination  
@\_MealsOnWheels

**National Association of Area Agencies on Aging (n4a)**

Amy Gotwals  
Chief, Public Policy and External Affairs  
Mary Kaschak  
Deputy Director, Aging and Disability Business Institute  
@n4aACTION

**The George Washington Institute for Spirituality & Health (GWish)**

Christina Puchalski, MD, MS, FACP, FAAHPM  
Director  
@caringatgwish

**HomesRenewed**

Louis Tenenbaum  
Founder  
@louis\_tenenbaum

## About the Roundtable

## ROUNDTABLE SPONSORS

- Aetna
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- American Academy of Hospice and Palliative Medicine
- American Cancer Society
- American Geriatrics Society
- Anthem
- Ascension Health
- Association of Professional Chaplains
- Association of Rehabilitation Nurses
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- Blue Cross Blue Shield of MA
- Blue Cross and Blue Shield of NC
- Bristol-Myers Squibb Company
- The California State University Institute for Palliative Care
- Cambia Health Solutions
- Cedars-Sinai Health System
- Center to Advance Palliative Care
- Centers for Medicare & Medicaid Services
- Coalition to Transform Advanced Care
- Common Practice
- Excellus BlueCross BlueShield
- Federation of American Hospitals
- The Greenwall Foundation
- The John A. Hartford Foundation
- Hospice and Palliative Nurses Association
- Kaiser Permanente
- Susan G. Komen
- Gordon and Betty Moore Foundation
- National Academy of Medicine
- National Coalition for Hospice and Palliative Care
- National Hospice and Palliative Care Organization
- National Institute of Nursing Research
- National Palliative Care Research Center
- National Patient Advocate Foundation
- National Quality Forum
- New York Academy of Medicine
- Oncology Nursing Society
- Patient-Centered Outcomes Research Institute
- Social Work Hospice and Palliative Care Network
- Supportive Care Coalition
- UnitedHealth Group



# ABOUT THE ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS



The National Academies of Sciences, Engineering and Medicine's **Roundtable on Quality Care for People with Serious Illness** fosters ongoing dialogue about improving care for people of all ages facing all stages of serious illness. To that end, the Roundtable's work and activities focus on five priority areas:

- delivery of person-centered, family-oriented care
- communication and advance care planning
- professional education and development
- policies and payment systems
- public education and engagement

**The Roundtable on Quality Care for People with Serious Illness** convenes a diverse group of key stakeholders, and sponsors public workshops to explore critical topics. Roundtable membership includes patient advocates, health care professional organizations, health care providers and insurers, foundations, federal agencies, researchers, and others interested in improving care for people of all ages and all stages of serious illness.

## 2018 PUBLIC WORKSHOPS

### **Implementing Quality Measures for Accountability in Community-based Care for People with Serious Illness** (April 17, 2018)

This workshop explored approaches to implementing quality measures for accountability purposes in community-based care programs for people with serious illness. Presentations focused on the implementation of quality measures from the perspective of patients and caregivers, health care providers and private and public sector health plans, and the future use of quality measures for accreditation to support accountability for high-quality serious illness care.

### **Integrating Health Care and Social Services for People with Serious Illness** (July 19, 2018)

This workshop examined the range of services necessary to provide high-quality care for people facing serious illness, the strengths and limitations of existing models of integrated services delivery, the role of family caregivers in providing social services and supports, and identified gaps in research regarding the integration of health care and social services for people with serious illness.

### **Pain and Symptom Management for People with Serious Illness in the Context of the Opioid Epidemic** (November 29, 2018)

This workshop will explore effective approaches to addressing the pain and symptom management needs of people with serious illness in the context of widespread substance use disorder. The workshop will feature perspectives of patients and their families, clinicians, and payers, and will examine the impact on patients and clinicians of regulatory/legislative actions to address the opioid epidemic.



## 2016-2017 PUBLIC WORKSHOPS

### **Integrating the Patient and Caregiver Voice into Serious Illness Care** (December 15, 2016)

The workshop explored ways to identify and integrate the voices of seriously ill patients of all ages and their caregivers into person-centered care throughout the continuum of care. Workshop presenters shared personal perspectives and experiences about priorities and values important to patients and families coping with serious illness and approaches that support integration of these priorities and values into practice.

### **Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care**

(April 27, 2017)

The workshop highlighted innovative models of community-based care for people of all ages facing serious illness. The workshop featured presentations and panel discussions exploring community-based palliative care, pediatric palliative care, concurrent care, and the challenges and opportunities to scale and spread successful palliative care models and programs.

### **Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness**

(November 29, 2017)

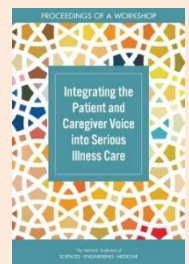
The workshop examined innovative payment approaches to support high-quality care for people with serious illness across a range of fee-for-service, value-based, and global budgeting arrangements. Workshop presenters discussed the challenges and barriers to innovative strategies and explored potential policy approaches to address them.

## Roundtable Publications

### **Integrating the Patient and Caregiver Voice into Serious Illness Care**

*Our report was released in July 2017 and has been widely disseminated with a total of **2,214** full text downloads, putting it in the top **14%** of all National Academies Press products. We have achieved a broad international reach to 89 countries and have garnered downloads in 48 states and the District of Columbia. Analysis of download domains (.org/.gov/.mil) showed local, state, federal and military agencies accounted for 16% of all downloads. The research and academic community (.edu) accounted for 20% and the public at large accounted for 63%.*

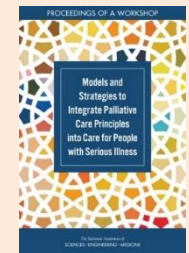
Available at: <http://bit.ly/PatientCaregiverVoice>



### **Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness**

*Our report was released in October 2017 and has been widely disseminated with a total of **2,793** full text downloads, putting it in the top **10%** of all National Academies Press products. We have achieved a broad international reach to 101 countries and have garnered downloads in all 50 states and the District of Columbia. Analysis of download domains (.org/.gov/.mil) showed local, state, federal and military agencies accounted for 14% of all downloads. The research and academic community (.edu) accounted for 16% and the public at large accounted for 69%.*

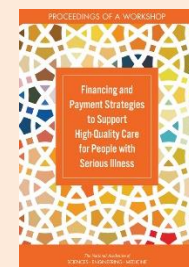
Available at: <http://bit.ly/PalliativeCarePrinciples>



### **Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness**

*Our report was released in May 2018 and has had a total of **611** full text downloads, putting it in the top 41% of all National Academies Press products. We have achieved a broad international reach to 54 countries and have garnered downloads in 44 states and the District of Columbia. Analysis of download domains (.org/.gov/.mil) showed local, state, federal and military agencies accounted for 19% of all downloads. The research and academic community (.edu) accounted for 14% and the public at large accounted for 65%.*

Available at: <http://www.nap.edu/read/25071>



## Roundtable Membership

**Leonard D. Schaeffer (Chair)**  
University of Southern California

**James A. Tulsky, MD (Vice Chair)**  
Dana-Farber Cancer Institute  
Harvard Medical School

---

**Jennifer Ballentine, MA**  
The California State Institute for  
Palliative Care

**Robert A. Bergamini, MD**  
Supportive Care Coalition

**Amy J. Berman, RN, BSN, LHD**  
The John A. Hartford Foundation

**Patricia A. Bomba, MD, FACP**  
Excellus BlueCross BlueShield

**Susan Brown, MS, RN**  
Susan G. Koman

**Grace B. Campbell, PHD, MSW,  
RN, CRRN**  
Association of Rehabilitation Nurses

**Steve Clauser, PhD, MPA**  
Patient-Centered Outcomes Research  
Institute

**Jeff Cohn, MD, MHCM**  
Common Practice

**Patrick Conway, MD**  
Blue Cross and Blue Shield of North  
Carolina

**David Debono, MD**  
Anthem, Inc.

**Christopher Dezii, RN, MBA,  
CPHQ**  
Bristol-Myers Squibb

**Andrew Dreyfus**  
Blue Cross Blue Shield of  
Massachusetts

**Carole Redding Flamm, MD, MPH**  
Blue Cross Blue Shield Association

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**Mark B. Ganz, JD**  
Cambia Health Solutions

**Ziad Haydar, MD, MBA**  
Ascension Health

**Pamela S. Hinds, RN, PhD, FAAN**  
Children's National Health System

**Haiden Huskamp, PhD**  
Harvard Medical School

**Kimberly Johnson, MD**  
Duke University School of Medicine

**Charles N. Kahn, III, MPH**  
Federation of American Hospitals

**Rebecca A. Kirch, JD**  
National Patient Advocate Foundation

**Tom Koutsoumpas**  
Coalition to Transform Advanced Care

**Shari Ling, MD**  
Centers for Medicare & Medicaid  
Services

**Bernard Lo, MD**  
The Greenwall Foundation

**Joanne Lynn, MD**  
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**Amy Melnick, MPA**  
National Coalition for Hospice and  
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National Institute of Nursing Research,  
NIH

**R. Sean Morrison, MD**  
National Palliative Care Research  
Center

**Brenda Nevidjon, RN, MSN,  
FAAN**  
Oncology Nursing Society

---

**Harold L. Paz, MD, MS**  
Aetna

**Sharon Scribner Pearce**  
National Hospice and Palliative Care  
Organization

**Judith R. Peres, LCSW-C**  
Social Work Hospice and Palliative  
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**Philip A. Pizzo, MD**  
Stanford University School of Medicine

**Wendy Prins, MPH, MPT**  
National Quality Forum

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**Diane Schweitzer, MPPM**  
Gordon and Betty Moore Foundation

**Katrina M. Scott, MDiv**  
Association of Professional Chaplains

**Katherine Sharpe, MTS**  
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**Joseph W. Shega, MD**  
American Geriatrics Society

**Christian Sinclair, MD, FAAHPM**  
American Academy of Hospice and  
Palliative Medicine

**Tanya Stewart, MD, MBA,  
FAAHPM, HMDC**  
UnitedHealth Group

**Susan Elizabeth Wang, MD**  
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## Roundtable Sponsors

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| Aetna                                                         | Federation of American Hospitals                   |
| Altarum Institute                                             | The Greenwall Foundation                           |
| American Academy of Hospice and Palliative Medicine           | The John A. Hartford Foundation                    |
| American Cancer Society                                       | Hospice and Palliative Nurses Association          |
| American Geriatrics Society                                   | Kaiser Permanente                                  |
| Anthem                                                        | Susan G. Komen                                     |
| Ascension Health                                              | Gordon and Betty Moore Foundation                  |
| Association of Professional Chaplains                         | National Academy of Medicine                       |
| Association of Rehabilitation Nurses                          | National Coalition for Hospice and Palliative Care |
| Blue Cross Blue Shield Association                            | National Hospice and Palliative Care Organization  |
| Blue Cross Blue Shield of MA                                  | National Institute of Nursing Research             |
| Blue Cross and Blue Shield of NC                              | National Palliative Care Research Center           |
| Bristol-Myers Squibb Company                                  | National Patient Advocate Foundation               |
| The California State University Institute for Palliative Care | National Quality Forum                             |
| Cambia Health Solutions                                       | New York Academy of Medicine                       |
| Cedars-Sinai Health System                                    | Oncology Nursing Society                           |
| Center to Advance Palliative Care                             | Patient-Centered Outcomes Research Institute       |
| Centers for Medicare & Medicaid Services                      | Social Work Hospice and Palliative Care Network    |
| Coalition to Transform Advanced Care                          | Supportive Care Coalition                          |
| Common Practice                                               | UnitedHealth Group                                 |
| Excellus BlueCross BlueShield                                 |                                                    |

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# ABOUT US

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## THE HEALTH AND MEDICINE DIVISION

### **We ask and answer the nation's most pressing questions about health and health care.**

The Health and Medicine Division (HMD)—an operating unit of the National Academies of Sciences, Engineering, and Medicine (National Academies)—helps those in government and the private sector make informed health decisions by providing evidence upon which they can rely.

Through our consensus studies, we offer straightforward answers to questions of national importance. Our convening activities bring together actors from across the health care spectrum to explore complex topics and work toward shared understanding on critical health issues.

Each year, more than 3,000 of the world's leading experts in industry, academia, and the health care sector volunteer their time, knowledge, and expertise with HMD. They work through committees composed to ensure the needed expertise and to avoid conflicts of interest. With the assistance of approximately 150 HMD staff members, their contributions help to advance health.

Our advice is steeped in science and led by evidence. For millions of people across the United States and around the globe, improving health is not merely an academic exercise; it is a matter of daily survival and well-being. In all we do to improve health policy and decision making, HMD is ever mindful of the impact of our work on the lives and health of individuals, families, communities, and nations.

***As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine.***

## OUR WORK

From alerting the public to the widespread problem of medical errors to setting the blueprint for the future of nursing to emphasizing the importance of end-of-life care preferences, our consensus studies provide independent, evidence-based advice on pressing issues in health and health care.

Many of the studies that HMD undertakes are requested by federal agencies and independent organizations; others begin as specific mandates from Congress. Before any National Academies report is released, it undergoes extensive peer review by a second group of experts, whose identities remain anonymous to the authoring committee until the study is published. For decades, this process has resulted in sound publications providing policy makers, the health professions, and the American people with objective advice grounded in evidence.

While our consensus committees are vital to our advisory role, HMD also convenes a series of forums, roundtables, and standing committees. These activities facilitate discussion; discovery; and critical, cross-disciplinary thinking, and when required can quickly gather experts to address matters of urgent importance, such as emerging infectious diseases and health-related disaster preparedness.

## OUR NAME

As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine. With this change, HMD is now fully integrated into the broader work of the National Academies, which is facilitating more collaborative and interdisciplinary approaches to the most pressing challenges facing the nation and the world.

Learn more at  
[nationalacademies.org/HMD](http://nationalacademies.org/HMD)

*The National Academies are private, nonprofit institutions that provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions related to science, technology, and medicine. The National Academies operate under an 1863 congressional charter to the National Academy of Sciences, signed by President Lincoln.*

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**Roundtable on Quality Care for People with Serious Illness**

***Pain and Symptom Management for People with Serious Illness  
in the Context of the Opioid Epidemic: A Workshop***

The Keck Center of the National Academies  
500 Fifth Street, NW - Room 100  
Washington, DC 20001  
November 29, 2018

An ad hoc committee will plan and host a one-day workshop to examine ways to best address the pain and symptom management needs of people with serious illness in the context of widespread opioid use disorder, including consideration of the underlying socioeconomic factors that contribute to the epidemic. The workshop will feature invited presentations and panel discussions on topics that may include:

- The Patient/Family Perspective
  - Impact of limitations in access to opioids on those with serious illness and their caregivers
  - Disparities in access to prescribed opioids for people with serious illness
  - Options for safe removal and disposal of opioids when they are no longer needed
- The Clinician Perspective
  - How restrictions on opioid prescribing affect clinicians and their ability to provide high quality care for those with serious illness
  - Ways in which clinicians manage the care of seriously ill patients who have comorbid conditions such as cancer and substance use disorder
- The Payer Perspective
  - Challenges of striking a balance between access to opioid medications for patients' pain and symptom management and patient safety and prevention of opioid use disorder
- The Legislative/Policy Perspective
  - Potential impact of regulatory/legislative actions to address the opioid epidemic
  - Measures to protect the population of people with serious illness whose pain can only be effectively addressed by opioids
- Strategies to address gaps in the evidence base on pain management for people with serious illness

The committee will develop the agenda for the workshop, select speakers and discussants, and moderate the discussions. Proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

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SCIENCES • ENGINEERING • MEDICINE

**Roundtable on Quality Care for People with Serious Illness**

**Planning Committee Roster**

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**Andrew Dreyfus (Co-Chair)**

President and Chief Executive Officer  
Blue Cross Blue Shield of Massachusetts

**James A. Tulsky, MD (Co-Chair)**

Chair, Department of Psychosocial  
Oncology and Palliative Care, Dana-  
Farber Cancer Institute  
Chief, Division of Palliative Medicine  
Co-Director, Harvard Medical School  
Center for Palliative Care  
Professor of Medicine, Harvard Medical  
School

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**Patricia A. Bomba, MD, FACP**

Vice President & Medical Director,  
Geriatrics  
Excellus BlueCross BlueShield

**Sean Morrison, MD**

Director, National Palliative Care Research  
Center  
Ellen and Howard C. Katz Professor and  
Chair of Geriatrics and Palliative  
Medicine  
Brookdale Department of Geriatrics  
and Palliative Medicine  
Icahn School of Medicine at Mount Sinai

**Steve Clauser PhD, MPA**

Program Director, Improving Healthcare  
Systems  
Patient-Centered Outcomes Research  
Institute

**Judith A. Paice, PhD, RN**

Director, Cancer Pain Program  
Division, Hematology-Oncology  
Feinberg School of Medicine, Northwestern  
University

**Rebecca A. Kirch, JD**

Executive Vice President of Healthcare  
Quality and Value  
National Patient Advocate Foundation

**Philip A. Pizzo, MD**

Founding Director, Stanford Distinguished  
Careers Institute  
Former Dean and David and Susan  
Heckerman Professor of Pediatrics and of  
Microbiology and Immunology  
Stanford University School of Medicine

**Jane M. Liebschutz, MD, MPH, FACP**

Chief, Division of General Internal  
Medicine  
UPMC Health System  
University of Pittsburgh School of Medicine

**Salimah H. Meghani, PhD, MBE, RN,  
FAAN**

Associate Professor & Term Chair in  
Palliative Care  
Associate Professor of Nursing  
University of Pennsylvania, School of  
Nursing

**Christian Sinclair, MD, FAAHPM**

Associate Professor,  
Outpatient Palliative Oncology Lead,  
Division of Palliative Medicine  
The University of Kansas Health System





## **Program of All-Inclusive Care for the Elderly (PACE)**

PACE programs coordinate and provide all needed preventive, primary, acute, and long-term care services so that older individuals can continue living in the community. PACE is an innovative model that enables individuals who are 55 years old or older and certified by their state to need nursing home care to live as independently as possible. Through PACE, today's fragmented health care financing and delivery system comes together to serve the unique needs of each individual in a way that makes sense to the frail elderly, their informal caregivers, health care providers, and policy makers.

### **PACE Programs Offer High Quality Care and are Proven Cost Effective**

PACE is an integrated model of care and utilizes interdisciplinary teams – including physicians, nurse practitioners, nurses, social workers, therapists, van drivers, and aides – to exchange information and solve problems as the conditions and needs of a PACE participant change – all with the objective of enabling participants to live longer in the community.

- PACE provides participants regular access to doctors and other primary care professions who know them and who specialize in caring for older people.
- PACE participants have improved health status and quality of life, lower mortality rates, increased choice in how time is spent, and greater confidence in dealing with life's problems, according to a recent Abt Associates study.
- The PACE financing model combines payments from Medicare (approximately 40%) and Medicaid (approximately 60%) or private pay sources (a small percentage) into one flat-rate payment to provide the entire range of health care and services, including paying for hospital care, in response to individual needs. Additionally, PACE Programs are Medicare D providers.
- PACE utilizes transportation systems to enable participants to live as independently as possible in the community while having access to the supportive services, medical specialists, therapies and other medical care they need.

### **Characteristics of PACE Participants**

- The average age of PACE participants is 76 years old. Seventy-five percent of participants are female.
- A recent study found that the top diagnoses among PACE participants are vascular disease, diabetes with chronic complications, congestive heart failure, and chronic obstructive pulmonary disease, and major depressive, bipolar and paranoid disorders. Nearly 47% of PACE enrollees have dementia.
- While more than 90% of PACE participants live in the community, approximately 7% live in nursing homes for which the PACE program pays.



## The Challenge

Improving health largely falls outside of health care facilities. Home is where health is. People with functional limitations and chronic conditions are more than four times more likely than the general population to be among the 5 percent costliest users of health services. And yet, function is rarely addressed in medical visits.

## The Solution

CAPABLE addresses both function and cost. CAPABLE is a program developed at the Johns Hopkins School of Nursing for older adults to safely age in place. The approach teams a nurse, an occupational therapist and a handyman to address the home environment and uses the strengths of the older adults themselves to improve safety and independence.

Training by JHU professors and clinicians is available so that any health-related entity can easily provide the CAPABLE program. Our team of experts can design evaluation tools to gauge the program's effectiveness across criteria such as cost-savings or health outcomes that matter to the organization.

### CAPABLE IMPROVES HEALTH OUTCOMES AT LOWER COSTS:<sup>1</sup>



#### 7x RETURN ON INVESTMENT

Roughly \$3,000 in program costs yielded approximately \$22,000 in savings in medical costs.



#### HALVED DIFFICULTIES IN FUNCTION

Participants had difficulty with an average of 3.9 out of 8.0 Activities of Daily Living (ADLs) at baseline, compared to 2.0 after five months.



#### REDUCED SYMPTOMS OF DEPRESSION

Symptoms of depression, as well as the ability to grocery shop and manage medications also improved.



#### IMPROVED MOTIVATION

The change in physical environment further motivates the participant. Addressing both the people and the environment in which they live allows the person to thrive.

<sup>1</sup> In the period 2012–15, a demonstration project enrolled 281 adults ages sixty- five and older who were dually eligible for Medicare and Medicaid and who had difficulty performing ADLs. ADLs include eating, bathing, dressing, moving around, transferring and toileting.



In the words of a participant, “Before CAPABLE came in, everything was ‘I can’t. I can’t take the risk.’ CAPABLE taught me how to function. You gave me the tools to function with.... Everything you have done has given me my independence. *My independence.*”



For additional information, contact: Johns Hopkins School of Nursing CAPABLE Program, contact Sarah Szanton, Program Director, [sarah.szanton@jhu.edu](mailto:sarah.szanton@jhu.edu) or visit <https://nursing.jhu.edu/capable>





## **THE GEORGE WASHINGTON INSTITUTE FOR SPIRITUALITY & HEALTH (GWISH)**

The George Washington Institute for Spirituality & Health (GWish) was founded in May 2001 as a leading organization on education and clinical issues related to spirituality and health. Under the direction of Founder and Director Christina M. Puchalski, GWish is changing the face of healthcare through innovative research and training programs for physicians and other members of the interdisciplinary healthcare team, including clergy and chaplains.

The GWish mandate is four-fold:

- 1) Transforming healthcare through evidenced-based research supporting the inclusion of interprofessional spiritual care in healthcare;
- 2) Sustaining medical school curricular developments through the creation of national and international competencies;
- 3) Expansion of an interprofessional community of scholars in the U.S. and internationally;
- 4) Creating compassionate and patient-centered healthcare environments that improve the quality of patient care, increase healthcare provider satisfaction with work and reduce provider turnover, burn-out and medical errors.

The ultimate goal — ‘to restore the heart and humanity in health care’ — has been pursued in myriad ways. GWish has earned distinction as a national and international convener of interdisciplinary healthcare professionals from 48 US states, 28 countries on seven out of eight continents. Examples of these achievements are

- 1) 80% of U.S. medical schools have incorporated spirituality and health into their curriculum;
- 2) National consensus derived competencies in spiritual care have been used by AAMC and integrated into medical school curricula, helping to redefine the meaning of professional development in health care;
- 3) GWish led national and international consensus conferences resulted in developing a model of interprofessional spiritual care, standards and implementation strategies which have been recognized and used by WHO, ASCO, IOM, Dying in America report, EAPC, AAHPM, NHPCO, and The Vatican among others;
- 4) A Spiritual History Tool, Faith/Beliefs, Importance, Community, Addressed in Care or Action (FICA) is widely used in clinical settings;
- 5) Reflection is recognized as integral to personal and professional development of clinicians due to successful pilot implementations through the GWish-Templeton Reflection Rounds (GTRR);
- 6) Two consensus conferences in the U.S. (2013) and Geneva (2014) culminated in the call for a global movement led by Global Network for Spirituality and Health (GNSAH), housed at GWish, with the shared commitment of further building the evidence base for spiritual care as a fundamental component of high-quality compassionate health care.
- 7) GWish has developed an Interprofessional Spiritual care training program entitled "Interprofessional Spiritual Care Education Curriculum (ISPEC)". ISPEC is the first curriculum to be developed at the global level and offers a theoretically and research-grounded curriculum for teaching interprofessional spiritual care. Curricular development forms the basis of a train-the-trainer program to build leaders, consultants, advocates, and knowledgeable clinicians who can educate, empower, and guide other healthcare professionals at their institute in the integration of spirituality in healthcare.

“Historically,” writes Puchalski, “health care in the United States was founded on spiritual values — service, altruism, and compassionate care of those in need and those who suffer. Over the last 60 years, medicine and health care have been challenged by the tremendous explosion of technological advances and by the reality of increasing costs. These challenges have overshadowed the primary mission...to serve the whole person with care and compassion.” GWish aims to restore the balance.

**Christina M. Puchalski, MD, MS, FACP**

FAAHPM Professor, George Washington Medicine and Health Science Director, George Washington Institute for Spirituality and Health Co-Director

Christina Puchalski, MD, MS, FACP, FAAHPM, Christina Puchalski, MD, MS, is a pioneer and global leader in the movement to integrate spiritual care into healthcare in clinical settings and medical education. As founder and director of the George Washington Institute for Spirituality and Health (GWish) and Professor of Medicine and Health Sciences at The George Washington University in Washington, DC, she continues to break new ground in the understanding and integration of interprofessional spiritual care in a healthcare settings through educational curricula, including the GWish-Templeton Reflection Rounds which focus on inner development of clinicians, research and policy. She has co-lead national and international consensus conferences leading to recommendations for the integration of interprofessional spiritual care in palliative care focused on whole person models of care to address suffering and spiritual needs of patients and families.



GWish is fostering alliances globally to further this integration through the Global Network for Spirituality and Health (GNSAH), co-directed and founded by Dr. Puchalski. She developed the FICA spiritual history tool which is widely used in clinical settings. She is board certified in Palliative Medicine and Internal Medicine and is a Fellow of the American College of Physicians and the American Academy of Hospice and Palliative Medicine. At the George Washington University Medical Faculty Associates she directs an interdisciplinary outpatient Supportive and Palliative Care clinic in Oncology and is a Medical Hospice Co-Director for Professional Health in Washington, DC. She is recognized for her work in developing interdisciplinary educational curricula and innovative models of care in the US and other countries. She has also been awarded 2018 AAHPM Visionary in Hospice and Palliative Medicine by the American Academy of Hospice and Palliative Medicine (AAHPM).

Dr. Puchalski is widely published in journals with work ranging from biochemistry research to issues in ethics, culture, and spiritual care. She has authored numerous book chapters and published a book with Oxford University Press entitled *Time for Listening and Caring: Spirituality and the Care of the Seriously Ill and Dying*. She co-authored *Making Health Care Whole* with Dr. Betty Ferrell. She is co-editor of an international Textbook on Spirituality and Health published by Oxford University Press. She is a co-editor of the Humanities, Language, Art and Spirituality section of the *Journal of Pain and Symptom Management*; she also serves on many journal editorial boards. Her work has been featured on numerous print and television media. Her scholarship focuses on palliative care, spirituality and health and compassionate care as part of whole person health.

Puchalski has also served on many advisory committees or boards including The World Health Organization, The Vatican's Pontifical Academy for Life, and the Maruzza Foundation, The Academy of Hospice and Palliative Medicine and the Association of Professional Chaplains.

## **HomesRenewed Coalition and Resource Center**

*Increasing the number of homes prepared for residents to live throughout the modern lifespan.*

Extending longevity is probably the crowning achievement of the 20<sup>th</sup> Century. What is more important than *more* life? However, as with every advance, problems also emerge. Over the past few years the agenda on the subject of aging has focused on caregiving, isolation and ageism. Housing and healthcare are also top issues but have not received the same vigorous attention. New policies, programs and innovations are promoting the home as a site of care. According to the Harvard Joint Center for Housing Studies, “The bulk of long term care will occur in single family homes, but the homes are unprepared.” The flipside of extending life is the critical question: “Where can older citizens live happily and economically?” It seems fundamentally unjust to continue medical miracles that add years to life without also updating homes to live those lives joyfully and with dignity. To tackle this problem, HomesRenewed works to increase the number of homes that are prepared for residents to live throughout the modern lifespan.

Over time, American ingenuity has impacted all aspects of life including housing. Houses built without plumbing are still in use with plumbing, electricity, heating, insulation, fiber optic cable and solar updates. All these advances were supported by public policy that invested in industries, rights of way, transportation, and jobs to improve living conditions for Americans. One way to advance policy goals is to provide tax breaks or other financial incentives. Witness the rapid growth of hybrid cars and solar collectors since incentives were introduced. This will work for home updates too.

HomesRenewed is at the forefront of promoting innovative private and government incentives that will encourage homeowners to update their homes to prepare for longevity. Updates will improve our housing infrastructure -- bringing jobs, training, and business growth. While at the same time, enabling older citizens to remain in the home of their choice will reduce health costs and improve the quality of life not only for them but also for their families and those who work to support them.

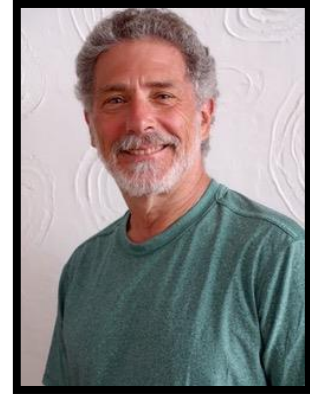
The HomesRenewed Resource Center publishes research and educates consumers, professionals and government leaders about the value that home updates provide, elevating these issues in the national aging agenda. HomesRenewed Coalition builds networks among diverse industries that will benefit from a greater number of updated homes, including tech and building product manufactures and installers; home and community based service providers; insurers; health providers; and consumers. By bringing these sectors together HomesRenewed will amplify their voices to be heard by legislators at local, state, and federal levels.

HomesRenewed, founded by Louis Tenenbaum, the author of Aging in Place 2.0, to drive the next steps to aging-in-place, creates opportunities to play a leadership role in shaping the future of the nation’s housing infrastructure to serve the welfare of older Americans. Please contact Louis Tenenbaum for further information and to discuss.



## **Louis Tenenbaum**

In the early '90s, Louis Tenenbaum was one of the first contractors to focus his remodeling business on aging in place. It became painfully obvious that although everyone said that home modification is such a good idea, no one was doing it. In response, Louis wrote the visionary white paper in 2010, *Aging in Place 2.0: Rethinking Solutions to the Home Care Challenge*, published by the MetLife Mature Market Institute, (year), which secured his role as a leading authority on Aging in Place. Louis has given over 200 consumer presentations as well as keynotes, panels and workshops for professionals in many related fields including aging, business, healthcare, policy, housing, and marketing to older consumers. Uniquely straddling the building, aging, and policy worlds, in 2016 Louis was named a Next Avenue "Influencer in Aging" and awarded a HIVE (Housing, Innovation, Vision and Economics) award from the building industry. In 2017, Louis founded HomesRenewed, an organization advocating incentive policies to increase the number of homes prepared for residents throughout the modern lifespan.



# About LeadingAge

## Who We Are

LeadingAge is the largest association of nonprofit aging services organizations in the country helping older adults thrive.

- We are a 501(c)(3) tax exempt charitable organization focused on education, advocacy, and applied research
- We are the creators of innovative solutions for our members' challenges and are committed to developing new ways to improve operations and quality of service
- We are the trusted voice for aging and envision an America freed from ageism

## Our Members

Our members are driven by a higher moral purpose to help transform the field of aging from the ground up.

LeadingAge's membership includes:

- 6,000+ nonprofit organizations representing the entire field of aging services
- 38 state partners
- Hundreds of businesses, consumer groups, foundations and research partners

## Our Impact

There is little that LeadingAge members do that doesn't have a ripple effect on individuals, their families, providers, and communities. Together, our members touch over 4 million lives a day.

With a passion and dedication for helping older people live and thrive wherever they call home, LeadingAge is the catalyst for innovation, providing creative approaches for new and needed services for older adults. LeadingAge inspires, serves, and advocates on behalf of today's elders and for the future of aging services.

The Trusted Voice for Aging

For more information, please visit [LeadingAge.org](http://LeadingAge.org)

**LeadingAge**<sup>®</sup>

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@LeadingAge   

**Janine Finck-Boyle**

Vice President, Regulatory Affairs

Janine Finck-Boyle, MBA/HCA, LNHA is the Vice President of Regulatory Affairs for LeadingAge. In her current position, she oversees the public policy team that specializes in the regulations and operations for all members. She is responsible for managing LeadingAge's response to and intervention in the regulatory-related issues impacting LeadingAge members, including implementing an effective process for state and member input into proposal rules, ensuring LeadingAge is responsive and thorough in its comments, engaging in dialogue with federal agencies on regulatory matters and coordinating work in and across issues where regulations may align. She came to LeadingAge, over a year ago as the Director of Health Regulations and Policy, working directly, with the nursing home members. Ms. Finck-Boyle is a licensed nursing home administrator for twenty years (20) and has worked in both the non- profit and for profit section of long term services and supports. She was the C.E.O and Administrator of Hadley Memorial Hospital and SNF and built the long term acute care hospital setting in D.C. Before coming to LeadingAge, Ms. Finck-Boyle was the Administrator of The Washington Home and Community Hospices, the oldest long term care facility in Washington, D.C. She has spent time in the cities of Boston and Cleveland, starting her career in health information systems and electronic medical records.





## IMPROVING HEALTH OUTCOMES FOR VULNERABLE SENIORS

Meals on Wheels America is a national leadership organization supporting 5,000+ local, community-based senior nutrition programs across the country through advocacy, education, research and national partnerships and campaigns. The nationwide network of independent programs collectively supports nearly 2.5 million seniors annually by delivering nutritious meals, friendly visits, safety checks and connections to services and resources in the community.

### OUR VISION

An America in which all seniors live nourished lives with independence and dignity

### OUR MISSION

To empower local Meals on Wheels programs to improve health and quality of life so no senior is left hungry or isolated

### OUR IMPACT

Meals on Wheels' evidence-based services provide a cost-effective solution that addresses the biggest threats to health and well-being of older adults. Malnutrition, social isolation and in-home safety hazards not only jeopardize seniors, but place a significant financial strain on our country's healthcare system. Our programs are welcomed into the homes of at-risk, homebound seniors, providing invaluable "eyes and ears" that can monitor health, identify changes in a senior's condition and intervene when needed. Meals on Wheels helps keep more seniors safe, healthy and independent at home, where they want to be.

#### NUTRITION

Nutrition is a vital component of assuring the health and well-being of older adults, but access to good nutrition can be a challenge as we age. Plus, age-related biological, social, economic and functional challenges can limit an older adult's ability to acquire, prepare and consume nutritious foods. The core of Meals on Wheels services is the delivery of consistent, nutritious meals.

#### SOCIALIZATION

Older adults with limited social supports are less able to access in-home and community-based services, and research suggests that chronic social isolation is associated with serious health challenges. Meals on Wheels provides social interaction that contributes to overall physical and emotional well-being of homebound seniors, reducing isolation and loneliness and increasing positive health outcomes.

#### IN-HOME SAFETY

Seniors often want to remain living in their own homes for as long as possible; however, in-home safety hazards – if left unaddressed – increase the likelihood of a harmful fall and other health problems. Daily, home-delivered meals for homebound seniors have been shown to reduce the rate of falls among this at-risk population. Meals on Wheels programs can identify and address potential dangers, helping seniors to feel safe and more secure in their own homes.

#### CARE COORDINATION

In the case of a health event in a homebound senior's life, their condition and environment must be closely and regularly monitored, often requiring coordination across multiple parties. Community-based Meals on Wheels programs provide the ability to monitor and report changes in condition or environment in the home on a regular basis, and facilitate community connections and interventions that enhance the health, safety and well-being of seniors.

For more information, visit [www.mealsonwheelsamerica.org](http://www.mealsonwheelsamerica.org).

## **MEALS ON WHEELS AMERICA**

The mission of the National Association of Area Agencies on Aging (n4a) is to build the capacity of our members so they can help older adults and people with disabilities live with dignity and choices in their homes and communities for as long as possible. n4a is a 501(c)(3) membership association representing America's national network of 622 Area Agencies on Aging (AAAs) and providing a voice in the nation's capital for the more than 250 Title VI Native American aging programs. Our vision is to build a society that values and supports people as they age.

### **Marci LaFevre**

Senior Director, Care Coordination

With 15-plus years of experience in the nonprofit sector, Marci joined Meals on Wheels America to advance the Association's strategy, programmatic work, partnerships and thought leadership in the area of Care Coordination. In this role, she works closely with her colleagues, Meals on Wheels programs around the country, and external partners to integrate and scale the delivery of nutrition, safety, socialization, and care coordination services. Prior to joining Meals on Wheels America, Marci worked at AARP and the Southeast Senior Housing Initiative (Baltimore, MD), where she developed and led national and community-based programs that helped older adults age in place in their homes and communities, and enhanced their health and economic security. Marci She holds a Master's degree in Public Policy and Women's Studies from The George Washington University and a Bachelor of Arts degree in International Relations and Political Science from The College of Wooster.



## **NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING (n4a)**

The mission of the National Association of Area Agencies on Aging (n4a) is to build the capacity of our members so they can help older adults and people with disabilities live with dignity and choices in their homes and communities for as long as possible. n4a is a 501(c)(3) membership association representing America's national network of 622 Area Agencies on Aging (AAAs) and providing a voice in the nation's capital for the more than 250 Title VI Native American aging programs. Our vision is to build a society that values and supports people as they age.

### **Amy Gotwals**

Chief, Public Policy and External Affairs

Amy E. Gotwals joined n4a in September 2005 and currently serves as Chief, Public Policy and External Affairs, a position created in 2014. Amy previously served as Director, Public Policy and Legislative Affairs.

In her role, Amy leads n4a's public policy, advocacy, communications, external relations and membership relations activities. Representing local aging agencies, Amy serves as the lead in outreach to Congress and the Administration to ensure that needed resources and support services are available to older Americans and their caregivers.



Amy has 22 years of public policy, lobbying and grassroots organizing experience. She has represented diverse groups including the Older Women's League, the Center for Science in the Public Interest, the Alliance of Nonprofit Mailers and the National Network for Youth.

Amy has a Bachelor's degree in American Studies from Mount Holyoke College and earned a Master of Legislative Affairs from the George Washington University.

### **Mary Kaschak**

Deputy Director, Aging and Disability Business Institute

Mary Kaschak, Deputy Director, Aging and Disability Business Institute, joined n4a in 2009. Mary provides technical assistance designed to leverage the infrastructure, service capacity and expertise of aging and disability community-based organizations, enabling them to play a meaningful role in the delivery of efficient, high-quality managed long-term services and supports (MLTSS) and other integrated care initiatives.

Mary also leads an n4a initiative with the primary objective of assisting the Aging Network in evaluating its effectiveness in key programmatic areas related to systems change. By gathering and analyzing data on Aging Network progress in health and long-term care programs, she helps the Network determine the impact and success of programs and provides guidance for future planning and training.



Prior to joining n4a, Mary worked as a graduate research assistant at Scripps Gerontology Center at Miami University while pursuing a Master of Gerontological Studies. Her graduate work focused on LTSS, social policy and quantitative research. Mary also holds a BA in Scientific and Technical Communication from Miami University.



National Hispanic Council on Aging (NHCOA), established in 1979, is the largest constituency-based organization representing Hispanic older adults in the world. An umbrella organization, NHCOA represents a network of 42 community-based organizations across the continental U.S., the District of Columbia, and Puerto Rico. The organization maintains a broader network of 7,000 individuals and reaches 10 million Hispanics each year through its work and that of its affiliates. NHCOA's mission is to improve the quality of life for Hispanic older adults, their families, and caregivers.

Headquartered in Washington, DC, at Casa Iris, with satellite offices in Dallas, Texas and Miami, Florida, NHCOA is a strong voice dedicated to promoting, educating, and advocating for research, policy and practice in the areas of health, economic security, leadership and housing. NHCOA manages many multi-state program operations and core organizational functions. It is recognized nationally for its effective programs and high-quality research projects, its qualified and dedicated staff, and its unique ability to reach its constituency in a culturally, linguistically, and age-appropriate manner.

**Yanira Cruz, DrPH**

President and Chief Executive Officer

Dr. Yanira Cruz is the President and CEO of the National Hispanic Council on Aging. She focuses on providing the Latino perspective on public health, older adult and caregiver issues to increase policy-maker and public understanding of the needs impacting vulnerable sectors of our society, and to encourage the adoption of programs and policies that equitably serve everyone. To further these efforts, Dr. Cruz serves on the National Senior Citizens Law Center and is a member of the Leaders of Aging Organizations (LAO) collaborative - Eight of the nation's leading aging-focused organizations have formed this unprecedented partnership to create a better public understanding of older adults' needs and contributions to society — and subsequently to improve the lives of all people as they age. She is also a founding member of the Diverse Elders Coalition and Executive Committee Member of the National Hispanic Leadership Agenda (NHLA). Dr. Cruz is an appointee serving on the Advisory Council on Alzheimer's Research, Care, and Services, which advise the Secretary of the Department of Health and Human Services. She holds adjunct faculty appointment at The George Washington University School of Public Health.





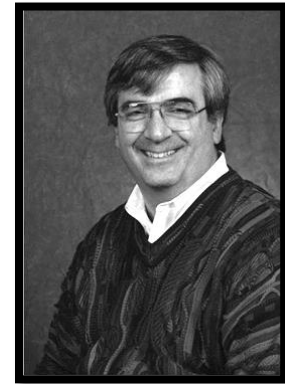


**WORKSHOP SPEAKERS, MODERATORS, AND PLANNING COMMITTEE MEMBERS**

**Robert A. Bergamini, MD**

Mercy Clinic Children's Cancer and Hematology  
*Representing the Supportive Care Coalition*

Robert A. Bergamini has spent most of his 35-year career as a pediatric hematologist-oncologist, and from the beginning, included palliative care as a priority of his practice before the field was formally defined. This approach to whole person care provided a firm foundation for his current role as Mercy's ministry-level Medical Director for Palliative Care, which serves 39 hospitals and outpatient facilities/clinics across Missouri, Oklahoma, Arkansas and Kansas. He was appointed in 2013 to the Supportive Care Coalition's Board of Directors and is a member of the Coalition's Executive Committee. He is the chair-elect for 2019.



Following his Fellowship in Pediatric Hematology Oncology at St. Louis Children's Hospital, Washington University Department of Pediatrics, and serving as Clinical Instructor in Pediatrics at Washington University, in 1985 Dr. Bergamini entered private practice at Mercy St. Louis. Dr. Bergamini and his team established the first support group in the St. Louis area for siblings of children with cancer, and an educational support and intervention program to provide supplemental educational assistance and diagnostic testing. With the help of patients and staff, Friends of Kids with Cancer, a local charity was founded.

Under Dr. Bergamini's leadership as Mercy's medical director of palliative care services, programs have started in three new communities and a pilot program is under way for palliative care and hospice care via telemedicine to meet the ministry's large rural population where density is less than six people per square mile. Mercy now has an accredited palliative care fellowship and welcomed their first fellow on July 1, 2017. Dr. Bergamini serves as the medical liaison to local faith-based communities. Initiatives include providing palliative care education in the communities served by Mercy. In 2016, Dr. Bergamini became the director of the Mercy Kids Complex Care Team. This team provides care to children with complex illness across the communities that are served by Mercy with a combination of outreach clinics, home care, and telemedicine.

**Amy Berman, BSN, LHD**

John A. Hartford Foundation



Amy Berman is a Senior Program Officer at the John A. Hartford Foundation, and heads the Integrating and Improving Services program, focusing on developing innovative, cost-effective models of care for older adults. She also directs a number of collaborations with the U.S. Administration on Aging/AARP that address the needs of family caregivers. Prior to joining Hartford, Ms. Berman served as Nursing Education Initiatives Director at the Hartford Institute for Geriatric Nursing at New York University's College of Nursing, and before that she worked in home health care administration. She has also served on the New York State

Department of Health's Emergency Preparedness Task Force, and is a member of numerous organizations, among them the Aging Task Force for Healthy People 2020, the Gerontological Society of America, and the Honor Society of Nursing, Sigma Theta Tau. Ms. Berman earned a B.S. in nursing from New York University, a B.S. in health care administration from the University of Massachusetts, Amherst, and a Geriatric Scholar Certificate from the Consortium of New York Geriatric Education Centers.

**Lynn Friss Feinberg, MSW**  
AARP Public Policy Institute

Lynn Friss Feinberg is Senior Strategic Policy Advisor at the AARP Public Policy Institute, responsible for family caregiving and long-term care issues. She came to AARP from the National Partnership for Women & Families, serving as the first Director of the Campaign for Better Care. Previously, Ms. Feinberg served as Deputy Director of the National Center on Caregiving at the San Francisco-based Family Caregiver Alliance (FCA). At FCA, she directed the National Consensus Project for Caregiver Assessment, and led the first 50-state study on publicly-funded caregiving programs in the U.S. She has published and lectured widely on family care policy and practice, and has held leadership positions on numerous advisory boards and committees to address aging, caregiving, and long-term care issues, including the American Bar Association's Commission on Law and Aging, the National Academies of Sciences, Engineering, and Medicine's Committee on Family Caregiving for Older Adults, and as Chair of the American Society on Aging (ASA) Board of Directors. Currently, Ms. Feinberg is Chair of the Public Policy Committee at the Gerontological Society of America (GSA), and an elected member of the National Academy for Social Insurance (NASI). In 2007-2008, Ms. Feinberg was selected as the John Heinz Senate Fellow in Aging, serving in the office of former U.S. Senator Barbara Boxer. In 2015, she received the Paul Nathanson Distinguished Advocate Award from Justice in Aging, for her career work on family care issues. Ms. Feinberg holds a master's degree in social welfare and gerontology from the University of California at Berkeley.



**Sarita Gupta**  
Caring Across Generations



Sarita Gupta is the Co-Director of Caring Across Generations, a national movement with over 200 national, state and local partner organizations, working to transform the way we care for one another in America. Caring Across Generations harnesses the power of social action, social media and storytelling to spark connections across generations, strengthen family and caregiving relationships, and advocate for policies that protect the dignity of seniors, people with disabilities and the people who care for them. Sarita is also the Executive Director of Jobs With Justice. She is a nationally recognized expert on the economic, labor and political issues affecting working people across all industries, particularly women and people employed in low-wage sectors, and on issues related to home care. As a member of the "sandwich generation," Sarita is grappling with and can speak to the care issues facing more and more Americans, balancing caring for

young children with caring for aging parents. She is a family care provider for her father who has Alzheimer's. She lives in Silver Spring, MD with her husband, daughter, and parents.

**Gwendolyn Graddy-Dansby, MD**

PACE Southeast Michigan



Gwendolyn Graddy completed her undergraduate education at the University of Michigan, Ann Arbor and medical school at Wayne State University School of Medicine in 1984. In 1987, she joined the Henry Ford Health System (HFHS). She is Board Certified in Internal Medicine and has achieved additional certification in Geriatric Medicine. She is Chair of the National PACE Association's Primary Care Subcommittee and is a Fellow in the American College of Physicians.

She is currently the Chief Medical Officer for PACE Southeast Michigan, which she joined in 2001. Dr. Graddy has helped develop the Utilization Management process at PACE Southeast Michigan, which has resulted in reduction of 30-day readmissions, avoidable ED visits and improvement of flu vaccine compliance.

Special interests include: Alzheimer's disease, Nursing Home care, Spirituality, Aging and Wellness, health disparities and cultural competency, the role of women's support groups on stress reduction and improvement of work-life balance just to name a few. She speaks extensively on healthy aging, caregiving and Alzheimer's dementia. She is the founder of Daughters of Christ Standing Steadfast (DOCSS).

Hour Detroit Magazine has consistently named Dr. Graddy as "Top Doc" in her field. In 2015, Crain's Detroit Business named her as Healthcare Hero and the Henry Ford Health System presented her with the Diversity Hero Award. She is also a Physician Advisor for Community Catalyst.

**Kathy Greenlee, JD**

Center for Practical Bioethics

Kathy Greenlee is the Vice President of Aging & Health Policy at the Center for Practical Bioethics (CPB) where her work focuses on advance directives and end of life planning, health care reform, strengthening community organizations and raising awareness about elder abuse. During her career, Kathy has worked on programs and policies at the local, state, national and international level. In addition, Kathy has worked closely with members of the disabilities and LGBT communities to improve access to community-based and culturally competent services. Prior to joining CPB, Kathy had a 25-year career in public service. In 2009 she was appointed U.S. Assistant Secretary for Aging by President Obama. She served in that position, located within U.S. Department of Health and Human Services, until July 2016. Before leaving for Washington, Kathy spent 18 years in Kansas state government. Among the positions she held was Kansas Secretary of Aging, Kansas State Long-Term Care Ombudsman, General Counsel of the Kansas Insurance Department, and Assistant Attorney General. She served as the first Chief of



Staff for then-Governor Kathleen Sebelius. Throughout her career, Kathy has been known as a visionary leader with a deep commitment to public service. Kathy graduated from the University of Kansas with a B.S. in Business Administration and a J.D. from the KU School of Law. Kathy currently services on numerous boards and commissions including the National Council on Aging, the American Bar Association Commission on Law and Aging, the National Academies of Medicine Forum on Aging, Disability and Independence and Saint Luke's Home Care and Hospice. For more information, please visit [www.kathygreenlee.com](http://www.kathygreenlee.com).

**Haiden Huskamp, PhD**  
Harvard Medical School



Haiden Huskamp is a health economist and 30th Anniversary Professor of Health Care Policy at Harvard Medical School. Dr. Huskamp has three primary areas of research: 1) the financing and utilization of end-of-life care services; 2) mental health and substance use disorder policy; and 3) prescription drug policy. Dr. Huskamp's research on end-of-life care has examined the changing characteristics of the hospice industry and the effects of industry changes on the provision of end-of-life care, the timing of discussions about hospice care that occur between physicians and patients, and patient-level variation in hospice costs. She served on the Centers for Medicare and Medicaid Services Technical Expert

Panel for Hospice Payment Reform and on the Institute of Medicine Committee on Care for Children Who Die and Their Families. Dr. Huskamp recently authored a paper on the financing of end-of-life care services published in the Institute of Medicine report "Dying in America."

**Kimberly Johnson, MD**  
Duke University School of Medicine

Kimberly Johnson is an Associate Professor of Medicine with Tenure in the Division of Geriatrics and a Fellow in the Center for the Study of Aging and Human Development at Duke University School of Medicine. She received her undergraduate education at Dillard University in New Orleans, Louisiana and her M.D. from Johns Hopkins University School of Medicine. She completed her residency training in Internal Medicine, fellowship in Geriatrics, and clinical research training (MHS) at Duke University. Dr. Johnson is board-certified in Internal Medicine, Geriatrics, and Hospice and Palliative Medicine and provides clinical care to seriously ill adults in long-term care and inpatient settings. Dr. Johnson's research focuses on understanding and eliminating racial disparities in palliative and end-of-life care. She has published widely and is nationally recognized for her work investigating how cultural beliefs and preferences and organizational practices and policies may influence the use of hospice care by older African Americans. Dr. Johnson has received awards for her research from the American Academy of Hospice and Palliative Medicine and the American Geriatrics Society. She was the recipient of the prestigious Beeson Career Development Award in Aging Research and the National Palliative Care Research Center Career Development Award, and has received additional research funding from the NIA, Greenwald Foundation, and AHRQ.





**Will Kennedy, DO**  
CareOregon



Will Kennedy is the Senior Medical Director for Advanced Illness at CareOregon. Will completed a fellowship in hospice and palliative medicine at the Mount Carmel Health System, in Columbus, Ohio, in 2005. In Oregon, he served as medical director for hospice and palliative medicine programs before joining CareOregon in 2013. Over this time, CareOregon has participated in Duke University's palliative care quality consortium, the Nous Foundation's Advance Care Planning program, and the Coalition to Transform Advanced Care's efforts to develop a sustainable model for underserved palliative care. Recent work has included a partnership with Central City Concern to build a dedicated inpatient palliative care unit for the homeless (scheduled to open in early 2019). Finally, CareOregon recently merged with

Housecall Providers, a non-profit home based care organization providing primary, palliative and hospice services, to create a continuum of care for vulnerable populations in the Portland metro area.

**Sutep Laohavanich**  
Gordon and Betty Moore Foundation

Sutep's background and experience has focused on serving older adults and vulnerable populations through the creation and implementation of healthcare and long-term care delivery systems.

Prior to joining the foundation, he managed two separate Health Care Innovation Awards at the University of California, San Francisco and at the Pacific Business Group on Health; funded by the Center for Medicare & Medicaid Innovation aimed at serving high-risk beneficiaries and care delivery innovation. Sutep has also consulted for state units on aging and health services in Hawaii, Alaska, Illinois and Minnesota in long-term supports and services focused on home and community based services. Earlier in his career, Sutep was an information systems developer at Merck Research Laboratories in vaccine development. Sutep has a master's in gerontology from the University of Southern California, Davis School and is a graduate of the University of California, Berkeley with a bachelor's degree in molecular and cell biology.



**Joanne Lynn, MD**  
Altarum Institute



Joanne Lynn is the Director at Altarum's Center for Elder Care and Advanced Illness. Dr. Lynn M.D., M.A. (philosophy and public policy), M.S. (evaluative clinical sciences) is a geriatrician, hospice physician, health services researcher, quality improvement advisor, and policy advocate who has focused upon shaping American health care so that every person can count on living comfortably and meaningfully through the period of serious illness and disability in the last years of life, at a sustainable cost to the community. She now leads the

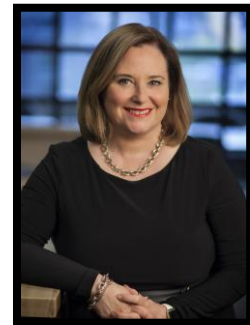
Program to Improve Eldercare for Altarum. Dr. Lynn has been a consultant to the Administrator of the Centers for Medicare & Medicaid Services, a faculty member of the Institute for Healthcare Improvement, and a clinical expert in improvement for the Care Transitions Project at the Colorado Foundation for Medical Care. She has also been a senior researcher at RAND and a professor of medicine and community health at Dartmouth Medical School and The George Washington University. Dr. Lynn has published more than 250 professional articles, and her dozen books include *MediCaring Communities: Getting What We Want and Need in Frail Old Age at an Affordable Cost*, a model for reform; *The Handbook for Mortals*, a guide for the public; *The Common Sense Guide to Improving Palliative Care*, an instruction manual for clinicians and managers seeking to improve quality; and *Sick to Death and Not Going to Take it Any More!*, an action guide for policymakers and advocates. She has also authored amicus briefs for key appellate court cases and has been often interviewed by reporters. Dr. Lynn is a member of the National Academy of Medicine and the National Academy of Social Insurance, a fellow of the American Geriatrics Society and The Hastings Center, and a Master of the American College of Physicians. Her areas of expertise include chronic disease management, end of life care, quality improvement, and community organizing.

**Peggy Maguire, JD**

Cambia Health Foundation

Peggy serves as president of the Cambia Health Foundation, where she works with a wide range of stakeholders to advance palliative care leadership, access and awareness through Sojourns, the Foundation's signature program. As a member of Cambia Health Solutions senior leadership team, Peggy also orchestrates Cambia's comprehensive approach to improving care for people living with serious illness, which includes a regional health plan program known as "Personalized Care Support," as well as resources for family caregivers and strategic investments that address aging, caregiving and coordinated care.

Peggy is very active in the philanthropic community. She chairs the Board of Directors of the Doernbecher Children's Hospital Foundation. She also serves as a member of the All Hands Raised Leadership Council, and is a senior fellow of the American Leadership Forum of Oregon. Peggy chaired the American Heart Association's Go Red for Women campaign in 2017. She is the immediate past chair of the national board of Friends of the Children and the Oregon-based Start Making a Reader Today (SMART).



In 2017, Portland Monthly magazine recognized Peggy as an Extraordinary Board Member for her service to the community and her leadership of the Cambia Health Foundation. Peggy was honored by Dress for Success Oregon with its Athena Award in 2016, by the Girl Scouts of Oregon and Southwest Washington as a Woman of Distinction in 2015, and by the Portland Business Journal as a Woman of Influence in 2014. Peggy received her bachelor's degree in philosophy and anthropology from Lawrence University and her law degree from Northwestern School of Law of Lewis and Clark College. She completed the Stanford Executive Program in 2016, and is a member of the Stanford Graduate School of Business Alumni Association.

**Jeri L. Miller, MS, MSc, PhD**

National Institute of Nursing Research, NIH



Jeri Miller is Chief, Office of End-of-Life and Palliative Care Research, National Institute of Nursing Research (NINR), National Institutes of Health (NIH). NINR, the lead NIH institute for end-of-life research, established the Office of End-of-Life and Palliative Care Research (OEPCR) to support the ongoing research efforts in end-of-life and palliative care science, including stimulating research initiatives, creating opportunities for collaborative activities and facilitating interdisciplinary science. In her role as OEPCR Chief, Dr. Miller coordinates the development, implementation and evaluation of end-of-life and palliative care science in interdisciplinary collaboration with the senior leadership of NINR, NIH Institutes, federal research agencies, academia, and other outside experts

and constituencies. The Office builds on work Dr. Miller led as the former lead science policy analyst and Head of the NINR Office of End-of-Life and Palliative Care Research, Training, and Education, including support of numerous NIH symposia on the state-of-the-science, NINR's pediatric palliative care national awareness campaign, and the development of the report titled: "Building Momentum: The Science of End-of-Life and Palliative Care", which looks at the trends in end-of-life and palliative care research, including information on federal research awards, funding patterns, and the contributions of public and private investments in end-of-life and palliative care science. Dr. Jeri L. Miller was a previous NIH Intramural Program scientist with expertise in biomedical and clinical research.

**Debra Parker Oliver, PhD**

University of Missouri School of Medicine

Debra Oliver wants to improve the dying experience for individuals diagnosed with a terminal illness and find ways to support family members who dedicate their time and energy to assure comfort for those they love. The hospice patients and families in her research reside either at home or in a nursing home. As the principal investigator on a National Institute of Aging grant, Dr. Oliver is studying the use of web conferencing to help families of nursing home patients attend quarterly plan-of-care meetings. Also, with funding from the National Cancer Institute, she is studying the use of Facebook to provide education and support to caregivers of cancer patients.



**Sharon Scribner Pearce**

National Hospice and Palliative Care Organization



Sharon Scribner Pearce has served as the Vice President for Public Policy at the National Hospice and Palliative Care Organization (NHPCO) since 2015. In that role, Sharon serves as the primary liaison between Capitol Hill and the NHPCO leadership and membership; manages the day-to-day operations of the NHPCO Hospice Action Network (HAN); leads a dynamic team of policy professionals; and coordinates advocacy and policy work across the department and organization. Sharon arrived at NHPCO with almost 20 years of health policy experience, including six years advising members of Congress on Capitol Hill, five years as a hired-gun lobbyist at a large K Street firm, and seven years as in-house lobbyists at the National PACE Association and Girl Scouts of the USA.

**Judith R. Peres, LCSW-C**

Social Work Hospice and Palliative Care Network

Judith Peres is an Expert Consultant in the Nursing Home and Palliative/End-of-life care policy and a clinical social worker serving Medicare Beneficiaries. Her career spans over four decades in health policy development and analysis and in direct clinical work. In her capacity as a policy consultant, Ms. Peres has worked with the Altarum Institute's Center for Elder Care and Advanced Illness, the Center for Practical Bioethics and the National Institute of Nursing Research. In addition, she worked for the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, where she developed a report to Congress on advance care planning. She also served as vice president for policy and advocacy at the former Last Acts Partnership—an initiative of The Robert Wood Johnson Foundation—where she developed major policy pieces such as *Means to A Better End*, the first national report on the state of dying in the United States. Ms. Peres has led health policy efforts at the American Association of Homes and Services for the Aging (currently Leading Age) and the Villers Foundation (currently Families USA). She began this journey with 15 years at the Department of Health and Human Services working in Medicare and Medicaid reimbursement and financing policy. She has served on the Board of Directors of the Social Work Hospice and Palliative Care Network (SWHPN) since its inception in 2007. Ms. Peres has a Master of Social Work from the University of Maryland and post-graduate training at the Mind/Body Institute in Washington, DC, and Rational Emotive Behavioral Therapy at the Albert Ellis Institute in New York. She served on the Institute of Medicine committee that authored the 2014 report *Dying in America*, and represents SWHPN on the Roundtable on Quality Care for People with Serious Illness.





**JoAnne Reifsnyder, PhD, RN, FAAN**

Genesis Healthcare

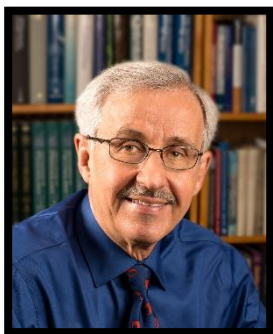
*Representing the Hospice and Palliative Nurses Association*

JoAnne Reifsnyder has been the Chief Nursing Officer of Genesis Healthcare, Inc. since July 2012 and also serves as its Executive Vice President of Clinical Operations. Dr. Reifsnyder has held executive and leadership roles in both for profit and not for profit health care settings. Prior to joining Genesis, Dr. Reifsnyder was Senior Vice President, Care Transitions, with Moorestown, NJ-based Care Kinesis, LLC. In this role, she served as a consultant to Genesis HealthCare and to Bayada Nurses, working with executives and clinical team members to develop a skilled nursing facility to home transitional care model for vulnerable older adults. Dr. Reifsnyder was Chief Quality Outcomes officer for excelleRx, Inc., a Philadelphia-based medication management therapy company. She was also co-founder and partner in Ethos Consulting Group, LLC, a company focused on program development, education/training and research/evaluation to advance end of life care. She was formerly the Director of the Hospice Program for the VNA of Greater Philadelphia and was Director of Patient Services for Samaritan Hospice in Marlton, NJ. Dr. Reifsnyder served as President of the Board of Directors for the Hospice and Palliative Nurses Association, Pennsylvania Hospice Network, and LifeChoice Hospice and currently serves on the Board of Hospice Foundation of America. She is a member of the American Nurses Association, the American Academy of Nursing, American Organization of Nurse Executives (AONE), the National Gerontological Nurses Association (NGNA) and Sigma Theta Tau International, the Honor Society of Nursing. In 2002, Dr. Reifsnyder co-developed and was the coordinator of a palliative care minor at the University of Pennsylvania School of Nursing, where she taught both core courses to nursing, social work and medical students. In 2009, she led the development of the first Masters' program in Chronic Care Management at Jefferson School of Population Health (JSPH), Thomas Jefferson University in Philadelphia, PA. Dr. Reifsnyder completed a postdoctoral fellowship in psychosocial oncology at the University of Pennsylvania School of Nursing, and holds a PhD in nursing from the University of Maryland, a Master's Degree in nursing from Thomas Jefferson University, and a BSN from Holy Family College. She will complete the requirements for a Masters in Business Administration from George Washington University in December, 2016.



**Richard Schulz, PhD**

Aging Institute of UPMC Senior Services and the University of Pittsburgh



Richard Schulz is Distinguished Service Professor of Psychiatry, Director of Gerontology, and Associate Director of the Aging Institute of UPMC Senior Services and the University of Pittsburgh. He earned his PhD in social psychology from Duke University.

Dr. Schulz has spent most of his career doing research and writing on adult development and aging. His work has focused on social-psychological aspects of aging, including the impact of disabling late life disease on patients and their families. He has been funded by the National Institutes of Health for more than three decades to conduct descriptive longitudinal and intervention research on diverse older

populations representing illnesses such as cancer, spinal cord injury, stroke, Alzheimer's disease, heart disease, and arthritis.

He has been a leading contributor to the literature on the health effects of caregiving, Alzheimer's disease caregiving, and intervention studies for caregivers of persons with Alzheimer's disease. This body of work is reflected in more than 300 publications, which have appeared in major medical, psychology, and aging journals including the New England Journal of Medicine, the Journal of the American Medical Association, and the Archives of Internal Medicine. He is also the author of numerous books, including Handbook of Alzheimer's Caregiver Intervention Research; Quality of Life Technology Handbook; and Families Caring for an Aging America.

In the last decade, Dr. Schulz has become interested in supportive interventions, including technology-based approaches designed to enhance patient functioning and quality of life of both patients and their families.

Dr. Schulz is the recipient of several honors, including the Kleemeier Award for Research on Aging and the Distinguished Mentorship in Gerontology Award from the Gerontological Society of America, and the M. Powell Lawton Distinguished Contribution Award for Applied Gerontology, the Baltes Distinguished Research Achievement Award, and the Developmental Health Award for Research on Health in Later Life from the American Psychological Association. In 2014, he was appointed by The National Academies of Sciences • Engineering • Medicine to Chair the Committee on Family Caregiving for Older Adults.

**Katrina Scott, MDiv, BCC-HPCC**

Massachusetts General Hospital

*Representing the Association of Professional Chaplains*

Katrina Scott is the Oncology Chaplain and Palliative Care Service Chaplain Liaison at Massachusetts General Hospital and represents the Association of Professional Chaplains, a national not-for-profit professional association with more than 5000 members that advocates for quality spiritual care. Her ministry focuses on supporting and nourishing the spiritual resources of patients and families in dealing with a life threatening illness and also recognizes the clinical importance of supporting health care providers in ensuring patient-centered care. She has written and presented extensively on providing spiritual care to patients/families, advanced care planning and end of life care issues. Ms. Scott is Board Certified by the Association of Professional Chaplains and holds a Specialty Certification in Hospice and Palliative Care. She received her Master of Divinity from Harvard Divinity School and is endorsed by the American Ethical Union (Ethical Culture).



**Joseph Shega, MD**

VITAS Hospice Care

*Representing the American Geriatrics Society*



Joseph Shega joined VITAS in 2013 as a regional medical director, but he has been caring for, studying and teaching about geriatric patients and end-of-life care since 1999. He came to VITAS with a mission: to improve access to hospice services for underserved populations. In addition, Dr. Shega's focus is on the care transition to hospice and palliative care as a way to meet the goals of all stakeholders. As a regional medical director, Dr. Shega oversees the medical care and treatment of VITAS patients in their homes, nursing homes, assisted living communities, personal care homes and inpatient units in Florida and Georgia, as well as the physicians in those programs. He is board certified in geriatrics and hospice and palliative medicine. He chairs the Ethics Committee for the American Geriatrics Society and previously served on the Quality Committee for the American Academy of Hospice and Palliative Medicine. Prior to joining VITAS, Dr. Shega was an associate professor of medicine at the University of Chicago in geriatrics and palliative medicine. He worked as a primary care physician for 13 years on Chicago's South Side, providing inpatient geriatric and palliative medicine consults, inpatient palliative care, nursing home care, outpatient geriatrics, home visits and hospice services. He also evaluated and managed patients with memory disorders from diagnosis to the end of life. Dr. Shega completed medical school at Northwestern University in Chicago, residency in internal medicine at the University of Pittsburgh and a geriatrics fellowship at University of Chicago.

**W. June Simmons, MSW**

Partners in Care Foundation

June Simmons, President and CEO, has enjoyed a long career as a health care executive in hospital and home health settings. Since founding Partners in Care in 1997, June has pioneered the development and scaling of evidence-based innovative interventions for management of medications at home, self-management of chronic conditions, coordinated care to improve health outcomes, and care transitions.



Throughout her distinguished career, she has been instrumental in envisioning, creating, funding, and operating forward-looking health and social service programs that meet the mutual needs of patient populations, health care delivery networks and health plans. Her priority is sustainable patient-driven integration of care across settings, from primary care and hospital to home and community in the 21st century.

Partners continues to serve as a catalyst for shaping a new vision of health care by partnering with organizations, families, and community leaders in the work of changing health care systems, communities and lives. Partners in Care is now building prototype regional community delivery systems for the new health environment, developing strong partnerships between medicine, home and community based services and those who draw on the health and community systems of care. Partners also works to scale these innovations through shared learning systems at the national level.

**MaryAnn and Frank Spitale**  
Patient-Caregiver Voice



MaryAnn And Frank Spitale are both Medicare beneficiaries, who care for their daughter, Andi, who is a wheelchair-bound young adult with a developmental disorder. In these later years, both Frank and Mary Ann are dealing with their own chronic conditions and, unfortunately, Frank has been challenged by multiple hospitalizations and serious illness in this last year (COPD, CHF, osteoporosis, sepsis, bladder cancer). The Spitales moved from their home in Michigan to Maryland in order to be closer to their oldest daughter and help care for Andi, which they are finding increasingly difficult due to age and illness.

**Tanya L. Stewart, MD, MBA, FAAHPM, HMDC**  
UnitedHealthcare Retiree Solutions

Tanya Stewart is the Senior Medical Director for UnitedHealthcare Retiree Solutions. In this role, Dr. Stewart is responsible for developing innovative clinical programs, quality improvement initiatives, revenue accuracy and affordability initiatives. She oversees and ensures effective execution of the business' clinical programs and operations, Medicare payment management and provider engagement. Dr. Stewart joined UnitedHealth Group in 2010 as market medical director for Evercare of Oregon. During that time, Dr. Stewart expanded her responsibilities within the organization to support Washington State and California. In 2013, she became the medical director for a new division of Optum called Care Plus in the Community, a longitudinal home visiting program serving the Northern California's frail elderly and disabled populations. Nationally, Dr. Stewart served as a founding member and exam committee chair of the Hospice Medical Director Certification Board. She has served on or chaired many committees for the American Academy of Hospice and Palliative Medicine including public policy committee, nominating committee, industry relations taskforce, heart failure special interest group chairperson and annual assembly conference planning.



Dr. Stewart is a nationally recognized speaker with invitations to speak at numerous conferences including: American Academy of Hospice and Palliative Medicine; the American Medical Directors annual meeting; Oregon Geriatrics Society; Statewide Palliative Care Conference of Oregon; Washington Guardian Association; and Florida Hospice and Palliative Care Association. Over her career she has chaired three conferences: one state, one national and one international. Attendance at these conferences has ranged from 400-1400 attendees. She has multiple publications in the Journal of Palliative Medicine on topics such as palliative sedation, defibrillators at the end of life and intravenous fluid use at the end of life.

Prior to joining UnitedHealth Group, she worked as a primary care physician at Northwest Permanente in both the inpatient and outpatient setting. She then transitioned to the role of

hospice medical director at Adventist, where she spent the next five years developing the program, creating a home visiting clinic, and cultivating community volunteer partnerships. During this time she was recognized as a clinical professor of medicine by Oregon Health & Sciences University, where she created the first residency and medical school home visiting rotation and also co-taught a course called “Living with Life Threatening Illness”.

Dr. Stewart is a member of several professional organizations, including; the American Medical Association, the American College of Physicians, the American Geriatrics Society, the American Academy of Hospice and Palliative Medicine and the American Medical Directors Association. In 2010, she was honored with the Sojourn’s Award for leadership in Palliative Care for the state of Oregon and donated the \$50,000 award to Adventist Home Hospice Outpatient Palliative Care initiative.

Dr. Stewart graduated with honors from the University of San Diego in San Diego, California where she double majored in biology and religious studies and minored in biochemistry. She earned her medical degree from Tufts University, School of Medicine in Boston, Massachusetts. She completed her internal medicine residency at Legacy Health System in Portland, Oregon. Dr. Stewart is board certified by the American Board of Medical Specialty in Internal Medicine as well as Hospice and Palliative Medicine. She is also certified as a hospice medical director by the Hospice Medical Director Certification Board. In June of 2017, Dr. Stewart graduated with an MBA in health care from Oregon Health & Sciences University and Portland State University.

### **Robyn Stone, DrPH**

LeadingAge

Robyn I. Stone, a noted researcher and internationally recognized authority on long-term care and aging policy, is Sr. VP for Research at LeadingAge. She has held senior research and policy positions in both the U.S. government and the private sector. She was a political appointee in the Clinton Administration, serving in the U.S. Department of Health and Human Services as Deputy Assistant Secretary for Disability, Aging and Long-term Care Policy and Assistant Secretary for Aging. Dr. Stone is a distinguished speaker and has been published widely in the areas of long-term care policy and quality, chronic care for the disabled, aging services workforce development, low income senior housing and family caregiving. She serves on numerous provider and non-profit boards that focus on aging issues. Dr. Stone is a fellow of the Gerontological Society of America and the National Academy of Social Insurance. She was elected to the National Academy of Medicine (formerly the Institute of Medicine) in 2014.





**Sarah Szanton, PhD, ANP, FAAN**

Johns Hopkins Bloomberg School of Public Health



Sarah L. Szanton is a Professor and Director of the Center for Innovative Care in Aging at the Johns Hopkins School of Nursing. She holds a joint appointment in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. She tests interventions to reduce health disparities among older adults. Her work particularly focuses on ways to help older adults “age in place” as they grow older. These include ways to improve the social determinants of health such as modifying housing and improving access to food. In 2016, she was named to the PBS Organization’s “Next Avenue 2016 Influences in Aging” a list of thought-leaders who are changing how we age and think about

aging in America. Szanton completed undergraduate work in African-American Studies at Harvard University and earned a bachelor’s degree from the Johns Hopkins School of Nursing. She holds a nurse practitioner master’s degree from the University of Maryland and a doctorate from Johns Hopkins University. She is Core Faculty at the Center on Aging and Health, the Hopkins Center for Health Disparities Solutions and Adjunct Faculty with the Hopkins Center for Injury Research and Policy. She has been funded by the National Institutes of Health, the Center for Medicare and Medicaid Services Innovation Center, the Robert Wood Johnson Foundation, the John A. Hartford Foundation, the Rita and Alex Hillman Foundation, and the AARP Foundation.

**Lauren Taylor, MDiv, MPH**

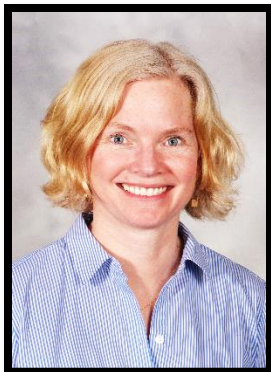
Harvard Business School

Lauren A Taylor is a health services researcher based at Harvard Business School, where she is earning her doctorate in health policy and management. Prior to joining HBS, Lauren co-authored a book titled *The American Health Care Paradox*, which has become required reading at a variety of medical and public health schools across the country. Lauren’s work focuses on organizational theory and strategy in health care, with a particular emphasis on the integration of health and social services. She holds a BA in the History of Medicine and a Master in Public Health from Yale University. She has also worked as a health care chaplain and studied ethics as a Presidential Scholar at Harvard’s Divinity School.



**Courtney Van Houtven, PhD**

Duke University Medical Center



Dr. Courtney Van Houtven is a Professor in The Department of Population Health Science, Duke University School of Medicine and a Research Scientist in Health Services Research and Development in Primary Care at the Durham Veteran’s Administration. Dr. Van Houtven’s aging and economics research interests encompass long-term care financing, intra-household decision-making, informal care, and end-of-life care. She examines how family caregiving affects health care utilization, expenditures, health and work outcomes of care recipients

and caregivers. She is also interested in understanding how best to support family caregivers to optimize caregiver and care recipient outcomes.

In an R-01 from The National Institutes of Nursing Research, NIH, Dr. Van Houtven examined the relationship between family structure, informal caregiving, and long-term care insurance (2011-2014). She recently completed an RCT testing the effectiveness of a skills training program for family caregivers of Veteran patients with functional and/or cognitive limitations who were referred to community-based long-term care, or HI-FIVES (VA HSR&D IIR 11-345). She is co-PI on the newly awarded QUERI Program Project, "Optimizing Function and Independence", leading implementation of HI-FIVES at 8 sites nationally. She directs the VA-CARES Evaluation Center in the Durham COIN, which recently completed a national evaluation of the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC), a program that supports family members who care for injured post-9/11 Veterans. She is a co-investigator on the NIA/NIH CARE IDEAS R01 study examining outcomes among care partners and persons with cognitive impairment and dementia (Vince Mor, PI) and on an R01 called "Informal Caregiver Burden in Advanced Cancer: Economic and Health Outcomes" (Siminoff and Matsuyama, Co-PIs).

### **Bruce C. Vladeck, PhD**

Greater New York Hospital Association

Bruce C. Vladeck currently serves as a Senior Advisor to the Greater New York Hospital Association and to LiveOnNY, and as a consultant to a number of other health care organizations. He also chairs the Board of Medicare Rights Center, and serves on the board of Penn Medicine.



During his professional career, Vladeck held a number of senior positions, including:

- Assistant Commissioner, New Jersey State Department of Health (1979-1982);
- President, United Hospital Fund (1983-1993);
- Administrator, Health Care Financing Administration (1993-1997);
- Senior Vice President, Mount Sinai Medical Center (1998-2003);
- Interim President, University of Medicine and Dentistry of New Jersey (2006-2007).

He has also been a member of the full-time faculty at Columbia University and Mount Sinai School of Medicine, and has held adjunct appointments at Rutgers, Princeton, and the Aquinas Institute of Theology.

Previously, Vladeck also served as a trustee or director of many organizations, including New York City Health and Hospitals Corporation, Ascension Health, the Hadassah Hospital, the Kaiser Family Foundation, Health Care for the Homeless, the Primary Care Development Corporation; and the March of Dimes. He was a Presidential Appointee to the National Bipartisan Commission on the Future of Medicare, and served 14 years on the New York City Board of Health and Mental Hygiene.

Vladeck received his BA, magna cum laude, from Harvard College, and an MA and PhD in Political Science from the University of Michigan. He is the author of *Unloving Care: The Nursing*

Home Tragedy (Basic Books, 1980), still considered the standard reference on nursing home policy in the United States, and of more than one hundred articles in the professional literature.

**Gail Wilensky, PhD**  
Project HOPE



Gail Wilensky is an economist and senior fellow at Project HOPE, an international health foundation. She directed the Medicare and Medicaid programs from 1990 to 1992 and served in the White House as a senior health and welfare adviser to President GHW Bush. Dr. Wilensky currently serves as a trustee of the Combined Benefits Fund of the United Mine Workers of America and the National Opinion Research Center, is on the Board of Regents of the Uniformed Services University of the Health Sciences (USUHS) and the Geisinger Health System Foundation. She also served as president of the Defense Health Board, a Federal advisory to the Secretary of Defense, was a commissioner on the World Health Organization's

Commission on the Social Determinants of Health and co-chaired the Dept. of Defense Task Force on the Future of Military Health Care.

She is an elected member of the Institute of Medicine and has served two terms on its governing council. She is a former chair of the board of directors of Academy Health, a former trustee of the American Heart Association and a current or former director of numerous other non-profit organizations. She is also a director on several corporate boards.

From 1997 to 2001, she chaired the Medicare Payment Advisory Commission, which advises Congress on payment and other issues relating to Medicare and previously chaired one of its predecessor commissions, the Physician Payment Review Commission. From 2001 to 2003, she co-chaired the President's Task Force to Improve Health Care Delivery for Our Nation's Veterans and in 2007, served as a Commissioner on the President's Commission on Care for America's Returning Wounded Warriors (Dole/Shalala Commission).

Dr. Wilensky testifies frequently before Congressional committees, serves as an advisor to members of Congress and other elected officials, speaks nationally and internationally before professional, business and consumer groups. She received a bachelor's degree in psychology and a Ph.D. in economics at the University of Michigan and has received several honorary degrees.

**Jennifer Wolff, PhD**  
Johns Hopkins Bloomberg School of Public Health

Jennifer Wolff is the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and Director of the Roger C. Lipitz Center for Integrated Health Care at the Bloomberg School of Public Health and holds a joint appointment in the Division of Geriatric Medicine and Gerontology at the Johns Hopkins University School of Medicine. Dr. Wolff's research focuses on the care of older persons with complex health needs and disabilities and on applied studies and initiatives directed at better supporting family caregivers within systems of care. Her research has been continuously funded by the National





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Institute of Health and other federal agencies and private foundations. Dr. Wolff is a member of AcademyHealth, the American Society on Aging, and the Gerontological Society of America. She recently served on the National Academies of Sciences, Engineering, and Medicine Committee on Family Caregiving for Older Adults.