Roundtable on Quality Care for People with Serious Illness

Keck Center of the National Academies
500 Fifth Street, NW
Room 100
Washington, DC 20001
November 7, 2019

Dear Colleagues:

Welcome to the workshop on Building the Workforce We Need to Care for People with Serious Illness. This workshop is hosted by the Roundtable on Quality Care for People with Serious Illness at the National Academies of Sciences, Engineering, and Medicine. The workshop is dedicated to the legacy of Ruth McCorkle, whose innovative contributions to the field of patient-centered care, nursing research, and education excellence over the course of her 45-year career are legendary.

Opening with an overview of the current and projected state of the workforce for care of people with serious illness, the workshop will then unfold over four sessions. The first session will focus on the development of specialists to care for people with serious illness. Recognizing that insufficient numbers of specialists exist, the second session highlights the importance of preparing all health care professionals to care for people with serious illness. The workshop’s third session shines a light on the workforce for community-based care. The final session of the workforce explores ways to maximize the contributions of interprofessional team members, showcasing examples of workforce models designed to provide care to people with serious illness. The speakers will discuss the reproducibility and scalability of innovative care models, specific considerations in the care of special populations and long-term care settings, and approaches to promoting resilience and retention of all health care professionals.

We hope you will find the presentations informative, thought provoking, and inspiring, and that the suggestions made by the workshop speakers will contribute to improved practice and informed policymaking regarding this critical issue.

A major goal of the workshop is to facilitate discussion about opportunities related to educating, training, and retaining the serious illness care workforce. Each session includes an 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:

We invite you to share your insights, thoughts and reactions throughout the workshop using the Twitter hashtag: #SeriousIllnessCareNASEM.

Sincerely,

Brynn Bowman, MPA
Vice President, Education
Center to Advance Palliative Care
Planning Committee Co-Chair

Brenda Nevidjon, RN, MSN, FAAN
Chief Executive Officer
Oncology Nursing Society
Planning Committee Co-Chair
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://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2019-NOV-07.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://nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2019-NOV-07.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

  Like NASEM Health and Medicine Division on Facebook: www.facebook.com/NASEMhealth

  Follow NASEM Health and Medicine Division on Twitter: @NASEM_Health

  Follow NASEM Health and Medicine Division on LinkedIn: http://www.linkedin.com/company/nasemhealth

  We encourage you to share your thoughts, reactions, and insights about the workshop via Twitter with #SeriousIllnessCareNASEM
IN MEMORIUM
RUTH MCCORKLE

The Roundtable on Quality Care for People with Serious Illness dedicates this workshop to the legacy of Ruth McCorkle.

Ruth was internationally renowned as a pioneer in the fields of oncology nursing, patient-centered care, palliative care, and symptom management. Ruth was elected to the Institute of Medicine in 1990 and was a valued member of our community. On August 17, 2019, Ruth passed away at her home in Connecticut, surrounded by family. She will be greatly missed.

Margaret Ruth McCorkle was born on March 4, 1941 in Johnson City, Tennessee to John Joseph and Virginia Upchurch McCorkle. From 1964-1966 Ruth served as a second lieutenant and captain in the United States Air Force Nurse Corps in Vietnam. Ruth graduated from the University of Maryland with a bachelor’s degree in nursing, received a master’s degree in medical-surgical nursing from the University of Iowa, and studied at St. Christopher’s Hospice in London. She later cofounded the Hospice of Seattle and the Northwest Regional Oncology Society. In 1975, she earned her doctorate in mass communications at the University of Iowa’s School of Journalism.

Ruth’s professional and academic career included positions as a Professor of Nursing at the University of Washington and University of Pennsylvania. At Yale University, Ruth was the first Florence Schorske Wald Professor Emerita of Nursing and a Professor Emerita of Medicine and Public Health. She served as the director if the Center for Excellence in Chronic Illness Care, and the director of Psychosocial Oncology at the Yale Comprehensive Cancer Center. Ruth’s contributions to oncology research are unparalleled. She developed the Symptom Distress Scale and the Enforced Social Dependency, served as the Principal Investigator on seven clinical trials, and has published extensively in international and American nursing and medical journals. She has mentored more than 70 doctoral and 30 post-doctoral students.

The recipient of numerous accolades, Ruth was the first non-medical researcher to receive a National Cancer Institute Research Training Grant. Other awards include the Council of Nurse Researchers Nurse Scientist of the Year (1993), a Distinguished Merit Award from the International Society of Nurses in Cancer Care, a Distinguished Research Award from the Oncology Nursing Society, the Yale Cancer Center Lifetime Achievement Award (2017), and the American Academy of Nursing’s “Living Legend” award (2018). She was also named the Nurse Scientist of the Year by the Council of Nurse Researchers of the American Nurses Association and is a 2014 inductee of the International Nurse Researcher Hall of Fame.

Beyond her successful professional career, Ruth exemplified passion, wisdom, gratitude, and generosity - improving the quality of life of everyone who knew her. Ruth is survived by her sister, six children, three nieces and her granddaughter.
# Building the Workforce We Need to Care for People with Serious Illness

**A Workshop**

The Keck Center of the National Academies  
500 Fifth Street, NW - Room 100  
Washington, DC 20001  
Thursday, November 7, 2019

## WORKSHOP AGENDA

<table>
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<tr>
<th>Time</th>
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<tbody>
<tr>
<td>8:00 am</td>
<td>Registration and Breakfast</td>
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| 8:30 am | Welcome from the Roundtable on Quality Care for People with Serious Illness  
Leonard D. Schaeffer, University of Southern California (Chair) and  
James Tulsky, MD, Harvard Medical School, Brigham and Women's Hospital, and  
Dana-Farber Cancer Institute (Vice Chair)  
**Overview of the Workshop**  
Brynn Bowman, MPA, Vice President of Education  
Center to Advance Palliative Care  
Brenda Nevidjon, RN, MSN, FAAN  
Chief Executive Officer  
Oncology Nursing Society  
*Planning Committee Co-Chairs* |
| 8:45 am | Overview of the current state of the workforce for serious illness care and future needs  
Michelle Washko, PhD, Director, National Center for Health Workforce Analysis  
Health Resources and Services Administration, HHS |
<table>
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<tr>
<th>Time</th>
<th>Session One: Developing the Workforce to Specialize in Care for People with Serious Illness</th>
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<tbody>
<tr>
<td>9:00 am</td>
<td><strong>Moderator:</strong> Karen Bullock, PhD, LCSW, Professor and Head of the Department of Social Work, North Carolina State University</td>
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</table>
|            | **Speakers:** Arif Kamal, MD, MBA, MHS, FACP, FAAHPM, FASCO, Associate Professor of Medicine, Population Health Sciences, and Business Administration, Duke University  
|            | Jennifer Ballentine, MA, Executive Director, The California State University Shiley Institute for Palliative Care  
|            | Barbara Head, PhD, CHPN, ACSW, FPCN, Professor, University of Louisville School of Medicine, Palliative Care and Medical Education, Associate Professor at Kent School of Social Work  
|            | **Panel Discussion to include above speakers and:**  
|            | Michelle Washko, PhD, HRSA  
|            | Laura Dingfield, MD, MSEd, Assistant Professor of Clinical Medicine, Director of Education, Penn Palliative Care Program, Program Director, Hospice and Palliative Medicine Fellowship, Perelman School of Medicine, University of Pennsylvania  
|            | Denise Hess, MDiv, BCC-HPCC, LMFT, Executive Director, Supportive Care Coalition, Member, Association of Professional Chaplains  
|            | **Audience Q & A**  
| 10:45 am   | **Break**  
| 11:00 am   | Session Two: Preparing all Health Care Professionals to Care for People with Serious Illness |
|            | **Moderator:** Miguel Paniagua, MD, FACP, FAAHPM, Medical Advisor, Solution Design & Delivery, National Board of Medical Examiners, Adjunct Professor of Medicine, Perelman School of Medicine, University of Pennsylvania  
|            | **Speakers:** Betty Ferrell, RN, PhD, MA, CHPN, FAAN, FPCN, Director, Division of Nursing Research and Education, Professor, City of Hope Medical Center, PI, End-of-Life Nursing Education Consortium (ELNEC)  

Follow the [conversation](#) #SeriousIllnessCareNASEM
<table>
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<tr>
<th>Time</th>
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<tr>
<td>12:30 pm</td>
<td>Lunch</td>
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<tr>
<td>1:30 pm</td>
<td>Session Three: Developing the Workforce for Community-based Care</td>
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<tr>
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<td>Moderator: Tamarah Duperval-Brownlee, MD, MPH, MBA, FAAFP, Senior VP, Chief Community Impact Officer, Ascension President and CEO, Providence Health System</td>
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<td>Speakers:</td>
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<td>Joanne Spetz, PhD, Professor, Philip R. Lee Institute for Health Policy Studies Associate Director of Research, Healthforce Center, UCSF</td>
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<td>Angelina Drake, Chief Operating Officer, PHI</td>
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<td>Amy M. York, Executive Director, Eldercare Workforce Alliance</td>
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<td>Lauran Hardin, MSN, RN-BC, CNL, FNAP, Senior Advisor of Partnerships and Technical Assistance, Camden Coalition of Healthcare Providers and the National Center for Complex Health and Social Needs</td>
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<td><strong>Audience Q&amp;A</strong></td>
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<td>3:15 pm</td>
<td>Break</td>
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<td>3:30 pm</td>
<td>Session Four: Using Interprofessional Teams Effectively to Care for People with Serious Illness</td>
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<td>Moderator: JoAnne Reifsnyder, PhD, RN, FAAN, Executive Vice President, Clinical Operations, Chief Nursing Officer Genesis Healthcare Member, Hospice and Palliative Nurses Association</td>
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<td>Speakers:</td>
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<td>Sister M. Peter Lillian Di Maria, Director, Avila Institute of Gerontology, Inc.</td>
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<td></td>
<td>Jody Chrastek, RN, DNP, CHPN, FPCN, Pediatric Advanced Complex Care Team Coordinator, Fairview Home Care and Hospice</td>
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Jeanie Youngwerth, MD, FAAHPM, Director of Palliative Care Curriculum, Program Director, Palliative Care, University of Colorado School of Medicine

Panel Discussion to include above speakers and:
Karen Bullock, PhD, LCSW
Betty Ferrell, RN, PhD, MA, CHPN, FAAN, FPCN

**Audience Q&A**

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<th>Time</th>
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<th>Co-Chairs</th>
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<tr>
<td>5:15 pm</td>
<td>Closing Remarks</td>
<td>Brenda Nevidjon and Brynn Bowman</td>
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<td>Workshop Planning Committee Co-Chairs</td>
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<td>5:30 pm</td>
<td>Adjourn</td>
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Roundtable on Quality Care for People with Serious Illness

The National Academies of Sciences, Engineering, and Medicine (the Academies) has established a Roundtable on Quality Care for People with Serious Illness. Through meetings, public workshops, and background papers, the Roundtable fosters an ongoing dialogue about critical policy and research issues to accelerate and sustain progress in care for people of all ages with serious illness. Inspired by previous work at the Academies, including the 2014 Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, the roundtable convenes key stakeholders to focus on five priority areas:

- Delivery of person-centered, family-oriented care, including mechanisms to reduce multiple transitions between care settings during serious illness and in the final phase of life; recognition and support for the role of family caregivers; and efforts to ensure that critically ill individuals and their families understand the benefits of, and have access to, palliative care.
- Communication and advance care planning, including clinician-initiated conversations with individuals and loved ones about end-of-life care values, goals, and preferences; policies to support and incentivize such conversations; and methods to record individual preferences and ensure that they are honored.
- Professional education and development, including attention to palliative care in medical and nursing school curricula; reducing educational siloes to improve the development of interprofessional teams; and health care providers’ communication skills.
- Policies and payment systems, including policies to reduce payment siloes and incentives that will result in use of helpful services; scale-up of successful programs that integrate health care and long-term social services; policies to incentivize the provision of comprehensive palliative care; and the development of quality standards and measures.
- Public education and engagement, including strategies to promote informed understanding of advanced care and end-of-life care issues among diverse groups; efforts to motivate health care consumers to seek high-quality care for themselves and their loved ones; and efforts to normalize conversations about death and dying through storytelling and advocacy at multiple levels.

The Roundtable is limited to a three-year term in order to focus its activities on tangible, short-term goals. Roundtable activities include expert meetings, public workshops and webinars, summary publications, and targeted communications and community engagement activities. Roundtable membership includes federal agencies, health insurers, advocates, patients, health care providers, foundations, academics, and others interested in the topic.

Laurie Graig  
202-334-1484  
lgraig@nas.edu

Sharyl J. Nass  
202-334-2320  
snass@nas.edu

Andrew M. Pope  
202-334-1739  
apope@nas.edu
ROUND TABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

SPONSORS

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- American Geriatrics Society
- Anthem
- Ascension Health
- Association of Professional Chaplains
- Association of Rehabilitation Nurses
- Blue Cross Blue Shield Association
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- The California State University Shiley Institute for Palliative Care
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- National Coalition for Hospice and Palliative Care
- National Hospice and Palliative Care Organization
- National Institute of Nursing Research, National Institutes of Health
- National Palliative Care Research Center
- National Patient Advocate Foundation
- New York Academy of Medicine
- Oncology Nursing Society
- Patient-Centered Outcomes Research Institute (PCORI)
- Social Work Hospice and Palliative Care Network
- Supportive Care Coalition
Save the Date!

May 7, 2020

The Roundtable on Quality Care for People with Serious Illness

Advance Care Planning: Challenges and Opportunities: A Workshop

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

Workshop Statement of Task:

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and host a one-day public workshop that will explore the current state of advance care planning and examine the role of effective communication across the lifespan about the care and treatment preferences of patients facing serious illness. The workshop will feature invited presentations and panel discussions on topics that may include ways to:

- Improve communication between clinicians and patients and their families
- Coordinate advance care planning discussions across care transitions
- Achieve and measure goal-concordant care
- Assess the impact of effective advance care planning on patient outcomes and health care spending
- Incorporate advance care planning in electronic health records
- Overcome challenges with health literacy and cultural competency
- Educate and involve younger generations in advance care planning

The planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.
# ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Building the Workforce We Need to Care for People with Serious Illness: A Workshop

## WORKSHOP PLANNING COMMITTEE

<table>
<thead>
<tr>
<th>Name</th>
<th>Title/Position</th>
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<tbody>
<tr>
<td>Brynn Bowman, MPA</td>
<td>Vice President, Education, Center to Advance Palliative Care</td>
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<tr>
<td>Brenda Nevidjon, RN, MSN, FAAN</td>
<td>Chief Executive Officer, Oncology Nursing Society</td>
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<tr>
<td>Jennifer Ballentine, MA</td>
<td>Executive Director, CSU Shiley Institute for Palliative Care</td>
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<tr>
<td>Robert Bergamini, MD</td>
<td>Medical Director, Palliative Care Services, Mercy Clinic Children’s Cancer and Hematology</td>
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<tr>
<td>Grace B. Campbell, PhD, MSW, RN, CRRN</td>
<td>Assistant Professor, Acute &amp; Tertiary Care, University of Pittsburgh School of Nursing</td>
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<tr>
<td>Clese Erikson, MPAff</td>
<td>Deputy Director, Health Workforce Policy Research Center, The George Washington University</td>
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<tr>
<td>Denise Hess, MDiv, BCC-HPCC, LMFT</td>
<td>Executive Director, Supportive Care Coalition, Representing Association of Professional Chaplains</td>
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<tr>
<td>Amy Melnick, MPA</td>
<td>Executive Director, National Coalition for Hospice and Palliative Care</td>
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<tr>
<td>Jeri Miller, PhD, MS, MSc</td>
<td>Chief, Office of End-of-Life and Palliative Care Research, Senior Policy Analyst, National Institute of Nursing Research, NIH</td>
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<tr>
<td>Miguel Paniagua, MD, FACP, FAAHPM</td>
<td>Medical Advisor, Solutions Design &amp; Delivery, National Board of Medical Examiners, Adjunct Professor of Medicine, Perelman School of Medicine, University of Pennsylvania</td>
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<tr>
<td>Philip Pizzo, MD</td>
<td>David and Susan Heckerman Professor and Foundation Director, Stanford Distinguished Careers Institute</td>
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<tr>
<td>JoAnne Reifsnyder, PhD, RN, FAAN</td>
<td>Executive Vice President, Clinical Operations and Chief Nursing Officer, Genesis Healthcare, Representing the Hospice and Palliative Nurses Association</td>
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<tr>
<td>Joe Rotella, MD, MBA</td>
<td>Chief Medical Officer, CatalystHPM, American Academy of Hospice and Palliative Medicine</td>
</tr>
<tr>
<td>Tracy Schroepfer, PhD, MSW</td>
<td>Professor, School of Social Work, University of Wisconsin</td>
</tr>
<tr>
<td>Joseph Shega, MD</td>
<td>Regional Medical Director, VITAS Hospice Care, Representing the American Geriatrics Society</td>
</tr>
<tr>
<td>Joan Weiss, PhD, RN, CRNP</td>
<td>Chief, Geriatrics and Allied Health Branch, Health Resources and Services Administration</td>
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ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Building the Workforce We Need to Care for People with Serious Illness: A Workshop

WORKSHOP SPEAKERS AND MODERATORS

Jennifer Ballentine, MA
Executive Director
California State University Shiley Institute for Palliative Care

Brynn Bowman, MPA
Vice President, Education
Center to Advance Palliative Care

Karen Bullock, PhD, LCSW
Professor and Head of the Department of Social Work
North Carolina State University

Jody Chrastek, RN, DNP, CHPN, FPCN
Pediatric Advanced Complex Care Team Coordinator
FACE-TC Research Interventionist
Fairview Home Care and Hospice

Laura Dingfield, MD, MSEd
Assistant Professor of Clinical Medicine
Director of Education, Penn Palliative Care Program, University of Pennsylvania Health System
Program Director, Hospice and Palliative Medicine Fellowship, Hospital of the University of Pennsylvania

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Chief Operating Officer
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Sr. M. Peter Lillian Di Maria
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Avila Institute of Gerontology, Inc.

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Camden Coalition of Health Care Providers
National Center for Complex Health and Social Needs

Barbara Head, PhD, CHPN, ACSW, FPCN
Professor
University of Louisville School of Medicine
Palliative Care and Medical Education
Associate Professor
Kent School of Social Work

Denise Hess, MDiv, BCC-HPCC, LMFT
Executive Director
Supportive Care Coalition
Representing the Association of Professional Chaplains

Eric Holmboe, MD, MACP, FRCP
Chief Research, Milestone Development, and Evaluation Officer, Milestones Department
Accreditation Council for Graduate Medical Education

Arif Kamal MD, MBA, MHS, FACPM, FAAHPM, FASCO
Associate Professor of Medicine, Population Health Sciences, and Business Administration
Duke University
ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Miguel Paniagua, MD, FACP, FAAHPM
Medical Advisor
Solutions Design & Delivery
National Board of Medical Examiners
Adjunct Professor of Medicine
Perelman School of Medicine, University of Pennsylvania

JoAnne Reifsnyder, PhD, RN, FAAN
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Clinical Operations and Chief Nursing Officer
Genesis Healthcare
Representing the Hospice and Palliative Nurses Association

Joanne Spetz, PhD
Professor, Philip R. Lee Institute for Health Policy Studies
Associate Director of Research
Healthforce Center, UCSF

Deborah Trautman, PhD, RN, FAAN
President and CEO
American Association of Colleges of Nursing

Michelle M. Washko, PhD
Director
National Center for Health Workforce Analysis
Health Resources and Services Administration

Jeanie Youngwerth, MD, FAAHPM
Associate Professor of Medicine
Associate Program Director,
Colorado Palliative Medicine Fellowship
Director, Palliative Care Service
Department of Medicine
University of Colorado Anschutz Medical Campus

Amy York
Executive Director
Eldercare Workforce Alliance
Jennifer Moore Ballentine, MA, has more than 20 years’ experience in hospice and palliative care, healthcare ethics and public policy, adult education, change design, and nonprofit leadership. As Executive Director of the California State University Institute for Palliative Care, she oversees this unique enterprise developing innovative online and in-person curriculum for palliative care clinicians and other healthcare professionals caring for people with serious illness worldwide, as well as students in the healthcare professions throughout the CSU system. Her past leadership positions include President of The Iris Project; Vice President for Hospice Analytics; Executive Director of Life Quality Institute; and Director of Professional Programs for the Colorado Center for Hospice and Palliative Care. She also serves with several national projects committed to improving quality in palliative care: the NHPCO Palliative Care Advisory Council, the Patient Quality of Life Coalition Steering Committee, and the National Academy of Medicine Roundtable on Quality Care of People with Serious Illness. Jennifer has presented hundreds of educational workshops and keynotes at state and national conferences and is published widely in clinical literature, textbooks, and trade press. Jennifer holds a Master’s degree with graduate honors in End-of-Life Studies from Regis University, a professional advancement certificate in gerontology from University of Colorado—Colorado Springs, and a Bachelor’s degree, Phi Beta Kappa, from Oberlin College.

Robert A. Bergamini, MD 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. 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 is in the final stages of obtaining accreditation for a palliative care fellowship and effective July 1, 2017, will have two positions available. Dr. Bergamini serves as the medical liaison to local faith-based communities. Initiatives include providing palliative care education for the Diocese of Little Rock and the Archdiocese of St. Louis. Dr. Bergamini is working with the Diocese of Little Rock on introduction of POLST legislation during the next session of the Arkansas legislature.

Brynn Bowman, MPA is Vice President of Education for the Center to Advance Palliative Care (CAPC). Ms. Bowman promotes access to palliative care services through development of tools, technical assistance, and training for provider organizations. She does this work through development of new CAPC content, including program design technical assistance for palliative care teams in all care settings, and online clinical training in core palliative care skills for clinicians working in all specialties and care settings.

Ms. Bowman has written and spoken about the urgent need for clinicians from all specialties to integrate palliative care principles and practices in their care of patients living with serious illness. Under Ms. Bowman’s direction, CAPC’s education team launched an online clinical training curriculum in January 2015 that has since been used by tens of thousands of clinicians nationwide.

In addition to co-chairing CAPC’s National Seminar since 2015, Ms. Bowman convenes national palliative care leaders to synthesize best practices in palliative care delivery and develop practical tools for palliative care teams. Her work includes CAPC’s Palliative Care in the Home: A Guide to Program Design, online curriculum in program start-up for inpatient and community palliative care, and a quality measurement toolkit for palliative care programs, among others. Prior to joining CAPC in 2013, Ms. Bowman served as strategy director at LevelUp, a startup technology company specializing in mobile payment and small business marketing. Ms. Bowman received an AB in biological studies from Harvard College in 2008 and her MPA from New York University in 2017.
Karen Bullock, PhD, LCSW is Professor and Head of the Department of Social Work at North Carolina State University, in the College of Humanities and Social Sciences. She earned her PhD in Sociology and Social Work from Boston University, her Master’s degree in Social Work, from Columbia University, and her Bachelor of Social Work degree from North Carolina State University. She is Affiliate Faculty at the Institute for Collaboration on Health, Intervention, and Policy (InCHIP) at the University of Connecticut. Dr. Bullock has more than 20 years of clinical practice experience in mental health and aging, with interests and expertise in health care disparities and end-of-life care issues. She is a John A. Hartford Faculty Scholar and serves on several national boards and committees, including Social Work Hospice & Palliative Care Network (SWHPN), the American Cancer Society (ACS) Oncology Social Work Research Peer Review Committee, and is current Chair of the NASW Mental Health Section Committee. Dr. Bullock’s research focuses on cancer care and social support for older adults with non-curable illnesses. Her article on The Influence of Culture on End-of-Life Decision Making, won the 2012 Best Article Award by the Routledge Journal of Social Work in End-of-Life & Palliative Care. She has been a leading force in advancing social work practice, education, and training in gerontology, mental health, palliative and end-of-life care. In addition, Dr. Bullock has been quoted in the Washington Post, USA Today and LA Times as an expert in these areas. Dr. Bullock has published and presented nationally and internationally on these topics. She was a Visiting Scholar at the Mailman School of Public Health at Columbia University and previously held appointments at the Institute of Living/Hartford Hospital, the University of Connecticut, Salem State College, Smith College, and UNC-Wilmington.

Grace B. Campbell, PhD, MSW, RN, is Assistant Professor, Acute & Tertiary Care, University of Pittsburgh School of Nursing. She is a Certified Rehabilitation Registered Nurse with clinical and research interests in assessing the impact of chronic disorders on physical function, and in developing behavioral interventions to improve physical function for individuals with cancer and their family caregivers. She maintains an active program of research exploring the development and progression of chemotherapy induced peripheral neuropathy and its related functional impairments in women with ovarian cancer. Dr. Campbell is also interested in using novel technologies to measure physical function in naturalistic settings. She also serves in the GynOnc Family CARE Center at UPMC Magee Women’s Hospital where she is a core team member of an ASCO Quality Training Program-sponsored quality improvement project to improve identification and assessment of family caregivers needs. Dr. Campbell has numerous peer reviewed publications of her clinical and scientific work and has presented her work nationally and internationally in both peer reviewed and invited presentations. She has served as a Subject Matter Expert for Cancer Rehabilitation on
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the NIH Clinical Center’s Cancer Rehabilitation Expert Consortium and currently represents the Association of Rehabilitation Nurses on the National Academy of Medicine’s Roundtable for Quality Care of Persons with Serious Illness. Dr. Campbell is a member of the Board of Directors of the Association of Rehabilitation Nurses.

Jody Chrastek, RN, DNP, CHPN, FPCN is the PACCT (Pediatric Advanced Complex Care Team) Coordinator for Fairview Home Care and Hospice, Minneapolis, MN, USA. The program works in close collaboration with University of Minnesota Masonic Children’s Hospital. She was born and brought up in India and trained as a nurse in Scotland. She has worked as a midwife and hospice nurse in the UK, India and the USA with adults and children. She has worked in hospice and palliative care for over 30 years in both inpatient and community settings. Her Doctorate in Nursing Practice focused on assisting adult community hospice programs accept children. She is a member of the Minnesota state Palliative care advisory committee, Co leader of the Pediatric Palliative Care Coalition of MN, an EPIC and ELNEC trainer and consults internationally on palliative care nursing issues.. She has published and presented on hospice and palliative care issue in journals and textbooks.

Laura Dingfield MD, MSEd serves as the Director of Education for the Penn Palliative Care Program and the Hospice and Palliative Medicine Fellowship Program Director at the University of Pennsylvania. She received her medical degree from the University of Michigan Medical School, and completed residency training in Internal Medicine and Pediatrics at the Hospital of the University of Pennsylvania and the Children’s Hospital of Philadelphia. Following residency, she served as a chief resident in Internal Medicine and Pediatrics for one year. She completed a fellowship in Hospice and Palliative Medicine at the Hospital of the University of Pennsylvania, and then joined the faculty as an Assistant Professor of Clinical Medicine on the Palliative Care Service at Penn. Dr. Dingfield obtained her Master’s in Education at the Graduate School of Education at the University of Pennsylvania.

Dr. Dingfield seeks to develop innovative educational programs to improve the delivery of primary and specialty palliative care education, and to expand the hospice and palliative medicine workforce. She has developed the first-ever competency-based, time-variable fellowship program in hospice and palliative medicine for mid-career faculty physicians.
Angelina Drake is the Chief Operating Officer at PHI, a national nonprofit dedicated to improving jobs for direct care workers and quality of care for those they serve. Drawing from her own experience as a home care worker, Angelina has launched several projects to improve job quality in long-term care through recruitment and retention, career advancement, and asset-development programs. She has provided technical assistance to direct care upskilling, advanced role, and care integration demonstrations across the country and published an article on these topics in Health Affairs in March 2019. In 2018, she was named a Job Quality Fellow at The Aspen Institute.

Angelina has held various titles since joining PHI in 2011, including Chief of Staff and Director of Development. Prior to PHI, she led projects to secure public funding for health services technology at an IT company and worked as a freelance writer. Her work has been featured in national health, food, and arts publications. Angelina holds a BS in Nutritional Science and BA in Health Studies from the University of Toronto and completed the Developing Leaders Program for Nonprofit Professionals at the Columbia University Graduate School of Business. She is a Florida native and lives in Brooklyn, New York.

Sister M. Peter Lillian Di Maria, O.Carm. has over forty years' experience in the continuum care ministry as a Carmelite Sister for the Aged and Infirm. Sr. Peter Lillian has served her community in many administrative positions and has lectured many times on Alzheimer’s disease, palliative care, geriatric spiritual care, family care issues, stress reduction, leadership development, and team building. Sr. Peter has developed successful dementia care programs, dementia care curriculums and assisted in developing a palliative care resource manual that is specific for geriatric care. Sr. Peter Lillian worked with Kaplan Media and directed the film, “Palliative Care: The Difference is Love.” The film was recognized with a nomination for a 2017 Suncoast Emmy Award under the category, “Societal Concerns.” Sr. Peter Lillian holds three state licenses as a Nursing Home Administrator and is currently the Director of the Avila Institute of Gerontology, the educational arm of the Carmelite Sisters for the Aged and Infirm in Germantown, NY.
Tamarah Duperval-Brownlee, MD, MPH, MBA, FAAFP is the Chief Community Impact Officer at Ascension. Dr. Tamarah Duperval-Brownlee provides direct oversight for the development and implementation of strategies to strengthen communities within Ascension markets, where patient needs demand an evolution of the investment in healthcare delivery, programs, space and facilities. This work includes developing and transforming campuses, which socially integrates healthcare and non-healthcare partners to optimize the physical, mental, and financial health and well-being of a defined community. She also serves as the President and CEO for Providence Health System in Washington DC, currently undergoing a transformation into a vibrant health village that expands ambulatory care, addresses social determinants and provides key services that enables members in communities to be healthy. In her time at Ascension, where she directed the creation and implementation of the strategy to advance health equity for Ascension, including efforts of accelerating safety and quality improvement, building healthy communities, and identifying and eliminating disparities in healthcare outcomes.

Prior to joining Ascension, Dr. Duperval-Brownlee practiced clinical medicine and served as a clinical and operational leader in Federally Qualified Health Centers, where she advocated for equitable access and quality of care and built programs to address health disparities.

A board-certified Family Physician for over 20 years, Dr. Duperval-Brownlee earned a Bachelor of Science in Chemical Engineering from Northwestern University and earned her Doctor of Medicine from the University of Illinois at Chicago College of Medicine. Upon completing residency in Family Medicine in Illinois, she earned a master’s Degree in public health from the Harvard School of Public Health and later an Executive MBA from the University of Tennessee at Knoxville. She is also a graduate of the Commonwealth Fund Harvard University Fellowship in Minority Health at Harvard University.

Clese Erikson, M.P.Aff is the Deputy Director of the Health Workforce Research Centers on Emerging Health Workforce Issues and Health Equity in Health Professions Education at The George Washington University (GW) and a member of the senior leadership team of the GW Health Workforce Institute. She has published peer review articles on the workforce implications of new care delivery models, accountable care organizations, care coordination roles in value based care, consumer interest in seeing nurse practitioners and physician assistants, primary care and specialty specific workforce issues, and medical school enrollment trends. Prior to joining GW, Ms. Erikson was senior director of the Center for Workforce Studies at the Association of American Medical Colleges (AAMC) where she was responsible for overseeing
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the Center’s research strategy, directed efforts on how workforce needs are evolving under new payment and delivery models and regularly convened workforce researchers to enhance methods and dissemination of findings. Ms. Erikson was also a founding member of the leadership team of an interprofessional student learning collaborative on hot spotting sponsored by the Camden Coalition, Primary Care Progress, and the AAMC. Prior to joining the AAMC, Ms. Erikson was director of research for the American Medical Group Association where she focused on patient safety and quality improvement initiatives and patient and provider satisfaction studies. She received her Master of Public Affairs from the Lyndon B. Johnson School of Public Affairs at the University of Texas.

Betty Ferrell, RN, MA, PhD, CHPN, FAAN, FPCN has been in nursing for 41 years and has focused her clinical expertise and research in pain management, quality of life, and palliative care. Dr. Ferrell is the Director of Nursing Research & Education and a Professor at the City of Hope Medical Center in Duarte, California. She is a Fellow of the American Academy of Nursing and she has over 450 publications in peer-reviewed journals and texts. She is Principal Investigator of a Research Project funded by the National Cancer Institute on “Palliative Care for Patients with Solid Tumors on Phase 1 Clinical Trials” and Principal Investigator of the “End-of-Life Nursing Education Consortium (ELNEC)” project. She directs several other funded projects related to palliative care in cancer centers and QOL issues. Dr. Ferrell is Co-Chairperson of the National Consensus Project for Quality Palliative Care. Dr. Ferrell completed a Masters degree in Theology, Ethics and Culture from Claremont Graduate University in 2007. She has authored eleven books including the Oxford Textbook of Palliative Nursing (5th Edition, 2019) published by Oxford University Press. She is co-author of the text, The Nature of Suffering and the Goals of Nursing published in 2008 by Oxford University Press and Making Health Care Whole: Integrating Spirituality into Patient Care (Templeton Press, 2010). In 2013 Dr. Ferrell was named one of the 30 Visionaries in the field by the American Academy of Hospice and Palliative Medicine.

Lauran Hardin, MSN, RN-BC, CNL, FNAP is the Senior Advisor for the Camden Coalition’s National Center for Complex Health and Social Needs. In this role, she builds upon her extensive experience providing consulting, co-design and coaching in care re-design and complex care transformation.

Hardin was previously the Director of a Complex Care Center serving hospitals, multiple providers and more than 1,500 high frequency/complex patients in the Mercy Health System. The Center’s model of complex care has resulted in better patient navigation and
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Barbara Head, PhD, CHPN, ACSW, FPCN is presently a professor at the University of Louisville School of Medicine and affiliated faculty at the Kent School of Social Work. Her research interests include workforce issues for hospice and palliative professionals, financial concerns in serious illness, geriatric palliative care, and interprofessional palliative education. Her work has been funded by the Robert Wood Johnson Foundation, the Foundation for a Healthy Kentucky, the National Cancer Institute, the Hospice and Palliative Nurse’s Association, and the Human Resources Services Association. She is currently the principal investigator on a grant funded by the Gordon and Betty Moore Foundation to develop a specialty certification program for hospice and palliative social workers and serves as the President of the Board of the Advanced Palliative and Hospice Social Work Certification program. She has served as both board member and president of the Hospice and Palliative Nurses Association and the National Board for Certification of Hospice and Palliative Nurses and is a current member of the SWHPN Board of Directors. Prior to entering academics, she worked at Louisville’s large hospice program as a homecare nurse, quality improvement director, and staff/community education director. Barbara has taught the End-of-Life Nursing Education Curriculum (ELNEC) geriatric curriculum nationally since its inception in 2006 in the U.S., Malaysia and India. She is also principal investigator for the iPEx project which is training faculty teams from across the nation to develop interprofessional curricula in palliative care at their home institutions.
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Denise Hess, M.Div., BCC-HPCC, LMFT comes to palliative care through over a decade of work as a palliative care chaplain with Providence St. Joseph Health in Torrance, California. Denise has a master’s degree and license in marriage and family therapy, a master’s degree in divinity, and is an ordained minister with the Presbyterian Church (USA). She was board certified with the Association of Professional Chaplains in 2011 and received palliative care and hospice advanced certification in 2014. She is currently the Executive Director for the Supportive Care Coalition, a national partnership of Catholic health ministries committed to advancing excellence in palliative care.

Eric Holmboe, MD, MACP, FRCPC is Chief, Research, Milestones Development and Evaluation Officer at the ACGME. He is also Adjunct Professor of Medicine at Yale University, the Uniformed Services University of the Health Sciences, and the Northwestern University Feinberg School of Medicine.

He served as the Associate Program Director, Yale Primary Care Internal Medicine Residency Program, and as the Director of Student Clinical Assessment, Yale School of Medicine. Before joining Yale in 2000, he served as Division Chief of General Internal Medicine at the National Naval Medical Center. He also previously served as a medical student clerkship director and residency training officer at the Portsmouth Naval Medical Center. Dr. Holmboe retired from the US Naval Reserves in 2005.

His research interests include interventions to improve quality of care, outcomes-based medical education across the continuum, and methods in the assessment and evaluation of clinical competence. His professional memberships include the American College of Physicians, where he is a Master, the Society of General Internal Medicine, and the Association of Medical Education in Europe. He is an Honorary Fellow of the Royal College of Physicians in London and the Royal College of Physicians and Surgeons of Canada. He is also an Honorary Fellow of the Academy of Medical Educators in Europe.

Dr. Holmboe is a graduate of Franklin and Marshall College and the University of Rochester School of Medicine. He completed his residency and chief residency at Yale-New Haven Hospital, and was a Robert Wood Johnson Clinical Scholar at Yale University.
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Arif Kamal MD, MBA, MHS, FACP, FAAHPM, FASCO is the Physician Quality and Outcomes Officer for the Duke Cancer Institute and an Associate Professor of Medicine, Business Administration, and Population Health Sciences in the Division of Medical Oncology and Section of Palliative Care at Duke University. As a fellowship-trained palliative medicine physician and medical oncologist, Dr. Kamal studies the link between delivery of high-quality palliative care and improved patient, caregiver, and health system outcomes. He has research funding from the Agency for Healthcare Research and Quality (AHRQ), Gordon and Betty Moore Foundation, National Cancer Institute, and Alliance for Clinical Trials in Oncology. He has published over 130 peer-reviewed manuscripts on palliative care, oncology, and healthcare quality in JAMA, Annals of Internal Medicine, Journal of Clinical Oncology, Lancet Oncology, and others.

Dr. Kamal serves in several national capacities in the areas of healthcare quality and palliative care. He is a Past Chair for the American Society of Clinical Oncology (ASCO) Quality Committee and Co-Chairs the American Academy of Hospice and Palliative Medicine (AAHPM) Quality Committee and its e-Measures Workgroup. He has also serves on the AMA-PCPI Measures Advisory Council and Cancer Technical Expert Panel, and The Joint Commission’s Palliative Care Quality Measures project, and National Quality Forum Geriatrics and Palliative Care Standing Committee. He was also recently elected to the AAHPM Board of Directors, named a national “40 under 40” in palliative care, and honored as an Academy Visionary by the AAHPM.

Dr. Kamal completed Internal Medicine residency and Hospice and Palliative Medicine fellowship at the Mayo Clinic – Rochester, MN and Hematology/Oncology fellowship at Duke University. He holds a Masters in Health Sciences in Clinical Research (MHS) from the Duke Clinical Research Training Program and a Masters in Business Administration (MBA) from the University of Massachusetts – Amherst.

Amy Melnick, M.P.A. is the Executive Director of the National Coalition for Hospice and Palliative Care (Coalition). Amy’s career has focused on health policy, legislative and regulatory advocacy, and coalition building with diverse stakeholders. Amy guides the Coalition efforts to better communicate, coordinate and collaborate within the ten national organizations representing the interdisciplinary field of hospice and palliative care. The Coalition was founded over a decade ago by leaders from the hospice and palliative care field. One of the Coalition’s first successful projects was the publication of the National Consensus Project, Clinical Practice Guidelines for Quality Palliative Care, now in its 4th edition. As the Coalition’s first Executive Director, Amy leads the Coalition’s efforts on behalf of its 10 Member
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organizations and engages with various internal and external partners to identify areas of common interest and consensus to collectively work to improve the care of people with serious illness and those at the end of life. Amy guides the Coalition operations and stakeholder engagement with various health care policy organizations such as Congress, Centers for Medicare and Medicaid Services, National Institute of Health, National Academy of Sciences, National Quality Forum, Patient Centered Outcomes Research Institute, Patient Quality of Life Coalition and the Joint Commission. Prior to joining the Coalition, Amy was the Vice President, Advocacy, for the Arthritis Foundation in Washington D.C. where she successfully advocated for the creation of a congressionally directed federally funded arthritis research program at the Department of Defense. Amy has also represented physicians, scientists, and nurses, while serving as the Vice President for Health Policy at the Heart Rhythm Society. She began her career on Capitol Hill as Committee Staff at the US House of Representatives’ Select Committee on Aging where she focused on issues affecting older Americans. Amy attended the London School of Economics and Political Science and received her undergraduate degree from Wellesley College and her Masters of Public Administration from George Mason University.

Jeri L. Miller, M.S., M.Sc., Ph.D. is currently the Acting Deputy Director of the National Institutes of Health, (NIH) National Institute of Nursing Research’s (NINR) Division of Extramural Science Programs (DESP), the Chief of the NINR Office of End-of-Life and Palliative Care Research (OEPCR) and NINR Research Centers Program, and an NINR Senior Science Policy Analyst. NINR, the lead NIH Institute for end-of-life care research, established the Office of End-of-Life and Palliative Care Research (OEPCR) to support 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 collaborations with the senior leadership of NINR, NIH Institutes, federal research agencies, academia, and other outside experts and constituencies. The Office builds on work led by Dr. Miller as the former Head of the NINR Office of End-of-Life and Palliative Care Research, Investigator Training, and Education in NINR’s Division of Science Policy and Public Liaison where she focused on projects to develop and support numerous NIH symposia and presentations on the state-of-the-science in end-of-life and palliative care, collaborations in NINR’s pediatric palliative care Conversations Matter national awareness campaign, and the development of the NIH NINR 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. Miller was a previous NIH Intramural Program scientist with expertise in biomedical and clinical research. She completed her NIH post-doctoral IRTA fellowship through the NIH Eunice Kennedy Shriver National Institute of Child
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Health and Human Development with a cross-post-doctoral appointment at the National Institutes of Health’s Clinical Center. She continued as an NIH Intramural Scientist within the NIH Clinical Center where she was the Principal Investigator of numerous NIH research protocols. She spearheaded scientific collaborations and research training and mentorship with the then National Naval Medical Center- Department of the Navy and various academic centers. Dr. Miller is an international speaker and author with numerous awards and honors for her research at NIH and for her leadership at NINR. She received the National Institute of Nursing Research’s Team Award for the development and operationalization of the NINR end-of-life and palliative care science program and received the 2018 Presidential Citation from the American Academy of Hospice and Palliative Medicine for her work in building national programs of science in palliative care. She is a member and consultant to numerous federal and national advisory groups and technical panels, including AHRQ technical reviews of palliative care research. She serves on a variety of NIH and national committees that focus on the care for persons and families faced with the challenges of advanced illness, including the National Academies of Sciences, Engineering and Medicine’s Round Table on Quality Care for People with Serious Illness. In addition to her administrative roles, Dr. Miller oversees the NINR Research Centers program, the NINR-supported Palliative Care Research Cooperative (PCRC) group and serves as the Scientific Officer of several large multi-site pragmatic trials through the NIH Health Care Systems Research Collaboratory.

Brenda Nevidjon, R.N., MSN, FAAN, is the Chief Executive Officer of the Oncology Nursing Society (ONS), a professional association of more than 39,000 members committed to promoting excellence in oncology nursing and the transformation of cancer care. Immediately prior to her position at ONS, she was a professor at Duke University School of Nursing and taught graduate students in nursing and healthcare leadership programs. Throughout her career in Canada, Switzerland and the United States, she has focused on bridging practice settings and academic environments to advance patient care, creating innovative work environments, promoting scholarship in practitioners, and developing leaders. After two decades in oncology clinical and administrative settings, she transitioned to health care executive practice, culminating with her being the first nurse and the first women to be chief operating officer of Duke University Hospital in 1996. Her bachelors’ degree is from Duke University, her master’s from the University of North Carolina, and she has done doctoral work at the Fielding Graduate Institute and Duke University. She completed the Johnson & Johnson - Wharton Fellows Program in Management for Nurse Executives, was in the inaugural class of the Robert Wood Johnson Nurse Executive Program and is a fellow in the American Academy of Nursing.
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Miguel A. Paniagua, MD, FACP, FAAHPM serves as Medical Advisor for Solutions Design & Delivery at the National Board of Medical Examiners and is adjunct professor of medicine in the faculty of the Perelman School of Medicine at the University of Pennsylvania. His work at NBME includes the development of novel assessments, consulting and teaching, work on patient characteristics and wellness and burnout. Dr. Paniagua has served on multiple item writing and reviewing committees at the NBME over the last ten years, and has served as a representative member of the National Board from 2011 to 2014 and on the Executive Board from 2013 to 2014. In addition, Dr. Paniagua teaches and practices consultative Hospice and Palliative Medicine at the Hospital of the University of Pennsylvania one day per week. He is the co-editor of the fifth edition of “Essential Practices” (UNIPAC) palliative medicine book series.

Philip A. Pizzo, M.D. is the David and Susan Heckerman Professor and Founding Director of the Stanford Distinguished Careers Institute. Dr. Pizzo served as Dean of the Stanford School of Medicine from April 2001 to December 1, 2012, where he was also the Carl and Elizabeth Naumann Professor of Pediatrics and of Microbiology and Immunology. Dr. Pizzo has devoted much of his distinguished medical career to the diagnosis, management, prevention and treatment of childhood cancers and the infectious complications that occur in children whose immune systems are compromised by cancer and AIDS. He has also been a leader in academic medicine, championing programs and policies to improve the future of science, education and healthcare in the US and beyond.

Dr. Pizzo received his MD degree with Honors and Distinction in Research from the University of Rochester in 1970, and completed an internship and residency at Children’s Hospital Medical Center in Boston, a teaching fellowship at Harvard Medical School, and a clinical and research fellowship in pediatric oncology at the National Cancer Institute. Dr. Pizzo served as head of the Institute’s infectious disease section, chief of the NCI’s pediatric department, and acting scientific director for NCI’s Division of Clinical Sciences between 1973 and 1996. Before joining Stanford in 2001, he was the physician-in-chief of Children’s Hospital in Boston and Chair of the Department of Pediatrics at Harvard Medical School, where he was also the Thomas Morgan Rotch Professor of Pediatrics.

Dr. Pizzo is the author of more than 615 scientific articles and 16 books and monographs, including Principles and Practice of Pediatric Oncology, the Seventh Edition of which was published in 2015. He co-led a multidisciplinary committee for the Institute of Medicine (IOM) that resulted in the 2011 report Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and
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Research; he also co-chaired the IOM report "Dying in America: Improving Quality and Honoring Individual Preferences at the End of Life" that was published in 2015.

Dr. Pizzo has received numerous awards and honors, among them the Public Health Service Outstanding Service Medal in 1995, the Barbara Bohen Pﬁefer Award for Scientiﬁc Excellence in 1991, the Elizabeth Kubler-Ross Award in 2008, the Ronald McDonald Charities “Award of Excellence” in 2009, and the John and Emma Bonica Public Service Award in 2013. He is the 2012 recipient of the John Howland Award, the highest honor for lifetime achievement bestowed by the American Pediatric Society. He has been elected to a number of prestigious organizations and societies, including the Association of American Physicians, the American Society of Clinical Investigation, the American Pediatric Society and the Institute of Medicine of the National Academy of Sciences, where he was also elected to the Governing Council. The IOM became the National Academy of Medicine in 2015. He has served as Chair of the Association of Academic Health Centers and Chair of the Council of Deans of the Association of American Medical Colleges and was elected to the Board of Directors of the American Society for Clinical Oncology and the Infectious Diseases Society of America. He was President of the International Immunocompromised Host Society (1998-2011). He served on the Governing Board for the California Institute of Regenerative Medicine from 2004-2012. In 2009 he was elected to the Board of Trustees of the University of Rochester and the Board of Overseers of Koc University in Istanbul, Turkey. He was a member of the Board of Directors of MRI Interventions (2013-2017) and the Academic Advisory Council for Merritt Hawkins (2015-present). In 2014 he was elected to the Board of Directors of the Ludwig Institute for Cancer Research and in 2015 he was elected to the Board of Directors of Global Blood Therapeutics. He also serves as Editor-in-Chief of Current Opinion in Pediatrics.

JoAnne Reifsnyder, PhD, RN, FAAN 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 Master’s in Business Administration from George Washington University in December, 2016.

Joe Rotella, MD, MBA, HMDC, FAAHPM, served as Chief Medical Officer for Hosparus, a community-based hospice in Louisville, KY for 15 years. During his tenure, he helped establish hospice inpatient units, palliative care consultation services, and a palliative medicine fellowship. Heeding a call to leadership and innovation, Rotella earned an MBA in Entrepreneurship from the University of Louisville. His work with the American Academy of Hospice and Palliative Medicine (AAHPM) includes serving on the Quality and Practice Standards Committee, Choosing Wisely Task Force and co-chairing the AAHPM and HPNA Measuring What Matters initiative and the AAHPM Hospice Medical Director Conference.

Tracy Schroepfer, PhD, MSW is a professor at the University of Wisconsin-Madison School of Social Work. She is a recipient of the Hartford Geriatric Social Work Faculty Scholar Award, and serves on the national Association for Gerontology Education in Social Work Board, the national Social Work and Hospice Palliative Care Network Board, the National Coalition for Hospice and Palliative Care Committee and the National Quality Forum Geriatrics and Palliative Care Standing Committee. For the past two years, Dr Schroepfer served as Co-Chair for the NCP Clinical Practice Guidelines for Quality Palliative Care Writing Workgroup and has just been selected to serve on AAHPM’s MACRA Palliative Care Measure Project. Dr. Schroepfer’s research focuses on improving the care provided to those who are terminally ill by gaining an understanding of factors that motivate a terminally elder’s consideration of a hastened death, determining the best strategies for meeting the psychosocial,
cultural and spiritual needs of terminally ill elders, improving the assessment instruments used by hospice and palliative care social workers, as well as reducing the health disparities faced by medically underserved communities in Wisconsin.

**Joseph W. Shega, M.D.** is Board Certified in Geriatric and Hospice and Palliative Medicine and maintains an academic appointment at the University of Central Florida as an Associate Professor of Medicine. The first 15 years of his career was in academic medicine at Northwestern University and the University of Chicago doing clinical care, education, and research including NIH funding around serious illness and dementia care. For the past 6 years, Dr. Shega has practiced in Central Florida initially as a regional medical director, then as the national medical director, and more recently as the chief medical officer for VITAS Healthcare. In his current role, Dr. Shega has been instrumental in adapting a "mobile first" platform to bring technology to the bedside in patients homes to improve clinical care through enhanced clinical documentation, medication management, care coordination, and most recently virtual reality as an alternative treatment modality. Also, he has spearheaded efforts to integrate clinical research as a core pillar at VITAS with recent partnering with NYU and participation in the NIH funded, “The Hospice Advanced Dementia Symptom Management and Quality of Life Trial.” At the national level, Dr. Shega helped spearhead development of quality measures for persons with dementia that incorporate geriatric and palliative principles as a member of the American Academy of Neurology Dementia and Mild Cognitive Impairment measurement group. He has been appointed and serves on the National Academy of Medicine Roundtable on Quality Care for Persons with Serious Illness representing the American Geriatrics Society. Dr. Shega is co-managing editor for the Essential Practices in Hospice and Palliative Medicine and has over 40 peer-reviewed publications focusing on the care of persons with serious illness.

**Joanne Spetz, PhD** is a Professor at the Institute for Health Policy Studies at the University of California, San Francisco, and Associate Director for Research at Healthforce Center at UCSF. She is the Principal Investigator and Director of the UCSF Health Workforce Research Center on Long-Term Care. She has conducted research on health workforce labor markets, education, shortages, and employment for 25 years. Dr. Spetz has been the Principal Investigator of national and state surveys of registered nurses and nursing schools, including the 2008 National Sample Survey of Registered Nurses, and the ongoing California Board of Registered Nursing Surveys of RNs and Schools Surveys. She also has led research on the impact of the Affordable Care Act on the health workforce, the impact of regulations in the hospital industry, effects of health information technology
on hospital staff and patients, effect of medical marijuana policy on youth substance use, and quality of patient care. Dr. Spetz is a member of the National Academies of Science Engineering and Medicine Committee on Consideration of Generational Issues in Workforce Management and Employment Practices. She previously served on the Institute of Medicine Standing Committee on Credentialing Research in Nursing and was a consultant to the Institute of Medicine Committee on the Future of Nursing. She is an Honorary Fellow of the American Academy of Nursing.

Deborah Trautman, PhD, RN, FAAN, assumed the role of President and Chief Executive Officer of the American Association of Colleges of Nursing (AACN) in June 2014. Formerly the Executive Director of the Center for Health Policy and Healthcare Transformation at Johns Hopkins Hospital, Dr. Trautman has held clinical and administrative leadership positions at the University of Pittsburgh Medical Center and the Johns Hopkins Medical Institutions. She also served as the Vice President of Patient Care Services for Howard County General Hospital and as Director of Nursing for Emergency Medicine at the Johns Hopkins Hospital. She has held a joint appointment at the Johns Hopkins University School of Nursing.

Dr. Trautman received a BSN from West Virginia Wesleyan College, an MSN from the University of Pittsburgh, and a PhD in health policy from the University of Maryland, Baltimore County. She has authored publications on health policy, intimate partner violence, pain management, clinical competency, change management, cardiopulmonary bypass, the use of music in the emergency department, and consolidating emergency services.

Since her appointment at AACN, Deb has been asked to join a number of high-profile boards and advisory groups. The Secretary of U.S. Department of Veterans Affairs’ Special Medical Advisory Group (SMAG), which advises the VA Secretary on matters related to healthcare delivery, research, education, training of healthcare staff and planning on shared care issues facing VA and the Department of Defense. In addition, the Robert Wood Johnson Foundation (RWJF) named her program director of the New Careers in Nursing project, and her colleagues with the Interprofessional Education Collaborative (IPEC) elected her to serve as Chair as of 2019. Dr. Trautman has served as an advisory board member and past chair for Academy Health’s Interdisciplinary Research Interest Group on Nursing Issues. Dr. Trautman is a 2007/2008 Robert Wood Johnson Health Policy Fellow who worked for the Honorable Nancy Pelosi, then Speaker of the U.S. House of Representatives.
Michelle Washko, PhD is a national expert on the health care workforce and currently serves as the Director of the National Center for Health Workforce Analysis in the U.S. Department of Health and Human Services. She joined the National Center in August 2013 and served as its Deputy Director from 2014 to 2018. Her areas of expertise are around the U.S. health care workforce and employment for older adults. Dr. Washko previously worked at the Administration for Community Living as a Senior Advisor on workforce and employment policy, and in the U.S. Department of Labor where she developed employment initiatives for older workers. Prior to her Federal service, she was a Senior Research Associate at LeadingAge, conducting applied research on the long-term care workforce. Dr. Washko holds a Ph.D. and Master’s degree in Gerontology from the University of Massachusetts, and a Master’s degree in Individual and Family Studies from the University of Delaware.

Joan Weiss, PhD, RN, CRNP, FAAN is an adult and gerontological nurse practitioner who serves as the Senior Advisor in the Division of Medicine and Dentistry at the Health Resources and Services Administration. She is the primary advisor to the Director on geriatrics-related issues and all phases of management responsibilities for the Division of Medicine and Dentistry. Her experience in interprofessional practice and education spans 30 years. She is the Designated Federal Official for the Federal Advisory Committee on Interdisciplinary Community-Based Linkages. She is the HRSA representative on the U.S. Department of Health and Human Services’ (HHS) Advisory Council on Alzheimer’s Disease Research, Care, and Services; the Family Caregiver Advisory Council; the Advisory Council to Support Grandparents Raising Grandchildren, and HHS interagency workgroups on palliative care, elder justice, and caregiving. She is the HRSA Federal Liaison to AARP’s Global Council on Brain Health. She advises on the development of performance measures for HRSA’s geriatrics education programs. She has served in many leadership positions at HRSA including Director of the Division of Public Health and Interdisciplinary Education and Acting Director of the Division of Nursing. She is the recipient of the 2015 Secretary’s Meritorious Group Award for taking important steps to find a cure and improve care for people with dementia. She is the recipient of the 2011 University of Pennsylvania School of Nursing Outstanding Nursing Alumni Award and numerous Public Health Service awards. She was inducted as a Fellow into the American Academy of Nursing in 2013.
Jeanie Youngwerth, MD, FAAHPM is an Associate Professor of Medicine at University of Colorado School of Medicine (UC SOM), board-certified in Internal Medicine and Hospice and Palliative Medicine. Dr. Youngwerth was a past president of the Alpha Omega Alpha at the University of Illinois at Chicago during medical school, and completed internal medicine residency at the University of Colorado Health Sciences Center. Dr. Youngwerth is a Hospitalist with the Section of Hospitalist Medicine at UC SOM since 2004, and is the Director of the University of Colorado Hospital Palliative Care Service since 2009. Dr. Youngwerth has been instrumental in leading the University of Colorado Hospital palliative care team to providing the highest level of clinical care, recognized nationally with the Joint Commission Advanced Certification in Palliative Care since 2013. She is the Associate Program Director of the Colorado Palliative Medicine Fellowship Program at UC SOM. In addition, she is the Medical Director for Halcyon Community Palliative Care and Hospice programs. Dr. Youngwerth was voted one of Denver’s 5280 Top Docs in Hospice and Palliative Medicine for 8 years. Dr. Youngwerth received training at the Program in Palliative Care Education and Practice through the Harvard Medical School Center for Palliative Care. She received the honor of Fellow Status from the American Academy of Hospice and Palliative Medicine (FAAHPM) in 2014. Outside of the hospital, Dr. Youngwerth enjoys mountain biking.

Amy York is currently the Executive Director of the Eldercare Workforce Alliance (EWA). EWA is a group of 35 national organizations – representing consumers, family caregivers, and health care professionals, including direct care workers – joined together to address the immediate and future workforce crisis in caring for an aging America. Amy collaborates with member organizations and volunteer leadership to direct the policy and communication efforts of the Alliance. She looks for practical solutions to expand the eldercare workforce. “As the daughter of early baby boomers, I feel a sense of responsibility to ensure there is a well-trained workforce to care for our nation’s parents and grandparents as they age.”
ROUND TABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

Building the Workforce We Need to Care for People with Serious Illness: A Workshop

BRIEF PROGRAM DESCRIPTIONS

Speakers were invited to provide brief program descriptions to include in the workshop materials:

American Association of College of Nursing (AACN)
   Deborah Trautman

Association of Professional Chaplains (APC)
   Denise Hess

The Advanced Palliative Hospice Social Work Certification Program (APHSW-C)
   Barbara Head

Avila Institute of Gerontology, Inc.
   Sr. M. Peter Lillian Di Maria

The California State University Shiley Institute for Palliative Care
   Jennifer Ballentine

Center to Advance Palliative Care (CAPC)
   Brynn Bowman

End-of-Life Nursing Education Consortium (ELNEC)
   Betty Ferrell

Fairview Home Care and Hospice
   Jody Chrastek

The Interprofessional Education Exchange Program (iPEX)
   Barbara Head

PHI
   Angelina Drake

The National Center for Complex Health and Social Needs
   Lauran Hardin

University of Colorado Hospital (UCH) Palliative Care Service
   Jeanie Youngwerth
AACN IN BRIEF
Visit us at www.aacnnursing.org

MISSION: As the collective voice for academic nursing, AACN serves as the catalyst for excellence and innovation in nursing education, research, and practice.

MEMBERSHIP: AACN member schools offer a mix of baccalaureate, graduate, and post-graduate programs. The dean or chief nurse administrator serves as the representative to AACN, though the association serves the entire academic enterprise, including faculty, administrative staff, and students. AACN maintains seven Leadership Networks for nursing school faculty and staff involved in instructional development, research, organizational leadership, faculty practice, business operations, graduate student recruitment, and communications/development. Each network hosts an annual meeting for participating members.

MEMBERSHIP
From an original 121 member institutions in 1969, AACN today represents 825 member schools of nursing at public and private universities nationwide. These schools offer a mix of baccalaureate, graduate, and post-graduate programs.

825 Schools
45,000 Faculty Members
540,000 Students

AACN PROGRAMS
- Curriculum Standards
- Health Policy Advocacy
- Research and Data Services
- Conferences and Webinars
- Special Projects
- Accreditation and Certification
- Communications & Publications
- Diversity and Inclusion
- Leadership Development
- Interprofessional Education
Learn more at www.aacnnursing.org/about-aacn

GOVERNANCE
AACN is governed by an 11-member Board of Directors, each of whom represents a member institution. The Association has several regular committees, including the Government Affairs, Finance, Nominating, Membership, Diversity and Inclusion, and Program Committees, and sponsors task forces on a variety of professional concerns.

BOARD OF DIRECTORS
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The Association of Professional Chaplains is a professional organization representing more than 5,500 affiliate members and certified chaplain members who work across all settings where chaplaincy care is utilized. The APC and our members are dedicated to providing chaplaincy care to all persons, respecting their diverse cultures, identities, abilities and beliefs.

Our certified chaplains are educated, trained and committed to providing high-quality spiritual care to persons of all faiths and are pledged to adhere to the standards of practice for professional chaplains which includes a statement of professional ethics. APC has cultivated a high standard of excellence in chaplaincy care by establishing common qualifications and competencies for certification of professional chaplains; and by encouraging the continuing education and support of chaplains providing chaplaincy care in specialized settings.

Beyond our members commitment to chaplaincy care, the APC continues the organization’s commitment to research and improve spiritual care for those most in need and most vulnerable to substandard spiritual care. To better assist these sections of the population, APC contributes resources to continue to help develop best practices and effective models for spiritual care in palliative and hospice care settings.

Our collaborations include:
- Membership and support for the National Coalition for Hospice and Palliative Care including work on various committees and taskforces.
- Working with California State University, Shiley Institute for Palliative Care, APC helped to develop the Essentials of Palliative Care Chaplaincy training program.
- In conjunction with the National Association of Catholic Chaplains, APC has developed a Palliative Care and Hospice Advanced Certification for board certified chaplains.

To learn more about APC’s efforts to advance the cause of spiritual care in all settings, or to learn more about the organization, visit us at www.professionalchaplains.org.
The Advanced Palliative Hospice Social Work Certification Program

Specialty certification is a process by which a nongovernmental agency verifies, based on predetermined standards, an individual’s qualifications (knowledge, skills, abilities and experience) for practice in a defined area. Thanks to a grant from the Gordon and Betty Moore Foundation, the Social Work Hospice and Palliative Network (SWHPN) and the University of Louisville collaborated to develop an evidence-based certification program for hospice and palliative social workers, the Advanced Palliative Hospice Social Work Certification (APHSW-C). The certification program is now administered by an independent Board of Directors.

This certification is similar to the specialty certifications of physicians and nurses in hospice and palliative care. Certification is awarded based upon years of experience, verification of licensure and ethical practice, and passing of an entry-level exam. The content of this exam is based upon a nationwide survey of 482 hospice and palliative social workers. Exam items were developed by experienced content experts with the expert leadership of PSI, a testing company with over 70 years of experience. Those who complete the requirements for certification receive the designation Advanced Palliative and Hospice Social Worker Certified (APHSW-C).

The next testing cycle is scheduled for March 15 – April 15, 2020. Applications will be received and processed between January 1 and February 15, 2020.

You can learn more about the program at www.swhpn.org/aphsw-certification.
Palliative Care Implementation in Long-Term Care Facilities

“[Palliative care] is an expression of the properly human attitude of taking care of one another, especially of those who suffer. It bears witness that the human person is always precious, even if marked by age and sickness.”
— Pope Francis

About the Carmelite System:

• Catholic, not-for-profit health system of senior care facilities
• 14 long-term care facilities in Florida, Illinois, Iowa, Kentucky, Massachusetts, New York, Ohio, and Ireland
• Palliative care principles and practices integrated at all facilities

Palliative Care in Carmelite Residences

The Avila Institute of Gerontology has developed a palliative care implementation guide book to support development of palliative care services within each of its facilities.

Program components developed at each location:

• Interdisciplinary Palliative Care Steering Committee
• Steering Committee Chairperson – palliative care ‘Champion’ leader
• Palliative Care Unit Team established for each floor/wing
• Training delivered to nursing, social work, and spiritual care staff
• Comprehensive assessment for all domains of pain and suffering: physical pain, emotional pain, psychiatric pain, spiritual pain, and family pain
• Care plan prioritizes relief of pain

Design Principles

Accounting for local variation: Palliative care Steering Committee makeup and activities are determined at the local level, within parameters set at the system level

Accounting for high turnover in LTC: Continuous education driven by the Palliative Care Champion ensures a culture of palliative care despite staffing changes
Accounting for resource scarcity: Empower local palliative care leaders (Chairperson and Steering Committee) to use creativity in meeting the needs of residents

Educating staff: Palliative care curriculum developed by the Avila Institute of Gerontology based on the ELNEC curriculum with modifications; Train existing staff rather than hiring certified palliative care specialists

Ensuring quality and performance improvement across facilities: System-level dissemination of training, implementation guide, and clinical tools to each facility

Sustainability over time: Palliative Care Steering Committee and Unit Teams responsible for evaluating effectiveness, collecting feedback, training, and performance improvement over time
About the Center to Advance Palliative Care
The Center to Advance Palliative Care (CAPC) is a national organization dedicated to increasing the availability of quality health care for people living with a serious illness. As the nation’s leading resource in its field, CAPC provides health care professionals and organizations with the training, tools, and technical assistance necessary to effectively meet this need.

CAPC is funded through organizational membership and the generous support of foundations and private philanthropy. It is part of the Icahn School of Medicine at Mount Sinai, in New York City.

Vision
CAPC addresses its vision of ‘Palliative Care Everywhere’ using the following strategies:

- Improving the knowledge and skills of all clinicians who serve seriously ill patients and their families
- Supporting health care organizations to reliably deliver high-quality palliative care to patients and families in need across all care settings
- Helping the public understand—and know to ask for—palliative care when they are living with a serious illness
- Educating policymakers about high-value care models for the population living with a serious illness
- Collaborating with health plans, accountable care organizations, large insurance purchasers, and other stakeholders to ensure reliable financing of palliative care services
- Promoting adherence to national quality standards in the care of patients with serious illness

Recognizing the Gaps
A large body of evidence demonstrates that palliative care improves quality of life for patients and families, which in turn reduces crisis hospitalizations and the total costs of care. While there is widespread recognition of the benefits of palliative care, the reach of specialty palliative care programs cannot possibly meet the needs of the millions of seriously ill patients in the US. For this reason, a new model has emerged in which the specialty palliative care team supports all front line clinicians through consultation for patients with the most complex needs, while front line clinicians from other specialties—such as oncology, cardiology, and primary care—are trained in and are able to address core palliative care needs including symptom management, communication, and family support.

Making an Impact through Online Clinical Training
In 2015, CAPC launched an online self-study clinical training curriculum with the goal of equipping the health care work force with core skills needed to reduce suffering for patients with serious illness and their families. Accessed through an annual organizational membership, CAPC courses enable clinicians from all specialties and disciplines to strengthen their care of patients with serious illness through skill-building in pain management, symptom management, communication about patient goals and values, and support for family caregivers. In addition, CAPC offers operational and implementation courses that provide the training and tools necessary to launch or grow a specialty palliative care program in any care setting. All CAPC courses provide continuing education credits for physicians, advanced practice providers, nurses, social workers, certified case managers, and licensed professional counselors. ABIM-boarded physicians receive Maintenance of Certification (MOC) points.
Since launching the curriculum in January 2015, more than 45,000 individual clinicians have completed nearly 350,000 online CAPC courses.

CAPC course users represent diverse organizations and care settings, including many of the country’s top-ranked and highest quality health systems, critical access facilities providing care to underserved patients, hospice, home health, clinician group, and long-term care organizations serving patients in their communities, and the health plans that are implementing strategies on behalf of their members with serious illness.

The Future: “Palliative Care Everywhere”

83% of CAPC course users are from specialties other than palliative care – including hospital medicine, primary care, oncology, cardiology, surgery, and others. This is a critical first step to achieving ‘Palliative Care Everywhere,’ and reflects a growing awareness of the opportunity to improve care and relieve suffering for people living with serious illness and their families through clinician education.

To learn more about CAPC’s curriculum, visit capc.org/training.
Founded in 2012, the CSU Shiley Institute for Palliative Care is a workforce initiative of the California State University system, located in San Marcos, CA.

We are the only provider of evidence-based, specialty and primary, comprehensive and topic-focused palliative care education across all disciplines. All our education is ONLINE for maximum convenience, flexibility, and affordability.

Our focus is working as an educational partner to individuals and organizations striving to improve quality care for patients and families.

We custom-curate course selections to meet practice goals, deliver education with exquisite customer service, and measure impact and outcome to demonstrate value.

Professional certificate programs in palliative care skills are available in

- **Advance Practice Nursing**
- **Nursing**
- **Social Work**
- **Chaplaincy**
- **Pediatric Palliative Care**

Our Primary Palliative Care Skills for NPs, PAs, and Physicians offers 34 CE/CME for primary care providers or non-palliative specialists to hone skills in prognostication, communication, psychosocial-spiritual care, pain & symptom management, and referral to specialty care.

Short series courses address

- **Advance Care Planning**
- **Communication Skills for All Clinicians**
- **Interprofessional Core Concepts of Palliative Care**
- **Building a Community-based Palliative Care Program**
- And more . . .

Contact Brandon McDonald (bmcdonald@csusm.edu) or Jim Shaw (jshaw@csusm.edu) or visit [https://csupalliativecare.org](https://csupalliativecare.org) to learn more.
CSU Shiley Institute for Palliative Care Fact Sheet

CSU Shiley Institute for Palliative Care was founded in September 2012 under its original name, the CSU Institute for Palliative Care. In the past seven years, we have:

- Advanced the understanding of palliative care as a patient-centered approach that focuses on delivering the best care possible to people in any stage of a serious illness
- Received significant support from major foundations and philanthropists including Darlene Marcos Shiley, the California Health Care Foundation, the Archstone Foundation, the SCAN Foundation, and others.
- Educated more than 12,542 doctors, nurses, social workers, chaplains and other healthcare professionals in palliative care best practices through convenient online courses and other programs
- Expanded its curriculum from six courses during the first year to more than 187 courses today, reaching students in all 50 states and 34 countries
- Forged partnerships with CSU campuses in Fresno, Monterey Bay, and San Marcos to integrate palliative care into undergraduate curricula and educate the community about palliative care
- Integrated a state-of-the-art learning management system that allows health professionals to enroll in online courses on their own schedule and engage with peers in an exciting and meaningful way
- Helped deliver palliative care training to more than 24,000 future health professionals through our campus partners
- Educated more than 21,000 community members about palliative care and its benefits
- Created an annual National Symposium for Academic Palliative Care Education and Research, drawing educators and researchers from across the United States and around the world
- Awarded more than $75,000 in scholarships provided by Mrs. Shiley to help educate San Diego County healthcare professionals in palliative care
- Developed partnerships with national organizations including the National Hospice and Palliative Care Organization; the Association of Professional Chaplains; the Coalition for Compassionate Care California; Familias En Accion; the Supportive Care Coalition; the Physicians Assistants in Hospice and Palliative Medicine, and many more
End-of-Life Nursing Education Consortium (ELNEC)

FACT SHEET
(Updated 9/2019)

The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve palliative care and is a partnership between the American Association of Colleges of Nursing (AACN), Washington, DC and the City of Hope, Duarte, CA. The project provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students, practicing nurses and other healthcare professionals. The project, which began in February 2000, was initially funded by a major grant from The Robert Wood Johnson Foundation (RWJF). Additional funding has been received from the National Cancer Institute (NCI), American Association of Colleges of Nursing (AACN), US Cancer Pain Relief Committee, the Aetna, Archstone, California HealthCare, Cambia Health, Milbank, Oncology Nursing, Open Society, and Stupski Foundations and the US Department of Veterans Affairs (VA).

To date, over 24,500 nurses and other healthcare professionals, representing all 50 US states, plus 100 international countries have received ELNEC training through attending national/international train-the-trainer courses and are sharing this new expertise in educational and clinical settings. In addition, over 330 Schools of Nursing have accessed the ELNEC-Undergraduate curriculum with more than 30,500 nursing students completing the online course via Relias. ELNEC Trainers are hosting professional development seminars for practicing nurses, incorporating ELNEC content into nursing curriculum, hosting regional training sessions to expand ELNEC’s reach into rural and underserved communities, presenting ELNEC at national and international conferences, coordinating community partnerships, and improving the quality of nursing care in other innovative ways. It is estimated that since its inception, that ELNEC trainers have returned to their institutions and communities and have educated over 735,000 nurses and other healthcare providers.

KEY ELNEC FACTS

- People in the United States deny death, believing that medical science can cure any patient. Death often is seen as a failure of the health care system rather than a natural aspect of life. This belief affects all health professionals, including nurses. Despite their undisputed technical and interpersonal skills, professional nurses may not be completely comfortable with the specialized knowledge and skills needed to provide quality palliative care to patients. The ELNEC project gives nurses the knowledge and skills required to provide this specialized care and to positively impact the lives of patients and families facing serious illness and/or the end of life.

- The curriculum was developed through the work of nationally recognized palliative care experts with extensive input from an advisory board and reviewers and is revised annually to include new advances in the field and is modified for each distinct audience. The curriculum focuses on core areas in end-of-life/palliative care reflecting AACN’s 2016 Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES), formerly known as Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care (1998). In addition the 2019 Graduate-CARES competencies provide a higher level of direction for advanced practice nurses. These competencies outline specific aspects of professional nursing care considered requisite for each graduate. Other landmark documents used in the development of the ELNEC curricula include the 2018 National Consensus Project’s (NCP) Clinical Practice Guidelines for Quality Palliative Care, the 2013 Institute of Medicine (IOM) Report entitled Delivering High Quality Cancer Care: Charting a New Course for System in Crisis and the 2014 IOM Report entitled Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, the 2019 Oxford Textbook of Palliative Nursing, and the 2016 Advanced Practice Palliative Nursing Textbook.
• ELNEC includes the following modules: Nursing Care at the End of Life; Pain Management; Symptom Management; Communication; Loss, Grief, Bereavement; and Preparation for and Care at the Time of Death. Concepts of ethical/legal issues and cultural/spiritual considerations are embedded in each of these 6 modules.

• Participants receive a comprehensive 1,000+ page syllabus, palliative care textbook, and a wealth of resources and strategies to teach this content to others. Teaching materials are furnished in hard copy as well as on a flash drive so nurse educators can use them efficiently for their own instructional purposes.

ELNEC CURRICULA

• ELNEC-CORE: Approximately 19,000 nurses and other interprofessional colleagues from diverse clinical backgrounds have been educated to date in this curriculum. ELNEC-Core is used to educate staff nurses, advanced practice nurses, undergraduate and graduate nursing faculty, administrators, and researchers who work in acute care settings (i.e. medical-surgical and oncology units), clinics, homecare, hospice and palliative care settings. Several national ELNEC-Core courses are held each year.

• ELNEC-ADVANCED PRACTICE REGISTERED NURSES (APRN): This first course, supported by Cambia Health Foundation, debuted in 2013 with 115 APRNs, representing 26 states. There are many palliative care teams across the US being led by APRNs and they are key team members who exemplify commitment to their varied roles in not only leadership, but practice, education, and research. Participants receive advanced education in pain and symptom assessment/management and communication. Additional education in palliative care operations and budgets, quality improvement, education, and leadership are also provided. Participants can choose to attend one of 2 tracks—adult-or pediatric-focused care.

• ELNEC-COMMUNICATION: The Foundation of Excellent Practice: The area of communication has been a key part of the ELNEC curriculum since the project began in 2000. However, the national ELNEC Project Team receives consistent feedback that more education is needed on this important topic. The new ELNEC Communication curriculum is based on the National Consensus Project (NCP) Guidelines for Quality Palliative Care with separate modules developed to address communication in each of the domains including structures and processes of care, physical aspects, psychological, social, spiritual, cultural, end of life care, and ethical aspects of care. It is also an interprofessional curriculum and is presented as a train-the-trainer course with extensive teaching materials, slides and lab sessions designed to facilitate teaching communication principles as well as application through skills-based learning. This course is appropriate for those who work with neonates to older adults.

• ELNEC-CRITICAL CARE: This course has been developed for nurses who work in intensive care, coronary care, burn and dialysis units, emergency departments and other clinical areas encompassing critical care. Those who work in critical care settings are on the front line of seeing seriously ill patients. For many patients, the emergency department is their “life line.” Thousands die in intensive care units each month. Critical care nurses have found this course to be helpful as they learn to communicate with patients and their families about goals of care and the importance of honoring those goals. They recognize the vulnerability of their patients and are committed to providing excellent holistic care.

• ELNEC-GERIATRIC: With life expectancy increasing and the numbers of aging adults growing each day, the healthcare system in the U.S. and abroad requires nurses to be educated in meeting the palliative care needs of older adults. The ELNEC-Geriatric curriculum addresses the specific educational needs of nurses who provide care to people who reside at home or are being cared for in community-based settings, such as assisted living, nursing communities, skilled nursing settings, hospices, home health agencies, or ambulatory care clinics. Each module captures essential elements of geriatric palliative care that is easy to teach or implement across the continuum of community care settings. Unique features of the course include a focused module on geriatric palliative care that elaborates on physiologic changes in older adults, medications, and chronic conditions using a person-centered approach. Geriatric syndromes are integrated across all 7 modules. Undergraduate and graduate nursing faculty find its supplemental teaching materials and case studies invaluable to their current lectures. In addition, the curriculum includes supplemental
teaching strategies for educating unlicensed personnel that work with geriatric patients and their families. Plan now to attend a course, as it provides critical referenced materials and education for the broadest category of the persons served by nurses—the geriatric population.

- **ELNEC-ONCOLOGY APRN**: This course was developed in 2017 with a grant from the National Cancer Institute. The purpose of this project is to educate and provide resources to advanced practice nurses who work in oncology settings in an effort to prepare them to be generalists in palliative care. This course offers two tracks: Adults and Pediatrics. The first of five ELNEC-Oncology APRN courses was held in 2018.

- **ELNEC-PEDIATRIC PALLIATIVE CARE**: ELNEC-Pediatric Palliative Care was developed by 20 pediatric palliative care experts and piloted in 2003. Each year, at least two national train-the-trainer courses are offered across the US. The curriculum also includes perinatal and neonatal content.

- **ELNEC-UNDERGRADUATE**: Cambia Health Foundation has invested funds to develop an innovative ELNEC online curriculum to integrate palliative care in undergraduate nursing education across the nation. The online format means the ELNEC curriculum is equally available to students in rural areas and helps standardize palliative care nursing education. This online curriculum debuted January 2017 and is built on the 2016 American Association of Colleges of Nursing’s (AACN) *Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES)*. [http://elnec.academy.reliaslearning.com/](http://elnec.academy.reliaslearning.com/)

- **ELNEC-GRADUATE**: Because of the tremendous success of ELNEC-Undergraduate, Cambia Health Foundation provided further funding to develop an online curriculum for graduate nursing students in 2018. This curriculum became available September, 2019 and is built on the 2019 AACN *Graduate-CARES* document, outlining the competencies for both masters and doctoral nursing students. This curriculum will assist future nursing leaders to develop skills in primary palliative care so they can succeed in advanced nursing practice roles in clinical practice, administration, and/or academia. [http://elnec.academy.reliaslearning.com/](http://elnec.academy.reliaslearning.com/)

- **ELNEC-FOR VETERANS**: The ELNEC-For Veterans curriculum is designed to meet the unique needs of nurses caring for Veterans with serious illness. The expertise gained at these courses promises to improve the quality of palliative care for thousands of Veterans in 153 Department of Veterans’ Affairs Medical Centers across the U.S. To date, six national train-the-trainer courses have been held across the US with 745 nurses and other members of the interdisciplinary team in attendance, representing over 200 VA facilities (i.e. medical centers, clinics, CLC’s, etc). Community partners with VA (i.e. homecare, hospice, etc) have attended these courses, too, as they care for many Veterans in various community settings. In 2017, ELNEC-For Veterans was up-dated and is now on the National Hospice and Palliative Care Organization’s (NHPCO) website: [https://www.wehonorveterans.org/elnec—veterans-updated-curriculum](https://www.wehonorveterans.org/elnec—veterans-updated-curriculum)

**INTERNATIONAL EFFORTS TO IMPLEMENT AND DISSEMINATE ELNEC**

While the initial efforts, launched in 2000, were focused in the United States, many ELNEC trainers have had opportunities to travel internationally and provide this education to nurses and other healthcare providers throughout the world. Currently, ELNEC trainers and faculty have traveled to six of the seven continents, representing 100 countries. Many trainers have provided ELNEC educational courses, while others have gone as consultants to work with educators, health administrators, and community leaders to improve care of the seriously ill in their countries. It is estimated that over 25,000 nurses and other healthcare providers have received ELNEC training internationally. Some are working on translating ELNEC into other languages and adapting it to increase the relevance to other cultures. For example, ELNEC has already been translated into Albanian, Czech, Romanian, and Russian, where nursing administrators and faculty are using the curriculum throughout Eastern Europe. ELNEC is also translated in Spanish (Core and Pediatric Palliative Care versions) and is being widely disseminated in Mexico, Central America, and parts of South America. ELNEC-Hindi is being developed to reach nurses throughout India. Lastly, ELNEC-Japanese, ELNEC-Korean, ELNEC-Chinese, and ELNEC-German are available.
Building palliative care leaders has been a major emphasis of the national ELNEC team. To date, 75+ nurses and physicians have attended leadership courses in Romania (2014 & 2015), Kenya (2016), Hong Kong (2016) and Austria (2019 for eastern European nurses). For more information about ELNEC trainers’ efforts to disseminate ELNEC internationally and for a listing of efforts by country, go to: http://www.aacnnursing.org/ELNEC/About/ELNEC-Curricula

ELNEC RESOURCES

• Website: The ELNEC project is described in detail at www.aacnnursing.org/ELNEC
ELNEC Trainers use the complete list of Trainers found on the website by state to locate colleagues with whom to consult and partner. Those outside the ELNEC network can also use this list to contact experts as consultants and instructors.

• Publications: Many articles have been written about the ELNEC Project since its inception in 2000. Numerous articles have been published regarding outcomes of various ELNEC courses/curricula. In addition, the ELNEC Project has been featured in various national and international journals and in electronic publications. For listings of these articles, go to http://www.aacnnursing.org/ELNEC/Resources

• Newsletter: The quarterly newsletter, ELNEC Connections is sent to ELNEC Trainers, various palliative care organizations and projects, governmental agencies, and media representatives. ELNEC Connections provides information on palliative care and offers a forum through which the network of ELNEC Trainers can stay in contact and share successful education strategies. The newsletter is available online at http://www.aacnnursing.org/ELNEC/Resources

• ELNEC Online: Since 2007, ELNEC modules have been available on-line, developed by national nursing leaders in palliative care. In 2014, communication vignettes were videotaped and are now available. The vignettes and ELNEC curricula (Core, Undergraduate, Critical Care, Geriatric, and Pediatric Palliative Care) are useful teaching tools in schools of nursing, acute care facilities, clinics, hospice, homecare, long-term care and skilled nursing facilities. To obtain more information about these modules, which are available through Relias, go to https://www.relias.com/product/elnec-training
(Reminder: ELNEC-Undergraduate and ELNEC-Graduate are also available through Relias at http://elnec.academy.reliaslearning.com/)

• ELNEC on Social Media: Check out ELNEC on Facebook, Instagram, Twitter, and YouTube. For more information, go to www.aacnnursing.org/ELNEC

For more information on the ELNEC project, please refer to the website, https://www.aacnnursing.org/ELNEC or contact us directly at elnec@coh.org
Fairview Home Care and Hospice, Minnesota,  
Jody Chrastek RN DNP FPCN

Fairview Home Care and Hospice (FHCH) is part of a non-profit, integrated health system offering a full spectrum of health care services across the state of Minnesota. FHCH provides care to children and adults in both urban and rural settings across sixteen counties in Minnesota, including the cities of Minneapolis and St. Paul. To meet the diverse needs, FHCH’s model trains interdisciplinary team to provide care for adults, children, and their families.

The Pediatric Advanced Complex Care Team (PACCT) is a subset of FHCH providing complex nursing care, palliative care and hospice for children, ages 0 through age 21, and their families.

Challenges and solutions:

**Challenge:** Reimbursement of home visits does not cover cost to provide them, agency loses money  
**Response:** judicious use of services, restriction on which children are served.

**Challenge:** A relatively small number of children needing this specialized care is spread across the state. Although this care is essential for children and families, not all areas have the resources to pay for or staff a pediatric team  
**Response:** Cross-training interested and experienced interdisciplinary team members to provide care across the lifespan; expanding the definition of Interdisciplinary team to include the broader community, including school and county.

**Challenge:** Fragmented care occurs when children use different health care systems to receive the care families want.  
**Response:** PACCT follows the child wherever they are and is the key contact point in the fragmented system.

**Challenge:** Significant numbers of under-resourced, non-English speaking families.  
**Response:** Using interpreters/ cultural liaisons for all visits as needed, offering telephone or video distance interpreters for more anonymity; social workers work with every family from start of care, and remain involved over the disease trajectory.

**Challenge:** “Palliative care” and “Hospice” are viewed by many as giving up.  
**Response:** Listening to the needs of the child and family before suggesting what program would be best for them; using the HCA Concurrent Care to provide hospice as an addition to the care - not necessarily a change in direction.

**Challenge:** Lack of public and professional understanding of pediatric palliative care and hospice.  
**Response:** Outreach and education informally and formally, just in time resources for other programs .

**Challenge:** Low-frequency but high-impact occurrences that can be overwhelming to clinicians  
**Response:** Regular team meetings (in person and remote); skilled debriefing after difficult situations or deaths; individualized self-care plan and organizational support for staff.
Statistics about Pediatric Palliative Care (PPC). (Friebert and Williams 2015)

- 7.3 deaths/ US standard population
- 11.2 million children have special health care needs 27% could benefit from PPC
- PPC home care showed 11% cost savings per month, and 32% reductions in average number of hospital days.

The basic requirements for PPC

- Awareness of the need and benefits of pediatric palliative care.
- Education of health care clinicians
- Appropriate reimbursement to adequately cover the cost of care
- Flexible programs and benefits
The Interprofessional Education Exchange Program (iPEX)

This national training program offers training, mentoring and resources to selected faculty teams from across the nation. This training will enable teams to create and implement an evidence-based IPE curriculum in oncology palliative education. Funded by the National Cancer Institute (R25CA203637), iPEX has research components and IRB approval. Teams from eight institutions are selected annually for the iPEX program. These teams are composed of three to five members representing a minimum of three professions involved in palliative care. The program lasts one year and includes institutional self-evaluation, on-line modules, webinars, a supporting mentor, a workshop, and monthly team video conferences. The workshop focuses on IPE skills training and each institution’s tailored program development. The teams exchange ideas and experiences throughout the year. Training costs, including workshop expenses and travel, are covered by grant funds. Recruitment of teams for the next training cohort will begin in early 2020.

For more information about iPEX, the InterProfessional Education EXchange: A National Program to Advance Interprofessional Education in Cancer Care, visit this website:  http://iPEXproject.org/

Feedback from 2018 iPEX Workshop participants:

- Thank you for an incredible opportunity. I learned so much and am so grateful for focused time with my site team. The whole program was extremely thoughtfully put together and was led by people who are master educators.
- I have a MA in instructional design and I thoroughly enjoyed attending such a well-designed, effective workshop. The Louisville team modeled best practices so well.
- The most valuable aspect of this workshop was the great sense of being part of an incubator to foster the development of our ideas within our own group and across all the different groups. The workshop faculty was very good at promoting creative big idea thinking but also promoting concrete practical skills and planning of next steps—very productive time.
The Interdisciplinary Curriculum for Oncology Palliative Education (iCOPE) Project

iCOPE is an innovative, interdisciplinary curriculum for learners from the schools of nursing, medicine and social work as well as chaplaincy residents. iCOPE was developed at the University of Louisville and was funded by a grant from the National Cancer Institute (#1R25CA148005). Didactic online modules, clinical rotations in palliative care, reflective writing exercises and related sharing, and an interdisciplinary case management experience are used to teach students of the four disciplines the knowledge and skills needed to provide interdisciplinary palliative care in oncology. Through interactive learning experiences, students develop the collaboration and communication skills necessary for effective teamwork.

All iCOPE teaching materials are available for educators’ use. For more information and to download resources, visit the website: http://icopeproject.org
Founded in 1991, PHI is a national nonprofit that improves the lives of people who need home and residential care and the lives of the direct care workers who provide that care.

Direct care workers are the home health aides, personal care aides, and nursing assistants who provide hands-on care to older adults and people with disabilities. They ensure their clients’ well-being, lend emotional support, and meet daily health needs. Caring, committed relationships between these paid caregivers and their clients are at the heart of quality care.

Yet despite their crucial role in the lives of clients and families, direct care workers are consistently denied opportunities for training, fair pay, advancement, and respect. Without the chance to learn, grow, and earn enough to support their families, it is harder for these caregivers to provide the quality care their clients deserve. It’s also harder for employers to attract and retain professionals to meet the growing need for quality long-term care.

Understanding that quality jobs are the foundation of quality care, PHI draws on 25 years of experience working side-by-side with direct care workers and clients across the country to offer providers, payers, and policymakers the tools to transform our system of long-term services and supports.

PHI’s trainers, curriculum developers, researchers, and policy experts work together to:

- Learn what works — and what doesn’t — in meeting the needs of direct care workers and their clients, in a variety of long-term care settings;

- Share lessons and implement best practices through hands-on coaching, training, and consulting to help professionals across the industry deliver high-quality care; and

- Support policymakers and advocates in understanding direct care in the U.S. and crafting evidence-based policies to improve it.

Through our online and social media channels, PHI is the primary source for direct care news and analysis — anchored at www.PHInational.org and @PHInational.
PHI’s Care Connections Project created an advanced role for home care workers designed to maximize the value of home care in: improving care transitions, reducing emergency department usage, and preventing unnecessary rehospitalizations.

With lead funding by the New York State Department of Health over 18 months, the Care Connections Project saw the design and roll-out of an advanced home care training curriculum, training of 14 home care workers, and deployment of 8 full-time “Care Connections Senior Aides” across three New York City home care agencies.

This new model of care was successful in optimizing caregiving resources, implementing tested care transition practices, and using technology to support and deliver timely communication to help reduce incidence of some of the costliest health outcomes among clients receiving long-term care. It also created a pathway to advancement in home care, in a field that does not traditionally offer career growth.

GOALS

The goals of the project were to: i) create and test an advanced role for home care workers, ii) maximize the role and value of the home care worker in the home, iii) improve linkages between care management staff and home care agencies, and iv) strengthen care transitions.

The 18-month pilot implementation targeted the following outcomes:

- **Improved linkages between care management staff and home care workers** in areas of communication, collaboration, and information-sharing related to specific symptoms, health outcomes, promoting health for Medicaid-eligible individuals served, and reducing potentially avoidable hospital admissions.
- **Strengthened care transitions to reduce preventable hospital re-admission** to acute care and long-term services and supports institutions among clients.
- **Reduced emergency room (ER) visits.**
- **Reduced caregiver burnout** among clients’ family or other informal caregivers, improving satisfaction with care.
- **Increased availability of home- and community-based services** to serve additional clients through the three participating home care agencies.

INTERVENTIONS

- **Care Connections Senior Aides (CCSAs)** were trained to provide coaching and support for home care workers and family caregivers and serve as a resource to a client’s care team, strengthening monitoring and communication about the client’s condition. CCSAs receive an annual salary with benefits, meaningfully increasing their earnings by 60% compared to entry-level home care positions.

CCSAs contact home care workers whose clients are coming home after a hospital stay to help them understand medication management, physician visits, and signs and symptoms that indicate changes in
health. When there is a high turnover of workers, CCSAs determine the underlying cause of the disruption and report back to the client’s care team. Often, CCSAs provide an intervention in the home, such as mediating a dispute or training caregivers in new skills.

❖ A telehealth program was piloted with 10% of clients impacted by the project. In it, software on mobile devices installed in client homes facilitated direct, timely communication between home care workers and a Registered Nurse (RN) at their employer agency. The software prompted home care workers with up to 13 yes-or-no questions to answer each shift, to encourage observations and reporting on changes in the client’s condition. The questions, developed by clinical staff, were weighted to signify the severity of the changes; those that warranted attention generated an alert by the software, which could be seen by the RN. RNs responded to red alerts within 30 minutes, yellow alerts within two to three hours, and green alerts by the end of the day. The RN would then conduct an evidence-based telephone triage assessment with the home care worker on the next steps in care.

IMPLEMENTATION

❖ From October 2014 to January 2015, PHI designed and delivered customized CCSA training to 14 experienced home health aides. The training focused on the key areas of:

- **Communication Skills**: Learning to build trust and support effective communication with home care workers and family caregivers.
- **Chronic Disease Knowledge**: Supporting enhanced care for chronic and secondary conditions that place clients at risk for hospitalizations and adverse health outcomes.
- **Enhanced Observe, Record, Report Skills**: Recognizing and relaying signs of deteriorating conditions and other factors to prevent emergencies and unnecessary rehospitalizations.
- **Telehealth Device Use**: Utilizing mobile technology and coaching home care workers in software that transmits vital client information to the care team.

❖ Project implementation began in February 2015, with 8 full-time CCSAs deployed in the field whose work was managed by a RN embedded at each participating home care agency. PHI designed and delivered monthly booster sessions to maintain and strengthen CCSAs’ skills.

❖ The Care Connections Project benefitted more than 1,400 ICS clients in its first 18 months.

❖ While additional evaluation is needed, preliminary project outcomes show improvements in reported caregiver strain and an 8% reduction in the rate of ER visits among clients served by CCSAs in the pilot, compared to the prior year.

MEDIA


New York Times article: [nyti.ms/2wdS5q6](nyti.ms/2wdS5q6)

FUTURE WORK

The Care Connection Project’s partners supported the continuation of the advanced aide role beyond the initial pilot funding period for the majority of the full-time CCSAs employed. PHI is leveraging the Project’s findings to develop similar career advancement models with home care agencies and long-term care systems across the country.
What is the National Center?

The National Center for Complex Health and Social Needs, launched by the Camden Coalition of Healthcare Providers in 2016, serves as a professional home for the field of complex care. Complex care aims to improve well-being for people with complex medical, behavioral, and social needs.

The National Center is catalyzing the emerging field by inspiring, connecting, and supporting an evolving community of complex care practitioners and leaders, including providers, healthcare systems, social service organizations, and individuals with lived experience who are working to develop equitable, person-centered, relationship-based ecosystems of care. We also engage and collaborate with payers, funders, researchers, and policymakers to build the knowledge base and payment environment required for complex care to spread to communities throughout the nation.

What is complex care?

There’s a growing recognition — coinciding with efforts to reform how we pay for care — that to see different results we must deliver care differently. Care must be flexible, interdisciplinary, and centered on individuals’ needs, goals, and circumstances.

Complex care is a person-centered approach to address the needs of people whose combinations of medical, behavioral health, and social challenges result in extreme patterns of healthcare utilization and cost. Complex care works at the individual and systemic levels: it coordinates better care for individuals while reshaping ecosystems of services and care delivery.

Complex care is person-centered, equitable, cross-sector, team-based, and data-driven. It is designed in partnership with consumers and communities, transcends traditional boundaries, and is financed and delivered in new and more integrated ways.

Who are people with complex health and social needs?

People with complex health and social needs experience combinations of medical, behavioral health, and social challenges that result in extreme patterns of healthcare utilization and cost. They repeatedly cycle through multiple healthcare, social service, and other systems but do not derive lasting benefit from those interactions.

The National Center for Complex Health and Social Needs’ founding sponsors are the Atlantic Philanthropies, the Robert Wood Johnson Foundation, and AARP. It is an initiative of the Camden Coalition of Healthcare Providers.
Advancing the field of complex care

*Putting Care at the Center*

*Putting Care at the Center* is the annual conference for the National Center for Complex Health and Social Needs, and is the only annual conference on complex care in America. *Putting Care at the Center* takes place in a different city each year, and attracts over 650 experts in healthcare, social services, research, and policy, including complex care consumers, who come together to share their perspectives and experience and advance the growing field of complex care.

Learn about *Putting Care at the Center* at [www.centering.care](http://www.centering.care).

**The Blueprint for Complex Care**

The *Blueprint for Complex Care*, a joint project of the National Center, the Center for Health Care Strategies, and the Institute for Healthcare Improvement, is a strategic framework for the field of complex care. Released in December 2018, the *Blueprint* assesses the current state of the field and outlines actionable recommendations to grow the field’s capacity to improve care delivery for the nation’s most vulnerable individuals. More than 70 organizations have signed on as Complex Care Champions, endorsing the *Blueprint*’s recommendations and helping to strengthen the field.

Learn more about the *Blueprint for Complex Care* and download the document at [www.nationalcomplex.care/blueprint](http://www.nationalcomplex.care/blueprint).

**Student Hotspotting**

The Interprofessional Student Hotspotting Learning Collaborative is an annual program that trains interdisciplinary teams of professional students from schools around the country to learn to work with complex medical and social needs using a person centered approach. Our hotspotting hubs Samuel Merritt University, Southern Illinois University, Thomas Jefferson University, and University of Utah operate the program in partnership with the National Center for teams within and outside their institutions.

**Technical assistance**

We offer coaching, expert advising, and training from complex care experts at the Camden Coalition who have developed the Camden Core Model and other successful complex care models across the country. We work with organizations looking to launch or improve complex care initiatives and to develop complex care ecosystems in their communities. Learn more by emailing camdentA@camdenhealth.org.

**About the Camden Coalition of Healthcare Providers**

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of complex care by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals in Camden and regionally.

Through our **National Center for Complex Health and Social Needs** (National Center), the Camden Coalition works to build the field of complex care across the country. Launched in 2016, the National Center exists to inspire people to join the complex care community, connect complex care practitioners with each other, and support the field with tools and resources that move the field of complex care forward.

[www.camdenhealth.org](http://www.camdenhealth.org) | [www.nationalcomplex.care](http://www.nationalcomplex.care)
A negative patient experience is often the catalyst from which positive change can grow. Such an experience of witnessing immense suffering of a hospitalized patient with a serious illness prompted Valley View Hospital (VVH) to reach out to the University of Colorado Hospital (UCH) Palliative Care Service to bring specialty level palliative care to VVH to optimize care of people with serious illness and their loved ones.

VVH is a non-profit hospital community hospital with 79 beds, a 6-bed intensive care unit, 4 stepdown beds, and a multidisciplinary cancer center that serves the extended rural mountain community. UCH is a 678-bed non-profit academic medical center with an interdisciplinary palliative care service since 2005, achieving Joint Commission Advanced Certification in Palliative Care in 2013. The distance between hospitals is 3 ½ hours without traffic. The lack of medical specialists in the mountain communities highlights the workforce shortage in palliative care. VVH was building a tele-stroke program with UCH at that time and the Chief Medical Officers of the 2 hospitals knew each other.

VVH and UCH collaborated to build an innovative, interdisciplinary team model of palliative care in the hospital setting, leveraging the technology of telemedicine. The interdisciplinary team built is composed of local, in-person VVH providers (advanced practice providers, social work and chaplain) working with UCH board-certified palliative medicine physicians through telemedicine. The UCH palliative care physician is brought to the bedside as a video visit with the VVH team members present in-person, facilitating a cohesive, specialty-level interdisciplinary team consultation at the bedside of patients with serious illness and their loved ones.

The UCH physicians provide mentoring to the VVH team members telephonically and through telemedicine. The VVH physician assistant on the team pursued formal palliative care training by enrolling in the University of Colorado Master of Science in Palliative Care (MSPC) program. The MSPC is a primarily on-line interprofessional program which enables physicians, nurses, advanced practice providers, social workers, spiritual care providers, psychologists, and others to receive formal training to become community palliative care specialists while remaining in their home practice setting.

In addition, a VVH emergency medicine physician who joined the palliative care service is currently enrolled in the MSPC and will be an inaugural, alternative-pathway hospice and palliative medicine fellow through the Advancing Innovation in Residency Education (AIRE) pilot in 2020. AIRE is a hybrid on-line MSPC degree combined with a mentored clinical practice
portfolio with Accreditation Council for Graduate Medical Education oversight, facilitating physicians who complete the MSPC to become board certified in hospice and palliative medicine.

The combination of the VVH-UCH telemedicine palliative care service with the formal palliative care training through the MSPC and AIRE programs, promotes VVH to become a self-sustaining, community specialist palliative care program, scaling back the need for UCH palliative care physicians over time. This innovative model of care meets the needs of the rural community by increasing access to specialty level interdisciplinary palliative care through telemedicine and addresses the palliative care workforce shortage through the MSPC and AIRE programs. The goal is for rural programs to become self-sustaining community specialists in palliative care. This model is reproducible in other rural settings.

Federal policy changes in need to support bringing the interdisciplinary palliative care team-based model to scale include:

1) Expanding Medicare reimbursement of telemedicine services, including home-based telemedicine;
2) Adding and expanding Medicare reimbursement of home-based community palliative care services;
3) Eliminating cost-sharing so patients do not have co-pays for telemedicine visits; and
4) Expanding Medicare-funded graduate medical education fellowship slots and grants to support providers in alternative training programs for interdisciplinary palliative care team members.