Welcome to the Conference



On behalf of the Board, I'd like to welcome you to the conference, which is a great opportunity to re-charge and re-connect with friends and colleagues. When we met last year, the organization was embarking on significant changes, including in leadership, to start our next decade of advocacy. Our staff has done a tremendous job in coming together and maintaining their focus on residents and consumers of long-term care. They have worked hard to pull together a terrific agenda that focuses on the most important issues facing long-term care consumers today. With so many changes and challenges facing individuals needing long-term care, the work of the Consumer Voice is as important as ever. We

appreciate your attendance at the conference and encourage your active support and involvement with the organization.

Warm regards,

Michael Koenig President

Consumer Voice Governing Board

Welcome to the Consumer Voice Annual Conference! My Voice Matters! Our theme this year is meant to highlight efforts for engaging long-term care consumers at the policy table and in national discussions around long-term care and services. Whether we're talking about quality standards in nursing home regulations, the implementation of more person-centered care in home and community based services, or how managed care is changing long-term services and supports, consumers need to be fully engaged in shaping the future of long-term care. Let's come together at this 40th annual conference and explore our best efforts for making Our Voices Matter! We're glad you're here!



Lori Smetanka Executive Director

In Smetanka

Consumer Voice Leadership

2015-2016 Governing Board

The Governing Board is responsible for traditional governance functions, including fiscal oversight and fundraising.

Michael Koenig	Iris Y. Gonzalez, J.D. President-Elect	Hanna Fink	Lori Walsh
President		Treasurer	Secretary
Jonathan Evans, MD	Nancy Stone, J.D. MPH	Yvette Green	Mary Ellen Jacobs
Member	Member	Member	Member
Peter Reed, PhD	Joshua M. Wiener, PhD	Judy Peres	
Member	Member	Member	

2015-2016 Leadership Council

The Leadership Council is responsible for developing the organization's policy and programmatic agendas.

 Josh Casper	Anne Montgomery	Bernie Vonderheide
Carmen Castro	Deanna Okrent	Patricia Warnick

Erin Pettegrew

Consumer Voice Staff

Jennifer Golle

Lori Smetanka, J.D., Executive Director

Robyn Grant, MSW, Director of Public Policy and Advocacy

Amity Overall-Laib, MA, Director of the National Ombudsman Resource Center

Carol Scott, Ombudsman Specialist

Katie Kohler, Program and Outreach Associate

Alisha Lineswala, Public Policy Specialist

Alejandra Ona, Bookkeeper/Accountant

Christina Steier, Communications and Membership Coordinator

Sara Hunt, Consultant to NORC

Maria Greene, Consultant to NORC

Making It Happen: Conference Supporters

The Consumer Voice sincerely thanks the following organizations and individuals for supporting the 40th Annual Conference & Meeting. This support enables the Consumer Voice to keep registration fees affordable and to offer scholarships to consumers and those who would otherwise be unable to attend.

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National Consumer Voice for Quality Long-Term Care

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Care and Choice at the End of Life

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Consumer Voice Friends







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Additional Contributors

Mary Anne Brennan Barbara Frances Delo Sue Drumm

Arlene Germain Elma Holder Mary Ellen Jacobs

Wednesday, November 2

7:00am - 7:00pm Registration Open

7:30am – 12:00pm New State Long-Term Care Ombudsman Orientation (invitation only)

Studio D

12:00pm – 6:15pm Consumer Voice Governing Board Meeting (invitation only)

Presidential Suite

1:00pm - 5:00pm NASOP Meeting (invitation only)

Studio B

1:00pm - 4:00pm Intensives

Studio E

1. Striking a Balance: LTC Residents' Sexual Rights and Diminished Capacity

During this intensive, participants will explore the complex issues surrounding the ability to consent to sexual activity among long-term care residents. Discussion will include determining consent, including among residents with diminished capacity; protection of residents' rights; and the LGBT perspective. Collaborative efforts will be explored; and the session will include recommendations and strategies for establishing effective partnerships, protecting rights, and addressing the challenges of Dementia-related illnesses.

Presenters: Merea D. Bentrott, Executive Officer, Iowa Office of the State Long-Term Care Ombudsman; Deanna Clingan-Fischer, Iowa State Long-Term Care Ombudsman; David Godfrey, Senior Attorney, ABA Commission on Law & Aging; Sadiya Abjani, Training Specialist, SAGE

Studio D

2. The ABCs of the LTCOP for Ombudsmen

Delve into your heritage as an ombudsman, affirm the strengths of your role, and gain a national perspective on the long-term care ombudsman program. In this session, you will explore the program's roots and how they affect ombudsman practice today. Learn why misunderstanding of the ombudsman role occurs and how to respond. Ethical considerations and core ombudsman principles will be discussed and clarified through examples. Be introduced to national resources and tools for ombudsmen. Gain tips from experienced ombudsmen. This interactive session is open to all advocates; however, it is designed for ombudsmen who have been serving residents two years or less or those wanting a refresher course to revitalize their advocacy efforts.

Moderator and Presenter: Carol Scott, Ombudsman Specialist, National Long-Term Care Ombudsman Resource Center

Presenters: Becky Kurtz, Director, Office of Long-Term Care Ombudsman Programs, Administration for Community Living; Denise Kennedy, District Ombudsman, Bluegrass Area Development District, Kentucky; Lynn B. McCamie, Manager, Long-Term Care Ombudsman Program Baltimore County Department of Aging, Maryland

4:15pm – 6:15pm Studio E

Consumer Voice Leadership Council Meeting

7:00pm - 9:00pm Welcome Reception for All Attendees

Salons 1-3

Thursday, November 3

7:30am – 8:15am Breakfast on your own

8:00am - 7:00pm Registration Open

8:30am - 9:00am Opening Remarks & Welcome Ballroom

9:00am - 10:30am *Ballroom*

Plenary - The Changing Long-Term Care System - The Impact of Managing Care

As states look to control health care costs, they are looking to options such as managed care and demonstrations such as CMS's Medicare-Medicaid Financial Alignment Initiative. But what does this mean for the consumer receiving care? For this session, hear about the new CMS final rule on Medicaid Managed Care, and the important role for advocates in state implementation. Get the latest on the Financial Alignment Initiatives and what we have learned from them. Take advantage of the opportunity for dialogue and ask national experts what these systems will mean for consumers in your state.

Presenters: Diane Menio, Executive Director, CARIE, Philadelphia, PA; Lindsay Barnette, Director, Models, Demonstrations and Analysis Group, Medicare-Medicaid Coordination Office, CMS; Eric Carlson, Directing Attorney, Justice in Aging

10:30am - 11:00am Break

11:00am - 12:30pm Workshops

Studio B

The Wave of the Future for the Long-Term Care Ombudsman Program

Three major initiatives are impacting the Long-Term Care Ombudsman Program and its services to residents. How will the implementation of the federal rule and the 2016 reauthorization of the Older Americans Act impact the program? A comprehensive evaluation of the program is underway. What will ACL do with the results? What is the expected impact on the program? How will the revision of the data collected (NORS) benefit ACL, ombudsmen, researchers, reporters, and others? Hear the views of NASOP and NALLTCO. Join the discussion.

Presenters: Becky Kurtz, Director, Office of Long-Term Care Ombudsman Programs, Administration for Community Living; Louise Ryan, Ombudsman Program Specialist, Office of Long-Term Care Ombudsman Programs, Administration for Community Living; Patty Ducayet, Texas State Long-Term Care Ombudsman, President, National Association of State Long-Term Care Ombudsman Programs; Cindy Englert, Ombudsman Program Coordinator, Centralina Area Agency on Aging (North Carolina), Chair, National Association of Local Long-Term Care Ombudsmen.

Facilitator: Patricia Hunter, Washington State Long-Term Care Ombudsman

Studio D Raise the Floor: Quality Nursing Home Care Depends on Quality Jobs

Nursing assistants and workers providing laundry, food, and housekeeping services in our nation's nursing homes are underpaid, often viewed "as a cost to be managed rather than an asset in which to invest." Keeping the wage floor low leads to 50 percent of nursing home workers leaving their positions each year and adds to the growing number of vacant positions. This session provides an overview of key findings and policy recommendations from the Paraprofessional Health Institute's (PHI) recent report, "Raise the Floor: Quality Nursing Home Care Depends on Quality Jobs." To recruit and retain CNAs to provide improved quality care to nursing home residents, PHI recommends that workers receive higher pay, full-time hours with consistent scheduling, better training, and opportunities for career advancement. Participants will also hear first-hand accounts directly from a panel of certified nursing assistants and support staff regarding their experiences in the industry and how, as part of the largest movement of underpaid workers, they are fighting to improve working conditions and quality of care for nursing home residents

Presenters: Stephen Campbell, Policy Research Associate, Paraprofessional Healthcare Institute (PHI); Maribel Rodrigues, Certified Nurse Assistant, Waterbury, CT; Kayley Westfall, Certified Nurse Assistant, Erie, PA

Studio E

Welcome Home: Supporting LGBT Older Adults in Residential Communities

Residential communities serve as a cornerstone to quality care for older adults. Approximately 3 million lesbian, gay, bisexual and transgender (LGBT) older adults live in the United States today, growing to 7 million by 2030, so residential communities large and small are exploring ways to ensure that LGBT older adults feel welcome and supported. This session provides volunteers and professionals with skills and knowledge to advocate for LGBT older adults.

Presenter: Sadiya Abjani, Training Specialist, SAGE

Studio F

Nursing Home Quality Measures: What Advocates Need to Know

Newer nursing home/skilled nursing facility (SNF) quality measures (QMs) have been recently developed for public reporting. Gain an understanding of the purpose of QMs, how they are developed, the data they're based on, risk adjustments, and exclusions. Learn why new QMs were developed, their purpose, and how they are different from the current QMs on Nursing Home Compare. Hear about the purpose of the SNF Quality Reporting System and how it incorporates QMs. How can the new measures and the SNF Quality Reporting System be useful to consumers, advocates, policymakers, researchers, and providers? Find out how current QMs are being used for consumer education and advocacy and how advocates might work with and be informed by the new measures.

Presenters: Karen Reilly, Director of Quality Measurement and Health Policy Program, RTI International; Beverley Laubert, Ohio State Long-Term Care Ombudsman

12:30pm - 2:00pm Ballroom Awards Luncheon

Lunch provided by Consumer Voice (open to all conference attendees)



Janet Tulloch Memorial Advocacy Award Penelope Shaw

This award was established in 2000 after the death of Janet Tulloch, a nursing home resident, author, committed advocate and long-time member of the Consumer Voice's Board of Directors. It honors a citizen advocate, family caregiver, or long-term care consumer who has worked directly with and for consumers to improve the lives of long-term care consumers.

Penelope Ann Shaw PhD, has been interested in people from other cultures from a young age - the Mennonites and Native Americans she saw on vacation in Northern Michigan, her pen pals in Germany and Japan, and especially her high school French teacher sent by the Fulbright Program.

At age 16 she applied to, and was accepted by, the University of Grenoble, France where she spent her freshman college year. Eventually, she completed a PhD in French Language and Literature with a specialization in psychology and literature. Her professional career was spent as a foreign-language faculty member and administrator - French at the University of Michigan/Ann Arbor and the Peace Corp Training Camp/St. Thomas/USVI; English Language Learning at the University of Michigan/Ann Arbor, the Instituto de Estudios Superiores /Santo Domingo/Dominican Republic, Boston University, UMass/Boston and the Kennedy School of Government at Harvard.

In 2001, Penny had an acute non-resolving episode of Guillain-Barre syndrome with respiratory failure requiring intubation. Decannulated in 2006, she rebuilt her life slowly. In 2011, she had the chance to join the Board of the Massachusetts Advocates for Nursing Home Reform and soon thereafter that of the Disability Policy Consortium in Boston. She is also currently a policy advisor to the Nursing Home Division and Survey and Certification Group, CMS [central office]. Now in her 14th year as a resident, with the help and support of her colleagues, she speaks, testifies, participates in work groups, and writes and publishes in the professional long-term care journals. In all these endeavors, she takes a resident's perspective on topics related to improving the quality of care and life of residents. She also answers a helpline providing resources and support to residents, family members and others who call. Penny feels this opportunity to provide direct service gives her the most satisfaction as an advocate.



Howard Hinds Memorial Award

Carmelita Karhoff

The Howard Hinds Award was established in 2005 in memory of the late Howard Hinds, a Tennessee District Long-Term Care Ombudsman. Howard was a true champion for residents and for the ombudsman program as well as a passionate advocate on national issues. The award honors an individual who has effectively advocated for long-term consumers on the local level.

Carmelita Karhoff is Regional Long-Term Care Ombudsman for Triangle J Council of Governments' (TJCOG) Area Agency on Aging in Durham, North Carolina. Carmelita joined the TJCOG staff in November 2006 after working in hospital administration and

Thursday, November 3

management consulting for over 20 years . Since then, in her role as a Long Term Care Ombudsman, she represents the interest of residents in Durham County and serves as advocate for their rights to quality of life and quality of care. Additionally, she co-convened the NC Local Area Network for Excellence in Long-Term Care (NC LANE), held a leadership role for the North Carolina Action Collaborative for Excellence (NC ACE) for Long-Term Care project, and served as Co-Chair of the NC Long-Term Care Ombudsman Association.

Presently, Carmelita is spearheading the planning, development, and implementation of the pilot *Dementia Inclusive Durham*, a community-wide project dedicated to serving as a catalyst in enhancing the well-being of persons living with dementia in Durham County. She continues to lead the Music in My Mind and the TJAAA Sowing the Seeds of Culture Change initiatives in the triangle region. She holds a Master of Science in Health Administration from University of Colorado's Executive Program, Denver, CO; a Bachelor of Science in Business Administration from Gwynedd Mercy University, PA; and a Graduate Nurse Diploma from Saint Paul University, Philippines.



Cernoria Johnson Memorial Advocacy Award

Sarah Slocum

Cernoria McGowan Johnson (1909-1990) set up the national program of Nursing Home Ombudsmen in 1974. The award in her honor is presented to someone whose work has had national impact or is a model for national excellence and who exemplifies accomplishment in his or her chosen field.

Sarah Slocum is Michigan's State Long Term Care Ombudsman. She has served in this capacity at the Michigan Office of Services to the Aging since December 1, 2003. Prior to this appointment, Ms. Slocum served as long term care policy staff for AARP Michigan from 2001 to 2003. Her service at AARP followed 7 and a half years as director of the statewide Medicare Medicaid Assistance program.

Ms. Slocum served as an Assistant State LTC Ombudsman at Citizens for Better Care from 1984 to 1994, and prior to that spent one year as a VISTA Volunteer working for the Area Agencies on Aging Association of Michigan. Ms. Slocum relies on her 30 plus years of experience in service to Michigan seniors and people with disabilities as she works toward better care and quality of life for Michigan's long term care consumers.

Janet Wells Public Policy Leadership Award

National Association of State Long-Term Care Ombudsman Programs

The Consumer Voice's Policy Leadership Award recognizes an individual or organization who has provided exemplary leadership in the public policy field in advancing quality of care and quality of life for residents receiving long-term care services.

The National Association of State Long-Term Care Ombudsman Programs (NASOP) was formed in 1985. The non-profit organization is composed of state long-term care ombudsmen representing their state programs. NASOP seeks to advocate for a stronger long-term care ombudsman program and enhance program effectiveness to serve consumers and their families; develop and implement professional education, training, and support programs for long-term care ombudsmen; facilitate information and best practices exchange between long-term care ombudsman programs; collaborate with consumer and advocacy organizations, governmental bodies, and health care providers; and promote the interests of long-term care residents before national level policymakers, including federal agencies and Congress, and before national aging and health organizations.

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Public Service Award

Karen Schoeneman

The Consumer Voice Public Service Award recognizes an individual or organization whose work has profoundly expanded coverage and public understanding of longterm care issues.

Karen C. Schoeneman, MPA, is currently the owner of Karen Schoeneman Consulting, providing education and consulting in Quality of Life, Culture Change, and Regulatory Affairs. She retired in 2012 from a 22 year career in the CMS Division of Nursing Homes, which has responsibility for survey and certification of all nursing homes. While at CMS, Karen specialized in quality of life and resident rights for

nursing home residents. She is one of the founders of the national Culture Change movement and Pioneer Network. She is a founder of the Maryland Culture Change Coalition and a member of the Pennsylvania Culture Change Coalition.

At CMS, Karen was widely known as the agency lead for culture change. She was the project lead from CMS for the two CMS/Pioneer Network national symposia on the regulations and the physical environment (2008) and on dining/food choice (2010). Karen has trained over 5000 State surveyors in quality of life and has produced and moderated several CMS training broadcasts on a variety of topics including culture change, dementia care, activities, unnecessary drugs, and others. She is the co-developer of the culture change measurement tool, the Artifacts of Culture Change (with Carmen Bowman) which is now being used by hundreds of nursing homes to help them measure their progress in changing their organizational culture. She is the executive producer of the CMS Hand in Hand person-centered dementia care training toolkit, mailed by CMS to 15,000 nursing homes in 2012.



Elma Holder Founder's Award

Mitzi McFatrich

Established in 2002 as a lifetime achievement award to honor a person whose life work exemplifies leadership in the field of long-term care reform, the award is also a tribute to Elma Holder, the Consumer Voice's founder and friend. Elma's personal commitment, integrity, and vision shaped the organization and quality of care and life in long-term care.

Mitzi is the Executive Director of Kansas Advocates for Better Care (KABC), a consumer advocacy organization, and is a member and the current Chair of the Consumer Voice Leadership Council. Since coming to KABC in 2007, she has worked to amplify the

voices of older adult consumers, caregivers and elder advocates in policy decision-making by training 6,000+ self and caregiver-advocates, building strong consumer coalitions, and advocating for equity in older consumer representation on state agency workgroups and advisory boards. Mitzi expanded KABC's engagement by launching a six year, 30 community, multi-disciplinary training approach to prevent and intervene in elder abuse, neglect and exploitation; bringing together law enforcement, social services and older adults. She was selected as one of fifteen to launch a health advocacy fellowship for Kansas non-profits and has trained numerous subsequent fellows on advocating in Kansas since 2008. She looks for innovative ways to bring the needs of older adults and concerns about quality of care to the awareness of policy makers including testimony, participation in state and national work groups, tracking and analyzing facility and provider inspection data, and sharing video recordings of older adults and caregivers describing their experiences.

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Mitzi began her professional career as a United Methodist Minister in a four-congregation rural parish whose members average age was 74. For a decade she served as an advocate for battered women and for abused and neglected children in the juvenile justice system. She has advocated for women and children in legal, social service, educational, and legislative arenas. In 1990, she left her position as Director of the Court Appointed Special Advocate (CASA) Project in Kansas City and moved to New Mexico to study alternative medicine. She returned to Kansas and was a co-founder of the first integrated health care clinic in Johnson County; fellow founders were a former chair of the KU Family Practice Medicine department, a therapist and a Chinese Medicine doctor. The clinic staff promoted a person-centered wellness approach to care and actively advocated on behalf of their clients within the clinic setting. In 2003 Mitzi signed on to lead the Foundation on Aging and their initiative to create a regional planning for aging in the metropolitan area.

2:15pm - 3:45pm Workshops

Studio B

The Legal and Practical Impact of the Olmstead Integration

Since the groundbreaking 1999 Supreme Court decision, Olmstead v. L.C. ex rel. Zimring, local governments have been required to provide sufficient services so nursing home residents with disabilities can live in the most integrated settings appropriate to their needs. However, transitioning nursing home residents to the community can be challenging with barriers presented by facilities and the government agencies tasked with making the move possible. This session will explore the legal and practical impact of the Olmstead integration mandate on nursing home residents. The session will discuss the class action litigation brought by AARP Foundation against the District of Columbia on behalf of residents of city nursing homes who want to live in their own homes. The lawsuit alleges that as many as 3,000 city residents with disabilities are institutionalized in nursing homes despite their ability to live independently if provided information about, and meaningful access to, home and community based services. The lawsuit began in 2010, and the trial has been ongoing since September. This session will review all steps of this litigation and its impact on the class members—nursing home residents. The session will conclude with a discussion by the D.C. Long-Term Ombudsman Program about the practical impact of Olmstead on working with residents who want to move to the community.

Presenters: Iris Y. Gonzalez, JD, Senior Attorney, AARP Foundation; Mary Ann Parker, Attorney, D.C. Long-Term Care Ombudsman Program/Legal Counsel for the Elderly

Studio D

Fighting for Dignity: Prevention of Distressing and Harmful Resident-to-Resident Interactions (DHRRI) in Long-Term Care Homes

Distressing and harmful resident-to-resident interactions in dementia in long-term care homes are a prevalent, concerning, but under-recognized public health problem. Most direct care staff, interdisciplinary teams, and Ombudsman staff may not receive adequate training in addressing this problem. Based on an extensive review of the practice and research literature, and the presenter's 10-month direct observation study, the session will equip attendees with the knowledge, skills, and tools needed to understand and prevent these behavioral expressions. Several case examples will be used for illustration.

Presenter: Eilon Caspi, Gerontologist, Founder and Director of Dementia Behavior Consulting LLC

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Studio E

Nursing Home Closures: There is a Better Way

The closing of a nursing home can have significant detrimental effects on the residents who must then be relocated to a new home. Incidences of chaos, violations of residents' rights, and transfer trauma are commonly reported. A recent Consumer Voice study, being released for the first time at this conference, explored the issue of voluntary and involuntary closures and identified promising practices in states that have been instrumental in protecting the rights of residents and mitigating potential negative outcomes. Join a discussion around recommendations for improving the closure process for residents, and hear from states incorporating best practices in this area.

Presenters: Cynthia Rudder, Consultant, Consumer Voice; Thomas LaDuke, Ombudsman Relocation Specialist, Wisconsion State Long-Term Care Ombudsman Program; Nancy Shaffer, Connecticut State Long-Term Care Ombudsman; Erin Pettegrew, Ombudsman Projects Coordinator, Ohio State Long-Term Care Ombudsman Program

Studio F

Preventing Avoidable Hospitalizations: A Primer for Consumer Advocates

Preventing avoidable hospitalizations starts with early recognition of a slowly developing medical condition, and then escalation of care whereby nursing home staff practice at the top of their license. For early recognition and effective intervention, organizations need stable engaged staff who work consistently with the same residents and each other. Organizations need an infrastructure of huddles and rounding for frequent communication across the care team. Through this workshop, you will learn about the early indicators of preventable conditions and effective interventions, and the management systems and practices needed to implement them.

Presenter: Barbara Frank, Co-founder of B&F Consulting

3:45pm - 4:15pm

Break

4:15pm - 5:45pm

Workshops

Studio B

Getting the Most Value from LTCO Volunteer Representatives

This interactive session will concentrate on how to create and maintain a vibrant, active, and effective volunteer component in the LTC Ombudsman program. Leadership from the Washington, D.C. and Georgia Ombudsman programs will guide participants through the challenges and successes of volunteer management. Participants will leave with fresh ideas for recruitment, training, and retaining these Ombudsman representatives.

Presenters: Liang-Lin Chao, Ombudsman Services Coordinator, Georgia Office of the State Long-Term Care Ombudsman; Melanie McNeil, Esq., Georgia State-Long Term Care Ombudsman; Mary Ann B. Parker, Attorney, D.C. Long-Term Care Ombudsman Program/Legal Counsel for the Elderly; Genesis Cachedon, Volunteer Coordinator, D.C. Long-Term Care Ombudsman Program/Legal Counsel for the Elderly

Studio D

Partnering to Prevent Catheter-Associated Urinary Tract Infections (CAUTI): It Takes a Village

Healthcare associated infections (HAIs) are a growing problem in nursing homes today. There are 1-3 million serious infections occurring in nursing homes annually, resulting in up to 380,000 deaths. Intervention requires efforts on many fronts. Learn about an exciting and successful project and tools to educate local ombudsmen about CAUTI so they, in turn, can educate nursing home residents and families. The project was adapted to work in different states. Project participants will discuss their experience in delivering trainings, accomplishments, challenges, and lessons learned. Hear the latest research on prescribing practices and efforts to help clinicians know when it is appropriate to prescribe an antibiotic. A wide range of resources and training materials will be introduced.

Presenters: Sue Collier, Clinical Content Development Lead, American Hospital Association/Health Research Educational Trust; Jodi Holsclaw, Eastern Regional Long-Term Care Ombudsman, Kentucky State Long-Term Care Ombudsman Program; Joseph Rodrigues, California State Long-Term Care Ombudsman; Darcy McMaughan, Assistant Professor, Department of Health Policy and Management, Texas A&M University School of Public Health and Director, Program on Disability Research and Community Based Care (PDRCC); Robyn Grant, Director of Public Policy and Advocacy, National Consumer Voice for Quality Long-Term Care

Studio E

Integrating the Patient's Voice into Health Care: What Medical Aid in Dying Means for Patient-Centered Care

Over the past two years, the end of life choice movement has gained considerable traction. End-of-Life advocates like Brittany Maynard have become household names; legislation passed in California, a citizen-led initiative qualified for the ballot in Colorado, several state medical societies have changed from opposition to neutral positions and dozens of state legislatures are considering legislation. Hundreds of thousands of people are getting together, demanding change and creating it. Given that Americans are typically reluctant to talk about death, why has this issue gained so much momentum? What does it mean for patient centered care? And how should it inform future policy reforms that the end-of-life care movement proposes? Join us for this gripping session to learn about the direction of the end-of-life care movement, its impact on consumers, in the halls of power, and in the medical system itself.

Presenter: Kim Callinan, Chief Program Officer, Compassion and Choices

Studio F

The Jimmo Case: Getting Medicare coverage in a SNF

Although nursing home residents who need care by professional nurses or therapists to maintain their function or to prevent or slow their decline or deterioration qualify for Medicare coverage, they are usually told this is not the case. This session is about the Jimmo case, which confirms that Medicare pays for maintenance as well as improvement. Learn what the case means and how to get its benefits for residents under both Parts A and B.

Presenter: Toby Edelman, Senior Policy Attorney, Center for Medicare Advocacy

6:30pm - 9:30pm Ballroom

Reception

Join us for a fun evening of music and dancing, catch up with old friends, and make some new friends! Heavy hors d'oeuvres will be available.

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Friday, November 4

Friday, November 4

7:00am - 7:30am

Breakfast on your own

7:30am - 8:30am

Consumer Voice Business Meeting

Studio B

8:30am - 7:00pm Registration open

9:00am - 10:30am Ballroom

Plenary -Something Old, Something New: The Revised Federal Nursing Home Regulations

At the end of September, CMS issued newly revised nursing home regulations, the first major overhaul since they were released in 1991. Hear top CMS officials discuss their view of the most important changes and key provisions that were retained. Take advantage of this opportunity to ask questions and to discuss key provisions that advocates and consumers need to know.

Presenters: David Wright, Director, Survey and Certification Group, Centers for Medicare & Medicaid Services; Karen Tritz, Director, Division of Nursing Homes, Survey and Certification Group, Centers for Medicare & Medicaid Services

10:30am - 11:00am Break

11:00am - 12:30pm Workshops

Studio B Quality Nursing Home Care: Getting Our Money's Worth

> The cost of nursing home care consumes a significant percentage of the federal and state budgets. Despite the multi-billions of dollars paid to facilities, there is no guarantee of receiving quality care. This session will examine some of the reasons why we, as taxpayers, are not getting our money's worth, such as the impact of Private Equity firm facility ownership. How can payment and quality of care be linked to improve outcomes? Learn about different approaches state advocates can take to connect payments to quality of care. Ask questions and gain tips that may be adapted for your state.

> Presenters: Laura Katz Olson, Professor of Political Science, Lehigh University; Cynthia Rudder, Consultant, Consumer Voice; Cheryl Hennen, Minnesota State Long-Term Care Ombudsman

Studio D

Engaging & Educating Nursing Home Families & Ombudsmen to Improve Dementia

Dementia is a common condition in nursing homes, with the majority of residents having some degree of cognitive impairment. While there have been national efforts to educate providers and surveyors, little has been done to equip nursing home families and ombudsmen with the knowledge and skills that they can use to improve dementia care and reduce inappropriate antipsychotic drugging in their facilities. This session will present the results of a two-year project to educate and engage families and ombudsmen. Attendees will learn about the principal standards that support nursing home resident care and dignity and the easy-to-use resources developed for the project that can support their advocacy for residents.

Presenter: Richard Mollot, Executive Director, Long Term Care Community Coalition

Studio E

Culture Change: Progress, Pitfalls & Possibilities

Almost 20 years have passed since the first Pioneers gathered in Rochester, NY, initiating a movement based on shared principles and beliefs. The Pioneer Network vision, a culture of aging that is life affirming, satisfying, humane and meaningful, continues to resonate as an important, but still distant, goal today in many nursing homes. What has been achieved by the Pioneers? Why have we not made more progress? What are the best practices in resident care and staffing that Pioneers have worked to make a reality and what are the opportunities for disseminating broader-scale reforms? Hear experts discuss what can be done to grow the movement and accelerate the pace of change, including a proposal to initiate a culture change demonstration proposal authorized under Section 6114 of the Affordable Care Act.

Presenters: Ruta Kadonoff, Executive Director, Pioneer Network; Anne Montgomery, Deputy Director, Center for Elder Care and Advanced Illness, Altarum Institute; Daniel Wilson, Director of Federal Affairs, Paraprofessional Healthcare Institute (PHI); Elizabeth Blair, Research and Management Associate, Center for Elder Care and Advanced Illness, Altarum Institute

Studio F

Exploring State Advocacy to Support Family Caregivers

Learn about what is happening across the states to support family caregivers, and how consumers can effectively engage to influence state public policy. Hear about recent legislative successes in helping family caregivers through the use of telehealth, in the workplace and through transitions of care. Learn how to make the case to policymakers for these supports.

Presenters: Ilene Henshaw, Director, State Health & Family Team, State Advocacy & Strategy Integration, Government Affairs, AARP; Rhonda Richards, Senior Legislative Representative, Federal Health and Family Team, AARP

12:30pm - 2:15pm Ballroom

Resident Empowerment Luncheon

Lunch provided by the Consumer Voice. Welcome to all of our guests from long-term care facilities! Remarks from William A. Rivera, Senior Vice President of Legal Advocacy, AARP Foundation. Also featuring a special guest speaker from StoryCorps! (Open to all conference participants)

2:15pm - 2:30pm

2:30pm - 4:00pm

Workshops

Break

Studio B

Advocating for Residents with Dementia: Common Scenarios

Approximately 50% of long-term care residents have dementia. population ages, researchers estimate that number will rise. Unfortunately, many nursing homes are not prepared or willing to provide the person-centered care that would benefit residents with dementia. This session will address some common scenarios that ombudsmen and families encounter when advocating for a resident with dementia.

Presenters: Denise Kennedy, Bluegrass District Ombudsman, Kentucky State Long-Term Care Ombudsman Program; Mark Burress, Western Regional Ombudsman, Nursing Home Ombudsman Agency; Sherry Culp, Kentucky State Long-Term Care Ombudsman

Friday, November 4

Saturday, November 5

Studio D Struggling to Stay In: Protecting Residents from Facility Evictions

Nursing facility and assisted living involuntary discharges are – like other evictions - among the most urgent cases legal services lawyers address and among the top complaints long-term care ombudsmen receive. This interactive session explores practical and legal strategies to respond to the tsunami of involuntary discharges. It considers federal and selected state laws, individual representation and appeals, systemic advocacy, and innovative best practices in collaborations among lawyers, ombudsmen, regulators, and other advocates.

Presenters: Alison Hirschel, Director, Michigan Elder Justice Initiative; Eric Carlson, Directing Attorney, Justice in Aging; Lori Smetanka, Executive Director, National Consumer Voice for Quality Long-Term Care; Mary Ann Parker, Attorney, D.C. Long-Term Care Ombudsman Program/ Legal Counsel for the Elderly

Studio E Wisconsin Collaborative: Bringing Quality Improvement to Assisted Living Communities

> Wisconsin Coalition for Collaborative Excellence in Assisted Living (WCCEAL) is an innovative public/private collaborative organized to improve the outcomes of consumers living in Wisconsin assisted living communities (ALC). At this session, you will hear about how this collaborative was formed, how the data repository was built with consumer satisfaction, and quality measures. See a live demo of the website resource and see how ALCs are improving outcomes. Wisconsin is looking to expand the program nationally.

Presenters: Kevin Coughlin, Policy Initiatives Advisor, Wisconsin Department of Health and Services; Heather Bruemmer, Wisconsin State Long-Term Care Ombudsman

Studio F Finding Comfort: Care Planning for People with Dementia

> Care planning for people with dementia tends to focus on tasks, along with indications for difficult 'behaviors' such as resistance to care, or verbal or physical aggressiveness. However, these 'behaviors' are actually signals of significant distress for the resident; by identifying what actually brings comfort to someone with dementia, and integrating these comforts into the care plan, this distress can be prevented or greatly alleviated. The session will address specific care practices, as well as planning tools including the MDS, to assist staff, families, and other advocates in effectively meeting the needs of people with dementia living in residential settings.

Presenter: Ann Wyatt, Manager, Palliative & Residential Care, Caring Kind, New York

4:00pm - 4:15pm

Break

4:15pm - 5:45pm Studio D

Group Meeting: National Association of Local LTC Ombudsmen (NALLTCO)

6:oopm Dinner on your own

Breakfast on your own 7:30am - 8:00am

Registration open 8:15am - 12:15pm

8:30am - 10:00am Salon 4

Plenary - New Standards for Caring for Individuals with Dementia at Home and in **Assisted Living**

New standards of care established by the Home and Community Based Services (HCBS) settings rule are intended to significantly improve how individuals live and receive Medicaid funded services at home and in assisted living. Hear the federal perspective on the expectations regarding rule implementation, particularly for people with dementia, and the importance of the person-centered/community integration philosophy behind the rule. Learn about promising practices related to individuals with dementia, particularly practices related to community access, choice, and wandering/exit-seeking behaviors. Be informed by the recommendations of consumer advocates for people with dementia in both residential and non-residential settings. Gain tips and ideas for improving care in these settings for individuals with dementia in your state.

Presenters: Ralph Lollar, Director, Division of Long-Term Services and Supports, Disabled and Elderly Health Programs Group, Centers for Medicare & Medicaid Services; Serena Lowe, Senior Policy Adviser, Office of Policy Analysis & Development, Center for Policy & Evaluation, Administration on Community Living; Jennifer Goldberg, Directing Attorney, Justice in Aging

10:00am - 10:30am Break

10:30am - 12:00pm Salon 4

Closing Plenary - Overreach by Fiduciaries – Is Supported Decision Making the Answer?

Overreach by fiduciaries destroys the freedoms and choices of residents in long term care. We see it and hear about it every day. We believe the principles and practices of Supported Decision Making (SDM) are at least part of the answer. SDM is a change in mindset to include and empower the person to make choices and decisions as long as they are able to express a preference or choice. This session will explore integrating Supported Decision-Making methodologies into life care and advance care planning with an emphasis on person driven care planning. We will focus on identifying and honoring the choices, values, wishes and desires of the Individual by engaging and legally empowering the support network of advisors to assure that the person's choices are heard and carried out. We will talk about how training fiduciaries and caregivers in SDM principles will improve the quality of life for adults who are perceived as being vulnerable.

Presenters: Morgan K. Whitlatch, Legal Director, Quality Trust for Individuals with Disabilities, Lead Project Director, National Resource Center of Supported Decision-Making; David Godfrey, Senior Attorney, ABA Commission on Law and Aging, Washington, D.C.

12:00pm - 12:15pm Conference Closing Salon 4

For more conference information...

November 8 - 11, 2017 Here again at the Renaissance Arlington Capital View Hotel!



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