

Hello,

Thank you for attending our virtual roundtable *Successful Public Health Approaches in Dementia Caregiving: Rhode Island* on March 14th, 2023. Below is the content and resources shared in the Zoom chat by the speakers and by attendees. To help you navigate the following pages, we have highlighted a few key items:

- **Yellow**: these were questions that the presenters posed to the audience during their presentation. Chat entries following these questions, were responses and related resources the audience shared.
- **Blue**: resources and links to useful materials.

We encourage you to look through the list of attendees below and the links, to identify helpful resources and contacts.

Your BOLD Public Health of Center of Excellence on Dementia Caregiving team

Zoom chat:

00:25:19 Maria Smith: Maria R. Smith, TAADAS, Tennessee
00:25:45 Tiffany Robb: Hi Everyone! I am LuAnn Jensen, LCSW from the State of Idaho ADRD Program sitting in for Tiffany Robb, the ADRD Program manager.
00:25:52 Chethana Manjunath: Chethana Manjunath, WCCHD, Texas
00:25:52 Atheda Fletcher: Hello Everyone, Atheda Fletcher from the Absentee Shawnee Tribal Health System, Little Axe, Oklahoma
00:25:56 Elizabeth Scott: Elizabeth Scott
00:26:00 Pam Brandon: Hello from Texas! Pam Brandon, AGE-u-cate Training Institute
00:26:42 Angalar Chi: Angalar Chi from California Department of Public Health
00:26:42 Spencer Dickey (SC Department on Aging): Hello, this is Spencer Dickey from the South Carolina Department on Aging
00:26:47 Jane Carmody: Rani Snyder, JAHF in NYC
00:26:50 Brittany Dempsey: Hello Everyone! My name is Brittany Dempsey MCU Director for Heritage Center. I oversee an all female Memory Care Unit here in Evansville Indiana
00:27:01 Jen Rooney, ACT on Alzheimer's: Greetings! Jen Rooney, ACT on Alzheimer's in MN
00:27:01 Elisa Childs: Elisa Childs, University of Iowa
00:27:16 Sheila Lewis, SC Dept on Aging: Greetings from the South Carolina Department on Aging-Sheila Lewis
00:27:21 Sandra Richendollar: Sandra Richendollar, Florida Department of Health in Sarasota County sandra.richendollar@flhealth.gov 941-861-2778
00:27:23 Louise Noble: Louise Noble North Carolina Center for Health and Wellness at UNC Asheville

00:27:35 Richelle Kime: Richelle Kime, MSW Student at the University of Iowa, current intern for the Alzheimer's Association Iowa Chapter

00:27:38 Ozella Maynard: Ozella Maynard, Durham Public Health

00:27:41 Danielle Riley, City of Chicago Dept of Family & Support Service: Danielle Riley, Community Services Representative, City of Chicago Dept of Family & Support Services (Dept on Aging)

00:27:47 Kristi Wick: Kristi Wick, UT Chattanooga School of Nursing.

00:27:48 Helen Medsger - NAPA Advisory Council: Helen Medsger - Caregiver Representative to the NAPA Advisory Council under the U.S. Dept of Health & Human Svcs.

00:27:49 Theresa Heier: Theresa Heier East Shore District Health Department Branford, CT

00:27:49 Shirley Thomas: Shirley Thomas , Georgia SHIP counselor. Hello

00:28:01 Keayanna Gibson (Caregiver specialist): Good morning. My name is Keayanna Gibson. I am a Caregiver Specialist at St John Community Care in Collinsville Il. 62234

00:28:03 Michele Snyders: Michele Snyders- South Dakota Association of Healthcare Organizations

00:28:05 Al May, Maine CDC: Al May, Maine CDC Alzheimer's Disease Prevention Program

00:28:06 Erica Jablonski, UNH: Erica Jablonski, Ph.D., University of New Hampshire

00:28:13 Cynthia Ayala, AgeOptions: Cynthia Ayala, Caregiver and Dementia Program Specialist at AgeOptions

00:28:15 Heba AIDossary: Heba Aldossary , PhD student at Frances Payne Bolton School of Nursing, Case Western Reserve University

00:28:16 Lori P. McKenna, UVMDC Dementia Family Caregiver Center: Lori P. McKenna, LICSW University of VT Medical Center, Dementia Family Caregiver Center

00:28:22 Edith Hutchins - AACF - CHW: Edith Hutchins, AACF Community Health Worker - Frederick, MD

00:28:30 Debra Rootman: Hello from Vancouver, BC, Canada, from the public Older Adult Mental Health & Substance Use Team

00:28:40 Heather Carter, NC DHHS: Heather Carter, NC Department of Health and Human Services, Division of Aging and Adult Services

00:28:46 Charlene Pope: Charlene Pope, Chief Nurse for Research, Ralph H. Johnson VA Health Care System, Charleston, SC

00:29:03 Chiquita Briley: Chiquita Briley, LSU AgCenter- Family and Consumer Sciences

00:29:37 Beth Soltzberg, JF&CS Greater Boston: Beth Soltzberg, Dementia Friends Massachusetts and JF&CS Memory Cafe Percolator, JF&CS of Greater Boston

00:29:43 Kathleen Smith: Kathleen Smith, BOLD Grant Manager, Wisconsin Department of Health Services and the Wisconsin Alzheimer's Institute

00:29:48 Dona Giannotti: Dona Giannotti, PSS Circle of Care and Dementia Friends New York State Lead

00:31:07 January Johnson: January Johnson, BSW. Researcher at Memory Keepers Medical Discovery Team at the University of Minnesota- Duluth. Our organization focuses on brain health equity.

00:31:24 Karen Tennyson, ADRC of Rock County: Karen Tennyson, LCSW at the Aging and Disability Resource Center of Rock County, WI. I am a dementia care specialist.

00:32:34 Freda Cowan, NP: Freda Cowan, FNP, Director of Palliative Medicine Program, AMOREM

Question for the audience: "What are the potential benefits that come to mind as you consider implementing healthcare dementia-focused quality measures?"

00:36:49 Kimmie William, BPHC: early diagnosis

00:36:57 Angalar Chi, CDPH: Program Improvement

00:36:58 Haita Ndimbalan: Reacted to "early diagnosis" with 👍

00:36:58 MaryLea Boatwright Quinn, GA Division of Aging Services Director: Gives data to support further investment by our decision makers!

00:36:59 Sheila Lewis: Accurate diagnosis

00:37:01 Julie Cleaton AK DPH: increase referrals to services

00:37:01 Lauri Scharf: reduce stigma

00:37:06 Jolie Crowder, IHS, National Elder Care Consultant: If you can't measure you can't monitor

00:37:10 Tiffany Robb: Greater continuity of care for patients and their caregivers.

00:37:10 Kate Niderostek: Early diagnosis, early connection to resources, ability for family to plan for the future

00:37:13 Charlene Pope: Enhanced caregiver support and well-being

00:37:14 Erica Jablonski, UNH: Reacted to "Greater continuity o..." with 👍

00:37:18 mitsuo tomita: Address end-of-life preferences before cognitive function is lost.

00:37:20 Erica Jablonski, UNH: Reacted to "Early diagnosis, ear..." with 👍

00:37:22 Kimmie William, BPHC: support for caregivers

00:37:27 Erica Jablonski, UNH: Reacted to "Enhanced caregiver s..." with 👍

00:37:33 Erica Jablonski, UNH: Reacted to "Address end-of-life ..." with 👍

00:37:33 Sheila Lewis, SC Dept on Aging: sharing information with state legislators

00:37:39 Emily Branum, OTR/L (St. Cloud VA): Better equipped to age in place safely.

00:40:30 Haita Ndimbalan: Here are all the links on quality improvement measures mentioned by Victoria! MIPS- Merit Based Incentive Payment System for Medicare performance based payment system: Quality ID #288: Dementia: Education and Support of Caregivers for Patients with Dementia (mdinteractive.com)

American Academy of Neurology measure set: 15dmmeasureset_pg.pdf (aan.com)

RAND/ACOVE: Developing Quality of Care Indicators for the Vulnerable Elderly: The ACOVE Project | RAND

00:42:50 Haita Ndimbalan: MIPS-

https://mdinteractive.com/files/uploaded/file/CMS2022/2022_Measure_288_MIPSCQM.pdf

- 00:43:34 Haita Ndimbalan: American Academy of Neurology-
https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-measures/15dmmmeasureset_pg.pdf
- 00:44:23 Haita Ndimbalan:
[RAND/ACOVE-https://www.rand.org/pubs/research_briefs/RB4545-1.html](https://www.rand.org/pubs/research_briefs/RB4545-1.html)
- 00:46:18 Charlene Pope: Are materials available in Spanish or other languages?
- 00:48:14 Erica Jablonski, UNH: Also need multimodal data collection and follow-up (phone not just computer for instance for follow-up)
- 00:48:16 Gary Epstein-Lubow: It is very smart to begin with MIPS measures because the infrastructure exists for primary care to do the reporting. This review today is excellent! We reported on similar recommendations in this recommendation for payment reform:
<https://www.healthaffairs.org/content/forefront/payment-comprehensive-dementia-care-five-key-recommendations>
- 00:48:23 Jolie Crowder, IHS, National Elder Care Consultant: @ IHS we are looking at these exact questions / issues as re: EHR development. Super curious to hear from folks on their responses to these questions to identify some best or promising practices!!
- 00:48:27 Tiffany Robb: I have worked in a different health care system than where I am at now, that created a "collateral" electronic health record for caregivers that was helpful to document caregiver assessments and interventions separately from the patient.
- 00:48:44 Tenneh Turner-Warren: Can caregiver health and wellness be included in BRFSS questionnaire?
- 00:49:41 Tenneh Turner-Warren: For referrals, if you have current referral systems in place that are bi or multidirectional for other chronic diseases you could leverage that?
- 00:49:43 Gary Epstein-Lubow: Have we in Rhode Island looked yet at international solutions which might align with what we have available nationally? Such as the ICHOM quality measure set: <https://connect.ichom.org/patient-centered-outcome-measures/dementia/>
- 00:53:34 Atheda Fletcher: How does HIPAA work with all of this?
- 01:01:00 Bonnie Burman: Do you use the GSA KAER toolkit as you work with primary care practices and caregivers?
- 01:02:34 Helen Medsger - NAPA Advisory Council: UCSF's Care Ecosystem utilizes non-licensed, trained Care Team Navigators. It has had great success over the past 8 years heading into Phase 3
- 01:02:55 Jen Rooney, ACT on Alzheimer's: We are working to increase dementia education as part of CHW training curriculum, as we view CHWs as crucial in cultural outreach
- 01:02:58 Paulette Kozlowski RN: Is this limited to Rhode Island physicians?
- 01:03:05 Sally Steiner: Did this project (i.e. RIDOH's QI work) have IRB review?
- 01:03:13 Gary Epstein-Lubow: The Alzheimer's Association has a program to help health systems expand their dementia capability:
<https://www.alz.org/professionals/health-systems-medical-professionals>
- 01:03:39 Pam MacLeod, MA Office of Elder Affairs: Will the Practice Facilitators meet with each other to discuss challenges across the sites and the ways that some sites have addressed those challenges?

Question for the audience:

- **What practice facilitator equivalent role(s) do you partner with to support health system interventions?**
- **What support do they provide? Lessons learned?**
- **How could this role be expanded to identify caregiver needs and provide caregiver support?**

01:04:06 Karen Tennyson, ADRC of Rock County: The state of Wisconsin has a dementia care specialist in every county to provide support and education to those with dementia, their caregivers and the community.

01:04:12 Tenneh Turner-Warren: cultural health navigators, CHWs also looking at how your pharmacists could your pharmacists be leveraged

01:05:03 Elma Johnson (PHCOE-DC): Replying to "The state of Wisconsin...": Are the DCS in WI connected or collaborate with the healthcare system, and how?

01:05:08 Atheda Fletcher: We have a grant that supports our health system initiate caregiver support. This is thru the Administration for Community Living. Our two interventions are Savvy Caregiver in Indian Country and Music & Memory.

01:05:26 Gary Epstein-Lubow: Victoria, I think there may have been some review in RI of the KAER Toolkit which is an excellent resource: <https://www.geron.org/publications/kaer-toolkit>

01:07:57 Jane Carmody: <https://www.johnhartford.org/dissemination-center/view/best-practice-caregiving-infographic-series-on-dementia-caregiving-programs> and the online resources <https://bpc.caregiver.org/>

01:09:15 Jane Carmody: Thank you, excellent work ! I have to leave early

01:10:41 Helen Medsger - NAPA Advisory Council: UCSF's Care Ecosystem Toolkit: <https://memory.ucsf.edu/research-trials/professional/care-ecosystem>

01:12:27 Freda Cowan, NP: This has been GREAT

01:12:38 LaKeca Smith: Great information!

01:12:46 Sheila Lewis: Thank you!!!

01:13:02 Maria Smith: Great information shared, Thank you

01:13:04 Atheda Fletcher: What a great presentation. Invaluable information!

01:13:12 Tenneh Turner-Warren: Thanks for sharing your project- how large is your ADRD program?

01:13:16 Heather Carter, NC DHHS: Great presentation! Thank you!

01:13:34 Brittany Dempsey Evansville, Indiana Memory Care Director: wonderful presentation, very knowledgeable information!

01:14:10 Louise Noble: Thanks so much for this - excellent!

01:14:31 Wonsuk Ching: great presentation and great resources. Thank you

01:15:32 Public Health Center of Excellence on Dementia Caregiving: If you have a moment, please complete our brief evaluation survey. Thank you!

https://umn.qualtrics.com/jfe/form/SV_3UVM727SVBXDUua

01:15:39 Elizabeth Scott: Well done ladies. Thank you.

01:20:51 mitsuo tomita: DNR and tube feeding are part of advance care planning, but in dementia, hand feeding is not addressed as part of advance care planning discussion. Hand feeding can cause aspiration and pneumonia and persons may not want caregivers to spend

hours in hand feeding. How do you raise the question of hand-feeding in dementia and address end-of-life care in dementia?

01:22:32 Tenneh Turner-Warren: Are these implemented mostly through FQHCs and look alikes- if yes, have they mentioned being short staffed? We hear a lot of that from our PCA regarding the burden on the fqhcs to do QI projects like these

01:25:38 Freda Cowan, NP: gentle hand feeding and discussions regarding comfort and safety have to be addressed prior to the need for hand feeding

01:26:17 Helen Medsger - NAPA Advisory Council: Develop an AD/ARD Taskforce by county engaging the non-profits, government entities, etc. to elevate and share support options and to help alleviate duplication of services. Improved communication and collaboration.

01:28:51 Sheila Lewis, SC Dept on Aging: Great presentation, thank you for sharing.

01:33:22 mitsuo tomita: What is the purpose of early detection or diagnosis of dementia?

01:36:21 Nick Mirin: <https://bolddementiadetection.org/early-detection-of-dementia/>

01:36:22 Kate Nederostek: Being connected to resources as early as possible.

01:36:32 Erica Jablonski, UNH: It could help the caregiver as well to understand dementia symptoms.

01:36:38 Kate Nederostek: Being able to plan for the future now that you know what is going on.

01:37:24 Kate Nederostek: Being able to make decisions about your own care before dementia affects that, so you family doesn't have to guess your wishes.

01:37:53 Kate Nederostek: Getting connected to clinical trials to test upcoming medications

01:38:31 Kate Nederostek: Believe it or not, many have a sense of relief once they receive a diagnosis. They knew something was wrong, but didn't know what it was. Now they know and can move forward.

01:38:34 Lisa Mcguire: Maybe another webinar topic

01:38:54 Nick Mirin: Health system providers toolkit:

https://bolddementiadetection.org/wp-content/uploads/2023/01/BOLD_Toolkit_010323.pdf

01:39:59 Jake Sawyers, ADRC of Walworth County: Replying to "The state of Wiscons..." Hi Elma, the DCS in each county have many things in common however they also can operate differently depending on the partnerships they are able to build in their county. With that said it is definitely a goal of many DCS's to have a referral source from the various healthcare systems that are in their county.

01:40:28 Atheda Fletcher: better health care management as most individuals living with dementia have other diseases that create health care challenges for the patient as well as the primary care physician.

01:41:51 Natalie Tauzin, Spokane Regional Health District: Fantastic webinar!!! Thank you

01:42:02 Tiffany Robb: Thank you! From Lu Ann Jensen sitting in for Tiffany Robb, Idaho ARD Program.

01:42:12 Gary Epstein-Lubow: Yes...excellent work!

01:42:20 Ozella Maynard: Thank you!!

01:42:22 Danielle Riley, City of Chicago Dept of Family & Support Service: Thank you both for an excellent presentation!

01:42:31 Tenneh Turner-Warren: Thanks for the presentation

01:42:48 Ozella Maynard: What's the difference between bold PH and PH

01:43:27 Ozella Maynard: Thank you

01:44:05 Kate Nederostek: Great job, ladies!