

## State of South Carolina Department on Aging

Henry McMaster Governor Connie D. Munn Director

# Alzheimer's Resource Coordination Center Advisory Council Meeting March 22, 2024 MINUTES

The Alzheimer's Resource Coordination Center Advisory Council met Friday, March 22, 2024 at 10:00 am via Zoom.

This meeting is in compliance with the Freedom of Information Act's mandate that the public be notified when the public's business is being done and that furthermore, the public has been notified that this meeting is accessible to individuals with disabilities, and special accommodations can be arranged if requested in advance.

#### **Present:**

Ms. Margaret Alewine SC DHHS

Ms. Jennifer Brewton SC Department on Aging

Dr. Jessica Broadway VAMC, Charleston

Dr. Steve Carroll Medical University of South Carolina
Ms. Kelly Cordell SC Department of Social Services

Ms. Dana Daniel SC Department on Aging Dr. Nicole Davis Clemson University

Dr. Sara English National Association of Social Workers, SC Chapter

Dr. Miriam Evans South Carolina State University

Ms. Emma Kennedy DHEC
Ms. Denise Kish SCALA
Mr. Robert McBurney SC DDSN

Dr. Maggi Miller University of South Carolina, Office for the Study of Aging, AD Registry

Ms. Rebecca Smith South Carolina Silver Haired Legislature

Dr. Cynthia Port Coastal Carolina University

Ms. Kassie South

LeadingAge, South Carolina Chapter

Ms. Janae Stowe

SC Association of Area Agencies on Aging

Ms. Taylor Wilson

Alzheimer's Association, SC Chapter

**Absent**: Ms. Megan Beyers, Mr. Andrew Boozer, Dr. Miroslav Cuturic, Dr. Melissa Gilliam, Dr. Scott Habakus, Mr. Joseph

Meyers, Ms. Mary Peck

Guests: Coastal Carolina: Dr. Casey Woodling, Ms. Erica Ford, Mr. Matthew Tylor, Dr. Robert Coni

SC Department on Aging - Ms. Jenny Andrews

SC DHEC - Ms. Emily Ash, Ms. Karilyn Tremblay, Ms. Jillian Catoe

#### **CALL TO ORDER:**

Ms. Wilson called the meeting to order at 10:02 am, read the FOI statement/Americans with Disabilities Compliance Pledge, and welcomed all council members and guests to the meeting.

#### **APPROVAL OF MINUTES:**

Dr. Carroll motioned to approve the December 2023 meeting minutes, and Dr. English seconded. Minutes were approved.

#### **Coastal Carolina Presentation**

Ms. Wilson introduced presenters from Coastal Carolina University – Mr. Matthew Tyler, Ms. Erica Ford, Dr. Casey Woodling, and Dr. Robert Coni. Mr. Tyler stated that Coastal Carolina is currently offering an Alzheimer's Disease and Related Dementia Seminar led by Ms. Ford in partnership with the National Council of Certified Dementia Practitioners (NCCDP). All are welcome to attend this seminar. He also discussed a partnership with Osher Lifelong Learning Institute (OLLI), which offers educational opportunities for staying mentally and socially active. They are also building in education on ADRD Care Sessions. Mr. Tyler states that they are planning panels and roundtables surrounding dementia and dementia care and working with support groups for persons living with ADRD and their family caregivers. He discussed the importance of early intervention and connecting with individuals even before they receive a diagnosis. Coastal Carolina will soon be launching a Health and Wellness Related Research Center and there is hope that Alzheimer's and dementia care research will be included in the center.

Ms. Ford reviewed the curriculum for the NCCDP and what the course may look like for participants. She also shared that Coastal Carolina is creating a Health Aging Plan which will provide education and opportunities to individuals aged 25-60+ to assist in managing stress, eating healthy, learning, healthy sleep, and preventative wellness visits. They are planning to establish and launch an Integrative Health Coaching Certificate Program with a focus on ages 25-60, as well as a Corporate Wellness Certificate Program with a focus on employee well-being. The hope is that these programs will help to reduce statewide employee turnover, increase the quality of life and work-life balance of employees, and help individuals manage the modifiable risk factors for Alzheimer's disease and related dementia.

Dr. Coni mentioned that getting people to buy into the management of brain health as one ages (exercises, sleep, brain exercises, diet) is difficult. He stressed that these activities may help to mitigate the effects of other risk factors that we may not have control over, such as genetics.

In the chat, Ms. Kennedy emphasized that this program aligns strongly with the BOLD grant. Ms. Wilson agreed that there are opportunities between DHEC, the Alzheimer's Disease Research Center, and other agencies within the state as work is done on the Statewide Plan to Address Alzheimer's. Ms. Wilson applauded Coastal Carolina for the work that they are doing and expressed interest in serving as a model for other universities/colleges throughout the state in efforts to address ADRD. Mr. Tyler stressed that these programs are available to anyone with an interest. He shared his contact information for anyone to reach out to him to discuss more in detail: <a href="mailto:mctyler@coastal.edu">mctyler@coastal.edu</a>

#### **ARCC Council Votes**

Ms. Wilson opened the floor for two votes for the council to take part in.

#### a. Nominations for Vice Chair

Ms. Wilson announced that Ms. Stowe had volunteered to serve as Vice Chair for the ARCC Advisory Council and reviewed the duties of the Vice Chair as outlined in the ARCC Advisory Council Bylaws. Ms. Stowe spoke briefly about her background and qualifications. Ms. Kennedy moved to nominate Ms. Stowe as Vice Chair. Ms. Stowe was appointed as vice-chair by unanimous voice vote.

#### b. ARCC Grant Eligibility for ARCC Member Organization

Ms. Wilson announced that a Council Member requested that the Council revisit the idea of organizations with a representative on the ARCC Advisory Council being allowed to apply for ARCC grants. Ms. Daniel read the statement provided by the Council member who made the request and Ms. Wilson opened the floor for debate surrounding the issue.

Ms. South stated that she believes that there are protections in place that will allow entities/organizations with a representative on the Council to receive ARCC grant funds as long as that individual is not the one who is reviewing the submitted application. Dr. Carroll stated that this is a similar issue that comes up with NIH Grants and Grant Reviewers. He states that in those instances, grant reviewers whose organization is applying for funding are not allowed to review the application or discuss the application with other reviewers. He states that as long as such insulation is built in and conflict of interest (COI) is avoided, then such organizations with a representative on the Advisory Council should be able to receive funding. Ms. Kennedy voiced agreement with Dr. Carroll and Ms. South.

Ms. Wilson posited that should organizations with an Advisory Council representative be allowed to receive funding, it needs to be stated that funds cannot go towards the Council Member's salary; this would add an extra level of protection. Dr. Carroll asked about whether the ARCC Member's effort could be included in the grant. Discussion was had and it was agreed that their effort could be used as in-kind support. Ms. Tremblay questioned whether a COI form is currently utilized in the application process, Ms. Daniel stated that one is not currently being used. It was discussed that a COI form will need to be included in the grant application process moving forward. It was stated that although the application process has already begun, a COI can be introduced at any time. Ms. Alewine added that a structured COI process should also be introduced for grant reviewers. Dr. English seconded that thought, stating that it would allow for transparency on both the side of the applicants and reviewers.

Ms. Alewine states that she will share a copy of the transparency form utilized by the Developmental Disabilities Council for ARCC staff to review in the creation of such a form for ARCC Grantees.

Ms. Wilson opened the floor for a vote on 2 Counts:

- 1. The measures that need to be in place to create the ethical boundaries that are needed.
  - a. ARCC Council Member salary cannot be included in the grant budget, but their effort can be included in the in-kind match
  - b. ARCC Members cannot participate in the review process or have contact with the reviewers for a grant application from their home agency
  - c. A COI form must be included with the application declaring if there is a representative from their organization on the ARCC Advisory Council
  - d. All reviewers must complete a COI Form identifying a relationship with an organization applying for a grant, recusing them from the review process for that application.
    - Dr. Broadway expressed concern that grant applicants may not be aware that they have a representative on the ARCC. It was decided that during the initial pre-application webinar that is offered members of the ARCC would be disclosed to potential applicants.
    - ii. Ms. Kennedy shared the <u>NIH Grants guidelines</u> for managing conflict of interest and posed the question of whether wording could be added regarding family members of council members. It was agreed that such wording would be added to the COI forms.

A voice vote was held on whether these ramifications set a good ethical boundary for this process. Motion passed.

2. Organizations with a representative on the ARCC Advisory Council are eligible to apply for and receive ARCC grant funding given that they follow the requirements and proper processes set in place by the previous vote.

A voice vote was held and the motion was passed.

#### **BOLD Update**

Ms. Wilson opened the floor for an update on the BOLD grant. Ms. Tremblay mentioned that a program coordinator has not been hired and that the position will be re-posted. She also states that a solicitation has been made requesting a quote from a vendor to work on the implementation plan and DHEC is in the final stages of the procurement process. Ms. Tremblay stated that a tool is being worked on that will allow ARCC Advisory Council meeting minutes to be used to show momentum in the implementation of the Statewide Plan. They are also in the process of completing their continuation of funding application to the CDC which is due April 17. DHEC has formulated a partnership with the USC School of Public Health where a student is creating a primary care provider survey and the Council will later be asked to assist with choosing the appropriate questions for the survey.

Ms. Wilson states that this survey will not only help with the implementation of the Statewide Plan and how SC educates providers, it will also help on the national level for the passing of the Accelerating Access to Dementia & Alzheimer's Provider Training (AADAPT) Act (H.R.7688), which is asking for funds to expand the Project ECHO dementia training program into medically underserved and rural communities where the highest rate of physician turnover is found. Ms. Wilson states that she and Alzheimer's Association advocates will be heading to Washington, D.C. to advocate for AADAPT as well as the BOLD reauthorization.

Ms. Tremblay added DHEC is always looking for community partnerships, such as the one presented by Coastal Carolina, to help with the implementation of the Statewide Plan. She states that Ms. Kennedy will be presenting on BOLD in partnership with Georgia and North Carolina at the <u>Southern Gerontological Society Conference</u> in the first week of April 2024.

Ms. Wilson states that she and Ms. Kennedy were able to meet with South Carolina's EMS training services regarding dementia training specific to first responders in the community. Local municipalities determine what training is required for first responders, so blanket legislation requiring dementia training is not possible. Ms. Wilson states that she will be presenting on April 18 to the EMS Training Advisory Council about the importance of dementia training for EMS providers. She also states that the South Carolina Law Enforcement Association and the South Carolina Sheriff's Association will be pushing for training on dementia for law enforcement through the Criminal Justice Academy (CJA) to be utilized. The hope is that the training will go out in June 2024. She states that the training will be very basic/minimal so she is requesting that the ARCC reach out to community organizations in their region to determine who is already doing dementia training for first responders and provide their information to Laura Davis, the admin for the Alzheimer's Disease Research center as she has agreed to compile a list of local organizations that are already doing this work. Ms. Davis' email is <a href="mailto:davlaura@musc.edu">davlaura@musc.edu</a>. This list will be included on the resource website for law enforcement (ACADIS) and the EMS national training registry.

Dr. English commented that many rural communities have created, with their local sheriff's office, a community training program. These programs encourage local leaders to join law enforcement for the training, and the dementia training above would be a good way to educate not only first responders/law enforcement but also the community at large. Ms. Wilson suggested having Ms. Tori Anderson (toanderson@aging.sc.gov), the Dementia Care Specialist with the South Carolina Department on Aging, speak to these groups as she has been doing dementia training statewide.

#### **State House Update**

State House Advocacy Day had a great showing with 54 attendees despite the weather. \$1.1 million for 10 Dementia Care Specialists across the state has been verbally confirmed to be placed in the Senate's budget request and the House has been asked to support it in the final version of the budget. Ms. Brewton stated that Tori Anderson is currently the only Dementia Care Specialist in the state and is under a temporary grant position with the South Carolina Department on Aging that is scheduled to end on September 30, 2024, and while we are hopeful for the receipt of the funds in the Senate's budget to expand the program, the DOA is seeking other funding sources as well.

Ms. Wilson gave an update on Bill <u>S.915</u>, which is a Bill introduced by the SC Senate to merge several state agencies to create the Executive Office of Health and Policy. The bill has passed out of the Senate and its companion bill (<u>H.4927</u>) has passed out of the House. It is unclear which bill will be taken up in the final process. Ms. Wilson assured the Council

that despite the merger, the ARCC, its Advisory Council, BOLD, and the Statewide Plan on Alzheimer's Disease would still be around and a priority, even if the Council and its members have to be a bit more vocal to ensure its voice is heard.

Ms. Wilson mentioned that there is a bill requesting the creation of <u>Healthcare Study Committee</u> task force in the State House to potentially explore the expansion of Medicaid. The expansion of Medicaid likely will not make it through session, but legislaters are still considering having the Healthcare Study Committee pulled together. Mr. McBurney added that the Senate will include the Committee in its proposed budget.

Dr. Miller gave an update on the Alzheimer's Disease Registry. She states that the Registry celebrated its 35<sup>th</sup> year with a press conference about the 35<sup>th</sup> Annual Report that was released on March 13. This report includes data from 2020 and 2021, and the upcoming report will focus on data from 2022 and 2023. Ms. Wilson added that the Alzheimer's Association has county factsheets that are populated by Dr. Miller and the Alzheimer's Disease Registry that are available online for review as well. Ms. Wilson also added that the Alzheimer's Association is taking a stand to charge the state legislature to protect, support, and continue funding the Registry as it is the only resource with 35 years of data; because of this data, South Carolina has been able to compare its actual numbers with national estimates. She stressed that the ARCC Advisory Council also serves as the Advisory Council for the Alzheimer's Disease Registry in statute, and as such Council Members should be on the lookout for any communication regarding support for the Registry as well.

#### **ARCC Grants Review Committee Volunteers**

Ms. Daniel requested reviewers for the upcoming ARCC Grants. Volunteers include Dr. Broadway, Dr. English, Dr. Evans, Ms. Kish, Mr. McBurney, and Ms. South. Ms. Wilson thanked volunteers and added that serving as a grant reviewer helps to inform the council on what is going on in the communities regarding services for ADRD.

#### **Other Business:**

Ms. Brewton announced that Senior Day 2024 is scheduled for May 1, 2024. It will be held at the State Fairgrounds from 10 am to 1 pm, with registration opening at 9:30 am. Ms. Andrews added that the theme for Senior Day this year is Powered by Connection and stated that if anyone would like to be an exhibitor for Senior Day, want to contribute in any way, or know of any other organizations/agencies that may want to participate then to reach out to her at <a href="mailto:jandrews@aging.sc.gov">jandrews@aging.sc.gov</a>. Ms. Smith stated that the Senior Haired Legislature will be an exhibitor at Senior Day and will use it as a recruiting tool for volunteers/members.

Ms. Wilson stated in July 2023 Orangeburg, SC was identified as having the 8<sup>th</sup> highest prevalence of dementia in the nation. In November 2023, Ms. Wilson presented to the Orangeburg County delegation about their interest in doing several community needs assessments and getting the information back to them by November 2024. There will also be a virtual healthcare worker-focused needs assessment. The *Times and Democrat* will be doing stories to prepare the community for the needs assessments. Stakeholders, aging committees, community support programs, the most recent Alzheimer's Association Facts and Figures, etc. will be highlighted in these articles. *Times and Democrat* will be doing an article on the Alzheimer's Disease Registry press release and the Facts and Figures release, as well as what those numbers mean for Orangeburg and how the data will be used moving forward. *Post and Courier* will also be doing an article on the work being done on the State Plan, including the request for Dementia Care Specialists. Ms. Wilson requested that Council members share these articles on their social media to help engage the public in the cause against ADRD. Ms. Stowe stated that the AAA directors met with USC Brain Health recently and that Orangeburg is where they will be focusing their efforts next.

Mr. McBurney shared that Autism Connect will be meeting on April 23 with exhibitors and vendors to spread awareness about Autism. He stated that Alzheimer's disease and Autism face many of the same hurdles and he believes that this would be a good opportunity for Council Members to attend as well. Information about this event can be found at <a href="https://ddsn.sc.gov/ddsn-divisions/autism/autismconnect">https://ddsn.sc.gov/ddsn-divisions/autism/autismconnect</a>

#### Closing/Adjournment

There being no other business, Ms. Wilson adjourned the meeting at 11:55 am.

### **NEXT MEETING:**

Tuesday, June 18, 2024. This meeting will be an in-person meeting held at the South Carolina Department on Aging.

Respectfully submitted,

Dana M. Daniel, LMSW