



State of South Carolina  
Department on Aging

Henry McMaster  
Governor

Connie D. Munn  
Director

Alzheimer's Resource Coordination Center Advisory Council  
Tuesday, September 17, 2024  
Meeting Minutes

The Alzheimer's Resource Coordination Center Advisory Council met Tuesday, September 17, 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. Megan Beyers	University of South Carolina
Mr. Andrew Boozer	SC Association of Council on Aging Directors
Dr. Jessica Broadway	VAMC, Charleston
Dr. Steve Carroll	Medical University of South Carolina
Ms. Dana Daniel	SC Department on Aging
Dr. Sara English	National Association of Social Workers, SC Chapter
Dr. Miriam Evans	South Carolina State University
Ms. Emma Kennedy	SC Department of Public Health
Mr. Joseph Meyers	American Association of Retired Persons, SC Chapter
Dr. Maggi Miller	South Carolina Alzheimer's Disease Registry
Dr. Cynthia Port	Coastal Carolina University
Ms. Kassie South	LeadingAge, South Carolina Chapter
Ms. Taylor Wilson	Alzheimer's Association, SC Chapter

**Absent:** Dr. Miroslav Cuturic, Dr. Melissa Gilliam, Dr. Scott Habakus, Ms. Mary Peck, Ms. Kelly Cordell, Dr. Nicole Davis, Ms. Denise Kish, Mr. Robert McBurney, Ms. Janae Stowe, Ms. Margaret Alewine

**Guests:**

MUSC/SCAN: Dr. Nick Milano, Tracey Waring  
SC DPH - Ms. Emily Ash, Ms. Karilyn Tremblay, Ms. Jillian Catoe, Ms. Jessica Plair  
SCDHHS – Mr. Russel Morrison (proxy for Ms. Alewine)



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**CALL TO ORDER:**

Ms. Wilson called the meeting to order at 10:02 a.m., 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 March 2024 minutes, and Ms. Kennedy seconded the approval. Dr. Carroll motioned to approve the June 2024 minutes, and Dr. English seconded the approval.

**Guiding and Improved Dementia Experience (GUIDE) Model/SC Alzheimer's Network (SCAN) Update**

Dr. Milano reported that while working to get the MUSC program SCAN started last fall, Medicare announced the new GUIDE Model. GUIDE is a new payment model that improves the care received by patients living with dementia and ensures that they receive ongoing support and care from health systems. The payment model differs from the original "pay for service" model, where the provider receives payment at each visit, to a monthly payment. If a provider has a patient enrolled in GUIDE, the provider will receive a monthly payment from Medicare that varies based on how complicated the patient's care is. For an institution to qualify for GUIDE participation, the institution must have at least one clinician with expertise in dementia care and a care navigator. GUIDE Model sites must provide a comprehensive assessment and care plan, offer 24/7 patient care access, and provide ongoing monitoring and support, care coordination, respite, and caregiver education and support. All services provided do not have to be provided by the healthcare institution but can be done in partnership with other organizations. Dr. Milano is confident that they can use community partnerships to provide some of the required services, such as respite care.

When reviewing the GUIDE Model, the SCAN team recognized that the GUIDE requirements aligned with much of the work already being done by SCAN. However, they also recognized that SCAN was not designed to follow every patient with dementia but rather partner with primary care. MUSC decided to partner SCAN with the MUSC Geriatrics department. Patients will receive their initial diagnosis through SCAN, complicated patients/patients with atypical dementia will stay with neurology/SCAN, and patients who are more stable will be referred to geriatrics. Care navigators will be available for patients in both the SCAN and Geriatrics departments. This program will begin in July 2025.

Ms. South asked if there is a partnership between the GUIDE Model and retirement communities. Dr. Milano stated that any residents of retirement communities can enroll in GUIDE with providers who are at participating sites. He states that if these communities offer some of the required services, then they could be potential partners. Dr. Milano offered his email ([milano@musc.edu](mailto:milano@musc.edu)) for Council Members to reach out regarding potential partnerships as they work to get the GUIDE program up and running at MUSC.



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**Dementia Care Specialist Update**

Ms. Daniel provided a brief update on the Dementia Care Specialist (DCS) program. The SC Department on Aging was awarded \$1.1 million of recurring funds for 10 DCSs throughout the state. This will allow the current DCS to continue with the program and hire nine additional DCSs. Each DCS will be placed in one of the ten regions. The additional nine DCSs will be rolled out in three phases: the first three DCSs will be onboarded by November 2024 for the Upper Savannah, Lower Savannah, and Pee Dee Regions; March 2025 will see DCSs onboarded for Catawba, Santee Lynches, and the Lowcountry regions; and the final three DCSs will be hired by August 2025 for the Trident, Appalachian, and Waccamaw Regions. The Department on Aging is looking to partner with local libraries to house the DCSs so that they are in a neutral, nonmedical, and easily accessible location. Ms. Wilson expressed excitement over the program's expansion and asked that the positions be shared with the ARCC Advisory Council Members when available so that they can share the openings to assist with filling the positions.

**State Plan Implementation Update**

Ms. Tremblay reviewed the implementation plan for the Statewide Plan to Address ADRD. She states that a vendor was hired to help review the state plan's 52 objectives. She also reviewed the proposed timeline for the implementation plan. The hope is that by October, more resources will be available and provided for ARCC subcommittees, and subcommittees will meet in November to review the resources and discuss implementation plans. The implementation plan aims to make the Statewide Plan actionable, sustainable, and focused. The 52 objectives of the state plan were reviewed to see how they may be linked with the appropriate subcommittee.

In the coming subcommittee meetings, DPH will help facilitate guiding questions for state plan implementation. Ms. Tremblay stressed that they are looking for shared goal alignment, available resources, and ways to make the objectives sustainable and effective. She asks that council members consider their role and their current subcommittee assignment to ensure that they are appropriately assigned and that they can carry out the duties for that subcommittee. They are also looking for champions to take the lead on different initiatives. Ms. Tremblay stated that DPH may be able to assist with some funding initiatives and subcontracting out mini-grants, but not much funding is available. She noted that the champion for each initiative will need to know how attainable/relevant the initiative is and what resources, including funding, will be needed to get it off the ground.

Ms. Wilson held a vote asking if ARCC members will attend subcommittee meetings in November, based on schedule allowance, to help with the implementation of the state plan. Each subcommittee will meet for 90 minutes. The motion passed. Scheduling polls will be sent out from DPH.



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**Orangeburg Stakeholder Meeting Update**

Ms. Wilson reviewed the results from the stakeholder meetings in Orangeburg. She stated that a 2023 study found that Orangeburg County has the 8<sup>th</sup> highest prevalence of Alzheimer's in the nation. She states that Orangeburg County has one hospital and one neurologist, and there are several areas where no doctors are available. The Alzheimer's Association went to Orangeburg County to host stakeholder meetings to try to determine what services were already being offered in the community and what services may be needed. They planned to host three caregiver forums but canceled one due to inclement weather. There is a plan to hold a healthcare provider listening session on September 24 to look at all healthcare providers in Orangeburg County who serve persons living with ADRD. Once all meetings are done, the plan is to bring all stakeholders back together and provide recommendations.

Ms. Wilson stated that services are being offered in the area, but no one is willing to engage in those services. She reports that there is a high incidence of stigma in Orangeburg County surrounding ADRD. At one of the listening sessions, one caregiver admitted to lying to their spouse with dementia to attend the session so as to avoid the person with dementia feeling embarrassment or shame. A pastor in Orangeburg County stated that he has a memory café every Thursday that offers free food, sitter services, and live music that he has had to cancel the last four months due to too little to no attendance. Three long-term care facilities tried to come together to host a monthly support group, but no one came. In North, SC the mayor and the county clerk were the only attendees, but 17 people did request that they be provided with the brochures. Many people in Orangeburg County are afraid of being deemed "crazy," losing their homes and losing custody of grandchildren, hindering them from publicly seeking assistance. There is poor education and understanding of ADRD in the community, and individuals avoid talking about a dementia diagnosis/needing assistance publicly to avoid shame/embarrassment.

Ms. Wilson stated that only two healthcare providers have registered for the healthcare forum despite a heavy advertisement push from the Alzheimer's Association in the newspaper, online, local news blasts, and cold calling medical provider offices. She states that the Orangeburg County community feels strongly that medical providers do not care about the dementia population and often, after giving a diagnosis, do not provide any referrals or follow-up assistance. Ms. Wilson states that there is a serious issue regarding attitudes, knowledge, and behaviors in Orangeburg. She states that a public awareness campaign is needed and is asking permission from the Alzheimer's Association to request one-time funds from the state legislature to run a campaign in Orangeburg County providing education about ADRD. The goal is to try to get into the communities with an alternative public education model where one event is promoted, such as a crafts fair to create fidget blankets for long-term care residents, and while there, attendees will be provided education about ADRD to try to reduce some of the stigma, bias, and shame that is associated with these diagnoses. Ms. Wilson states that she is currently in discussions with several researchers, including the Maya Angelou Center in North Carolina, to try to determine how to develop a campaign to help address these misconceptions and feelings of guilt/shame surrounding a diagnosis of ADRD.



State of South Carolina  
Department on Aging

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Dr. Broadway addressed the lack of provider education in Orangeburg County surrounding ADRD. She suggested possibly seeing about a policy change requiring healthcare providers to have 1 CME each year surrounding dementia care. Dr. English agreed with the suggestion and added that she is working on a grant for CMS that deals with provider education. She also pointed out that many healthcare providers state that there is not enough time in the visits to provide the necessary counseling/education that this population needs, as they are required to complete visits in 15-minute increments. Ms. Wilson reported that policy change would be very difficult to accomplish in South Carolina as many people have very strong opinions about policy change and would push against it. She also mentioned the [CPT Code 99483](#), which allows for providers to bill for cognitive assessment and care planning services, among other resources. She states that educating providers about this billing code could be beneficial. She also noted that the mistrust those living in Orangeburg County have for their local healthcare community needs to be addressed, citing that many community members would rather drive 1.5 hours than go to their local hospital. Ms. Wilson noted this might be addressed through easily accessible education for medical providers in the Orangeburg County community and putting so much pressure that if providers were not a part of it, their patients would question them about it. Ms. Wilson states that many of the county's doctors are either older or "on loan" and will not be staying in the area. She reports that physician retention is poor in the area, so much of the education may need to go to the nursing staff and physician assistants, as they tend to stay in the area longer.

Ms. Kennedy stressed how important it is to address the stigma, even from a risk reduction perspective, and BOLD may be able to act as a contingency in the efforts to combat it. Ms. Wilson stated that she may ask for a letter of support from the ARCC to send to the state legislature, along with the request for funds to run a campaign in Orangeburg County to educate people about ADRD.

#### **PCP Survey Update**

Ms. Catoe reports that 71 responses have been received. The previous survey completed in 2022 had around 97 responses from providers. The goal is to reach at least 100 responses to be comparable. ARCC Council Members were encouraged to share the [PCP Survey](#) with any providers they may know, but at least with their own primary care provider, to get more respondents.

#### **Alzheimer's Association International Conference (AAIC) Update**

Ms. Wilson stated that the AAIC is the largest global convener of dementia researchers. 8,000 people from 101 countries attended in person this year, and about 5,000 attended virtually.

Dr. Carroll states that much of the AAIC focused on biomarkers. Researchers were looking at known biomarkers while also trying to find new biomarkers. He stated that a reason the biomarkers were so heavily looked at is that they may change/indicate a dementia diagnosis even before there is any clinical evidence of altered mental status, and the hope is that if treatment is rendered earlier, treatment will have a much larger impact and a greater chance of slowing disease progression. Genetics was another big focus at the



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conference. Researchers were looking at risk genes for developing the different causes of dementia. There was also discussion about ongoing clinical trials.

Dr. Broadway stated she attended the AAIC virtually. She noted that the focus of this year's conference was largely on blood-based biomarkers. There was also discussion about the Anti-amyloid therapies that are currently being utilized, and how long they should be used for treatment. She also mentioned good presentations on radiologic findings of the difference between Amyloid-related imaging abnormalities (ARIA\*) focusing on the difference in radiologic signatures between cerebral amyloid angiopathy (CAA) vs typical vascular changes one might expect to see comorbidly with Alzheimer's disease.

\*ARIA = microhemorrhages and edema that can occur with the anti-amyloid therapies

Ms. Wilson shared [research press releases](#) from AAIC. The Alzheimer's Association is launching a new journal on the impacts of behavioral, social, and economic factors on health and dementia care in aging. Dr. Crystal Glover from the Rush ADRC in Chicago will run it. The journal will focus on equity, health equity, and dementia risk as well as methods for risk reduction.

Using blood tests to help diagnose ADRD was another key release that was made. Ms. Wilson states that right now, the only things that can be utilized to identify biomarkers that can confirm an Alzheimer's diagnosis are PET Scans and a spinal tap. Dr. Broadway stated that the issue with PET Scans is that the tracer needed for the scan is limited, must be flown in, and cannot be made in South Carolina. Dr. Carroll stated that the ADRC is currently trying to get a cyclotron, which is a particle accelerator that produces the radioactive component of the tracer used for PET imaging.

Ms. Wilson also discussed sessions she sat in at AAIC, which included how to manage impairment of the senses (hearing loss, vision) in persons living with dementia, improving dementia outcomes in minority populations, and the relationship between chronic comorbidities and dementia. She stressed that the research from the AAIC focuses not only on diagnosis and prevention but also on how to reach the people most affected by these diseases and how to keep a quality-of-life measure for people with dementia.

### **Alzheimer's Disease Research Center (ADRC) Update**

Dr. Carroll confirmed that the ADRC application was submitted. A study session has not been scheduled yet, but the ADRC team has been working with a consultant to review the application for any improvements that may need to be made. The consultant is Dr. Zaven Khachaturian, who created the concept of ADRCs during his time at NIH. After reviewing the application, the consultants stated that they have not found any "fatal flaws" and that if the application is denied, it will likely be for minor details. As they wait for NIH review, they have been developing the ADRC infrastructure that the NIH requires. Much of the core equipment, including the instrumentation needed for biomarker testing, is already in place. They are also digging more into genetics.



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The first publications by the ADRC institutions (MUSC, USC, Clemson) have been accepted and are coming out. Dr. Carroll states that the next steps for the ADRC are to contact senior leadership at each institution to see what these universities can offer to help support/move the ADRC forward.

**Alzheimer's Disease Registry Update**

Dr. Miller stated that they have received the final source for registry data and hope to have the county-level fact sheets and the next iteration of the SC Alzheimer's Disease Registry Report out by the end of the year.

Dr. Miller also reports that they are continuing to work on utilizing data garnered through the registry for research purposes. They recently published a paper in partnership with MUSC focusing on the longevity within the SC Alzheimer's Disease Registry. They are also in the process of publishing additional papers, including two that focus on the veteran population and mortality and incidence rates.

Ms. Wilson asked if an executive summary could be shared as the papers were written so that fact sheets could be created to share with the legislature and other stakeholders. She mentioned that the information on the veteran population may be particularly helpful as there is a Veteran and Family Affairs subcommittee within the SC Senate, and the veteran population is one of the focuses of the SC ADRC. She stressed the need to figure out how to utilize these papers outside of the field of research to work on the deliverables of the state plan.

**Adjournment/Closing**

There being no other business, Ms. Wilson adjourned the meeting at 11:46.

**Next Meeting:**

Tuesday, December 10, 2024, at 10:00 am

Respectfully submitted,

Dana M. Daniel, LMSW