



State of South Carolina
Department on Aging

Henry McMaster
Governor

Connie D. Munn
Director

Alzheimer's Resource Coordination Center Advisory Council Meeting
Columbia
March 10, 2023

MINUTES

The Alzheimer's Resource Coordination Center Advisory Council met virtually Friday, March 10, 2023 at 10 a.m. This was a virtual meeting.

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:

Mr. Andrew Boozer	SC Association of Council on Aging Directors
Dr. Jessica Broadway	VAMC, Charleston
Dr. Steve Carroll	Medical University of South Carolina
Ms. Kelly Cordell	SC Department of Social Services
Dr. Miroslav Cuturic	SC Department of Mental Health
Dr. Sara English	SC National Association of Social Workers
Dr. Miriam Evans	South Carolina State University
Ms. Emma Kennedy	DHEC
Ms. Denise Kish	SCALA
Ms. Sheila Lewis	SC Department on Aging
Mr. Robert McBurney	SC DDSN
Dr. Maggi Miller	Alzheimer's Registry, Office for the Study of Aging, UofSC
Dr. Cynthia Port	Coastal Carolina University
Ms. Rebecca Smith	SC Silver Haired Legislature
Ms. Janae Stowe	SC Association of Area Agencies on Aging
Ms. Taylor Wilson	Alzheimer's Association, SC Chapter

Guests from DHEC:
Ms. Eboni Whitehurst

Guests from the Weather's Group:
Katie Zenger, Rita Drinkwine

Guest from South Carolina Alzheimer's Network (SCAN):
Dr. Robert Adams, Dr. Rick Foster, Ms. Tracy Waring

CALL TO ORDER

Ms. Taylor Wilson, Chair, called the meeting to order at 10:03 a.m., read the FOI statement/Americans with Disabilities Compliance Pledge, and welcomed all council members and guests to the meeting.

NEW BUSINESS:

Update on Statewide Strategic Plan to Address Alzheimer's and Related Dementias

Rita Drinkwine gave a high-level overview of the strategic plan. She informed the members that CDC recommended a few changes to include "prevention" and "risk reduction" in the mission and values statements. Ms. Drinkwine stated that the plan was in its fifth stage and that an updated version would be submitted to the CDC and DHEC. The five strategies of the plan were reviewed as well, they are:

- Education (Risk reduction/Prevention framework)
- Advocacy & Policymaking
- Access & Connection to Care
- Caregiver Support (Multidimensional)
- Data (Resources & Access)

Ms. Drinkwine thanked Eboni Whithurst for her invaluable assistance with the plan. Also noted that Ms. Whitehurst is currently writing for a new BOLD grant.

APPROVAL OF MINUTES:

Robert McBurney motioned to approve the December meeting minutes, Andrew Boozer, seconded. Minutes were approved.

CONTINUATION OF NEW BUSINESS:

Next Steps on Strategic State Planning

Ms. Wilson led this discussion. Topics of discussion included:

- Putting work into implementation plan (it's going to be up to the council to make happen)
- How will we make it happen, developing a timeline
- Turning a dementia crisis to an innovative success

Ms. Wilson shared a story about woman she met at Alz State House Day (March 1, 2023). The woman has a diagnosis of Alzheimer's disease, lives alone, and has no means of preserving quality of life with dignity.

Ms. Wilson informed the group that subcommittee meetings would start to take place in April. She encouraged members to attend the 90-minute virtual meetings or send a proxy if they are not able to attend. She thanked everyone for all of their hard work and dedication.

Update on State Plan Legislation

Ms. Wilson stated the purpose of the plan is to codify the process of the ADRD. This is a first for a state agency to be responsible for writing a state plan. This is a good opportunity. We must start the work (i.e. utilize the plan to educate our elected officials on the funding that is necessary for the things we want to work on (i.e. law enforcement training, health awareness campaigns, risk reduction awareness, and health care education).

ARCC Council is responsible every 5 years engaging in a process such as this (strategic plan). This will allow the Council to keep up with dementia science, keep up with changes in the law, keep up with the new needs that are arising (i.e. new symptoms of dementia), and be prepared for drug treatment. This makes us accountable; it would be progress for the state and open opportunity for funding for initiatives.

Ms. Wilson informed the Council that Senator Alexander, Senator Shealy, and Senator Peeler are on the Senate Bill. Those representing The House of Representatives, Pro Tempore Representative Pope, and Representative

Hiott, 27 other co-sponsors. Ms. Wilson stated that hopefully, by the end of June, we could have an ARCC bill signed. Ms. Wilson stated that the bill is out of full committee in the Senate with a favorable report and that it should pass through the House smoothly. She thanked DSS and APS for their support.

OTHER UPDATES:

USC Arnold School of Public Health Alzheimer's Disease Registry Update:

Dr. Miller gave an update on the annual report. The report will include two years of data for 2018 & 2019. She was hopeful that the report would be available next month (April). Ms. Wilson thanked Dr. Miller for the report, which was very helpful in collecting ADRD data statewide.

ARCC Grant Solicitation Update

Ms. Lewis gave an update on the process and progress of the ARCC Grant funding for FY 2023-2024. Solicitation announcement was made on February 10th; deadline for proposals is April 10th. Two pre-grant workshops were conducted, the first was for the faith-based community. This was a hybrid event held at the Columbia International University on February 9, 2023. Over 60 people attended in person, 105 virtual. The second workshop, held on February 27, was a virtual event for other entities statewide, over 50 people participated.

Family Caregiver and Alzheimer's Division Updates

Ms. Lewis reported that Dementia Care Specialist, Tori Anderson, would begin conducting "Dementia 101" webinars monthly. The webinars will be on the 1st Wednesday of every month at 1:00 PM. Registration information is posted on the SCDOA website.

OTHER BUSINESS:

Ms. Wilson informed the Council that the SCDOA and the Alzheimer's Association collaborated on the Caregiver Behavioral Risk Factor Surveillance System (BRFSS) data report. The report will be completed next month (April).

Alzheimer's Association Facts and Figures data will be released March 15. Special reports related to treatment coming down the pipeline, physician's scope of treatment, and physician's reticence to a diagnosis. Data for each state will also be available.

Subcommittee meeting requests will be sent out.

Final version of strategic plan to be completed by March 23.

NEXT MEETING:

In-person, June TBD (with potential press conference with Governor or Lt. Governor).

ADJOURNMENT:

There being no additional business, Ms. Wilson adjourned the meeting at 10:48 AM.

Respectfully submitted,

Sheila H. Lewis



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Alzheimer's Resource Coordination Center Advisory Council Meeting
Columbia
June 23, 2023

MINUTES

The Alzheimer's Resource Coordination Center Advisory Council met Friday, June 23, 2023 at 11 a.m. at the South Carolina Department on Aging, 1301 Gervais Street, Columbia, SC 29201.

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
Mr. Andrew Boozer	SC Association of Council on Aging Directors
Ms. Jennifer Brewton	SC Department on Aging
Dr. Jessica Broadway	VAMC, Charleston
Ms. Megan Byers	University of South Carolina, Office for the Study on Aging (via telephone)
Dr. Steve Carroll	Medical University of South Carolina
Dr. Scott Habakus	Consumer/Caregiver (via telephone)
Ms. Denise Kish	SCALA (via telephone)
Ms. Sheila Lewis	SC Department on Aging
Mr. Robert McBurney	SC DDSN
Dr. Cynthia Port	Coastal Carolina University
Ms. Rebecca Smith	SC Silver Haired Legislature
Ms. Janae Stowe	SC Association of Area Agencies on Aging
Ms. Taylor Wilson	Alzheimer's Association, SC Chapter

Guests from the Alzheimer's Association, SC Chapter:

Ms. Cindy Alewine, Sam Wiley (via telephone)

Guest from SC DHEC: Jillian Wilks

Guest from SC Department of Mental Health: Rochelle Canton (Proxy)

Guests from the SC Department on Aging: Director Munn, Tori Anderson, Jenny Andrews

Virtual guests from the South Carolina Alzheimer's Network (SCAN):

Dr. Robert Adams, Dr. Rick Foster, Ms. Tracy Waring

CALL TO ORDER:

Ms. Taylor Wilson, Chair, called the meeting to order at 11:03 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. Broadway motioned to approve the March 10th meeting minutes, Dr. Carroll seconded. Minutes were approved.

GREETINGS:

Director Munn greeted council members and guests and thanked them for their support and dedication to the ARCC.

NEW BUSINESS:

ARCC Grants Update

Ms. Lewis gave an update on the 2023-2024 Grantees. They are the following:

- Antioch AME Support Group Ministry-Eastover
- Feonix Mobility Rising-Richland
- Golden Corner Respite-Seneca
- Let's Walk-Charleston
- Magnolia Memory Care Inc.-York
- The ARK of SC-Charleston
- Think Different, LLC-Greenville

2nd Year Funding for FY 2023-2024 Grantees

- Alzheimer's Family Services of Greater Beaufort
- Leeza's Care Connection-Richland
- Lexington County Sheriff's Department (Project Hope Lifesaver Program)
- MapHapbit, Inc.
- Mother DeVeaux Adult Daycare-Eastover
- Newberry County Council on Aging
- Respite Care Charleston
- SC Christian Action Council, Inc.
- St. James South Santee Senior and Community Center
- Straight Road International-Richland

Mr. Boozer suggested that Antioch AME and Mother DeVeaux collaborate efforts since both grantees are located in Eastover.

Dr. Broadway raised the question of the cost of the Project Lifesaver Program. She suggested the use of AirTags (a tracking device developed by Apple). Discussions were made on the benefits and effectiveness of the PLP by Ms. Brewton, Ms. Taylor and Ms. Lewis.

State House Update:

Ms. Wilson gave an update on the budget. The budget has not been signed by the Governor but has made it through vetoes for a one-time funding amount of \$10 million for the three major research universities in SC, Clemson, MUSC, and USC, to collaborate and apply for a one of the unique designations for the National Institute on Aging, and the ADRC. Dr. Carroll is the leader of this initiative.

Alzheimer's Disease Research Center Update

Dr. Carroll gave the following update on the ADRC:

The due date to submit the application to the National Institute on Aging is June 14, 2024. The veterans' population was chosen for this initiative, which will be referred to as "CareNet ADRC", 250 veterans, 250 non-veterans will be recruited. The main research areas of the ADRC are; clinical, administrative, recruitment & community engagement, data management, biomarker (which will be two cellular and molecular cores and digital biomarker core, and an optional imaging core).

Dr. Broadway informed the members that the VA has selected seven sites statewide for this initiative, as the program matures, the VA will roll out national sites.

Visibility is what is needed to support this initiative.

Dr. Carroll informed the group about an upcoming aging symposium. Members discussed the need for more aging, caregiver, dementia-related symposiums/conferences for researchers to highlight their research. Dr. Foster noted the importance of finding settings to present to clinicians, to educate them on the difference between research and clinical care in the ADRD world. Mr. Boozer suggested that we cross-reference the ARCC Grantee participants, possibly recruiting participants to participate in this initiative. Ms. Wilson made an appeal to the members to notify herself, Ms. Lewis, or Dr. Carroll of any opportunities for researchers to present or sponsor an event. The Alzheimer's Association would be another source for sponsoring symposiums or conferences.

Ms. Wilson informed the group that the Alzheimer's Association has decided to take research trainings online, rather than in-person. Dr. Broadway suggested that the council form an on-line dementia/caregiver symposium.

Silver Haired Legislature Update:

Ms. Smith reported on the performing mission. They will have an orientation on July, 1st. Legislative session in September. Ms. Smith gave an overview of voting procedures and resolutions. Resolutions have been submitted for caregiver respite for families affected by ADRD.

Legislative Oversight Committee Update:

Ms. Brewton stated that the hearings went remarkably well. Every seven years the SCDOA gives a report to the Committee. Ms. Brewton reported that the Committee was very interested in learning more about dementia and about the work that the ARCC is doing. The Committee made recommendations to the ARCC, one, that the ARCC become more transparent (i.e. posting council members names, council meeting agenda, meeting minutes, and grantee information, on SCDOA website.). The Committee asked if ARCC needed more funding to support family members affected by ADRD.

Ms. Brewton gave an overview of the Family Caregiver Support Division.

ARCC Subcommittee "Discovery Meetings" Highlights and Discussion:

Ms. Wilson thanked all of those who attended the May Subcommittee meetings. Issues related to dementia are being noticed by researchers, data analyst, public health officials, community service providers, and public health friends. Subcommittee highlights:

- Dementia Dialogues (add Brain to Health to Heart, to expand program for state of SC)
- IMPH (presented Social Isolation Task Force Report on June 13)
- State Health Assessment (in final phase and is being reviewed)
- First Responder Training (needed but training must be tailored to each first responder)
- Telehealth Stations (Palmetto Care Connection providing technical literacy workshops)
- Toolkits (SCDOA creating toolkits for recently diagnosed)
- Celebrity "faces" (needed to help with destigmatization)
- Training for Trainers (for all ARCC grantees)
- DHEC LTC (promote facility locator on Take Brain Health to Heart Website and GetCareSC.com)
- Caregiver Needs (are we providing support to them when they can actually listen and receive the info?)
- Discussion on Advanced Directives and Health Care POA

Data Wish List:

- Senior daily travel radius
- Print ready DHEC LTC locations by county
- Number of Medicare Wellness visits in SC
- Caregiver data around family impacts (Dr. Carroll to send list)
- Array of services of families facing a dementia diagnosis
- Pockets of prevalence
- Data barriers
- Heat map (identifying underserved communities)

- Location of nearest neurologists to prevalence communities

Ms. Wilson provided a “Who are we missing” form for the members to use to identify other stakeholders to bring to the table. Those persons would be invited to serve on the subcommittees to share ideas and provide feedback.

OTHER BUSINESS:

There being no other business, Ms. Wilson adjourned the meeting at 12:50 PM.

NEXT MEETING:

September 2023. A doodle poll will be sent to members.

Respectfully submitted,

Sheila H. Lewis



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Alzheimer's Resource Coordination Center Advisory Council
Friday, September 29, 2023
10:00 AM – 12:00 PM
[Zoom Link](#)

MEETING AGENDA

1. Welcome and call to order

2. Welcome and Freedom of Information Act/Americans with Disabilities Act Compliance Pledge

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.

Ms. Wilson shared a tribute to Dr. Foster and a moment of silence was observed in his memory.

3. Review of June 2023 Meeting Minutes

Minutes approved by Dr. Carroll and Mr. McBurney

4. State Plan Report

- Ceremonial bill signing
- Received \$10M for Alzheimer's Disease Research Center
- Reviewed the ARCC legal requirements
- ARCC bylaws –
(Re) election time
 - Need to find a Chair, Vice Chair and Secretary. Role descriptions shared. Ms. Wilson announced she will run for another 2-year term.
 - Officers will be elected at our next meeting on December 12th. Ms. Brewton will send out email prior with list of self-identified nominees and asking for additional nominations. 3 min Q&A period for each candidate will be provided and then take vote. This will be a virtual meeting so everyone can attend and participate in the vote.
- State Plan report due 9/30. Ms. Wilson and Ms. Brewton working on this report – overall summary of why/how the State Plan was created. Importance of bringing all stakeholders to the table.

5. BOLD Grant – SC DHEC –

- Funded for component 2 for 5 implementation years for ADRD activities supporting state plan.
- \$450,000/yr to implement.
- Currently hiring for BOLD project manager



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- Lead – Emma Kennedy, MPH – SCDHEC

6. Subcommittee Meetings

- Ms. Wilson shared that implementation planning will resume late fall/early winter of 2023. Really need the BOLD project manager on board first. Regardless, will definitely have subcommittee meetings before December 12th, even if just for a quick update and to introduce the new Dementia Coordinator and BOLD grant manager.
- Reminder that the 4 subcommittees are:
 - Public health –
 - Professional Care
 - Community programs
 - Research and Evaluation

7. Alzheimer's Respite Funding Report

Ms. Brewton gave update on use of

Respite Program: \$1M respite funding to serve caregivers of people living with dementia:

- 10% toward admin and the remainder to family caregivers
- Used different funding formula that distributed more funds in regions with higher dementia rates. This was a big change for some regions and not all were able to spend the funds allocated, but they can roll over and now all are prepared for this next fiscal year.
- Reviewed caregiver demographics and services utilized.
 - Almost all were used for in home care.
- Heat map provided to show vouchers issued by county
 - Ms. Wilson asked if the data was captured based on the county of the care recipient or the provider? Reason for asking is understanding rural access to services (are people not receiving vouchers because there is nobody to provide the care.?) The answer is by county of the caregiver.
 - Ms. Margaret Alewine added that it would be helpful to have info available on provider network by county. What are the entities the vouchers are connected with. Ms. Brewton shared that they had asked for that information previously. Did not do so this E.g., Low country region has a high percentage of private in-home care because it is so rural. For that region, Beaufort county makes up over half of their population.

ARCC Grantees – 18 total grantees for FY 2023-2024

- 4 first time grantees – Antioch, Feonix Mobility Rising, Let's Walk, Think Different Dementia.
- 2nd year grantees will be eligible to reapply
- Grant activities tied to respite care, caregiver training and education, innovative programs
- Project Lifesaver – Ms. Brewton shared that we are inviting to speak at a future meeting. Ms. Wilson suggested June since it is in-person



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Job opening – New Dementia Coordinator focused on the ARCC at the SCDOA is starting October 17th. Once started, introductions will be made. Years of experience in the dementia space. Knowledgeable and passionate.

BOLD update: Emma Kennedy

- Restructuring division to better align – Karilyn Tremblay – newly appointed Director of Injury Prevention and Aging Programs. 2 years with SCDHEC, from NY with many years in Medicaid.
- Job opening - hiring a program manager – requested that council members share this with their contacts
- Today is last day of “Bold 1.0”. Bold 2.0 starts Monday.
 - First step is getting program manager position filled.
 - Working on vendor contract to assist with implementation to make the state plan actionable
- Working with Institute for Medicine and Public Health (IMPH) – applied for and awarded age-friendly public health grant. SCDHEC and IMPH partnering on the plan for that grant.

Ms. Wilson asked how this age-friendly grant changes initiatives for SCDHEC

Per Ms. Kennedy –looks at programs they provide within the health department - e.g., public health preparedness/disaster management – are they age friendly? Licensing – be sure people are dementia trained and have access to resources. How to make programs more age friendly. Ms. Wilson reminded of importance of working with DOT on training bus drivers and first responders. The Director of Public Health Preparedness – father had Alzheimer’s disease, so a good partner to help with training for first responders.

8. SC Alzheimer’s Registry Update

SC Alzheimer’s Registry - Megan Byers presented the Registry update as Dr. Maggi Miller is out of town–

Ms. Wilson - ARCC is advisory council for Registry. Big component of ADRC efforts.

Leadership – Megan and Maggi are co-directors. There is just 2 of them plus 2 graduate assistants. Seeking funding to add more help for all that they are doing.

Have received data from 2020 and 2021 so will be doing another 2-yr update. 35th report anniversary. **Press conference to release this update scheduled for March 13, 2024.** Will send save-the-date. Plan to have the report data available by end of this year. Hope to have it done by 12/12 meeting – challenge is getting the data clean and easy to read and updated by graphics department. Per Ms. Wilson: aiming to have county-specific fact sheets coming from Alzheimer’s Assoc by 12/12.

Per question from Ms. Wilson, Megan agreed to help with talking points regarding differences found prior to and since COVID shutdown



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Also asked if there are any hypotheses about what the 2020-2021 data will show – Megan shared that per Dr. Miller's first review: 2020, diagnoses tended to decrease and then came back to normal rate in 2021. Presumption that people were less often going to doctor to get treatments.

Kelly Cordell asked about sources for the data. A wide variety of sources – emergency rooms, long-term care facilities, anywhere you can get a diagnosis (see [Registry](#) for details)

Dr. Carroll shared building caregiver registry into ADRC plan. Goal to partner the caregiver registry with existing Alzheimer's disease Registry. Can have more conversations around the heat map to overlap data.

Dr. Carroll and Dr. Miller also met recently to discuss expanding the data in the Registry by coordinating findings in the brain bank to look at accuracy of clinical diagnoses in the state. Also working to collect and add genomic data to overlay that with hot spots to identify genetic contributions to dementia in SC.

- Ms. Wilson reminded of the importance of an accurate diagnosis for proper treatments. Latest drugs passed by FDA are specifically to treat Alzheimer's disease, not other forms of dementia. Also, no longer necessary to wait for an autopsy to diagnose with confidence
- Brining clinical trials to SC through ADRC

9. Member Highlights

- **Adult Education** - Mr. Andrew Boozer, Senior Resources reported on adult education as a prevention for Alzheimer's. Research out of Japan: 19% lower risk of developing dementia within 5 years. There is a place for university systems in our state as well as SC Department on Aging, and councils on aging to drive that education. Ms. Wilson – adult education often associated with technical schools. Brings up the point that we are missing technical college voice at this table – especially re: access to rural communities.

IMPH social isolation report – launching a new coalition working toward initiatives. Increase free tuition opportunities. Putting initiatives forward in the state tied to international research studies addressing social isolation.

Ms. Brewton suggested that the Osher Lifelong Learning Institute (OLLI) might be a good partner to bring to table. They sat on the social isolation coalition. Ms. Wilson suggested to ask Olli to present.

Another study link from this week that ties active aging and dementia risk reduction, shared by Andrew Boozer:
https://consumer.healthday.com/dementia-2665047418.html?WT.mc_id=enews2023_09_27&utm_source=enews-aff-&utm_medium=email&utm_campaign=enews-2023-09-27&utm_content=homeoffice&utm_term=Story1

Ms. Wilson stressed the importance of prevention. Referenced Lancet Commission study - 40% of dementia may be prevented or delayed through modifying certain risk factors. (link: [Lancet Commission Study](#))

Dr. Adams asked about our plans for joining forces with American Heart Association?

Ms. Wilson shared that Take Brain Health to Heart campaign is most comfortable space for that partnership right now.



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- **Silver Haired Legislature update** – Rebecca Smith. 2 main topics:
 1. Alzheimer's Respite Resolution put forth for legislative session this year was voted number 1, so will be going forward in January to the legislature.
 2. Pilot Club of Columbia working with RCSD to develop new region serving Hopkins, Eastover, Gaston. Providing funding for project lifesaver in that area.

Ms. Wilson commended the Silver Haired Legislature for their innovation and support of ARCC initiatives

Ms. Smith also shared that we need more engagement with the ARCC/state plan from civics organizations

- **Presentation for Senate Finance Committee on the ADRC and update** - Dr. Carroll – Clemson, USC and MUSC working together to submit collaborative ADRC grant application, due on *June 14, 2024*. Have executed an MOU, agreed on a plan and various groups have been meeting for each of the 9 cores. Each institution spoke:
 - MUSC** - Dr. Carroll informed legislative committee about ADRC structure and identifying target population (emphasis on veterans - cohort will constitute half veterans, half non-veterans). Also shared data on epidemiology, prevalence in the state. Areas where we had higher levels and that diagnoses in SC atypical compared to other areas.
 - USC** – Dr. Leo Bonilla presented on imaging studies (one of the imagers from USC came up with one of fundamental algorithms for analyzing radiology images in the Alzheimer's disease neuroimaging initiative). Also spoke about the ADRC Registry.
 - Clemson** – Dr. Lesley Ross spoke about digital biomarkers. Brought computers with software programs for legislators to try (they were surprised at the difficulty level). Follow up meeting this Monday 10/2/23 – hashing out final version to have a good overall structure. 1 researcher from each institution on the 9 cores. Exception of neuropathology core (Dr. Carroll only neuropathologist in the state focused on neurodegenerative disease). So, total of 25 researchers altogether.

Ms. Wilson noted that this is going to put a spotlight on our state that will help us grow this program. Also reminded that ADRC still in "seed phases" – but as soon as up and running, will get people involved. If anyone on the council is asked about it, we can send people to [trialmatch](#) to sign up for clinical trials through the Alzheimer's Association and/or to the VP of research office at each university to be connected to trials through their institution.

- **SCAN update**

Dr. Milano and Dr. Adams -

 - MUSC has provided pilot funding to start the program.
 - Planning 3 sites – Charleston, a fully virtual telemedicine site and then an MUSC regional site that will be disclosed at a later date.
 - Rolling out in waves. Starting to hire and will expand from there.



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- Challenges and benefits of the utilization of telemedicine were briefly discussed. Suggestion of supporting that initiative through one of the ARCC state plan subcommittees.

10. Other Business

Per Ms. Wilson, look out for:

- follow up email with the slides, recording and minutes
- subcommittee Doodle poll email
- Ms. Brewton and Ms. Wilson attending Alzheimer's/Dementia conference in D.C. – may come back with some ideas to share

Meeting Dates:

Tuesday, December 12th, 2023 from 10 am to 12 pm (Virtual)

Friday, March 22nd, 2024 from 10 am to 12 pm (Virtual)

June meeting will be in-person



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Alzheimer's Resource Coordination Center Advisory Council Meeting
Columbia
December 12, 2023

MINUTES

The Alzheimer's Resource Coordination Center Advisory Council met Tuesday, December 12, 2023 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
Mr. Andrew Boozer	SC Association of Council on Aging Directors
Ms. Jennifer Brewton	SC Department on Aging
Dr. Jessica Broadway	VAMC, Charleston
Ms. Megan Byers	University of South Carolina, Office for the Study of Aging
Dr. Steve Carroll	Medical University of South Carolina
Ms. Kelly Cordell	SC Department of Social Services
Ms. Dana Daniel	SC Department on Aging
Dr. Sara English	National Association of Social Workers, SC Chapter
Dr. Scott Habakus	Consumer/Caregiver
Ms. Emma Kennedy	DHEC
Mr. Robert McBurney	SC DDSN
Dr. Maggi Miller	University of South Carolina, Office for the Study of Aging, AD Registry
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

Guest from SC DHEC: Ms. Emily Ash, Ms. Karilyn Tremblay, Ms. Jillian Wilkes

Guests from the SC Department on Aging: Ms. Tori Anderson, Ms. Jenny Andrews

Guests from the South Carolina Alzheimer's Network (SCAN): Dr. Nick Milano

ARCC Grantee Guests: Ms. Cassandra Deveaux, Ms. Linda Jones, Ms. Peggy Lahmeyer, Ms. Joy Nelson, Ms. Dawn Wiggins

CALL TO ORDER:

Ms. Taylor Wilson, Chair, called the meeting to order, read the FOI statement/Americans with Disabilities Compliance Pledge, and welcomed all council members and guests to the meeting.

APPROVAL OF MINUTES:

Ms. Kennedy motioned to approve the September 2023 meeting minutes, Mr. McBurney seconded. Minutes were approved.

Welcome to New Dementia Coordinator

Ms. Wilson introduced and welcomed new SCDOA Dementia Coordinator, Ms. Daniel. Ms. Daniel provided a brief history of her experience before joining the SCDOA.

ARCC Officer Votes

Ms. Brewton opened the floor for the ARCC officers election. Ms. Wilson was re-elected as Chair and Ms. Beyers was re-elected as Secretary. No Vice Chair has been elected at this time. Councilmembers interested in the Vice Chair seat were encouraged to reach out to Ms. Daniel so that a vote can take place during the March 2024 meeting.

BOLD Plan Update

Ms. Kennedy and Ms. Tremblay provided an update on the BOLD Plan. A BOLD Program Coordinator is still needed, and the job position will likely need to be reposted. Once the position is posted it will be shared with the ARCC Council. Once a Coordinator is hired, DHEC will then focus on hiring a Vendor to assist with the implementation plan. They are working with the procurement department to come up with a timeline for getting the Vendor hired. Once a Vendor is in place, work will be done on the Take Brain Health to Heart campaign to make sure all resources and information are available.

Ms. Wilson and Ms. Kennedy held a lunch-and-learn on Nov 16 for all regional public health partners with over 60 people in attendance.

Ms. Wilson posed the question of what the timeline for getting a consultant on board is. Ms. Kennedy states that the timeline is fluid; they are working with the procurement office and believe that a realistic timeline will be Mid-Late February 2024.

State Plan Update

Ms. Wilson posed the idea of DHEC implementing a wide-scale survey of Primary Care Providers (PCPs) across the state regarding current and needed education of PCPs about ADRD.

Ms. Wilson brought up work being done to have first responder education done on a state level, this would include updating current EMS training and making it mandatory. Ms. Wilson and the Alzheimer's Association are also working with the Criminal Justice Academy to provide practicals on dementia which will hopefully be ready by January 2024. Ms. Wilson also mentioned that steps are being made to update the Geriatric Loan Forgiveness Program. The program has been in South Carolina for 28 years with a reimbursement of \$35,000. Steps are being made to have the reimbursement increased to \$100,000. The hope is that this will assist with the recruitment of geriatricians, neurologists, neuropsychiatrists and neuropsychologists to South Carolina.

The Alzheimer's Disease Research Center (ADRC) is working towards getting their application ready for June 2024.

Looking to educate more public health providers, as well as universities and colleges to be able to provide education to public health students on ADRD.

Ms. Kennedy informed the council that DHEC is going through some changes that will likely lead to changes in their website (including the Take Brain Health to Heart Campaign) and other name changes as they go through this transition.

ARCC Grants Update

Ms. Daniel provided information on a proposed change to the ARCC Grants award structure in the upcoming fiscal year. This change would see the ARCC grant award increased to an amount up to \$50,000 to be expended over a two year period. Current FY24 grantees in their first year have the option to stay in their current grant cycle and receive an

automatic \$10,000, which would preclude them applying for the \$50,000 grant. They also have the option to forgoe the \$10,000 and apply for the \$50,000. Ms. Brewton also mentioned that this would still be a 50/50 match, and the organization applying for the grant would still need to match funds with their own \$50,000. Applications will become available in February.

Mr. Boozer asked if there are any restrictions on how often organizations can apply for the grant. There are not currently any restrictions, but as an increase in funds will likely make the grant more competitive changes may be made as the process matures.

Ms. Brewton also mentioned that a call for reviews will be made once applications are received. Councilmembers who are interested in being a reviewer should share their interest with Ms. Daniel.

ARCC grantees on the call introduced themselves and how they are serving their communities.

ARCC Grantee Presentation

Ms. Nelson with Memory Matters presented on her organization and the services offered. They support families in Beaufort, Jasper, and Chatham Counties – Hilton Head Island, Bluffton, Beaufort City, Okatie, Hardeeville, and Savannah. Services offered include respite care, memory care programs, care planning, memory screenings, dementia education classes, and dementia training for law enforcement. They have partnerships with many faith-based organizations, neurologists, and assisted living communities.

Ms. Wilson posed the questions of how long it takes for participants who receive the memory screening to receive a diagnosis and after diagnosis, do they find barriers to receiving needed care. Ms. Nelson reported that many participants return with concerns about the wait (6+ months) to get in with a neurologist. This in turn has led to participants being enrolled in the Memory Matters early memory loss program to address cognitive concerns as they wait to see a provider.

Ms. Wilson posed the question of whether or not a cognitive intervention is beneficial as a “stop gap” once cognitive impairment is identified. Dr. Milano stated that any type of cognitive exercises are good for the brain, but if they do have a positive screening it is important for them to be seen as quickly as possible to avoid missing something that may be treatable. He voiced an interest in speaking further about ways in which to streamline the process for participants who receive a positive screening to be seen sooner so that they can receive the appropriate medical care.

ADRC Update

Dr. Carroll and other partners attended the national ADRC meeting which allowed them to network with other ADRCs and the National Institute on Aging (NIA), receiving feedback for what the NIA will be looking for in their application. Dr. Carroll expressed a need to establish ties with community providers as a way to identify ADRC participants.

Dr. Carroll expressed the need for ADRC designation due to the significant level of misdiagnosis among dementia causing illnesses, with the rate being around 25-30% even within ADRCs. To characterize the state of dementia within South Carolina, the ADRC team has initiated a number of projects. He identified Dr. Miller with the AD registry as a key component in this process, as the clinical core has been working with her to identify potential studies. They are also looking at genetics vs genomics, doing whole genome sequencing among current participants within the neuropathology core. This information is then shared with patients and families as clinical data to be used in their care moving forward. A number of biomarkers are being used for initial diagnosis so the ADRC has purchased the Quanterix HDX System which is highly sensitive and has established panels for measuring biomarkers that are abnormal in people with dementia. This system is the first of its kind in South Carolina and is the golden standard for ADRCs.

The ADRC team is also coordinating strongly with the VA to get participants from the VA involved with the ADRC. The VA in Charleston was recently named as the National Coordinating Center. Dr. Broadway brought up that at the AAIC meeting last summer, there was a discussion about coming up with a panel of biomarkers that would look at improving the sensitivity and specificity for diagnosing Alzheimer’s disease, and start to expand biomarker reliability other causes of dementia. She asked if the Quanterix HDX system would be able to assist with expanding on that as well, and Dr. Carroll confirmed that it would.

Ms. Wilson brought up that USC has an imaging core that will be utilized by the ADRC. Dr. Carroll agreed and stated that there is an Neuroimaging Core that has representation at all three institutions. He went on to mention that all of the

ADRC cores have representation at all three institutions except for the Neuropathology Core, the reason being that Dr. Carroll is the only neuropathologist in the state with a focus on neurodegenerative diseases. The ADRC team is focused on expanding the workforce of those who will be caring for people living with ADRD, developing a number of training opportunities targeting all providers. They are also planning to begin enrolling participants within the ADRC and are looking to hire a Clinical Coordinator to assist with this process. The ADRC team has been doing a lot of community outreach and Dr. Carroll expressed an interest in meeting with ARCC grantees who may be able to assist with identifying ADRC participants. The ADRC team is also looking at forming a Caregiver Registry.

AD Registry Update

Dr. Miller provided an update on the AD Registry. She states that they are working with the Alzheimer's Association to update the county level fact sheets, which they hope will be available before the next legislative session in January 2024. The 2023 Annual report will be highlighting cases from 2020-2021. They are also looking at self-projections looking at retrospectively and projecting 15-20 years.

Ms. Wilson asked if comparisons would be made between 2020 and 2021 numbers because of challenges presented by COVID-19. Dr. Miller states that they have noticed a reduction in the number of cases in 2020, which was expected, but that data in 2021 were more aligned with previous numbers.

There will be a press conference on March 13, 2024 to announce the SC Alzheimer's Disease Registry's 35th anniversary. Celebration of the 35th anniversary will be a two day event, the first being the press release and the 2nd day the Arnold School of Public Health will hold a lecture. Further information on these events can be found here: <https://osa-sc.org/programs/arnold-aging-lecture>

Announcements for 2024

Ms. Wilson shared that March 6, 2024 will be the Alzheimer's Awareness Day.

Ms. Wilson shared that the Alzheimer's Association will be holding a community needs assessment in Orangeburg County. They are in conversations to have 2-4 listening sessions. They are looking to bridge the gap of barriers to access to care and resources. They are to report back findings to the Orangeburg community in November 2024.

Ms. Wilson brought up the topic of telehealth and seniors. She posed the idea of having a "telehealth roundtable" where community providers (i.e. AAAs, senior centers, etc) would speak to members of the AARC about their experiences with telehealth. Mr. Boozer expressed that is a good idea to identify best practices and how to move forward on this subject. Ms. Wilson asked how to identify speakers and posed the idea of a planning committee for the telehealth roundtable. Mr. Boozer and Ms. Tremblay volunteered for the committee. Ms. Wilson stated invites would be going out next year.

Ms. Wilson asked that if anyone has any dates that the ARCC should be aware of, to please contact Ms. Daniel or Ms. Wilson so that an email can be sent out as quickly as possible. Ms. Wilson also mentioned that she and Ms. Daniel are working to find a forum where the ARCC can share such information along with grant opportunities, recruitment studies, and any relevant information with all councilmembers more easily.

Ms. Cordell stated that the World Elder Abuse Day walk will be held on Friday, June 14, 2024.

OTHER BUSINESS:

There being no other business, Ms. Wilson adjourned the meeting at 11:40 am.

NEXT MEETING:

March 22, 2024 - Virtual

Respectfully submitted,

Dana M. Daniel, LMSW