

Department on Aging

Henry McMaster Governor Connie D. Munn Director

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.
 - o 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 stared, 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 <u>Registry</u> 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. Caroll 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.

<u>IMPH social isolation report</u> – 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 <u>Osher Lifelong Learning Institute (OLLI)</u> 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: <a href="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: <u>Lancet Commission Study</u>)

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

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



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- <u>Silver Haired Legislature update</u> 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

• <u>Presentation for Senate Finance Committee on the ADRC and update - Dr. Carroll</u> – 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 ADRD 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