



Alzheimer's Disease and Related Disorders Commission Coordinated Care Work Group

Monday, November 04, 2024
2:00pm- 3:30pm

1610 Forest Avenue, Suite 100
Henrico, VA 23229

<https://dsa-virginia.zoomgov.com/j/1607524302>

Meeting Minutes

Members Present electronically:

Ishan Williams, *Chair*
Tracey Lewis
Rachel Coney
Guy Mayer
Glynis Boyd Hughes

Staff:

George Worthington

Guests:

None

Welcome & Introductions

Ishan Williams called the meeting to order at 2:08 pm, welcomed members and explained the purpose of the meeting.

Ishan Williams, *Chair*

Adopt Agenda

Action Item: Adopt draft Agenda

Ms. Williams asked whether there were any changes to the agenda. Tracey Lewis made a motion to accept the agenda as presented, seconded by Glynis Boyd Hughes. The motion passed unanimously, and the agenda was adopted as presented.

Ishan Williams

Review and Adopt Minutes for August 5, 2024 Meeting

There were no changes to the minutes, and they were adopted as presented.

Ishan Williams

Public Comment

No public comment was received.

Ishan Williams

George Worthington

Discussion

George Worthington announced the hiring of the new dementia services specialist and shared that one of this person's roles will be supporting the workgroups by staffing them, recording and sending out the minutes.

Mr. Worthington updated the group on the Dementia Care Coordination roundtable and on the State Alzheimer's Research Support (StARS) Center grant opportunity and research project. Highlights of this topic were:

- 45 people attended the most recent Care Coordination roundtable call on October 28.
- StARS is a National Institute of Health (NIH) grant for a state dementia care research center.
- Virginia and Maryland are the two spotlight states for the first year. An initial meeting is scheduled for mid to late November.
- Virginia will receive \$200,000 for one year to study dementia care coordination.
- StARS will provide technical advice along with the funds.
- DARS Goal: Use the grant and research to make a financial case for the benefits of dementia care coordination in terms of reducing long-term care costs to the state through Medicaid. Mr. Worthington asked for additional ideas for ways to use this funding.
- Mr. Worthington displayed a one-page StARS information sheet and will share it with this group,
- Going forward there is the opportunity to apply for second grant for a pilot demonstration project in year two.
- Members of the team expressed the importance of including people with lived experience of Dementia as part in the StARS project; the project will help Virginia convene a Lived Experience Panel (LEP) that will be integral to the work.

Mr. Worthington shared his plan is to change the format of the Dementia Care Coordination Roundtable to 45 minutes to discuss general care coordination discussion and the final 15 minutes to discuss the Guiding an Improved Dementia Experience (GUIDE) program.

Mr. Worthington informed the group of the new documentary "Living Well with Dementia" as well as the three previous documentaries related to dementia on Virginia Public Media

(VPM). He will send out the date of the documentary release to group members.

Members addressed the plan to review the Virginia hospice regulations and Assisted Living Facility (ALF) regulations. Regarding hospice regulations, it was noted that the legislature is reviewing regulations for technical changes but are not opening the regulations for a full review. When there is a change or update, Ms. Lewis will update the group. It was then decided that it is not worth the group pivoting to review the hospice regulations in full at this time.

The group discussed the need to review the ALF regulations to have a statement ready when public comments open up. Mr. Worthington explained the policy is for this work group to draft suggestions for public comment, then the full commission would approve these suggestions and submit them when the legislature opens the public comment period. This subject will be revisited in the February work group meeting. Mr. Worthington suggested that this group may want to focus their efforts on the regulations regarding training hours.

Ms. Lewis informed the group that there is a lot of regulatory action and opening of regulations this year due to an effort to reduce and condense regulations.

The group discussed the *Dementia Roadmap* revision. Mr. Worthington informed the group that the Building Our Largest Dementia (BOLD) Infrastructure team is discussing a revision, and he expressed that this group should take part in that revision. Mr. Worthington suggested the group particularly consider the *Caring for the Caregiver* section and the resource list in the back.

The group discussed a short pop-up survey that will be included on the new upcoming Dementia Capable website. This survey will also be sent out to people who have received a roadmap via mail. The final draft will be 3-5 questions. Suggestions of questions are as follows:

- Did you utilize any of the resources in the back?
- What stage of dementia when they came to the map?
- What section did you look at first?
- What was helpful in each section?
- Was there something you were looking for that you could not find?

- Who is answering questions: caregiver, organizational support person, person with dementia?
- One open ended question.

Mr. Worthington will draw up a draft of those questions and will send out to the group.

Focus groups for the *Roadmap* revision were briefly discussed. The group discussed the need for a focus group to help create a dementia map for the Spanish speaking community. Group members highlighted the need to hire a person from the Spanish speaking community or from one of the organizations that works closely with that community. Mr. Worthington asked group to suggest anyone they may know of.

Adding members to the group was briefly discussed. Ms. Coney suggested Mr. Worthington invite Shanteny Jackson to the group and connect with VACHWA. Mr. Worthington asked the group for additional suggestions of people who may want to join this group.

Mr. Worthington introduced Washington state's *Palliative Care Road Map*. The group acknowledged the complexities and questions around dementia, palliative care, and hospice care. They agreed on the importance of palliative care in the dementia journey and decided on folding in aspects of a palliative care roadmap into the *Virginia Dementia Road Map*. The idea would be to add a couple pages and a link that refers readers to a larger document that perhaps another organization in the state creates. The consensus was that this would be a project this group would like to take on. Mr. Worthington requested the members review Washington's *Road Map* in preparation for the February meeting.

Ms. Lewis mentioned other work being done in the Palliative Care space and will present the *Road Map* to the Hospice and Palliative Care council to ask their thoughts from a provider standpoint; she will share their feedback with this group. Mr. Worthington is sending the link to Ms. Lewis as well as sharing it with the rest of this group.

Lastly, the group discussed the plan for dementia care specialists/ care navigators. Mr. Worthington stated that the group is asking for funding from the legislature for a pilot of eight care specialists next year to be housed in Area Agencies on Aging (AAAs). The main function as he sees it is to help families with the "where to

start” question, connect families with resources and follow up a week or two later to see if there are additional identified needs.

Mr. Worthington explained that Virginia’s program would be based to some degree on the Wisconsin plan. He introduced Wisconsin’s three pillars of the program and explained how each pillar applied to this program’s efforts:

- Training all AAA staff all to be dementia capable and evaluating pre and post knowledge. (see Pillar 1)
- Community education and training, excluding long term care communities (or at least not to meet their license care requirements as that would take up much of our capacity). There would be less emphasis in beginning on this aspect it could be a small part of the specialist’s role and possible added to their role later. (see Pillar 2)
- Care Coordination Navigation would be the heart of the specialist’s role as explained above. Mr. Worthington emphasized the specialist short term relationship would be between 3-4 week, less than 6 months. (see Pillar 3)

Mrs. Williams expressed a question and concern: capacity will be an issue, asking how to scale and frame this program and training plan and equip people in these roles with very defined skill sets. Mr. Worthington answered it may be that we limit their community navigation piece and focus on the known need—the navigation piece that demonstrates the effectiveness and the value of the care navigators in the family context. This will be key to securing funding. That community training could be a vision for the future. He expressed the importance of navigation piece and the dementia capability of AAA employees emphasizing that the specialist would be the subject matter expert.

Next actions for February meeting:

Mr. Worthington will draft the questions for the short survey for the roadmap and send them to the group along with the minutes and the links to the *Virginia Dementia Road Map* and the Washington state *Palliative Care Road Map*. He will send the link to the ALF regulations. He will also draft standards for the dementia care specialist by the next meeting for review.

Ms. Williams thanked everyone for their contribution to the discussion

New Business:

No new business was discussed

Ishan Williams

Meeting Adjournment:

Ms. Williams adjourned the meeting at 3:30 pm.

Ishan Williams