Alzheimer's Disease & Related Disorders Commission
Fourth Quarter Meeting
June 16, 2015
Alzheimer's Association Richmond Chapter
4600 Cox Road
Glen Allen, VA 23060

Members Present
Lynne Seward, Chair, Laura Adkins, Vivian Bagby, Sharon Davis, Chris Desimone, Julia Dillon (phone), Janet Honeycutt , Valerie Hopson-Bell, Thomas Hudson, Lory Phillippo, Patricia Slattum, Courtney Tierney, Kevin Walsh
Members Absent
Carol Manning, George Vradenburg
Guests
Sherry Peterson, Alzheimer's Association
Carter Harrison, Alzheimer's Association
Patty Goodall, DARS
Donna Cantrell, DARS

Welcome
Chair Seward opened the meeting at 11:00 and welcomed members and guests. Ms. Seward asked members to introduce themselves and provide a brief description of their connection, if any, to Alzheimer's Disease.

Review and approval of March Meeting Minutes
Chair Seward asked if members had reviewed the March meeting minutes that were emailed to them and if there were any corrections or edits needed. Courtney Tierney made a motion to approve the minutes and Kevin Walsh seconded the motion. Members voted unanimously to approve the minutes.

Deputy Commissioner's Report
Deputy Commissioner Robert Brink welcomed members and thanked them for their service on the board. He commented on a recent trip he took to the Copper Ridge assisted living facility (ALF) with Ms. Davis and Ms. Arbogast. He was very impressed by the services for residents and families there and queried if a comparable facility existed in Virginia. He also discussed his recent visits to some of the Area Agencies on Aging (AAAs). Last fall and winter he visited many of the AAAs and he will have visited all 25 within his first year with Virginia Division for the Aging (VDA). The AAA directors have been contacted and were asked about an itinerary for the visit, which may include local legislators. On June 15, Deputy Commissioner Brink was visiting the Eastern Shore Area Agency on Aging, Community Action Agency. On June 18, he will visit the Lake Country AAA in South Hill. On June 19, he will travel to Roanoke to the Local Office on Aging (LOA) for their *Let's do Lunch* program. The annual fundraiser provides lunches prepared by LOA staff. Visitors can purchase a lunch by attending the eat-in portion of the program or they can use the drive-thru service in LOA's parking lot. The following week he will visit the Southern AAA in Martinsville and will meet with the executive director and some staff, will attend the first meeting of the Transportation Information Network – an initiative of

the agency's Mobility Management Program. After the meeting, Deputy Commissioner Brink and Executive Director Teresa Fontaine will travel to the Franklin County Department of Aging Services Essig Center and will tour the center. July is a busy month in the aging world. July marks the 50th anniversary of the Older Americans Act, as well as Medicare and Medicaid. The White House Conference on Aging takes place on July 13 and will be live streamed. Four areas of discussion are healthy aging, long-term services and supports, elder justice and retirement security. Deputy Brink and Dr. Watson of Senior Connections, The Capital Area Agency on Aging will appear on the local NBC network show Sunday Today to talk about the OAA anniversary, the White House Conference on Aging, and aging services. On July 14, Deputy Commissioner Brink and Dr. Watson will have another television appearance on the local CBS station. Next May 2016, Virginia will hold a Governor's Conference on Aging. The last Governor's conference was held in 2004. Deputy Commissioner Brink announced that the conference will be held in Glen Allen at the Hilton in Short Pump.

Dementia Services Coordinator Report (Handout)

Ms. Arbogast discussed her visit with Deputy Commissioner Brink and Ms. Davis to Copper Ridge in Maryland. Ms. Davis' husband is a resident there. The Vice President of Dementia Services and nursing staff met with them and talked about the facility. They operate an outpatient memory clinic. Other items Ms. Arbogast discussed:

- **Outreach and Education**
  Presentation to DARS staff at "Lunch & Learn" series April 3, 2015
  Presentation to the Southern Gerontological Society on dementia state plans
  Assisted with the VA Center on Aging presentation on special care units April 17, 2015
  Presentation to Statewide Annual Training of Public Guardians and Conservators
  Presentation and to the Community Integration Advisory Commission
- **Data**
  Hosted a meeting on March 11, 2015 for VCOA, DSS and Alzheimer's Association staff regarding assisted living facility data
  Continued research and collection of available data sets for researchers for AlzPossible
  Ongoing review and compiling of American Community Survey (ACS) data on low income older adults with cognitive difficulties and disabilities
- **Collaboration and Partnerships**
  Ongoing support and facilitation for the Alzheimer's Commission work groups
  Participation in the Lindsay Institute for Innovations in Caregiving Advisory Council and the first "Caring for the Caregiver Hack" event March 21-22, an intergenerational event. Plans are underway for a caregiver hack for next year.
  Working with the Alzheimer's Association to support a potential DMAS Civil Monetary Penalty (CMP) project
  Participation in the GMHP and its Antipsychotic Medication Initiative Work Group - possible 2015 ARDRAF project proposal
  Ongoing communication with CNI Trust Fund Board and DARS Brain Injury division
  Collaborations with Alzheimer's Association and Department of Criminal Justice Services on Alzheimer's training for first responders
- **Grant Writing and Administration**
  VCPEA grant is completed

ADSSP grant awarded and in-progress
ADI-SSS grant: proposal in development (due to ACL July 6, 2015)

- **Tracking Policy**
  Dementia State Plan Update in progress-Public Listening Sessions have been held in Big Stone Gap, VA, Roanoke, VA, Virginia Beach, VA and Fairfax VA a session in Richmond today with the Alzheimer's Commission.
  The Dementia State Plan committee will meet in July. The commission will approve the final plan in August.

Ms. Arbogast asked for the board to review the support letter for the ADI-SSS grant . Patricia Slattum made a motion to accept the letter of support for the ADI-SSS grant. Courtney Tierney seconded the motion. Members voted unanimously to approve and send the letter of support to DHHS.

Dementia State Plan (DSP) Listening Sessions

Charlotte Arbogast, Julia Dillon, Chris Desimone, Kevin Walsh, Lynne Seward

Ms. Dillon discussed the Mountain Empire Older Citizens (MEOC) Listening Session that was held on April 8th. She was very pleased that the local newspaper published two front page articles on the session and highlighted things. Several caregivers attended and shared their thoughts and their ideas for the DSP. The event was attended by new caregivers, caregivers who had been caring for a family member for many years, and some who had lost a family member and wanted to share their experiences. Recurring themes were the lack of coordinated care and overmedication.

Mr. Desimone discussed the Roanoke Listening Session on April 15. Personal caregivers and professionals attended and there was a high quality question and answer period. There was great media coverage that included TV, a radio show, and the Roanoke Times published a half-page article the next day.

Mr. Walsh discussed the Virginia Beach session on April 22. It was held in a fairly new facility in Virginia Beach. There was smaller attendance than anticipated, but family caregivers and professionals were present. The Mayor of VA Beach opened the session and shared a story about a friend who has Alzheimer's Disease and a little about his situation. There was discussion about how persons with Alzheimer's Disease and dementia are treated in hospitals, particularly emergency rooms and how medical personnel need to be educated about Alzheimer's and dementia.

Chair Seward and Ms. Tierney attended the Fairfax session. Ms. Seward said there were almost 20 attendees. There was discussion about services for Veterans and services in general, specifically how complex the service system is currently. Ms. Tierney shared comments made by two attendees who had complained about the local AAA. She later contacted the AAA asked staff what had happened with these particular clients. What struck her was the difference between expectation and reality. Certain caregivers expect AAAs to actually make the contacts for the loved ones for them rather than simply having the AAA provide information and referral. Chair Seward mentioned Goal 4 of the state plan to provide coordinated care may help to address. She mentioned that Carter Harrison and Charlotte Arbogast attended each session and Ms. Arbogast kept them very prepared with notes and prompts for each session. Chair Seward thanked all of the members who worked on the Listening Sessions. Ms. Arbogast commented that the sessions each had their own 'feel' and brought forth local issues that reflected the differing needs for services.

Nominating Committee
Dr. Walsh, Chair of the Nominating Committee, presented the slate of officers for the commission recommended by the Nominating Committee. Courtney Tierney was nominated for Chair and Lory Phillippo as Vice Chair by Ms. Adkins and the motion was seconded by Ms. Hopson-Bell. The Commission voted unanimously to approve the slate of officers: Courtney Tierney as Chair and Lory Phillippo as Vice Chair.

Legislative Committee
Tommy Hudson, Esq., Chair
The Legislative Committee met today before the full meeting. Mr. Harrison will work to educate legislators this session on Goal 4 related to coordinated care through Dementia Care Managers in a system of memory clinics. This year's legislative initiative will be a technical amendment to the informed consent for human research statute pertaining to persons with cognitive impairment. Finally, the MEOC Listening Session brought to the fore an issue about persons obtaining UAIs in out of state hospitals in order to get discharged to waiver placements. The Commission will adopt the legislative platform at the next meeting in August.

Working Lunch:
Virginia's State Plan for Aging Services
2015 – 2019
Lynne Seward and Amy Marschean, Senior Policy Analyst
Chair Seward commented that she was extremely pleased to serve on the workgroup. She was impressed with the dedication and work of the Commonwealth Four-Year Plan Workgroup of approximately 38 stakeholder organizations. Ms. Marschean sent the three boards and all stakeholders a copy of the draft plan May 1 for and it is also still available on the VDA website. Ms. Marschean convened several meetings of the workgroup. Prior to the workgroup meetings, the Commonwealth Council on Aging held a statewide public hearing at WWRC in Fishersville on February 13 with 4 other DARS sites joining in—Abingdon, Roanoke, Norfolk and Fairfax. The State Plan collapses a state and federal planning process into one. The state statute requires a survey of all state agencies to report on the impact of aging services on their agency. The state agency surveys and the valuable input of the Workgroup, especially on Virginia's 5 services goals, were the foundation for the State Plan. The State Plan is due October 1 to the state, yet the federal State Plan is due July 1. There is a 30-page narrative and the 5 goals of the plan are:

1. Assess and facilitate statewide community readiness for an aging population, recognizing both the untapped resources and the unmet needs of this population;
2. Empower older adults and their families to make person-centered and informed decisions about personal health and well-being, long-term services and supports, and end-of-life care options;
3. Enable people to live in the community as appropriate through the availability of formal and informal high-quality long-term services and supports, including supports for families and caregivers;

4. Strengthen statewide systems that protect the rights and prevent the abuse, neglect, or exploitation of older adults; and
5. Enhance effective and responsive management of programs serving older adults to ensure the fiscal and programmatic accountability of those programs.

The State Plan includes the goals of the DSP. Ms. Marschean presented on the State Plan at the annual VA Coalition for the Prevention of Elder Abuse (VCPEA) conference.

Future Meeting Dates August 25, 2015 and December 1, 2015

Public Listening Session:
Chair Seward welcomed everyone and opened the Dementia State Plan Listening Session at 1:15 pm. She told members of the public that they would hear a presentation of the Dementia State Plan and that this is their plan and the commission wants to hear your comments.
Chair Seward asked commissioner's to introduce themselves. The first VA plan was implemented in 2011 and has since been updated.

Ms. Arbogast gave a brief description of the state plan and the work that is ongoing with the listening sessions, updating the plan for submission in October.
Chair Seward told members of the public that the commission wants to hear their experiences, needs, suggestions.

Christy Talbot: Ms. Talbot is here with her husband who was diagnosed with early-onset Alzheimer's at age 41. He is now 50. He was diagnosed at UVA and was basically told to go home and "get their affairs in order". A few years later, the Talbot's met someone through the Alzheimer's Association. They participated in the Trial Match program. She thinks it is a shame that doctors don't refer people to Trial Match at the moment of diagnosis. Doctors need to help people more. There needs to be more awareness of what the public can do, what can be done for the families. They have also participated in studies at Duke and Johns Hopkins. Her husband was the first person to receive the brain stimulation therapy from Johns Hopkins. They had to fight for what they got. She credits the Alzheimer's Association with helping them. The #1 thing Commission can do is give people hope and help them get into research.

John Talbot. Mr. Talbot spoke about his early-onset Alzheimer's. He was diagnosed at 41 and was in the middle of his career when the doctor basically told him to go home & get his affairs in order. Fortunately, he had disability insurance and did not have to rely solely on Social Security and Medicare. There needs to be education about Alzheimer's, disability insurance and available facilities. Mrs. Talbot has MS so who would take care of him if she has an attack? Medicare does not cover anything related to Alzheimer's. Better care needed when someone needs to go into a facility.

Kitty Kennedy. Ms. Kennedy thanked the Commission members for the work that they have done. Ms. Kennedy's husband was diagnosed with early-onset. He was laid off from his job in 2008. Mr. Kennedy is in a facility and in the late stages. There is a need for something for the people who have Alzheimer's now. He can no longer speak and she is his voice. She receives a call about once a day from the facility that he has done something. There is a need for more

training and more compassionate care.

Carol Cooper Driskill and Rosemary Cooper. Rosemary's daughter Carol Cooper Driskill spoke first. Mrs. Cooper's mother had "senility/wandering" so she was afraid of getting it. She purchased long-term care insurance and it has helped pay for her care in the assisted living facility. One concern in looking at facilities is what happens when her funds run out. The nicer facilities, such as the one she is in now, do not accept auxiliary grants. She insisted when they bought a house early on that it was on one level, with a small lot, near shopping foreseeing future needs. Mrs. Cooper is in a memory care unit – 1 bedroom unit. Rosemary Cooper commented that when you get to be "elderly" it's quite different from when you were younger and active. "Remembering is difficult and I'm not used to that."

Jean Greenburg. This is her first experience with the Alzheimer's Association. Just heard about this yesterday. Up until two months ago, she and her husband owned and ran a business. Her mother passed away about four years ago from Alzheimer's. Her father bought LTC policy which was smart, and moved them to VA to be closer to their adult children. Two years ago her husband was diagnosed with Alzheimer's so they closed their business and she is caring for him at home. They tried to get him into a trial but he has some health issues that disqualified him from the trial. There is a need to get more info to the public about what Alzheimer's is and what help is available, such as support groups. The whole family is involved.

Christine Buchanan. Ms. Buchanan is the only APS worker for her county. Her clients don't walk through the door to see her and usually don't want to see her. She is in a rural county and cannot find services for her clients. Hospital discharge planning is a huge concern and virtually non-existent. A hospital in Charlottesville has several times put patients in a taxi, driven them to the mall and called Social Services. Financial exploitation is another concern as it happens all the time. Reports to law enforcement do not do any good. Most of her clients do not have the family supports like the people who are here today.

James Johnson. Doctors talk to his wife and ask what she wants to do, what is wrong with her. She will just stare but they insist on asking her.

Ellie Galloway with the Northern Neck-Middle Peninsula Alzheimer's Association.
There needs to be more discussion around those who require Medicaid and those who have resources. Additionally, there are many people who fall somewhere in the middle. Her frustration is that she cannot help people without resources.

Kitty Kennedy – The message of all of this is that Alzheimer's a societal problem. It's the family, the doctors, the facilities.

Patty Goodall from DARS. DARS has a respite care program that will provide you with up to $400 voucher to pay a caregiver to come in and be with your loved one so you can get rest, run errands, go to appointments, or whatever else you need.

Meeting Adjournment
Chair Lynne Seward adjourned the meeting at 2:15 pm.