Virginia Alzheimer's Disease and Related Disorders Commission
Dementia State Plan
Public Listening Session

FAIRFAX

May 19, 2015 Alzheimer's Association
7:00 pm - 9:00 pm 3701 Pender Drive, Suite 400
Fairfax, VA 22030

MINUTES

Members Present:
Lynne Seward
Courtney Tierney, MSW

Members of the Public:
13 attendees

DARS Staff:
Charlotte Arbogast, Dementia Services Coordinator

Alzheimer's Association Staff:
Carter Harrison, Public Policy Director
Cindy Schelhorn
Sadaf Ahmad

Welcome Lynne Seward started the meeting at 7:10. She welcomed and thanked attendees.	Lynne Seward
Introductions of Panel Commission members and staff introduced themselves. Attendees also introduced themselves and their connections with dementias and/or caregiving.	All
Overview of the Public Listening Sessions Lynne Seward reviewed the purpose of the listening sessions in the process of developing Virginia's next Dementia State Plan.	Lynne Seward
Walk Through of the Dementia State Plan Charlotte Arbogast provided an overview of the new Dementia State Plan, including highlighting the actions up to the point of the public listening sessions and what will happen moving forward. He noted that the Dementia State Plan goals are driven by the work groups and that the document will not sit on a shelf into the future. The Commission is very focused on accomplishing all the goals, objectives and strategies, some of which have received substantial edits since 2011.	Carter Harrison
Role of Public Comments Lynne Seward encouraged attendees to share their experiences and challenges.	Lynne Seward
Public Comments Below are the comments received during the listening session:	All

1. Mary Ann Sterling: Ms. Sterling noted that, including her in-laws, three of her four parents have had dementia. She discussed the challenges she experienced trying to arrange for and provide high quality care for them at different stages of the disease. She specifically mentioned the difficulties they experience with transitions of care. She noted the process was taxing and time consuming, that there needed to be more consistency across the area agencies on aging, and that there was a need for more direct support for families. She also mentioned that the Medicaid spend down for her father was financially devastating for her mother and that from her experience, many individuals living in "independent living" needed far more help than those places were providing, often leading to a drain on EMS personnel to respond to emergencies. Yet many stay in independent living because it is more affordable than the higher levels of care.
2. Robert Massie: Mr. Massie, who owns a home care company, mentioned that about 40% of his clients have some type of dementia and that in the last two years, his company has helped 100-150 families supporting loved ones with dementia. He reported that there is a high level of

awareness but a lack of knowledge and understanding. In other words, there needs to be more training, and more specifically, training that is role specific. Further, there needs to be more opportunities for and a best practices protocol for how professionals can sit down with families and help them understand and access services and resources.

3. Sabrina Akins: Ms. Akins talked about her struggles to arrange for and provide care to her father, a veteran with dementia. She mentioned that she specifically needed help navigating the different systems and processes to get care and that both she and her mother are overwhelmed. She also noted that there is a lack of support for individuals with younger onset who are younger than the "typical" individual with Alzheimer's disease.
4. Evelyn Brown: Ms. Brown recounted a negative experience she had while caring for her husband who was experiencing behavioral and psychological symptoms of dementia, resulting in law enforcement involvement and a visit to the emergency room. She noted the need for more help for families who are in crisis.
5. Harriet Epstein: Ms. Epstein mentioned the need for supports for families that are low income or that have limited resources. She highlighted the need for training across all levels and the need for more auxiliary grant support and payments. She noted that support groups are great resources for caregivers, especially when caregivers are dealing with emotional issues and stress associated with caregiving. She also said that Veteran's Affairs system can be challenging to navigate. She also said that changes at the state level have limited the ability to provide long-term care coordination.
6. Sarah Harris: Ms. Harris said that her husband was diagnosed with younger-onset and that she struggled to find a long-term care facility that met his needs and provided quality care. She also mentioned a similar experience to Ms. Brown's, in which her husband was admitted to psychiatric unit for help with the symptoms of the disease. She noted the need for more options and alternatives.
7. Kate Owens: Ms. Owens highlighted the need for 1) more education; 2) more resources for the middle class; and 3) more geriatric psychiatrists in the northern Virginia region. She noted that trainings should include information on the types of dementias and medications.
8. Karen Proffitt: Ms. Proffitt said she could relate to the stories of others and is concerned about the high cost of care should she ever need services.
9. Jodi Lyons: Ms. Lyons suggested some resources for attendees.
10. Regla Garrett: Ms. Garrett highlighted the benefits of adult day centers, which offer socialization and consistency. She also noted the need for education about dementia and the unique needs of each person.
11. Lois Passman: Ms. Passman mentioned that long-term care insurance has helped her.
12. Herschel Kanter: Mr. Kanter mentioned that sometimes caregivers are the ones that need protection from their loved ones, some of who experience behavioral and psychological symptoms. He noted the need for trained professionals in emergency rooms and hospitals.

Wrap-Up Lynne Seward wrapped up the listening session by reminding attendees that this is their plan also and the comments, suggestions, experiences, etc. that were provided today can help us move closer to that goal. Mr. Harrison added that the listening sessions have been informative and unique. He specifically highlighted Virginia's work on developing the Goal 4 and how the Plan will be used to guide policy development and implementation.	Lynne Seward
Adjournment Lynne Seward adjourned the meeting at 8:30 pm.	Lynne Seward