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

BIG STONE GAP
April 8, 2015
2:00 pm - 4:00 pm
Mountain Empire Older Citizens
1501 Third Avenue East
Big Stone Gap, VA 24219

MINUTES

Members Present:
Lynne Seward
Julia Dillon

DARS Staff:
Charlotte Arbogast, Dementia Services Coordinator

Alzheimer's Association Staff:
Carter Harrison, Public Policy Director

Members of the Public:
46 attendees

Welcome Lynne Seward started the meeting at 2:05. She welcomed attendees and thanked them for attending.	Lynne Seward
Introductions of Panel Commission members and staff introduced themselves.	Lynne Seward
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. She provided an overview of the Commission's purpose and highlighted the quality of comments received at Big Stone Gap when the Commission hosted a listening session there in 2011 with the first Dementia State Plan.	Lynne Seward
Walk Through of the Dementia State Plan Carter Harrison 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 in particular.	Lynne Seward

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Public Comments Below are the comments received during the listening session:	All

1. Mitch Elliot: Mr. Elliot noted that the often overwhelming and stressful experience he had helping care for his mother. He said that he particularly struggled with sundowning and behavioral symptoms of the disease and the need for more information on how to help her.
2. Jackie Hanrahan: Ms. Hanrahan said that MEOC has served as a good resource. She said there is a need for dementia to inform planning in all areas, including the market for alternative economies to meet the need and sustain people in the community. She said that hospice quality is not the same as it used to be.
3. Mr. Ronnie Mutter: Mr. Mutter said that, while caring for his mother-in-law, she experienced fear and paranoia. She was heavily medicated and hearing impaired. He noted that PACE and MEOC have helped her tremendously to communicate and minimize distress.
4. Zelma Aichel: Ms. Aichel reported that MEOC and her husband's long-term care insurance policy have been key to receiving the services they need.
5. Loretta Stapleton: Ms. Stapleton recommended more tax incentives and relief for caregivers who have to quit or leave full-time work to care for loved ones. She was pleased to see there was a Dementia Services Coordinator. She also noted challenges getting an accurate diagnosis, the need for training professional caregivers, and the need for more variety in support groups.
6. Marchida Hall: Ms. Hall said that she care for her grandchildren and her father. Her comments focused on Goal 4 and the need for quality coordinated care, compassion and understanding. She misses the Alzheimer's seminars that used to take place in her area.
7. Judy Miller: Ms. Miller said the plan was excellent and it needs to support caregivers and improved care transitions. She noted that challenges they have faced with residents going to out-of-state hospitals and then struggling to get screened for in-state services. She recommended reciprocal agreements to solve this issue as well as expanding PACE and making Virginians aware of the CARE Act. She also recommended more person-centered language, such as "briefs" instead of "diapers".
8. Betty Stewart: Ms. Stewart said that she is very pleased to have PACE for her mother. She told attendees to love their loved ones with the disease, give back to them, and validate them.
9. Jennifer Beverly: Ms. Beverly said she has been a professional and family caregiver. She recommended increased access to adult day services and increased training for professional caregivers.
10. Tony Lawson: Mr. Lawson, who cares for his mother, recommended more training medical and health professionals to use validated screening tools, pay for periodic screenings, create a memory clinic in southwest Virginia, lower threshold for Medicaid eligibility, set up a sliding fee scale for higher income population to access PACE, include referrals to PACE and others services once an individual receives a diagnosis, and create more PACE programs. He also noted that adult day services should not be referred to as "day care".
11. Regina Sayers: Ms. Sayers serves as the director of the Appalachia Area Agency on Aging and she suggested educating caregivers. She also noted the need for more providers in her area, coordinated care including care transitions, and the need for timely referrals as well as collaborations between partners.

12. Betty Elkins: Ms. Elkins reported that her caregiving experience was overwhelming and she felt isolated. She noted that older people need more help and education. 13. Carol Schoolcraft: Ms. Schoolcraft recommended more oversight of assisted living facilities. She said that if she was not consistently visiting her mother, she would not get the care she needed. She also noted her struggles of having too much income to qualify for services. 14. Janice Triplett: Ms. Triplett said there is no coordinated effort that includes evaluations, placements and medications. All the providers and services are not coordinating and many middle income residents cannot qualify for public support but also cannot afford care on their own. 15. Layne Walker: Ms. Walker said that she struggles with the guilt of making decisions on behalf of her mother. She noted the need for more support for caregivers. 16. Matt Bloomer: Mr. Bloomer reported on his caregiving experience for his father with dementia. She noted that his father was overmedicated and did not receive high quality of care at certain facilities. He recommended more training and a separate section at hospitals and emergency rooms for individuals with dementia so they are not stressed and upset.	
Wrap-Up Lynne Seward wrapped up the listening session by reminding attendees that this is their plan also. There is a need for Virginia to be dementia-capable and the comments, suggestions, experiences, etc. that were provided today can help us move closer to that goal.	Lynne Seward
Adjournment Lynne Seward adjourned the meeting at 3:45 pm.	Lynne Seward