Long Term Care Coordinating Council
Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders
Full Group Meeting
December 13, 2012
Run Time: 8:41 A.M. to 10:07 A.M.
Casey Family Services
1268 Eddy Street
Providence, RI 02903

Present: Lt. Governor Elizabeth Roberts, Lindsay McAllister (Lt. Gov.'s office), Richard Besdine (Brown), Ana Tuya Fulton (Butler), Maureen Margret (LTCCC), Kathy McKeon (Diocese of Prov.), Gary Epstein-Lubow (Butler), Thomas Enright (AZ Assc.), Marcia Werber Feldman (Charter Care), Valerie Topp (Home Instead), Alicia Cuktin (URI), Terry Rahon (HHCRI), Laurie Johnson (EOHHS), Donna Desmarais (EOHHS), Patricia Thomas (RIC), Kathleen Kelly (RIALA), Patricia Chace (Evercare), Kathleen Heren (Alliance), Patrice Cooper (United Healthcare), Marie Stoeckel (Division of Elderly Affairs), Tsewing Gyurmeg (PACE of RI), Ed Stopa (RIH), Catherine Taylor (Director, DEA).

1. **Call to Order**
   - Lt. Governor Elizabeth Roberts called the meeting to order at 8:41 A.M.
   - The Lt. Governor provided updates from the listening sessions that have been taking place; information about these meetings has been very successfully disseminated through word of mouth. There have been many people affected directly and indirectly by Alzheimer's and dementia who have come to the listening sessions and talked about their experiences. We have received some excellent input through these sessions.
     - The Lt. Governor also discussed the issues of multicultural and multilingual care that were brought up in previous listening sessions.
     - Both the workforce and access sub-groups have acknowledged the challenges associated with care of dementia patients affected by other barriers to access, for example, a developmental disabilities or not being able to speak English and a lack of Spanish, Portuguese or other language speaking providers/facilities.

2. **Approval of Minutes from Oct 25, 2012**
   - Kathleen Kelly moved to approve the minutes from the last meeting; Kathy Heren seconded. The minutes were approved without amendment.

3. **Report Outs from the Sub-Groups**
    a. **Caregivers**
        i. Kathy McKeon reported the Caregivers sub-group will meet on December 13th at 1:00 P.M. at United Way RI. This will be a joint meeting with the Access sub-group that will focus on issues of access and relaying information about resources available in the state to family caregivers.
    b. **Workforce**
        i. Lindsay McAllister reported that the Workforce sub-group is trying to create an updated list of Alzheimer's and dementia resources across the state. Specifically, the sub-group is investigating ways in which professionals are able to serve people who are dealing with dementia as well as other underlying mental health issues. The sub-group members are looking at ways in which training might also help to better integrate mental health illnesses with dementia care.
        ii. Later, Maureen Maigret noted that the access sub-group also discussed this need for appropriate diagnosis and screening tools for patients who are affected by dementia in addition to other mental illnesses or developmental disabilities.
            1. *Copies of a draft survey passed around for comments*
            2. Please send edits and comments for the survey to Lindsay McAllister before the second week of January so as to ensure that the survey will be distributed before the mid-to-end of January.
        iii. Potential partners for distribution: police chiefs (senior advocates), post offices, professional organizations, senior centers, adult day, nursing homes, assisted livings, emergency rooms.
        iv. Lt. Governor Roberts also noted that there should be efforts to distribute the survey to professionals who deal with the emergency care of Alzheimer's and dementia patients (urgent care centers).
    c. **Access**
        i. Maureen Margret reported that the access sub-group invited Dr. Brian Ott to discuss, at their previous meeting, the clinical pathways to care (primary care vs. mental health specialty care). The sub-group also continued to discuss potential policy options that can help families test a person's driving ability.
        ii. The access sub-group intends to invite nurse case managers to the next meeting to discuss the cognitive screening process and pathways for patient-centered home care.
        iii. On December 13th, the access sub-group will have a joint meeting with the workforce sub-group; they intend to gather more information on multicultural and multilingual conversations, which will be condensed in a memo (to be circulated).
    d. **LTC**
        i. Kathleen Kelly reported that the LTC sub-group continues its discussion about the different challenges that elderly people face when changing care settings (not just limited to AZ patients). The sub-group discussed the need for specialized, professional training to ensure sensitivity to AZ-

related behaviors, moving away from the use of medicine as the primary mode of treatment.

ii. There was a question raised about the cost of creating this training and it will be looked into. Several people commented on the clumsy categories and implementations of Medicaid reimbursements because they are based on the delivery of specific tasks. Kathleen Kelly noted that much of AZ supervision is not about deliverables.

iii. The next LTC meeting will discuss best practices across varied settings for care.

iv. Catherine Taylor noted that the state has just applied for a global waiver - or "1115 Waiver". Additionally, there is a concerted effort to engage all nursing homes in the state to coordinate care that is less medicine-based. The Lt. Governor commented that there should also be an effort to disassociate mental and physical frailty.

e. Research

i. Ana Tuya Fulton discussed the research sub-group's ongoing focus on the intersection of research and care delivery. The sub-group members agree that everyone should be able to access the ongoing research and findings related to Alzheimer's and dementia.

ii. The sub-group will be recommending that the state create a web-based resource that serves the following purposes:

iii. Allow caregivers and family members to enroll patients in clinical trials

iv. Allow professionals to read about the latest findings in AZ and dementia.

v. Additionally, the research sub-group is discussing the possibility of creating annual conferences or education summits that bring together people in this field to share new techniques for care.

vi. The sub-group would also like to engage with insurance carriers to find ways to reduce the rate of readmission into hospitals.

f. Legal

i. Thomas Enright reported that the legal sub-group has been focusing on guardianship issues and will bring in probate judges to discuss guardianship enforcement and different forms of guardianship (e.g. volunteer or public) – including how we can amend our existing laws in RI to improve this legal tool.

ii. There has also been discussion on the potential possibility of involving Roger Williams law students in the field of elder law. The sub-group may recommend the creation of an elder law clinic to encourage more interest in this field of law. We are working to define our "ask" or charge to these students.

iii. The subgroup is also continuing its discussion on driving issues related to Alzheimer's and dementia. The sub-group will potentially invite DMV officials to talk about the challenges. The subgroup also has an upcoming meeting with representatives from the Attorney General's office that will focus on determining what elder abuse crimes the office is interested in prosecuting, what they're able to prosecute and what barriers our state

laws may contain that are posing an obstacle to prosecution of these crimes.

4. **Overview of the Center for Gerontology and Health Care Research at Brown University -** *Dr. Richard Besdine, MD, Director of the Division of Geriatrics and Palliative Medicine and the Center for Gerontology and Health Care Research at the Warren Alpert Medical School of Brown University.*
    a. Richard Besdine discussed the resources and initiatives that Brown University oversees. Brown University is in charge of the Alpert Medical School, the public health program, as well as Lifespan, Care New England, and Veterans' Administration.
        i. All of Alpert's clinical departments are based in the hospitals (lifespan is the primary hospital with clinical trials).
        ii. At the Veterans' Administration, there is both a program for dementia care as well as the CREATE program, which was created by the Brown University Geriatrics Department.
    b. Lt. Governor Roberts asked if there is currently a geriatrics program at the medical school. Dr. Besdine noted that the medical school was awarded a $2 million dollar grant to create a mandatory curriculum that ensured geriatric care was discussed every year.
    c. Someone also asked if there was any discussion of geriatrics at an undergraduate level. Dr. Besdine answered that there are very few undergraduate programs at Brown that engage in geriatrics, but students admitted to Brown's students can participate in aging interest groups.
    d. Dr. Besdine discussed the initiative taken up by the Veneto region of Italy to create an online support and education program for family caregivers of Alzheimer's patients.
    e. The curriculum has twelve modules and Dr. Besdine is working with the National Alzheimer's Association to recreate this initiative in the United States at no cost to users.
    f. Someone asked the question of connecting research with everyday medical practice. Dr. Besdine stated that there is usually a decade of lag between the publishing of a proven effective technique to its widespread adoption. He stated that since professionals usually need continuing education, the techniques can be taught there.
    g. The Lt. Governor asked if there is physician training for the long term care settings? Dr. Besdine responded that the medical school fellows have block and longitudinal care giving. There are also medical students and students in residency who have a mandatory and abundant geriatrics module experiences.
    h. Kathy Heren noted that she is concerned about the nurse practitioners and caregivers who deal with high volume, intense illness populations.

5. **Introduction to the Norman Prince Neurosciences Institute**
    a. This presentation is postponed until the next meeting (February 21st).

6. **Administrative Items**

a. Updates on ongoing Listening Sessions (see Lt. Gov.'s comments in the call to order)

7. **Public Comments**
   a. Kathleen Kelly suggested that if other sub-groups also have surveys that they want to distribute, there should be coordination of surveys with the Workforce survey so that they can reach the same audience.

8. The meeting was adjourned at 10:07 A.M.