



Long Term Care Coordinating Council
State Plan for Alzheimer's Disease and Related Disorders

Full Commission Meeting

10:00 – 11:30 a.m.

Wednesday, February 19, 2014

Child and Family (formerly Casey Family Services)

Main Conference Room

1268 Eddy Street

Providence, RI 02903

DRAFT MINUTES

Kathleen Heren	Kelly Lee	Linda A'Vant-Deishinni
Kathy McKeon	Valerie Topp	Donna McGowan
Maria Fatima Barros	Faith Sands	Darlene Kershaw
Julianne Voss	Doreen Putnam	Rick Gamache
Douglas Casey	Kathleen Kelly	Martha Machnik
Marcia Mascena	Laurie Johnson	Donna Leong
Sadie DeCourcy	Dir. Taylor	Lt. Governor Roberts

I. Call to order

Lt. Governor Roberts called the meeting to order.

II. Approval of minutes from October 28th, 2013 meeting

The minutes and presentation from the full workgroup meeting on October 28th were sent out through email and updated on the Secretary of State's website. The minutes were approved.

III. Alzheimer's and dementia related events

Rhode Island has emerged as a model for state-led initiatives. Dir. Taylor and Lt. Governor Roberts have both been invited to speak at national conferences to represent the implementation plan of Rhode Island.

There are related events coming up. *More information available upon request.*

- February 25th – RI GEC Dual Diagnosis; Down Syndrome and Alzheimer's Disease.
- March 25th – Rhode Island Nursing Home Quality Care Collaborative conference. Topic: Reducing the use of psychotropic medicine in nursing homes.
- March 27th – Alzheimer's Association Caregiver Journey Conference. Registration is limited—please RSVP ASAP.

[http://www.alz.org/ri/documents/conference_brochure_2014a_1.4_\(2\).pdf](http://www.alz.org/ri/documents/conference_brochure_2014a_1.4_(2).pdf)

- April 3rd and 4th – Powerful Tools Training Workshop for 10 two-person teams of class leaders to learn more about providing service to caregivers. Applicants must be over the age of 60. For more information, please call 421-7833 x206.
- April 4th – Alzheimer’s Association Reason to Hope Luncheon. The luncheon will provide an opportunity for table sponsors to invite guests to learn more about Alzheimer’s Disease and the Association. Lunch is free; donations are welcome. Call 401.421.0008 for more information.
- April 7th – RI GEC Workshop; Alzheimer’s Disease and related dementias; difficult conversations across the spectrum; diagnosis through the end of life.
http://www.uri.edu/outreach/rigec/program_calendar.html
- Lt. Governor Roberts asked how many physicians are present at the RI GEC workshops. Faith answered that there were not too many in attendance, but they are working on outreach efforts to recruit physicians to join.

Lt. Governor Roberts suggested that RI GEC and Alz. Assn, might want to talk with RIPR and other media get more publicity.

Maria Barros is a member of the Alzheimer’s Association of Portugal. She has some tools and resources written in Portuguese. Maria is looking to create a video in Portuguese and Creole and is looking for funding.

Rick Gamache also stated that if anyone is looking to create an Alzheimer’s conference, they should keep in mind G. Allen Power, MD. Author of *Dementia Beyond Drugs: Changing the Culture of Care*, Dr. Power is a well-informed speaker and one of the most prominent researchers on Alzheimer’s Disease.

IV. State plan update

Medicaid 1115 Waiver Update

A new population is now covered under the 1115 Medicaid Waiver. There is a new expenditure authority for adults aged 19-64 who have been diagnosed with Alzheimer’s Disease or related disorders as determined by a physician, who are at risk for LTC admission, who are in need of home and community care services, and whose income is at or below 250% of the FPL.

Online Resource Task Force

Sadie DeCourcy stated that the URI GARIN (George and Anne Ryan Institute for Neuroscience) is interested in partnering with the state of Rhode Island in order to create the website for the state plan. Lt. Governor Roberts and Dir. Catherine Taylor were able to meet with URI President Dooley and Provost DeHayes, who both offered their support in the endeavor.

One of the goals of the Online Resource Task Force is to determine the content that the state plan would deem integral to the website. The Task Force invited Joshua Shreve, a MPH candidate at Brown, to discuss his thesis, which analyzes the websites and apps available to caregivers. Joshua has agreed to continue working with the Alzheimer’s Full

Commission and the Task Force in order to outline some examples of what would be beneficial for the website to contain.

Safe Driving

Dir. Taylor stated that there is now cooperative work going on between the state plan and the Citizen's Commission on the Safety and Care of the Elderly.

Kathy Heren asked if anyone has spoken to the Senior Advocates in the police departments. In particular, the advocate in East Providence has been an asset for families who want to take away the keys from their loved ones who are having trouble driving. There was discussion that perhaps the commission should reach out to the advocates in order to see what can be done to ensure that these best practices can be promulgated, formally or informally.

Elder Transportation

Dir. Taylor stated that there is no transportation broker yet because there are still ongoing discussions with RIPTA. The Division of Elderly Affairs is meeting with RIdE and adult day centers as well.

Maria Barros stated that the problem of unreliable transportation trickles down to the home care agencies. Home care workers are not supposed to drive their clients around in their personal vehicles. Given the scheduling delays of RIPTA and RIdE, their clients are often unable to go to the stores.

Rick Gamache asked if UBER, the new taxi/transportation system, would be able to find a market in elder transportation. There was consensus among the members that it would be worthwhile to reach out to Uber to discuss this potential market.

Family Caregivers

Sadie stated that one of the problems that the Family Caregivers Task Force brought up was the inconsistency of primary care providers in the diagnostic tools they use. The Task Force is attempting to get in touch with some PCPs or RIMS in order to further understand the diagnostic tools being used.

Workforce Training

Sadie stated that there is a lot of focus in this Task Force around creating consistent definitions of Dementia Care Units in Rhode Island. Drew Powers from the Department of Health presented to the Task Force on the steps needed for changes in regulations and the updates on the current assisted living regulations.

The main goal of creating consistent definitions is so that consumers will know that there is a baseline quality of care that will be provided to the dementia care units.

Conference

The full commission seeks to hold a summit for the state's researchers and those giving and receiving care. They are in the planning process.

Legal

Dir. Taylor was appointed to the Probate Commission, which is creating a guardianship subcommittee in order to pursue some of the recommendations that the state plan. The Probate Commission is looking to introduce the Uniform Adult Guardianship & Protective Proceeding Jurisdiction Act.

Donna McGowan stated that the Alzheimer's Association will hold a rally for guardianship at the State House.

Cultural Competency

There is a meeting scheduled for April 8th. Lt. Governor Roberts asked for suggestions of people who would be good participants in the meeting.

V. Alzheimer's Association update

Donna McGowan, Executive Director at the Rhode Island Alzheimer's Association chapter presented on the new initiative in the national Alzheimer's Association. There will be a focus on diversity. Some of the main groups that will be focused on are: African Americans, Latinos, and LGTB populations. Women, while not a designated group in this new outreach initiative, will also be the focus of the Alzheimer's Association as they will have a resurgence in targeting females living with Alzheimer's.

VI. Public comment

Maria Barros stated that as the Full Commission moves forward with its work to encompass different cultures, we should be mindful of the different labels that are being used to describe the different groups because it might unintentionally offend people.

VII. Adjourn

The Alzheimer's Workgroup meeting was adjourned at 11:30. The next meeting for the full commission will be on May 21st, 2014. Task force meetings will be ongoing in between full commission meetings.

Questions? Please email Donna Leong at dleong@ltgov.state.ri.us