Long Term Care Coordinating Council
State Plan for Alzheimer's Disease and Related Disorders
Full Commission Meeting
Tuesday, December 2, 2014
10:30am – 12:00pm
Child and Family
1268 Eddy Street
Providence, RI 02903

DRAFT MINUTES

Quinn Flatley Candace Blake Faith Sands Kathy McKeon Kathy Heren Terry Rochon Julie Dick Alicia Curtin	Paula Parker Jim Nyberg Mike Walker Doreen Putnam Elaine Jones Marianne Raimondo Kim Sanchez Erin Casey	Rick Gamache Maria Barros Darlene Kershaw Donna McGowan Peter Snyder Marea Tumber Lt. Governor Roberts

I. Welcome

II. State Plan Update

Lt. Governor Roberts gave an overview of the background of the Alzheimer's State Plan (ASP). The process to develop the RI State Plan for Alzheimer's Disease and Related Disorders (ADRD) began in the spring of 2012 as a collaborative effort between the RI chapter of the Alzheimer's Association, DEA and the Lt. Governor's office. The work on the ASP officially began upon passage by the RI General Assembly of a Joint Resolution directing the LTCCC to serve as the organizational structure for a work group to lead the process. The ASP contains recommendations for specific steps for improvement in ADRD resources.

1) Caregiver Task Force: Kathy McKeon is the chairperson of this Task Force and gave an update to the group.

ASP recommendations include:

- **Resources and Networking**
  Kathy described the Caregiver Guide, which was funded by Money Follows the Person. 211/The POINT is also a great resource for caregivers, as is the Samaritan

call line. "211" is the 911 for social services; it started helping people who were looking for housing and food. The Point is general resource for elders and caregivers, and does wrap-around services for callers. A caregiver assessment is now part of a LTC assessment, which is a great way to identify needs.

- **Engagement**
  The alzconnect.org website is a great resource for peer support. It is a 24/7 chat room that is monitored by the AA and volunteers. The Lt. Governor recalled that there was a woman at one of the listening sessions who was caring for two relatives with Alzheimer's. She worked outside of the home, so the only time she could find support was at night. This type of resource is ideal for employed caregivers. November was Caregiver Awareness Month, and there was a kickoff event at State House on November 3. There were caregiver awards for an agency, an individual and a family. The Langevin award went to Lt. Governor Roberts for her leadership and involvement with the ASP.
- **Respite Care**
  The Diocese serves 120 families a year through the Carebreaks program, and there is a wait list already this year. It is a cost-share program, so they try to give it to people with the greatest financial need. There is a tremendous need for this program because many people cannot afford to take a break from caregiving. Rep. Langevin supported the Lifespan Respite Grant, and it was refunded for 3 years. The Diocese also works closely with the VA. The VA is a resource for some, but it is difficult to navigate.
- **Respite Care Training and Education**
  Kathy described the "Powerful Tools for Caregivers" training program. They now have 16 licensed class leaders. The program teaches all kinds of care for adults, not just for those with cognitive impairments. Kathy said that Donna McGowan will discuss "Know the 10 Signs" later in the meeting. It is a list of warning signs for ADRD. The AA makes the information available in the community and at workplaces. The Lt. Governor suggested that someone from the AA should approach the state Chamber of Commerce for distribution of the brochure.
- **Caregivers in the Workplace**
  Act.org is specific to employed caregivers. The Caregiver Alliance recognized employer/agency this year, and they want to want to encourage employers to support their employee caregivers. The Lifespan Respite Grant will help to support the Caregiver Alliance of RI. There is a great need for affordable and available respite care. Wait lists do not work; we want to prevent institutionalization and respite care supports that goal.

Rick Gamache asked if Kathy had any data from past wait lists. He wondered if there was a higher likelihood that people on the wait list end up in a facility because they cannot access respite care. There is such a high cost to the system when a person ends up in a nursing home. Respite costs approximately $1,200 per family, so respite is very cost effective. The Lt. Governor said that this is an example of what happens when we pay by category of service, and that perhaps this is an issue that the Caregiver Alliance can take on moving forward. Hopefully, the 3-year grant will help the Alliance become a stronger partner able to deal with these kinds of issues. Paula Parker mentioned that the Lifespan Respite Grant

includes having CCRI and URI students provide respite care as part of their training. Paula also said that she thought that NHP was going to include respite as part of its package of benefits under the ICI.

Safe Driving Brochure:

- Marea Tumber stated that the development of the Safe Driving brochure was an action item in the ASP. The recommendation was to engage RWU Elder Law Society to develop a handout about safe driving. The brochure was available at the Commission for the Care and Safety of the Elderly Resource Conference for Police and Fire Senior Advocates on October 29. There is a link to the brochure on the Lt. Governor's website. The Lt. Governor and Marea met with the Mike Lewis at DOT about partnering to distribute the pamphlet. Additional partnership possibilities include AAA, DMV, State Police and AARP. The goal is to have a printed version of the brochure that is widely distributed throughout the state

2) Professional Workforce: Rick Gamache is the chairperson of this Task Force and gave an update to the group.

Developing an ADRD-capable workforce is a critical building block for many other pieces of the overall State Plan. This Task Force is examining current statutes and regulations in RI and comparing them to other states to see where gaps might exist. The goal is to have providers and facilities to have standardized training and requirements in order to promote best practices. Now that the Charter is finalized, invitations went out for Workgroup and they met for first time on November 13.

The Workgroup divided up into 4 Subgroups that will examine:

1. Training in the care of individuals with ADRD for all levels of health care workers and administrators
    a. Facilities: assisted living, adult day centers, NH and "memory care centers"
    b. Community-based organizations: home care & hospice, first responders
    c. Also education about ADRD for MDs, RNs, CNAs and case managers while still in school and also for continuing education requirements
2. Consistent screening instruments by health care providers to provide accurate diagnoses and treatments that follow best practices
3. Activities specifically geared towards individuals with ADRD
4. Physical Design: Use JCAHO standards to develop guidelines for a program's physical environment, i.e. anti-wandering methods and the use of physical design to promote a therapeutic environment.

The Workgroup also identified the need to heighten awareness of sports injuries and their impact on cognitive impairments, with a focus on preventive measures. Rick thanked the Lt. Governor for her vision in creating the ASP.

3) Cultural Competency: Maria Barros is the chairperson of this Task Force and gave an update to the group.

Maria said that this group has had poor attendance recently, even though she has held the meetings at different times of the day. Cultural needs are similar but not identical across different groups. There is a lot of illiteracy and many dialects that complicate communication.

Many providers are not meeting CLAS standards, and are asking family members to translate. Family should be enlisted only as a last resort. The group developed a needs assessment survey, and so far, Maria has 120 completed surveys. The participants' age range was 60-70 years old. Some were over the phone, but most were done in person. Twenty of the surveys were from clients, and the rest were from caregivers. The identified gaps were similar to the issues raised in LTCCC and ICI-CAC meetings, primarily transportation and communication issues with health care providers. Additional needs include: more training and education for case managers, discharge planners, first responders and home health providers.

Maria said that the MOST mini-mental diagnostic tool is commonly used in RI, and it is not culturally sensitive. The test is copyrighted and cannot be altered. However, the group hopes to find a standardized tool that is sensitive, and also administered by someone who speaks the examinee's language. For example, in Cape Verde, if you go to school you learn Portugese. If you don't go to school you speak Creole. So, if you use a Portuguese interpreter for someone who speaks Creole, a lot gets lost. The group would like to develop a video library, and perhaps students in the area could help with the video production. Many caregivers cannot read and also have a language barrier, so videos in their native language can help explain the disease and how to care for loved ones

4) Research Conference: Peter Snyder is the chairperson of this Task Force and gave an update to the group.

Peter said that having a local research conference is an action item from the ASP. National meetings are very expensive to attend. A local conference would help with patient recruitment, access to research, and promoting best practices at local institutions.

The inaugural conference will be March 5 at the Crowne Plaza in Warwick. The group is partnering with the Alzheimer's Association and their very well attended Caregiver Journey Conference. This is a great partnership, because it brings researchers and caregivers together. The conference has $10,000 in funding: $5000 from Tom Ryan and $5000 from DEA. The plan is to hold the conference biannually.

The conference will include:

- AM Session: Alzheimer's Disease in RI (3 speakers)
- Juried poster board session and student awards
- PM Session: State-of-the-Art in diagnosis and treatment planning, ethical issues and advances in imaging
- Opening & Keynote Speaker is Sid O'Bryant. He is a leader in minimally invasive blood-based biomarker research.
- CMEs/CEUs for health professionals
- An evening wine and cheese reception

The AA may form a research committee and they could provide an ongoing structure for this. The program is due to the AA by December 15. Donna McGowan said that she is excited to see the conference coming together. She is a little concerned about capacity at the Crowne Plaza, particularly for lunch, because they already have 600 people signed up. She said that the application for nursing CEUs is 41 pages long, but they still may try to get it completed and approved. The band from Cranston West will be there in the morning before Sid O'Bryant speaks. The AA is the fiscal agent, and is taking care of the program publication. The Lt Governor said that the joint conference will be very valuable for local institutions. Peter thanked Nasser Zawia and URI for their support of the conference. He also acknowledged the Lt. Governor for her invaluable support to the Task Force.

III. **Alzheimer's Association Update** (*Donna McGowan, Executive Director, Alzheimer's Association of RI*)

Donna announced that there was a culinary competition at Rhodes on Pawtuxet on December 3, and they had sold 300 tickets in advance. There were people's choice awards for best entrée, appetizer and dessert. The cocktail reception was 5:30-6:30 PM and food demonstrations 6:30-9:00 PM.

IV. **Alzheimer's Disease: Current State-Of-The-Art in Early Diagnosis And Treatment** (*Peter Snyder, Sr. Vice President & Chief Research Officer, Lifespan*)

Peter said that there has been a lot of progress in the field for people at high risk for Alzheimer's disease. His lab has an assay that combines a drug challenge and a memory test, and the test has almost 100% accuracy. PET scans cost thousands of dollars and are invasive, so this could make huge difference. The problem is that there is no treatment that slows progression of the disease, so this presents an ethical issue. The pre-clinical diagnoses emerge before anything can be down to help slow the disease, so treatments need to be developed rapidly. There are dozens of therapeutics trials worldwide, so there is reason to be guardedly optimistic. It is important to think about the impact of early diagnosis on people's lives, including health insurance, work, and financial and family planning. There will be a massive epidemic over the next 20 years if we don't have a treatment that slows progression. Research is currently funded at 1992 levels, with 93% of grants not being funded. It is difficult to draw quality people into the field without funding. Peter said that we need more people like the Lt. Governor, who is expert in social and political issues, to fight for better funding.

The Lt. Governor said that an update from today's meeting will be given at next week's LTCCC meeting. Lt. Governor-elect McKee will be there. The work of this Commission takes significant staff support, and we all want the work to continue. We need to continue to look for partners. The Lt. Governor thanked everyone for their valuable work in creating a better world for those with this disease.

V. **Public Comment:** none

VI. Adjourn