



Long Term Care Coordinating Council

Minutes of the meeting held on Wednesday, January 10, 2018

Child and Family, Main Conference Room, 1268 Eddy St., Providence, RI 02905

Attendance:

Audra DiChiaro	Kelly Lee	Mykahla Gardiner
Bonnie Sekeres	Laurie Ellison	Nancy Silva
Corinne Russo	Laurie Mantz	Nicholas Oliver
Deb Bonin	Lori Light	Paula Bradley
Deb Burton	Maria Petrillo	Rachel Azzolina
Dianne Shaw	Mary Barry	Renee Denelman
Donna McGowan	Mary Lou Moran	Rick Gamache
Gail Patry	Maureen Maignet	Sandra Fournier
Jim Nyberg	Michelle Brophy	Tarah Provencal
Karen Statser	Michelle Szylin	Travis Hermance
Kathy McKeon	Mike Walker	

Welcome: Meeting called to order by Lt. Governor Dan McKee at 10:05am. Asked for introductions throughout the room.

Approval of Minutes of 12/13/17: Motion to approve with corrections by Maureen Maignet, second by Kelly Lee. All in favor

Update on Lifespan Respite: Caregiver Support/CareBreaks Program: Michelle Szylin, Assoc. Director, DEA & Kathy McKeon, Supervisor, Catholic Social Services: [See Handout](#)

Q: Current total cost per year for program? **A:** reimbursement average \$1200-\$1400, total program cost is double that. We need to grow capacity and fill the gaps where need is not being met.

Q: Are there numbers to the areas that you listed provider capacity issues? **A:** We have the numbers, but now people know we may not have a worker for the program, so they stop calling. Demand is probably more than what we're hearing and we should work to fill the need.

Q: Is there a way to track the data? **A:** I'm sure every entity could pull their data and put it together. Public not aware of Respite Services currently available.

Q: Capacity to communicate with non-English speaking persons? **A:** Offer Spanish, Portuguese and an agency serves Asian. There seems to be more of an acknowledgement aimed at advocacy for Caregivers.

Awarding of the Lifespan Respite Grant has allowed for a staff person to be situated at the United Way.

It was discussed that the grant funding should be utilized to build a website for caregivers.

The family chooses the type of services they need and we determine which agencies can assist them.

Some people call the Catholic Social Services directly, or they get the information from centers they visit.

The US Senate passed the RAISE ACT. As a result, national awareness is rising for Caregivers.

Subcommittees Review

Alzheimer's Update: The State Plan will be updated as required per statute. The ALZ Association has been awarded \$30,000 grant to hire a subcontractor to revamp the plan. Tufts Health Foundation awarded \$15,000 and The RI Foundation also awarded \$15,000 for the completion of the project. Funding has been received and the next step is to send out an RFP for services. The goal is for the plan to be updated and submitted to the General Assembly in 2019. Lt. Governor McKee is encouraging everyone on this council to be attentive and provide input. We want to ensure this report represents current trends and treatments as well as financial costs to the government and businesses. We will be scheduling a press conference at the State House. Craig Dwyer will send information to the group and all who can make it are requested to attend.

Aging in Community / Age Friendly RI: Three focus groups held in December in Westerly, Woonsocket, and High Ground International. Tufts Health Foundation awarded funding for two additional years. Working to fully engage local communities. A proposal for legislation concerning family caregivers has been drafted. Bill would amend 2013 act to report on findings and require caregiver support services under the Medicaid program. There is collaboration with the Senior Agenda Coalition. Legislation will be reintroduced concerning the Aging & Disability Program. Meeting tomorrow to discuss the goals for 2018. AARP introduced legislation for the *livable home tax credit act*. Previous legislation did not pass, however, \$250,00 was put into the state budget for home modification grant money. We want to continue the program funded with the 2017 Tufts Foundation grant to provide behavioral health services. Age Friendly RI – has paid for several weeks of the Patricia Raskin Show every Saturday at 3 pm on WPRO. That venue will be used to promote Age Friendly RI concepts.

LGBT Report: SAGE RI is in the process of reorganizing

Oral Health: next meeting Jan 11th 3-430 at the Alliance for Better Long-Term Care

New Behavioral Health Subcommittee: organizational meeting happened to see if there is a need. Next get together January 18th at the Alliance.

Nursing Home Transitions & Behavioral Health Needs: Meeting was well attended. Focus was on transition services. They have added monthly policy meetings.

Pending Legislative Discussion: Perry Sullivan Law – LTC Reform and Rebalancing – there is a section on reporting. Working on proposed legislation to specifically require an annual report to determine funds available and expenses.

Public Comment

December 2016 meeting there were about 25 people who reported their Medicaid applications were delayed up to a year. – We will ask Secretary Eric Beane to attend the February meeting to report on the 2018 budget and progress with UHIP.

Newport Housing Authority not replacing Social Worker after she retires. They lost a great deal of funding. HUDD has pressured apartment owners to renew their contracts for 20 years.

“Money Follows the Person Program” scheduled to end in 2018 in RI. Federal legislation introduced, unsure if RI delegation signed on.

LTC Healthcare Insurance rate hikes. Some states have caps on increases. Researching now. RI DBR handling increases on a case by case basis.

Dementia Training for Life – training on January 26th to become a certified dementia caregiver.

Noticed on the December minutes that UHIP LTC applications being done manually. This is still the case for now.

Save the Date – Wed, April 11th 2:30 -4:00 – RI Home & Hospice

Next Meeting: February 14th at 10 am at Child & Family Services

Adjournment: Adjourned by Maureen Maignet and seconded by Donna McGowan at 11:24 am. All in favor.

Caregiver Update From Catholic Social Services of RI

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CareBreaks (Continued)

- ▶ CareBreaks relies on the RI network of licensed providers
- ▶ As of this date there is no wait list for service *due to funding*
- ▶ There are pockets of the state where service providers are just not available
 - ▶ Northwest RI
 - ▶ Aquidneck Island
 - ▶ Parts of Washington County

PTC (Continued)

- ▶ Catholic Social Services trained the first group of RI class leaders in 2014.
- ▶ Since 2014 forty four class leaders have been trained in RI.
- ▶ There are three Master Trainers in RI, capable of training additional class leaders.
- ▶ To date, 323 caregivers have participated in a PTC program.
- ▶ Evaluations from the programs have been most positive.
- ▶ The first RI class taught in Spanish was held for 9 family caregivers at the Elmwood Adult Day Center in 2017.

Lifespan Respite At Catholic Social Services

- ▶ Allows provision of subsidized respite care for caregivers caring for family members *of any age*.
- ▶ Provides funding for "First Sunday" programs and other group respite activities.
- ▶ Collaborates with four schools of nursing that offer credit for clinical service to students who provide respite care.

CareBreaks

- ▶ Options counseling and referral for family caregivers
- ▶ Subsidized respite care services
 - ▶ Cost share based on sliding scale of income (care recipient)
 - ▶ Annual service grant per family (\$ 3,000 to \$500) based on income of care recipient
 - ▶ Type of respite care is selected by the family
 - ▶ In home care
 - ▶ Adult day Center
 - ▶ Overnight in licensed facility
 - ▶ Other

Powerful Tools for Caregivers (PTC)

- ▶ Program began in the US in 1998
- ▶ Is now offered throughout the US as well as Canada and Korea
- ▶ Based on the Self Management Program developed by Dr. Kate Lorig and colleagues at Sanford University
- ▶ Is available in English, Spanish and Korean
- ▶ Offers a six part program for family caregivers designed to develop and reinforce the skills and behaviors needed to efficiently cope with the stress of long term caregiving

Lifespan Respite

- ▶ The Lifespan Respite Care Program was authorized by Congress in 2006 Title XXX of the Public Health Service Act (42 U.S.C 201).
- ▶ Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults, of all ages, with special needs.
- ▶ The program works to improve the delivery, quality and availability of respite services.
- ▶ Since 2009, Congress has appropriated approximately \$2.5 million per year to implement Lifespan Respite Programs.
 - ▶ As of 2016, competitive grants of up to \$200,000 each were awarded to eligible agencies in 35 states and the District of Columbia.

The year ahead

- ▶ Catholic Social Services of RI will expand "First Sunday" to 4 new sites
- ▶ Class leaders for Powerful Tools will be trained at Neighborhood Health Plan of RI
- ▶ The number of nursing schools accepting referrals for respite care will grow to 4.
- ▶ Lifespan respite funds have allowed the first staff person to be hired for the Family Caregiver Alliance of RI. Watch for the rebirth of this organization!

Good News for Caregivers

- ▶ An update to The Alzheimer's State Plan has been funded.
- ▶ Advocacy for caregivers continues in venues such as:
 - ▶ Lt. Governor's Alzheimer's Executive Board
 - ▶ Age Friendly RI
 - ▶ Money Follows the Person
 - ▶ EOHS Advisory Committee
 - ▶ DEA Home and Community Care Advisory Committee
 - ▶ Senior Agenda
 - ▶ AARP

For further information Catholic Social Services of RI

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Respectfully Submitted by Tabatha Dube, Office of Lieutenant Governor Dan McKee