



Long Term Care Coordinating Council
State Plan for Alzheimer's and Related Disorders Working Group
Caregivers Subgroup
11:00 – 12:00 am
Tuesday, April 16, 2013
Providence Diocese
One Cathedral Square
Providence, RI 02903

1. Review of Subgroup Work From Past Several Months
 - a. Adult Day care
 - b. Respite care
 - c. Employee support services
 - i. Adult Day programs at the work site
 - d. Informal community supports
 - i. Support groups and counseling
 - ii. Intergenerational assisted living
 - e. Remote caregiving (out-of-state caregivers)
 - f. Crisis prevention and management
 - g. End of Life resources
 - i. “burdensome transitions” at end of life
 - h. Cultural differences around attitudes towards dementia end of life care
2. Discussion of Recommendations – Reactions to Skeleton Outline (*provided below*)
3. Subgroup Planning
 - a. April – May: Following this meeting, the drafting process will begin, and the input provided today will be incorporated into a draft that will be presented on June 6th in a public meeting. Please keep an eye out for emails with a draft in the coming weeks as we will be soliciting your input prior to June 6th.
 - b. Other Needs or Concerns?
 - i. No other comments were provided.

4. Public Comment

- a. There was no public comment.

5. Adjourn

a. **Adult Day care**

- i. Adult Day can assist throughout the spectrum of the disease
- ii. Broad based service: care management and care planning, most centers do education programs and support groups
- iii. *Refer to LTC Subgroup's identification of need for adequate funding, support of the network*

b. **Young Onset:** support needs can be addressed and online platforms can enable this, but this cannot solve the care need

- i. LTC Insurance – policy can offset
 1. Day Care
 2. Assisted Living
 3. Nursing Home

c. **Respite care**

- i. The Subgroup recommends a “streamlined” or “fast-track” eligibility (i.e., kidney dialysis) for Medicaid, particularly for young onset.
 1. How does this change given new eligibility and enrollment process under ACA?
 2. Fast-track: very limited benefit coverage
 3. 1115 Waiver
- ii. Need to increase awareness of the CareBreaks program and push the message that you can be eligible no matter the age of the person you're caring for.
 1. Many think of respite as a secondary concern – need to change this mentality.
 2. Many caregivers don't self-identify as such – need to change this mentality
 - a. Caregivers hesitant to consider asking for formal help when dealing with a family member
- iii. Needs of the Alzheimer's and other related disorders population can be simple, but respite care worker needs to be trained in how to best care for this population
 1. Greater training opportunities are needed to prepare the workforce for respite care provision
 - a. Cost is a barrier
 - b. Online?
 - c. Need to bring “to the floor” and encourage dialogue

- d. High School programs with training programs for those who want to go into ltc/health field – great model
 - e. Alzheimer’s Association & GEC partnership
 - i. Capped at 24 attendees
 - ii. Capacity at URI-GEC to increase access
 - 2. Training needs to be focused on behavior management – avoid trigger/redirect and support
 - 3. Build in a first time meeting between respite provider, facilitator and family members
 - a. With respite, certain level of one-on-one training needed: preferences, triggers, cultural differences, etc.
 - iv. *Training modules for extended family
 - v. **Care team coordination: wrap around family and primary caregivers/respite workers. Would provide more options, more dynamic options.
 - vi. What is covered under Medicaid for respite services?
 - 1. Under existing 1115, adults do not have covered respite
 - 2. Was written into the waiver, but never funded: certain number of hours/year as support to the caregiver
 - 3. Shared Living: waiver available to enroll the family member as the caregiver. Back-up plan included. Annual budget for respite.
 - a. AD is eligible diagnosis
 - 4. New 1115 Application includes respite benefit request...?
 - 5. Supported by discharge policies at hospitals... caregiver in place at home?
 - vii. The Alzheimer’s Association offers the Live & Learn program; improve awareness and use of this program among Caregivers.
 - 1. This program is largely geared towards those in the early stages; any capacity to expand to mid and later stages and would that even make sense?
 - 2. How can we better support caregivers with loved ones in the mid and late stages? What model makes sense?
 - viii. Al’s Moving Minds model is providing respite activities for the person living with the disease to attend – great model and the subgroup recommends this type of approach; it is “person centered.”
 - ix. Emergency/short-term respite services with streamlined application process still needed.
- d. Employee support services
 - i. Adult Day programs at the work site?
 - 1. Examples?

- ii. Some large corporations provide EAPs. This is a service the Subgroup strongly supports and recommends these types of programs as well as more informal supports (e.g., brown bag lunches) be encouraged.
 - 1. RIEAS
 - 2. State employees - providence
 - iii. Alzheimer's Association offers 20 "Lunch and Learns" which are meeting a need – subgroup recommends this model
- e. Informal community supports
 - i. Support groups and options counseling are an ongoing need
 - ii. Intergenerational assisted living: *find examples and highlight in Plan*
 - iii. The Alzheimer's Association, Adult Day programs, etc. offers a hotline, counseling, caregiver education – is there a need to augment this?
 - iv. There is a need for one central place for caregiver resources and information exchange:
 - 1. Online portal/website – *research subgroup*
 - a. Caring Bridge-like service: post needs, share updates
 - b. Resource for all education and counseling programs offered by Alz. Assoc., Adult Day, nursing homes, assisted living, home health, etc.
 - 2. Caregiver Newsletter: caregiver.com, aging well – is there a need to augment these in any way?
 - a. Online portal helps meet this need
- f. Remote caregiving (out-of-state caregivers)
 - i. Connect this with law enforcement meeting
 - ii. Elder Care Locator
- g. Crisis prevention and management
 - i. Case management/care coordination programs need to expand
 - 1. E.g., BCBSRI provides nurse care coordinators, as part of their benefits, to help families and individuals navigate the system of care. This is provided at no additional cost.
 - 2. The POINT plays some role in connecting residents with case management services
 - a. Options counseling, done through The POINT is very helpful, however the Subgroup has two recommendations:
 - i. Advance planning is the best practice – need to move up timeline and encourage the public to reach out earlier
 - 1. One challenge here is transportation for the senior to go visit a residential facility
 - ii. The counseling is geared towards those looking for public options. Private pay options counseling needs to be improved.

1. Private pay counseling needs to be improved at The POINT, regional POINTS and DEA's case managers
 2. Go beyond what they're not eligible for
 3. Future planning: legal, needs, support system
 - iii. LTC Medical Home/care team/health home
 1. Duals/MME's – integration will have impact
 - ii. The Care Reassurance Program, run through Dr. Tremont's program at RIH, used to provide telephone-based coaching program for caregivers. This was valuable, but has since ended (was NIH funded). Need a similar program for caregivers to "touch base" with peer mentor or other experts for navigation assistance.
- h. End of Life resources
 - i. "Burdensome transitions" at end of life
 - ii. How can we improve awareness of the Brain Bank program?
 1. Families need more information, earlier on, to improve changes that it will be less emotionally fraught
 - iii. Subgroup recommends steps to improve awareness of palliative care and hospice options both among physicians and among families
 1. Need fundamental change here: perspectives, communication, criteria
- i. Cultural differences around attitudes towards dementia end of life care
 - i. Need more dynamic approach: don't rely solely on written materials: radio/video, online videos on caregivers
 - ii. Alz. Assoc – library, anything online?
 - iii. *Educational material or programming is needed to help families feel more comfortable dealing with medical care providers:
 1. What questions to ask about the disease – families want a checklist; i.e., how do I know what to ask when I don't know what to expect?
 2. How to seek a second opinion (without offending physician)
 3. The Alzheimer's Association offers counseling, a hotline and caregiver education; do these services cover this base?
 - a. Home visits/multi-lingual – social worker for visits and to staff hotline
 - b. Caregiver education is more focused on knowing the warning signs – any flexibility here to incorporate information on the stages and what to expect?
- j. ** Families need more information, more readily accessible that will help demystify the clinical trials process
 - i. For example, clinical trial participation typically makes the participant eligible for social work support, medical check-ins, etc. (similar to hospice care)

- ii. The Alzheimer's Association offers clinical trial matching. This may be a good starting point.