

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Alzheimer's Sub-Group Meeting  
Elmhurst Extended Care  
50 Maude Street  
Providence, RI 02908  
Wednesday, October 10, 2012

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**Attendees:** Sheila DiVincenzo (Access Point RI), Barbara Waterman (Alliance for Better Long Term Care), Marcia Werber Feldman (Charter Care Home Health), Jim Nyberg (Leading Age RI), Cathy Salerno (RIte Living grant), Kathleen Kelly (RIALA), Patricia Chace (Evercare RI), Jennifer Fiorini (Evercare RI), Deborah Castellano (DHS – LTC), Susan Adler (To Life Center Adult Day), Rick Gamache (*chair*, Administrator and VP of CharterCARE at Roger Williams Medical Center), Laura Rhue (Elmhurst Extended Care), Cathy Cranston (RIPHC), Sarah Collins (Evercare), Amanda Clarke (Advocacy Solutions), Lindsay McAllister (Lt. Governor Robert's office).

1. Rick Gamache, who will serve as chair for the sub-committee, began the meeting with a children's book, "Zoom." He asked the group why they thought he might kick off the group's work with this tool. Answers ranged from appreciating the perspective of a person with memory loss, understanding the ability and loss of ability to tell a story as a person loses cognitive function, and approaching this project from a global scale.
2. Rick also suggested several "ground rules" for the sub-committee and asked the attendees for their feedback or suggestions. The Ground Rules are as follows:
  - Leaving business "hats" at the door.
  - Approaching each conversation and issue from the perspective of someone putting their loved one in our hands to receive the treatment we're planning for.
  - Think big; start small. RI is the microcosm for this work – we have the ability to create and test a model that could have ramifications nationwide.
  - Encourage freethinking.
  - Be respectful. Remember that just because something has not worked in the past does not preclude it from working in the future.
3. The Group then went through each of the topics that were assigned to the Residential Care sub-group and opened them up for discussion:
  - a. Quality improvement across the spectrum of care:
    - i. The group expressed an interest in looking at other states' measures of quality, best practices to improve quality.
    - ii. We need a way to measure quality that is standardized across settings.

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- iii. The chair mentioned that we should remain cognizant of the fact that Alzheimer's medications are not extremely effective. Our conversation should focus on the well being of the person and not solely focus on a cure or treatment.
- iv. Jim Nyberg suggested that transitions be included in our measurement of quality because dementia truly adds a level of complexity to transitions to an assisted living facility from a nursing home or vice versa. Complications during transitions can cause major problems or setbacks.
- v. The group also agreed that family communications around *when* to make those transitions is a part of wellbeing and should be included. Family expectations may run counter to what is considered good or proper care so communication and support is paramount to successful transition.
- vi. Someone pointed out that families may become a helpful partner in care and in successful transitions – family members should be viewed as a barrier, but rather, potential partners.
- vii. Cathy Cranston mentioned that end of life care and the role of hospice care should be included when we are considering quality measures across facilities.
- viii. The chair clarified for the group that long term care facilities – assisted living, nursing homes – are typically what we think of when discussing facility-based care, but that we could expand that definition for our purposes.
- ix. It was suggested, and the group agreed, that including home care in residential setting sand in the home would be important. Lindsay pointed out that the Caregiver sub-group would also be looking at home care, but from a different perspective. The group agreed to keep the lines of communication open on this piece and potentially join forces in the future with the Caregiver's group.
- x. Someone also suggested looking at adult day services and night care which both serve critical roles in the overall care of those with dementia and are an essential component to the service available to caregivers. Adult day can also play a part in transitions. Theses will be included.
- xi. The question was raised of whether quality measures would differ between adult day programs and assisted livings/nursing homes. Would the staff ratios necessarily need to be the same? Are there other important differences?

### b. Non-residential Services:

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- i. The chair began this conversation by challenging the group to think about taking someone from the community, who had been living at home, and taking away all that's familiar and putting them into a nursing home environment. If nothing had been created and we were developing a system from scratch, one would easily recognize that approach makes little sense for the population with dementia.
  - ii. The chair continued that we ought to be able to pick off many options before landing on nursing homes – and maybe there are that many options. For every person who lives in nursing home there must be the exact same person who is still living in the community – the difference being that they have supports. Without those supports, you end up in a nursing home. By building supports you may be able to keep people where they are as long as possible. If you look at where long-term care is going, it's going to be the community-based model because of cost and because we recognize that is the best setting.
  - iii. Kathleen Kelly suggested looking at Housing with Services and Shared Living initiatives out of EOHHS. These are some of the options between home and a nursing home.
  - iv. Jim Nyberg added that senior housing providers are also dealing with residents with dementia.
- c. Concerns about capacity within the state to meet the need:
- i. There was general agreement that we should be concerned with capacity. There is capacity now within nursing homes because consumers are voting with their feet – there are beds but people are not choosing them.
  - ii. That said, there is a need for home and community based care. Tockwotton will set the bar high and we will see the state respond.
  - iii. Cathy Cranston added that in home-based care, because we don't have facilities, we are able to ramp up easily. It won't be hard for us to meet that increasing need.
  - iv. The sub-group then discussed the potential repurposing of beds in order to accommodate the sort of night programs that have been appearing in other states. Folks may need somewhere to go for night care and specific sections of nursing homes may change to night care and during the day may offer adult day services.
  - v. The chair posed the question of whether people have the capacity to replicate what Tockwotton is doing? While not many people have the dollars they do, the building is one thing and operation is another thing. Everyone has the capacity to change operation and delivery of care.

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- vi. Jim Nyberg described the Tockwotton model to the group; it's a new home and assisted living – there will be different households of about 15 people. Its assisted living and will have a dementia unit. The food is prepared and there are staff trained to be there. It's more interactive. Great environmental features; the staff organizes into teams and provide resident-centered care. Anyone can do that across the setting. Kevin McKay, the Director, says he's not the boss and puts the CNA, Med Tech and housekeeper in charge and they run the household. There are small group homes on each floor and each is self-sufficient and prepares their own meals and have their own flavor as you'd expect to see in a neighborhood. Innovation and culture change is very exciting.
  - vii. The group discussed that RI is a little behind on innovative thinking about culture change. The model Tockwotton is adopting is from Kansas – Meadow Lark Homes (Steve Shields).
  - viii. There was strong interest in doing a future meeting on culture change – perhaps by doing a review of what kind of culture change is going on in elder care, particularly residential settings, but there are many models like The Eden Alternative, Greenhouse, resident-centered care, etc.
- d. Do we have appropriate care settings in the state:
- i. It is a work in progress, some agree the answer is “no.”
  - ii. The ability to evolve to appropriate care settings exists and our job is to force that evolution. Sometimes you need policy to make that happen.
- e. Payment and Delivery Reform:
- i. There was consensus that there is a great need for payment and delivery reform.
  - ii. Kathleen Kelly has a working group on this.
- f. The Chair asked if there were any other items that needed to be added to the sub-group's jurisdiction?
- i. As a follow-up to the earlier conversation, the group agreed that transitions from one type of residential setting to another.
4. Group Participation:
- a. The chair asked if the group felt there were any folks missing from this group? The group confirmed that we have someone from adult day (Susan), home care (Cathy). As we cover certain topics, we have many people we can draw from.
  - b. The chair suggested three names of people who may be available to come speak to our group or potentially give some workshops:
    - i. Bill Thomas – Geriatrician and expert in elder care and does a visit to Elmhurst about once a month. Its possible we could team up on one of his future visits.
    - ii. Maggie Calkins – designer specializing in healthcare environments, especially for those living with dementia. She can

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- even assist those with low budgets to help them think through what they can do that will make a real difference
- iii. Al Power – Wrote, “Dementia Beyond Drugs” focusing on the idea that meds should be the last resort and not the first. The behaviors exhibited by those with dementia are really expressions of unmet need. Laura (on our sub-group) is one of the trainers in this area and Elmhurst. What is it that they're trying to express and how can we help?
- c. Anyone from DD population? Access Point is here, but others? Given prevalence of Alzheimer's among those with developmental disabilities, we would want representation from this population. We need to reach out to Director Stenning or Donna Martin.
5. The chair asked if there were any other comments before the group adjourned?
- a. It was suggested that when we say “transitions” we focus on the transitions of care for our elders – but that we make recommendations for major industry transitions. Given that fact, we need to consider the impact that will have on the greater RI community – the partners who are not here and that they'll need to understand how we arrived at our recommendations.
  - b. Rick and Lindsay discussed sending out a request to the sub-group members to please be ready to share best practices from their own care environments as a starting place for the group's work. Need to do this well before the next meeting and may want to mention it at the full group so that anyone could send us a comment.