

Alzheimer's Sub-Group Meeting
Elmhurst Extended Care
50 Maude Street
Providence, RI 02908
Wednesday, November 7, 2012

Attendees: Marcia Werber Feldman (Charter Care Home Health), Catherine Desautels (NHPRI), Gail Patry (Healthcentric), Kathy Heren (Alliance for Better Long Term Care), Andrew Powers (DOH), Donna Gilroy (Alz. Assoc.), Noriana Royles (BHDDH), Lisa Connell (Alz. Assoc.), Barbara Waterman (Alliance for Better LTC), Susan Adler (Life Center Adult Day Services), Jim Nyberg (Leading Age RI), Deborah Castellano (DHS-LTC), Amanda Clarke (Advocacy Solutions), Catherine Salerno (URI-Living RIte Grant), Kathleen Kelly (RIALA).

1. Lindsay shared some information on the Hebrew Home of Riverdale's Night Care program. The group discussed the merits of the program and raised a few questions:
 - a. How many people do they serve at once?
 - b. Its not always the best practice to keep folks up all night – does Hebrew Home have the ability to allow people to nap as needed?
 - c. Does agree it's a best practice we should look at (Marcia).
2. **Marcia Werber Feldman shared that Charter Care Home Health is looking at the ability to have home care providers provide care a bit differently than usual. Some patients do not sleep at night and the caregivers aren't necessarily trained to provide a different kind of support during the overnight hours.**
 - a. From Assisted Living perspective, those that have programs that specialize in Alzheimer's Disease (AD) and dementia, usually have trained staff, but could look at universal training in assisted living environments – they break out into memory impaired and traditional side of the house. **The behaviors of not sleeping on both sides – there's a need for more and better training for those activities.**
3. Lindsay asked about potential resources for those activities – what is considered a “best practice” in overnight care?
 - a. **Marcia answered that the activities might not differ that much – so long as can conduct them while not negatively impacting the other residents who are sleeping and they're meaningful...**
4. Jim Nyberg added that the Bronx model is hard to replicate within the adult day model because of its urban setting, etc., but nonetheless, looking at the best practices could help inform assisted livings and nursing homes in RI.
5. Susan Adler offered to call Hebrew Home and ask the questions the sub-group proposed.
6. The Hebrew Home also did a presentation at RI Generations in the past. Drew Powers added that there had been one inquiry from a group in RI following that presentation (an empty unit of nursing home) interested in doing the night

services, but there was no follow up. **Adult Day Care statute defines it as daytime hours.**

7. **Jim Nyberg also shared that the Medicaid reimbursement is about \$150 so that is another challenge, but best practices can nonetheless be incorporated into existing residences.**
8. Catherine Desautels added that, at a certain point, this population often cannot tell between day and night and they'll sleep when they feel the need. With regards to activities, the day versus night distinction only matters to not disturbing the other residents. Maybe it's as simple as a drink and snack and puzzle – they can sit in a certain area. Every individual will differ – but it can be simple and quiet – so long as it's something that interests them that perhaps they know well or used to do. Trying to turn around their rhythms, however, is not the goal.
9. Gail Patry said that **Healthcentric has been running a care transitions program for 4 years which includes all the acute care hospitals, home care's, many nursing homes and 5 community coalitions as well as statewide work.** They've all identified best practices in each setting for transitions. They've been working with providers in each to implement them.
 - a. BCBS has used those best practices in their contracting with hospitals so when they renew with them, they have to meet all care transition best practices: improved communications from provider to provider, to families, to patients, etc.
 - b. These best practices weren't developed specifically with dementia in mind, **but transitions are, generally speaking, bad across the spectrum so they can apply to dementia cases as well.**
 - c. **They've seen readmission numbers improve and the incorporation of those best practices into daily work has increased.** This is overseen by a Leadership Advisory Board from all state agencies and healthcare provider groups – they reviewed the National Plan and submitted recommendations. **There was a focus on individuals at the highest risk for burdensome transitions** (multiple over last 3 months or near end of life or with certain demographics) **and an increased focus on medical reconciliation during transitions especially for those with AD or dementia, recognizing that many medications are not appropriate for that population or there can be many opportunities for adverse drug interactions.** Finally, to increase the attention on the aging and disability resources center and community care transitions for those with AD or dementia. The states stack up very differently in those areas – some have great transitions or the ADRC is great in that state for that population and others don't.
10. **Kathy Heren shared that typically, the family hasn't done a lot of thinking ahead of time and near the end they're just looking for a bed in a dementia unit.** Another problem, especially with NP's is you could be hired as a midwife into the psychiatric setting and can prescribe medication without specialized knowledge of drug interaction... nursing home medical directors (best practices group – Dr. Stoukides).

- a. Lindsay will follow up with Dr. Stoukides to obtain more information about this group.
 - b. The integrated care that is being implemented will help the issue of medications reconciliation. The time needs to be taken to do this. Its not just finding a unit for the patient, it's ensuring that this reconciliation occurs.
 - c. Another challenge is that people are put into Assisted Livings when it might not be appropriate.
 - d. With respect to the night care program, we need to staff up the night staff already – how would we support a night care program (med techs have to be CNAs in assisted livings).
11. **Drew Powers agreed that staffing does need to be ramped up based on the patient mix they have. There is no ratio requirement.** The training is a huge piece of this. Healthcare providers, too. His day is spent on the regulatory side, but phone calls are often caused by family members not understanding what their loved one has and often times, the staff at the assisted living or nursing home also is not trained to understand the situation, nonetheless communicate it to the family.
 12. Education really is a huge issue challenge – woman transferred to hospital and there was insufficient knowledge to appreciate her needs and condition. The CNAs had no clue how to handle her or lift her or talk to her and help her into bed. The family could help, but the hospital was untrained in how to help her. They could send a CAN at home with the person and eventually hospice came in. This is a dignity issue.
 13. Gail Patry said that under the Medicare contract there is a nursing home collaborative on best practices for dementia care with a focus on eliminating overuse of medications. Mostly in a “train the trainer” format so that folks can go back and train their staff. Also working with GEC grant potentially to focus on nursing home staff with recognition that CNAs may not be prescribing the best medications.
 14. Lindsay asked if there will be a publication that comes out of the collaborative? Despite it being nursing home centric, the best practice could still nonetheless apply in other settings.
 15. Gail said that this hadn't been contemplated as part of the project.
 16. Someone also mentioned that it requires an entirely different type of insight and education to provide a very different kind of care – its not just being a good nurse. **Dealing hands on with an Alzheimer's patient means knowing how to deal with the appropriate situation at the appropriate time. Best Practices and education – this is the starting point and then you have to build off of that. It's a basic level that can then be built upon.**
 17. Kathleen Kelly said that 9 out of 10 it's the caregivers behavior that triggered a certain behavior.
 18. **Gail shared that their education program hopes to be different in that they'll set out to create environments that don't create behaviors.** Just addressing the noise level in the nursing home can make a huge difference. We understand noise

while the patient understands chaos. This is too overwhelming and chaotic for them.

19. **Gail added that “person-centric care” is another big focus** – their educational program will be best practices and best friends: meeting people where they are. Someone who has worked 3rd shift their entire career may not be prepared to work a different shift and may not have the skills needed.
20. **Kathleen Kelly added that we need to centralize the Alzheimer’s trainings going on. The information needs to be shared.**
21. Lisa Conwell said that their chapter does have a lot of educational programs and their reaching out to assisted livings to make them better aware. Professional and educational trainings – they’re on the website. They’re trying to enhance the training side. The Live and Learn – daycare is available for first stage dementia.
 - a. National Chapter is providing a large grant to the local chapter as well – new money. People can contact the association to be put onto the list – contact Marge Angilly to be put onto the list.
22. Lindsay and Gail – entire packet of information people can take. Homework, resource list, interactive trainings, this will be an education for professionals, non-professionals, cleaning staff, etc. Also, there are early conversations with DHS about having this training part of the incentive for quality incentive for nursing homes. More on that as conversation progresses.
23. **Another suggestion was made that a “person-centric” approach includes enough staff. Putting enough staff on a floor to do some one-on-one entertainment. It is expensive and in this reimbursement climate, this is very difficult.** Its one thing to know everything there is to know, but its another to have 2 CNA staff for 40-60 people...
24. **Catherine Desautels – Medicaid funding cuts to long-term care facilities makes this extremely difficult. This is a huge problem.**
25. Barbara Waterman added that best practices includes the assessment: identifying the individual’s needs and designing a plan that will address those needs instead of fitting the person into the programs you already have.
 - a. Home care requires better back-up systems. Many agencies struggle to find someone that can fill in that role.
 - b. **Assisted Livings: education is critical. When people are educated and comfortable with this, they can then help families and are better communicators and can engage in the process with families.**
 - c. Families: Need to acknowledge assisted living cost and that the person is in decline. Helping people to look at the whole picture – it often becomes a reaction to the situation and this doesn’t help serving the needs of the person to the best we’re able. **If they need nursing home care, that’s fine, but memory care unit waiver beds are hard to come by. When assisted living is appropriate for them, its important they get to go there first and not have to be transitioned.**
26. Deb Castellano – Education is important, but specifically, when the person is diagnosed early, families need a plan for “what happens if something happens to me?” and “What is our plan B?” **The assessment needs to include a biographical assessment – there may be something that triggers calm in the**

- person from way back in their lifetime. That entire biographical sketch needs to be done early because the family members may not be there down the road.** Food? Language? There may be a need for reevaluation of task-based payment out of DHS for Alzheimer's care – its more of a supervision need.
27. Kathy Heren: You have to tailor the setting based on the needs of the person.
28. **Jim Nyberg said there is a lot we can learn from the collaborative to reduce medications.** A process, for example, for bathing persons with dementia, translating these best practices. What adult days do for people with dementia – that can help caregivers at home. There needs to be a place for this sharing.
29. **Figure Eight of communication: clinical trials, researchers, providers, families, care settings – de-segment this information. We need to “grow them up” and broaden them out.**
30. Cathy Salerno – we cannot forget the needs of the developmental disabled population. Unsure what the best practices are, but it needs to be incorporated. Down Syndrome diagnosis indicates a nearly
31. Lindsay added that BHDDH, Director Stenning specifically, let us know that he would be designating someone.
32. Noriana Royles, from BHDDH, introduced herself as the designee. **She is new at doing the determination letters. It is very hard because often times, the sources are gone to provide the person's history.** Elderly parent's biggest concern is what will happen when they're gone.
33. **Additionally, there is no one pharmacy that holds a list of all the medications the patient is taking because families are shopping around for the best price and go to many places for the best price.** If they have Part D, that's searchable online, but if they're just going to different pharmacies without a single payer, its not tracked. Pharmacists should know.
34. **No one at DOH is able to do oversight. Federal mandates a trial decrease in anti-psychotics every 6 months.**
35. The meeting was then adjourned with a reminder that the next meeting would be in early December.