Appendix 2

The Project - Habilitation Therapy Training

JCHE's Memory Support Initiative was born out of a desire by JCHE staff to learn more about Alzheimer's disease and other dementias, and to have better tools to assist the residents. The goal of the project was to enable residents with Alzheimer's disease or a related form of dementia to remain in (low income subsidized and market rate) senior housing or independent living longer (even if only a few months) and happier by coordinating care and services through staff training, and specialized memory support teams.

The Alzheimer's Association of Massachusetts/New Hampshire teaches others how to use a model called Habilitation Therapy, which was developed by Paul Raia, Ph.D., Director of Patient Care and Family Support. The model is based on creating a milieu around the "whole person" that addresses not only their physical needs, but their emotional needs as well. Habilitation focuses on connecting with the person emotionally via verbal and non-verbal communication, knowing the individual, the physical environment, creating meaningful and purposeful ways for people to engage that not only promote a positive emotion, but also maximize the person's remaining skills and abilities, and minimize their limitations.

A key idea of Habilitation is for everyone to work together to try to figure out the best methods to care for each person using the same language of Habilitation. Although the model was designed primarily for those who provide care in skilled nursing and other institutional settings, our plan was to learn about it, train our staff on it, and adapt the model to be more accessible and appropriate for use in independent senior housing. This guide is a result of that process.

Expected Project Outcomes

- Higher quality of life for some residents vs. nursing home
- Delay in nursing home placements for lower income residents, even if only for a few months
- Significant cost savings to Medicare/Medicaid
- Fewer evictions related to behavioral issues or safety related problems
- A deeper understanding and improved involvement by families and a stronger sense of trust established between the families and the housing staff
- Reduced hospitalizations
- Improved living environment for all residents
- More staff confidence and competence, less staff-related stress, reduced staff burnout, greater job satisfaction and longevity in their positions

Training Process

The first activity was to form a seven member Memory Support Team (MST) comprised of staff from each of our four sites:

- Director of Strategic Planning and Partnerships (Project Director)
- Executive Director of the Brighton Campus
- Resident Service Administrator of the Suburban Sites
- Resident Service Coordinator/Dementia Specialist
- Resident Service Coordinators (3)

Responsibilities of the MST

- Attend the train-the-trainer course in Habilitation Therapy
- Participate in training JCHE staff
- Administer pre and post tests to trainees for each module
- Work cooperatively with our research partner, UMASS Gerontology Institute on collecting data for the process evaluation
- Meet monthly with the Alzheimer's Association liaison to discuss specific resident cases
- Be the in-house memory support resource (i.e. the "go-to" person) in the community in which each works
- Contribute to this guide

The MST attended the seven hour Alzheimer's Association of MA/NH Habilitation Therapy train-the-trainer course covering the nine modules of training (four modules have two sections). In order to accommodate the MST members' schedules and all the schedules of 105 staff members, each module was offered between three and five times. In total, the MST offered over 50 hours of training to the staff in the following modules:

1. Understanding Alzheimer's and Dementia (2 hours)
2. Habilitation Therapy Overview (1 hour)
3. Knowing and Understanding the Individual (1 hour)
4. Communication Skills: We Need to Know the Language (2 hours)
5. Does the Physical Environment Make a Difference? (1 hour)
6. Our Approach to Personal Care (2 hours)(the second hour was eliminated because it is related solely to the delivery of personal care)
7. Activity and Purposeful Engagement (1 hour)
8. Behavior as Communication: Understanding and Responding (2 hours)
9. Understanding and Working with Families (1 hour)

Following the train-the-trainer course, the MST decided which of the nine modules of training were appropriate for which departments at JCHE, depending on their level of interaction with the residents:

- Resident Services (all 9 modules)
- Maintenance (all 9 modules)
- Administrative (all 9 modules)
- Executive (1-4 and 8)
- Finance (1-4 and 8)
- Compliance (1-4 and 8)
- Fund Development (1-4 and 8)

The modules of training were then scheduled over several months, ranging from two hour trainings to full-day trainings. An online calendar was created, and the entire staff (105 employees) was notified as to the dates, times, locations and modules that were being offered. In some cases, we worked through the department managers, particularly for the maintenance staff who did not have e-mail or access to the online calendar. All departments were encouraged to attend by the senior leadership team, and we planned a graduation ceremony at the conclusion of the grant period at which every person would receive a certificate of attendance for the number of hours she/he attended.

The MST and the resident service coordinators met monthly with Dr. Paul Raia at the Alzheimer's Association to review challenging resident behaviors and to reinforce the five Habilitation domains (outlined below), and to promote the most positive emotion possible.

We developed a referral form, so all staff could refer residents to members of the MST (Attachment 1). We also developed a tracking form so we could track the interventions used by the MST (Attachment 2). We worked with the University of Massachusetts Gerontology Institute on a process evaluation (Attachment 3), which can also be accessed on our website – http://jche.org/guide.

In the months that followed the grant period, as a reminder for the staff we posted on our intranet reminders about the concepts taught during the training. We also plan to offer drop-in trainings on topics about which staff may have additional questions. Periodically, we will offer the training to new staff.

JCHE's Resident Service Coordination

For decades JCHE has invested time, energy, education and thought into resident services coordination (RSC). Our twelve RSC are bi or tri-lingual, and assist our multicultural resident population with everything from reading the mail, to interpreting with physicians and care providers, to executing community building events with flawless precision and fun. They work with residents who suffer from mental illness, dementia and a host of other challenges. But with more residents with Alzheimer's disease and other dementias, their responsibilities included tasks and interactions with which they thought they needed more education and skill-building. For example: a resident who was known to the staff to have dementia was in the dining room crying, insisting that she just saw her husband (who had been deceased for seven years), but upset that he didn't come to her. In the past, the RSC may have called 911, and made the cognitively impaired resident spend a confusing, agitating time in the emergency room of a hospital, only to be returned when no acute ailment was diagnosed. Following the Habilitation Therapy training, the RSC (or any staff) may, at the very least, try to use the techniques of the model to connect with the resident, focus on the feelings, and either redirect the upset resident, or simply join her in her reality, more on that later. Practicing the Habilitation methods is important to try to calm and refocus the resident, but it does not replace seeking medical attention when appropriate. The uncharacteristically upset resident may have been suffering from a urinary tract infection or other organic problem.

JCHE RSC report that being a resident service coordinator is a complicated, sometimes heart-wrenching, emotionally draining, but equally as fulfilling a career. Often, without a RSC residents would be lost in bureaucratic red tape, spending hours and hours trying to get onto certain government programs, arranging transportation, setting up homecare services… especially if their memories are failing them, and/or English is not their first language. JCHE believes RSC is the backbone to all resident programs! This is the ideal; but having RSC on staff may not be attainable for every community. All staff, whether a RSC is present or not, should know how to interact with a cognitively impaired person.

> *Just in case you are not familiar with the resident service coordinator position, HUD's definition is: Service Coordinators assist elderly individuals and persons with disabilities, living in federally-assisted multifamily housing, to obtain needed supportive services from community agencies. Services are intended to prevent premature and inappropriate institutionalization. Independent living with assistance is a preferable, lower cost housing alternative to institutionalization for many frail older persons and persons with disabilities. An estimated 365,000 persons living in HUD-assisted housing experience some form of frailty, and this number will increase as people living in those units grow older. By arranging for delivery of some services, Service Coordinators can extend the length and improve the quality of independent living. For more information: http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/progdesc/servicecoord*

Lease Termination/Eviction

It is worth mentioning here that HUD makes no mention of resident safety in the lease termination section of the HUD rules. There is only mention of disturbances of neighbors as a legitimate cause for lease termination. If you are concerned about a resident who is cognitively impaired, our advice is two-fold: 1. Do everything in your power to assist and support that resident to stay with you, with compassion for what they are experiencing, and 2. Document each time they knock on a neighbor's door in the middle of the night, or have some other behavior that causes a disturbance to their fellow residents. If there is a point at which you feel that this resident is unsafe and should no longer live in the community, and no support services are available or that the resident is willing to accept or afford, you will have built a record of acceptable HUD "disturbances". This still may not be enough for a court approved eviction, but it may be enough for the family or responsible party to know you are serious in your concern for the safety of the cognitively impaired resident, as well as the "peaceful enjoyment" of the community by the other residents.

It is also worth mentioning that nowhere do the HUD rules mention "disturbance of staff" by a resident. A cognitively impaired resident could come to you 30 times a day, every day to ask the same question, and they are not in violation of their lease. In this case, it is in the best interest of the staff to have some activity for the resident to do (see the Purposeful Engagement section), and be mindful of the fact that the resident's brain is dying (see What Happens in the Brain).

In addition to in-house staff familiar with the residents and their needs, JCHE also works closely with other community providers. In Massachusetts, Aging Services Access Points (ASAP) are the gatekeepers to elder services and supports; however, all states have Area Agencies on Aging (AAA), and many have Councils on Aging, which may be advocacy groups, but may also offer educational and social activities and programs for seniors in your area. Contacting your state's Alzheimer's Association (alz.org) is highly recommended to explore services and programs they could offer to your staff, residents and families.