

Speaker's Task Force on Alzheimer's and Dementia
Tuesday, September 12, 2017
Topic: Community and Facility Based Long Term Care and Services
Testimony by:
Vincent M. Antenucci
Research & Training Manager/C.O.O.
Center for Applied Research in Dementia
Solon, Ohio
www.cen4ard.com

Good afternoon, my name is Vincent Antenucci. I am Research and Training Manager and COO at the Center for Applied Research in Dementia, based in Solon Ohio. I want to thank the Speaker's Task Force for inviting me to offer testimony today.

My educational background is in public policy, and my early career focused on improving local transportation services in Ohio for older adults and persons with disabilities, and helping local service providers comply with the Americans with Disabilities Act through service coordination. Just over 20 years ago, I began working with Dr. Cameron Camp, who was doing pioneering research at the Myers Research Institute at Menorah Park Center for Senior Living in Beachwood, Ohio. His research, which has been funded by the National Institute on Aging, National Institute of Mental Health, National Alzheimer's Association and various other agencies, focuses on creating effective evidence-based interventions to enable persons with dementia to maintain their independence and quality of life as long as possible. In my work with Dr. Camp, I have been involved in research, grant management, staff training and consulting in long-term care.

Dr. Camp and I created the Center for Applied Research in Dementia as an independent research and training company. We are dedicated to changing the industry and culture of care that is still entrenched in a paradigm in which Alzheimer's disease and other types of dementia are viewed differently from other diseases. In this paradigm, persons with dementia are viewed as "sufferers" who must be cared for and kept from harm, often at the cost of their personal independence, dignity and quality of life. But just as we would want to live well with cancer or diabetes, we should also assume persons with a dementia diagnosis wish to live well; to continue being who they are, enjoying the things they enjoy, going to the places they want to go, contributing to the community, and having a purpose in life. These are things we all want for ourselves, so why should any diagnosis change the way we view ourselves or others as individuals?

There is quite a lot of information available about dementia, different types of dementia, amyloid plaques and tangles in the brain, different stages of dementia, behaviors and challenges, and so on. Although this information may be useful in understanding the disease and disease process, it does little to improve the lives of persons diagnosed with dementia. It is much more useful to understand the capabilities and strengths of each individual. We view dementia as a disability. Our job is to find ways to circumvent challenges presented by disabilities, and to enable persons to continue functioning successfully in their communities. Just as we build ramps to provide access for persons with physical disabilities, we also should create what we call "cognitive ramps" to enable persons with dementia to live independently.

Persons with dementia are normal persons who happen to have a cognitive disability. Behaviors that are often seen in persons with dementia are not random. They are rational responses to conditions that the individual is experiencing. For example, if we have pain that we are unable to verbally express, we may lash out at a caregiver whose actions are aggravating the pain. So instead of saying, “this person is crazy,” or “she’s doing this because she has dementia,” a more useful response is to assume there is a logical reason for the behavior. This approach leads to solutions rather than frustration and learned helplessness.

We also assume that persons with dementia can read. We use a simple test for determining an individual’s ability to read, and the size of print that is required. As simple and basic as this sounds, we often hear from care staff who have no idea whether or not their residents or clients can read. Why is this important? Because reading, which is a habit that remains well into the course of dementia, allows for simple interventions such as cuing for wayfinding, access to personally important information, and social participation. When we provide consultation and training to care providers, this is one of the first things we recommend.

In addition to reading, many capabilities remain in persons with dementia that can increase their functioning and independence. Unfortunately, within the current paradigm too many personal tasks are taken away. For the sake of efficiency, persons are dressed, bathed, fed and over-medicated. After time, persons in these environments tend to lose functioning more rapidly as a result of not maintaining use of their remaining abilities, not to mention side effects from psychotropic medications. We recommend taking time to understand why an individual may be having difficulty with a specific

activity, and to find ways to enable the person to be more successful. For example, if a person is not eating, it may be that they cannot see the food on their plate. A simple fix then might be to increase the contrast between the plate and food. It often takes a process of trial and error to find optimal solutions. A small investment in time has lasting benefits of maximizing and maintaining independence, as well as saving staff time in the long run.

Perhaps the most often overlooked need in long-term care is the need for purposeful activity. Too often, activities in long-term care are focused on passive entertainment or busy work. Every person has a need to contribute to their community in meaningful ways. Persons with dementia also must have a voice. The most successful memory care communities are the ones in which residents choose the activities they want to do, and decide on other matters that affect their lives. Our work takes us to many different care settings, and it is always clear where true communities exist.

Residents are active, engaged socially, and doing meaningful tasks. This is not about spending a lot of money creating the most beautiful building. The physical environment is important to the extent that it supports personal independence. Equally important is the social environment, and changing the way in which service providers view their residents or clients. Are they viewed as persons with talents, skills, and unique life experiences, or they viewed as needy sick people? This is a choice that we make. And it is about how we all want to live as we age, regardless of our diagnoses.

We provide training and consultation to service providers and caregivers in the United States and around the world. This year I have given presentations and trainings in Michigan, Alabama, Pennsylvania, Florida, Montana and Ohio. Dr. Camp has been working in Asia, is now in Europe,

and will be in Australia later this year. We have a strong appreciation for the wild variation in regulatory environments and cultures of care from country to country and state to state. One of the examples we use is from a community picnic that was given by residents of a memory care community in France. We show slides of the residents preparing food for the picnic. In one of the slides, a gentleman with dementia is shown making radish roses, and he is holding a paring knife. This typically elicits gasps from the audience. At a recent conference after viewing this slide, a person in the audience commented, "I don't know what the regulatory environment is like in France, but we could never let residents do that here." All too often, the fear of citation or litigation is used as an excuse to avoid change. The fact is, many care communities in the United States are enabling their residents to prepare food, and yes, even use a knife. If a person has skills with a paring knife, the risk that they will cut themselves is very low. But this is not about arming residents with knives, it's about enabling them to continue living their lives in ways that are familiar and personally fulfilling. Risk assessments are always advised, and it is important to proactively communicate with state inspectors to understand how to comply with specific regulations. In closing, I would just like to say that the status quo of the old paradigm in long-term care is not going to survive the aging baby boom generation. We are going to demand change. Long-term care service providers in Ohio must work now to create the environments in which they would want to live.

Thank you,

Vincent Antenucci

September 12, 2017