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**COMMENTS OF THE RI ASSISTED LIVING ASSOCIATION (RIALA)
SUBMITTED TO HHS ON THE**

***DRAFT Framework for the National Plan to Address
Alzheimer's disease***

JANUARY 31, 2012

Thank you for the opportunity to provide comments on the *Draft Framework for the National Plan to Address Alzheimer's disease*.

The Rhode Island Assisted Living Association and the forty eight of providers who are our members supported passage of the National Alzheimer's Project Act one year ago. We are pleased to see the Administration is currently pursuing a plan for a coordinated national strategy to address Alzheimer's disease. While the Draft Framework is a good start, we were dismayed to see the lack of acknowledgement of the role assisted living has in caring for individuals with Alzheimer's disease. In Rhode Island alone our members care for 3,500 residents most of whom experience some cognitive loss.

As you are aware, assisted living is a home and community based alternative to skilled nursing care. The philosophy is resident centered and the care is provided to support individual choice and help our residents maintain dignity and respect. In the past decade consumers have shown a preference for assisted living over more institutionalized care settings. The population of assisted living residents with Alzheimer's and related diseases is rapidly increasing. According to the 2009 Overview of Assisted Living (research conducted and analyzed by Acclaro Growth Partners), more than 1/3 of all residents living in assisted living communities have a diagnosis of Alzheimer's or a related dementia. A survey of the top 80 senior living providers by Senior Living Executive in 2011 confirmed that 17% of the total residents served by these top providers are residents living in special memory care accommodations. The 2010 National Survey of Residential Care Facilities conducted by the CDC's National Center for Health Statistics released data that 42% of the residents living in residential care have Alzheimer's disease. We expect this trend to continue as many consumers prefer the state of the art programming that has been developed for memory impaired residents in assisted living. Indeed there are some assisted living companies that are dedicated exclusively to caring for residents with Alzheimer's and related dementia.

How can assisted living communities not be part of a national plan to address caring for people with Alzheimer's and other forms of dementia? The fact is assisted living is becoming the most popular form of residential care and services among consumers. Assisted living is a professionally managed, community-based option seniors and their families can turn to when needing assistance with activities of daily living, including specialized care and service for seniors with memory loss.

The senior living business is growing to meet the demands of seniors with memory loss. The National Investment Center for Seniors Housing & Care Industry estimates there are 105,000 memory care apartments available in custom built, appropriately licensed senior living communities. Most of these apartments are part of a special neighborhood within more than 36,000 assisted living communities. About 600 memory care-only communities operate in the U.S. However, due to growing demand from families needing full time assistance with the care of a loved one with memory loss, more capacity is being added each year, but growth rates will need to increase in order to serve greater consumer demand expected in the next five to ten years.

Regardless of the increasing popularity of professionally-managed senior living communities as a care option for seniors with memory loss, both government and private sector reports continue to confirm that assisted living communities are more affordable than nursing homes, and potentially even more affordable than home care depending on the level of need and situation of the family and senior. Additionally, options like offering home care to every senior are not practical given the shortage of healthcare professionals interested in serving seniors.

Social and safety benefits of assisted living communities should also be considered for seniors with memory loss. Studies continue to demonstrate that seniors with mid to late stage Alzheimer's disease thrive with a meaningful and purposeful life. Assisted living communities help create this life for their residents with memory loss. Professionally trained caregivers focus on the seniors' interests – it could be as simple as singing songs, playing music, painting pictures or holding their hand. What's more, other residents and people are around as a supportive social network for the senior. Additionally, due to the professional and social nature of an assisted living community, more people are around to observe the resident to help both promote and protect his or her quality of life.

I am sure you can understand my concern that assisted living was not included in any of the goals or strategies that referenced care setting for individuals with Alzheimer's disease. Assisted living has been and will continue to be an option that can provide not only the most appropriate setting for individuals with this disease but a cost effective option as well.

Assisted Living providers in RI have been huge supporters of our local Alzheimer's Association Chapter, through frequent sponsorships of fund raising events; such as the walk and the golf tournament. Our industry helped create the Culinary Challenge Event that has raised a significant amount of money for the RI chapter. I was shocked to read that, to date Assisted Living has been left out of the frame work for a national plan.

The recommendations below cite some specific places in the report where we would appreciate the inclusion of assisted living.

We also respectfully request that the word “patient” used through out the document be changed to “individual” or “resident”. While we understand that someone under a physician’s orders is called a patient, individuals residing in assisted living and other home and community based options are referred to as individuals or residents. Thank you for your time.

- Goal 2. Add licensed assisted living communities to the list of settings in the opening paragraph after “hospitals”
- Strategy 2.A Change patients to individuals
- Strategy 2.B Change patients to individuals
- Strategy 2.C Change patients in the title to individuals
- Strategy 2.D Add assisted living as a care setting after “physicians office”
- Strategy 2.E Change patients to individuals and add assisted living to the list of transition settings after “home”
- Goal 3: Change the title to Expand Support of Individuals with Alzheimer’s and their Families, and add assisted living to the list of care settings after “hospitals”
- Strategy 3.B Add assisted living before “nursing home placement” in both references
- Strategy 3.D The use of the term “residential care facilities” in the first sentence is odd because that term has never been used throughout the document. A more consistent term could be “long term care settings”. In two places the term “assisted living facilities” is used and the term “facilities” should be replaced with “communities”. This strategy should be strengthened to support a zero tolerance for abuse of individual’s with Alzheimer’s, regardless of where they live. Criminal background checks, educating family members, residents and staff in how to recognize, respond and report suspected abuse and termination of staff when appropriate must be a top priority.

Sincerely,

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