TESTIMONY OF

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Thank you for the opportunity to testify on the report of the Assisted Living Workgroup and the Workgroup's process. We applaud you Mr. Chairman and the members of this Committee for encouraging a diverse group of organizations to come together around this very important and timely issue. We believe the process, while a bit "untidy," has helped to move the debate forward and will contribute to improvements in policies and practices affecting the assisted living industry and ultimately to better care for those in assisted living.

The Alzheimer's Association is concerned about assisted living and has been part of the Assisted Living Workgroup throughout its existence for one reason -- very large numbers of people with Alzheimer's disease and other dementias live in assisted living facilities. Recent studies show that 40-60% of all assisted living residents have Alzheimer's disease or dementia.[1] And, the number will only grow as current residents age in place.

We share the Committee's concern about problems with the quality of care provided by some assisted living facilities. We are particularly concerned about facilities that serve people with Alzheimer's disease and dementia but do not have appropriate programs or staff to meet these residents' needs. Sadly, some facilities that serve people with Alzheimer's disease and dementia do not even recognize the residents' cognitive impairments or the need to adapt care to take account of those impairments.

The Workgroup's report contains more than 130 recommendations. In our consideration of proposed recommendations, we were guided by five general principles:

- Care occurs in the interactions between providers and residents; good care – high quality care -- requires a partnership.
- Assisted living residents, including residents with dementia, are diverse; their care needs differ, and a single, strictly prescribed set of services is not going to work for all of them.
- The preferences of individual residents are important; the assisted living facility is their home; some flexibility is necessary to accommodate individual preferences.
- There are essentials that must be available for all residents; state regulations should mandate these essentials.
- It is important to move forward with recommendations that will improve the existing situation, even if they are not perfect.

[1] Sloane PD, Zimmerman S, and Ory MG, "Care for Persons with Dementia" in *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, S. Zimmerman, P.D. Sloane, and K. Eckert (eds.) (Baltimore, MD: Johns Hopkins University Press, 2001). Lyketsos C, Rosenblatt A, Steele C, et al. Maryland Assisted Living Study: Initial Findings from the First 100 Cases," presentation to the Maryland Gerontological Society, Baltimore, MD, 2002.

Guided by these general principles, we voted in favor of the final versions of almost all the recommendations. We voted in favor of almost all the recommendations, whether they are specific to dementia or not, because we believe that, if implemented, they will improve quality of care for all assisted living residents.

The Assisted Living Workgroup process was an enormous undertaking that attempted to find agreement among stakeholder groups with very different, often conflicting, perspectives. The inability to reach consensus, or even to gain a two-thirds vote on all the recommendations, is not a sign of failure. It is actually surprising that so many recommendations were approved with at least a two-thirds majority. It is also important to remember that each recommendation was voted on many times, and all the participating organizations worked to improve the recommendation before each vote. Thus, the final version of each recommendation reflects the contributions of many groups, including some that eventually decided they could not vote for it, because it went too far, or did not go far enough, or did not include a component they considered essential.

The definition is a good example. Workgroup members spent many, often difficult hours discussing the definition, preparing alternate wording, and trying to create a definition that all participating organizations would approve. In the end, 22 of the participating organizations voted for Part A of the definition which lists eight essential services that should be required by state law and regulation for all assisted living facilities. The 22 organizations included four organizations that were in favor of Part A only if one or both of the other two components of the definition were added: Part B that would require private, single occupancy rooms that are shared only by the choice of the resident, and Part C that would require states to establish at least two assisted living licensure categories. Ten other organizations voted against Part A, and their supporting comments explain why—basically, because Part A went too far for one organization, and not far enough for nine others. And one organization abstained. Certainly there was not consensus; there was some agreement, and the supplemental positions printed in the report provide useful information about why organizations voted as they did.

The Workgroup's report is not a set of regulations to be adopted word for word by states. We do not think that is what the committee wanted or requested. Rather, it is a detailed set of recommendations about what assisted living should look like—what it should be. As such, the report will be a valuable resource in ongoing policy discussions at the federal, state and local levels. It is valuable not only because of the recommendations that received approval of a 2/3 majority, but also because of the recommendations that did not receive a 2/3 vote and the supplemental positions that explain the array of opinions around many of the recommendations. To our knowledge, nothing like this has been available before.

We are pleased with the recommendations for state regulations about care and services for assisted living residents with dementia, especially recommendations requiring that:

- all staff be trained to recognize signs and symptoms of possible dementia in their residents;
- care plans be adapted for residents with dementia to take account of their cognitive impairments;
- direct care staff receive training about dementia care;
- individualized activities be available that match residents' abilities and interests; and
- residents be protected from danger, especially residents with unsafe wandering behaviors.

These recommendations would seem to make common sense. But, we are not aware of any state with regulations that include all of these dementia-specific recommendations. As described in Bob Mollica's 2002 report, 14 states had no provisions for residents with Alzheimer's disease and dementia in their assisted living regulations.[2] Many states have disclosure requirements that require facilities advertising themselves as providing special care units or services for people with Alzheimer's disease and dementia to disclose to potential residents, families and others what is special about the care they provide. The Alzheimer's Association strongly supports these disclosure requirements. Our chapters have worked hard to get them enacted. But they do not say anything about what kind of care should be provided.

Some states have regulations that do include detailed provisions for Alzheimer's and dementia care, but these regulations apply only to "special care units," and therefore miss what we think is a critical point: most assisted living residents with Alzheimer's disease and dementia are not in special care units. A 4-state study conducted by researchers at the University of North Carolina in 1997-98, found that, depending on the size of the assisted living facility, 68 - 89% of residents with moderate to severe dementia were in regular, nonspecialized units.[3] State regulations that apply only to special care units miss these people; their requirements for Alzheimer's and dementia care do not apply to the nonspecialized units and facilities that serve the great majority of assisted living residents with Alzheimer's disease and dementia.

Now that the report is publicly available, we will begin to use it with our Alzheimer's Association chapters that are working at the state and local level to improve the quality of care for assisted living residents with Alzheimer's disease and dementia. We have already presented information about the report and the recommendations to public policy staff from our chapters all across the country. We expect they will work with other groups in their communities—the state and local affiliates of the organizations that participated in the Assisted Living Workgroup-- to advocate for changes in state law and regulations, using the recommendations as a starting point. Each state is different; we do not think any state will adopt all the Assisted Living Workgroup's recommendations. We expect our chapters and the

[2] RL Mollica, *Assisted Living Policy 2002* (Portland, ME: National Academy for State Health Policy, Nov. 2002).
[3] Sloane PD, Zimmerman S, and Ory MG, "Care for Persons with Dementia" in *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, S. Zimmerman, P.D. Sloane, and K. Eckert (eds.) (Baltimore, MD: Johns Hopkins University Press, 2001).

groups they work with will focus on the recommendations they think are most important for their state. We also expect that some of our chapters will want to add to or change some of the recommendations; they may agree with the Workgroup organizations that argued that a recommendation did not go far enough or did not include a critical idea.

We will also be able to use the recommendations to provide information for families of people with dementia and other consumers who are trying to select a care setting for a person with dementia. The Alzheimer's Association has several publications that provide information about residential care and questions for families and other consumers to ask. The dementia-specific recommendations in the Workgroup's report provide a basis for specific questions for families and others to ask when considering an assisted living facility.

Finally, we would like to comment briefly about the ongoing federal role in assisted living. We applaud the leadership the Committee has provided on this issue. Thank you for convening the Workgroup and supporting its efforts. We are hopeful the Committee's continued leadership can lead to action by this Congress in two specific areas.

First, Congress should fund research on good care and on outcome measures. We support the recommendation for a Center for Excellence in Assisted Living to develop performance measures and tools and collect and disseminate quality information to consumers. The Committee can provide the leadership necessary to bring such a center into being. We would hope that this center would supplement research underway at the Department of Health and Human Services and the Department of Housing and Urban Development.

Also, Mr. Chairman and Members of the Committee, I urge you to find ways to make assisted living available to those who cannot now afford it. While assisted living is an important element in the array of long term care options, it is only available to a limited few. We do recognize the tight fiscal times and the budget challenges faced by Congress. Nonetheless, we hope that you will pursue opportunities through Medicaid and federal housing programs that could make assisted living affordable to more people. This issue of affordability underscores the need for development of a more coherent national long term care policy to meet the diverse needs of our nation's growing older population.

Thank you for the opportunity to testify today. We look forward to continuing to work with you on this and other issues important to the 4 million Americans with Alzheimer's disease and the 19 million family members who care for them.